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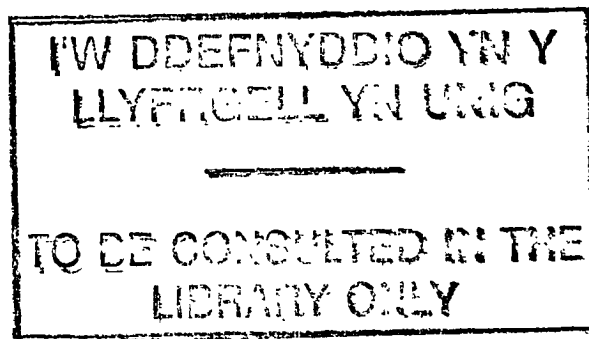
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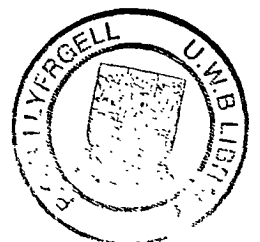
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The Dynamics of Dementia: A Modified Grounded Theory Study

**Thesis submitted in fulfilment of the requirements for
the Degree of Doctor of Philosophy in the University of
Wales, 1999**



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J. D. Keady
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SUMMARY

This thesis explores the experience of dementia as recounted by family carers and people with the early experience of dementia. Between October, 1992 and May, 1996 sixty four semi-structured interviews were conducted with family carers of people with dementia using a modified grounded theory approach. Constant comparative analysis of the data led to the emergence of a five stage integrated scheme to explain their experiences, namely: Recognising the Need (1); Taking it On (2); Working Through It (3); Reaching the End (4); and A New Beginning (5), with critical junctures attached to each stage which either locked the carer in, or moved the carer through, the model. A second phase of data collection comprised eleven interviews with ten people with the early experience of dementia and their family carers. Analysis of these data resulted in the emergence of the stage of Keeping it Hidden with its supporting strategies: Closing Down; Regrouping; and Covering your Tracks which help to explain how people with early dementia manage their changing cognitive abilities. Following a theoretical integration of the two phases of data collection the process of 'working' emerged in three forms, i.e. Working Apart; Working Together; and Working Alone to explain movement between the above two models. Transcending the data, the study also generated the linking scheme of Maintaining Involvement to help explain the dynamics of dementia. The 'fit and grab' of this linking scheme was subjected to preliminary empirical scrutiny via a third series of interviews with six carers of people with dementia. It is suggested that the grounded theory emerging from this study helps to explain the shared experience of dementia, while also having implications for policy and practice which are briefly explored in the concluding chapter, together with some of the methodological implications and limitations of the study.

PREFACE

In February 1983, at the age of twenty-two, the author began psychiatric nurse training with good intentions and a vague desire to 'help people', but no real experience of being with anyone who had a significant mental health need. After six week's induction, mainly consisting of biological sciences and a review of the main features of the 'new' Mental Health Act (Department of Health, 1983), 'real' mental health practice began with a 'safe' placement to one of the many single sex 'psychogeriatric' training wards scattered around the asylum where, it was considered, there were limited opportunities for neophyte nurses to do any real harm to human beings.

Whilst each of these 'psychogeriatric' wards had a soothing name, sequenced with others for ease of identification, it was apparent that from the moment the door was unlocked the name belied the reality of what lay within. It came as quite a shock to the author to find himself an integral member of a small nursing team providing continuing care to thirty five men with severe dementia, some ambulant, some chair-bound and others requiring terminal care. It soon became clear that this induction had been totally inadequate, consisting primarily of the reading of two set texts. The first, Altschul and Simpson's (1977; reprinted 1982) *Psychiatric Nursing* informed the reader that 'the preservation of the patient's appearance' (p.324) was the main nursing intervention for helping families to cope with their relative, whilst the maintenance of the patient's 'social acceptance' was the dominant nursing goal. Clinical knowledge of dementia was gained through reading the second set text, Pitt's (1982) *Psychogeriatrics*, which explored the clinical characteristics of dementia, diagnostic considerations and procedures to be followed during the inevitable double incontinence and faecal smearing. As Pitt (1982) himself indicated, dementia was a 'tragic disorder' where:

Sometimes it seems as if the true self dies long before the body's death, and in the intervening years a smudged caricature disintegrates noisily and without dignity into chaos. (p.39)

Chaos and faeces, hardly an auspicious introduction to dementia care practice. After reading the two set texts, there appeared, to the author, to be very little scope for any satisfying experience, with 'psychogeriatrics' being an ordeal to be endured before the

real business of psychiatric nursing began. How misleading this impression proved to be. In his desperately negative summary, Pitt (1982) failed to identify a potentially deeply rewarding aspect of this work, that is the fact that being with people with dementia provides an opportunity to preserve in another human being a sense of their identity and dignity.

As the author reflects upon his first exposure to the lives of people with dementia in a continuing care environment, many memories are rekindled. Chief amongst these are the institutional practices in which the author unwittingly engaged, including:

- Dehumanising segregation of men and women;
- Entrance and exit doors to the ward being permanently locked, and the radio constantly blaring out popular music for no good reason other than it made the day go a little quicker;
- Compulsory wearing of long white coats with coloured appellates to denote positions of authority;
- Ritual of the 'Friday afternoon enema' for all patients (a more apt descriptor than people) irrespective of individual need; and the
- Seemingly compulsory dispensing of major tranquillisers to control 'wandering' behaviour.

Having never seen or previously been involved with people with dementia, it was all too easy, disturbingly so, to fall into 'the ward routine' and accept such ritualised practices as normal. However, as the days and weeks of this first placement gradually wore on, the author's concerns over the care environment increased, particularly the feelings of powerlessness experienced by people with dementia and their visiting families. By the end of the placement, the initial devaluing of such environments was replaced by the author's desire to return to this particular field of psychiatric nursing.

This first placement exemplified some of the most impoverished forms of professional caregiving afforded to people with dementia and their families. While debate over the future direction and funding of continuing care continues (Department of Health, 1999a), it is all too easy to overlook the realities of care provided to people with dementia by the National Health Service just a little over a decade ago. Fortunately,

philosophies of care and societal attitudes have undergone a radical shift over the intervening years, embracing, in the process, an ever stronger consumer voice. The 'voice' of carers and people with dementia has been articulated most clearly through voluntary organisations, such as Alzheimer Scotland - Action on Dementia and the Alzheimer's Disease Society, and in the establishment of innovative schemes such as the Dementia Services Development Centre at the University of Stirling and the emerging network of Development Centres in areas of England, Eire and Wales. Policy initiatives have also emerged to stimulate an agenda for change by highlighting multi-agency frameworks for assessment (Department of Health 1996; 1997), with the focus on 'people', not just on 'the dementia' (see for example: Kitwood, 1997).

On a personal level, as the author journeyed through registration as a mental health nurse, a move to North Wales in September, 1986 and eventual employment for a number of years as a community psychiatric nurse within a community dementia team, it was possible to help promote some modest changes to multi-agency assessment practice by empowering family carers and stimulating a partnership approach to professional intervention and assessment (see: Keady and Nolan, 1994a).

However, despite such advances, it is important to remember that people with dementia remain on uncertain ground, falling, at both a policy and practice level, between the boundaries of what constitutes 'health' and 'social' care under the current community care legislation (Department of Health, 1990) and denied free continuing care on the National Health Service (Alzheimer's Disease Society, 1997). This applies even more so to the estimated 17,000 younger people with dementia living in the United Kingdom (Alzheimer's Disease Society, 1995) who, save from some notable service exceptions (see for instance: Health Advisory Service, 1996) and recent publications (see for example: Cox and Keady, 1999), remain far removed from the mainstream of dementia care practice and service planning.

Whilst addressing such issues is the collective responsibility of society, this cannot happen without the development of new knowledge and insights. It is important to continually explore new directions, building on the trail blazed so successfully by pioneers like the Bradford Dementia Group and its leader, Tom Kitwood. Developments must include a better preparation and support for dementia care

practitioners (Nolan and Keady, 1996a,b), and controlled evaluations of the effectiveness of dementia care practice. Most importantly, in the author's opinion, it is essential to better understand the experience of dementia and to create personalised, flexible services which recognise and respond to this experience (see also: Adams, 1999). It is hoped that this thesis can, in some small way, contribute to the present momentum towards a genuine partnership between people with dementia, their family carers and all those engaged in policy and practice.

INTRODUCTION

Nearly a decade ago Kahana and Young (1990) suggested that the challenge for the future of caregiving research was to build more theoretically rigorous and empirically relevant models which would account for caring's multi-dimensional and dynamic nature, especially by incorporating 'the voice' of the cared-for person (Rolland, 1988). In conditions such as dementia a more complete understanding also requires a temporal dimension which identifies shared and unique processes as they emerge over time, preferably, as Schultz, Visintainer and Williamson (1990) argue, by conducting longitudinal research.

Furthermore, if 'the voice' of the person with dementia is to emerge, the use of dehumanising discourse as evidenced in terms such as 'psychogeriatrics' (Pitt, 1982) and the 'elderly mentally infirm' (Welsh Office, 1989) must be countered. Such negative imagery has been assimilated into the titles of influential policy and planning reports, for instance *The Rising Tide* (Health Advisory Service, 1982), resulting in an unduly alarmist perception of the likely impact of dementia on health and social care providers.

The absence of a positive image of people with dementia, and the relative eulogising of carers, was characteristic of the social research agenda of the 1970s and 1980s. From the mid 1970s, building on the pioneering work of Sanford (1975), studies exploring the stress, burden, gender, satisfaction, coping patterns and temporal perspectives of family carers living with people with dementia, became priorities for social scientists interested in dementia. Consequently, people with dementia were consistently sidelined in the drive to interpret the caregiving experience, often being cast as incidental figures, or worse as the root cause of 'the problem'. Indeed, at the start of the research on which this thesis is based, the author himself inadvertently sidelined people with dementia, focusing instead on understanding the carer's experience. However, as the study progressed, it became apparent that the more complete understanding sought would not be achieved unless the perceptions of people with dementia were also included.

This thesis attempts, at least in part, to answer the call made by Kahana and Young (1990), by constructing a temporal model of the experience of dementia from the first

subtle signs as recognised by the person themselves, to the emerging awareness of the family carer and on to the carer's emotional adjustment once the instrumental demands of care come to an end. The research process was underpinned throughout by the methodology of grounded theory, especially constant comparative analysis, as described initially by Glaser and Strauss (1967) and refined later by Glaser (1978). The thesis traces the emergence of the model from its initial focus on the carers of people with dementia, to the inclusion of a small number of people with the early experience of dementia, and the eventual integration (both actual and theoretical) of both sets of experiences.

In recounting the evolution of the model the thesis remains as true as possible to the temporal sequencing of the research process, drawing in each phase only on literature existing at the time of data collection and analysis.

The thesis comprises a series of chapters as follows:

- **Chapter 1** explores the historical context of dementia and outlines definitions, epidemiology, assessment approaches and policy considerations from a United Kingdom, European and international perspective. In keeping with the temporal account of the research process that informed the study, the opening chapter will include literature up until the time of engaging in the first fieldwork (late 1992).
- **Chapter 2** reviews the caregiving literature on dementia thereby setting the context for the original study in 1992. This chapter places particular emphasis upon stress-coping frameworks and reviews temporal models of care.
- **Chapter 3** outlines the methodology and design for the initial study, which was centred on family caregiving in dementia. Grounded theory methodology is explored, together with a brief review of symbolic interaction(ism), and an argument is made for adopting the approach to grounded theory proposed by Glaser (1978) and modified by the present author.
- **Chapter 4** introduces the six stage temporal model of care generated from the carer's experience, and outlines the processes and critical junctures which shape the

dynamics of care over time. The chapter concludes with a consideration of a nine stage temporal model of the experience of dementia which arose during four carer-centred interviews in which people with an early diagnosis of dementia were present and contributed towards the research process. This development stimulated a second round of data collection focused upon the person with the early experience of dementia.

- **Chapter 5** reviews the brief literature on the subjective experience of dementia (up to 1994), before outlining the design and methods used in the second phase of the study. Particular emphasis is placed upon the issues of consent and the ethical implications that arose from operationalising a study which included interviews with people with the early experience of dementia and their carers. Subsequently, a two stage model of the experience of dementia resulting from on-going grounded theory analysis is presented. In addition, the emergence of the linking scheme of ‘maintaining involvement’ is described.
- **Chapter 6** integrates the family carer and subjective models of dementia, highlighting the central role of ‘maintaining involvement’, presenting its relationship to concepts identified during the earlier carer data. Passages from the full set of transcripts, representing 75 interviews, are used to illustrate the integrated model. Three case vignettes drawn from the data are presented in diagrammatic form to help explain transitions through the trajectory of dementia.
- **Chapter 7** considers the policy and practice implications of the integrated model, highlighting its limitations, and identifying areas for future research and development. The chapter places the results in the context of recent literature (mid 1998 with changes in mid 1999), updating concepts highlighted previously in chapter 1. Reflections on working within a grounded theory approach are also included in this chapter.

Referencing and Language Used in Text

- The *Harvard* referencing system is used in text, and the author cites up to three authors consecutively. If a supporting reference has four or more authors, the lead author will be cited followed by *et al.*
- The term 'people with the early experience of dementia' is used to refer to those with an early diagnosis of dementia and an awareness of its impact upon their life. Terms such as 'sufferer' and 'mild dementia' will be used only when they are cited by other authors, or, in the case of the latter term, when the medical model is being discussed.
- The descriptive prefix 'younger people with dementia' or 'younger onset dementia' is used when referring to people with dementia aged 65 years and under. Again, terms such as 'early onset dementia' and 'pre-senile dementia' are used only when they are cited by other authors, or when the medical model is being discussed.
- The author will use whole numbers in text whilst referring to sample sizes, and so on, unless a number starts a sentence or the written format is more naturally assimilated within the context of a sentence.

Appendix items, Figures and Tables will be referred to throughout the text.

CHAPTER ONE

THE CHARACTERISTICS OF DEMENTIA: AN OVERVIEW

**Deep within me I knew that something was terribly wrong
(Davis, 1989 p.56)**

1.1 Introduction

Writing a personal account of his journey through Alzheimer's disease, Davis (1989) highlighted a degenerative process that has been experienced by human beings for many thousands of years (Arendt and Jones, 1992). However, it was not until this century that an internationally agreed meaning of the term 'Alzheimer's disease' emerged (American Psychiatric Association, 1987; World Health Organisation, 1992). This chapter traces the medical, social and policy understanding of dementia as it emerged over time and the consequent labelling of people with dementia as having a mental disorder and being in need of institutional, residential and community psychiatric services.

The chapter begins with a review of the historical background to dementia and, in particular, the contribution of the German neuropathologist and clinician Alois Alzheimer (1864-1915), from whom the most common type of dementia takes its name (see: Stokes and Goudie, 1990; Jacques, 1992). Next, the chapter outlines the clinical characteristics of dementia, assessment processes and demographic trends, with a focus upon the course of mild dementia and the recent development of drug treatments for dementia (see: Whalley, 1989; Eagger *et al.*, 1992). The increasing importance of the primary health care team in relation to dementia is also presented (Cooper, Bickel and Schäufele, 1992). A summary of the main United Kingdom (UK) policy initiatives in dementia is subsequently discussed, and the chapter concludes by outlining emerging social constructions of dementia which seek to counter the current medical dominance (see: Kitwood, 1988; 1989; 1990a,b; 1992; Kitwood and Bredin, 1992a,b).

1.2 Historical Accounts

Based on the hieroglyphics of the Maxims of the Ptah Holy in the 9th century BC, Loza and Milad (1990) provided the following account of the experience of old age in Ancient Egypt:

My Sovereign master, old age, is here. Senility has descended on me; the weakness of my childhood has returned. My eyes are weak, my ears are deaf, my nose is blocked and can no longer breathe. My taste is completely gone. My spirit forgetful and I can no longer remember yesterday. What was nice has become bad. What causes senility in men is bad in every way. (p.403 slightly abridged)

From a sociological and historical standpoint, what is interesting in this quotation is not only the recognisable and enduring negative stereotypes associated with the ageing process (see for example: Comfort, 1977; Scrutton, 1990), but also that recent forgetfulness and memory loss were clearly associated with advancing age. Interestingly, the 'inability to remember what happened yesterday' forms a core diagnostic criterion for dementia as set out in the Diagnostic and Statistical Manual for Mental Disorders (*DSM-III-R*) (American Psychiatric Association, 1987 p.17). It is also apparent that problems relating to memory loss in older age have been acknowledged since ancient times.

In a series of authoritative reviews of the historical evidence, Berrios (1985; 1987; 1989; 1990) suggested that the first medical description of dementia was written by Galen around 130-200 AD. Galen was credited with naming a disorder 'morosis' in which the person's knowledge of letters was so damaged that 'they could no longer remember their own names' (Berrios, 1990 p.355). Moving on a millennium, Neugebauer (1978 cited in Brayne and Calloway, 1990 p.310), whilst undertaking historical sociological research into medieval life in England, discovered a battery of questions which were used in 1383 to assess Emma de Beston for Cambridge for 'idiocy'. These questions asked for a response to the following:

- In what town she was in;
- How many husbands she had had;
- How many days there were in a week;
- How many shillings there were in 40 pence; and
- If she would rather have 20 silver groats than 40 pence.

This battery of questions provide a prima facie assessment of Emma de Beston's abilities at problem solving, orientation and memory functioning, based upon her life history. Indeed, such a scale is not dissimilar in content from many of today's brief cognitive screening tools. For example, the Royal College of Physicians' (1981) Abbreviated Mental Test Score is used as a brief measure to test cognitive performance, with a score of less than seven, on a scale of ten questions, suggesting an underlying organic cause for the 'poor' performance. However, unlike the scale of 1383, the Abbreviated Mental Test Score (Royal College of Physicians, 1981) does not incorporate a biographical element into its series of questions, although it remains the recommended choice for use in general practice (Wattis, 1990). An appraisal of measures used to test orientation to time, place and person is included later in the chapter.

In Elizabethan times florid descriptions of 'old age madness and forgetfulness' can be drawn from some of the classic plays of William Shakespeare, with Hamlet, Prince of Denmark (1603) and King Lear (1608) providing prime examples. Indeed, in this latter play, some of the most stark literary images of forgetfulness and confusion in old age are made, with King Lear viewing himself as 'more sinn'd against than sinning' (Act III Scene II).

For people with a mental illness, the end of the 18th century and the beginning of the 19th century were times of great social change as the episodic periods of insanity exhibited by King George III (1782-1820) challenged the population to look more sympathetically at such issues. Indeed, as described by Skultans (1979 pp.10-11), the King's plight forced Parliament to set up a committee to review his insanity and plan how help could best be provided - this resulted in two reports published in 1807 and 1815. More importantly, and reflecting the public mood of the time, in 1806 Parliament passed an Act recommending that each county build an asylum for the care of its insane. This change of social attitudes towards 'the insane', which included people with dementia (see: Berrios, 1987), coincided with Pinel's (1787) pioneering research into 'brain disease' and his classification of 'demence' to define a cluster of signs that involved: a lack of judgement; disconnected ideas; and lost faculty of mental attention.

By the early part of the 19th century dementia - the English translation of 'demence' - was brought into medical discourse and practice to describe 'any state of psychological dysfunction associated with chronic brain disease' (Goldberg *et al.*, 1988 p.188). Dementia, therefore, was applied to any age group, hence the use of the term 'dementia praecox' became widespread in the latter parts of the 18th century and into the 19th century. As Goldberg *et al.* (1988) contend, 'dementia praecox' became associated with the signs and symptoms of what we would recognise today as schizophrenia in younger adults.

It was not until the latter parts of the 19th century that a more contemporary context for the understanding of dementia can be found (Allison, 1962). Whilst undertaking anatomical dissection of 'a diseased brain', Marcé (1863) reported the existence of cortical atrophy, enlarged ventricles and tissue softening, and suggested that this was the macroscopic hallmark of 'senile dementia'. Further, Binswanger (1898 cited in Allison, 1962 p.10) first coined the term 'pre-senile dementia', with 'pre-senile' being used to refer to symptoms developing in a person between the ages of forty to sixty years, and 'dementia' to imply impairment of memory and intellect. Accordingly, the initial focus of neurological research into the syndrome of 'dementia' was concerned with the link between younger, middle-aged, people with impaired memory and intellect and the (as yet unknown) role played by atheroma and arteriosclerosis in this process. Arnold Pick's writings between 1892-1908 exemplify this point when he described a rare and particular pre-senile 'cortical atrophy' in the frontal and temporal lobes of the brain; the reported syndrome {Pick's disease} continues to bear his name to this day and remains recognised as one of the 'early onset' dementias (see: Allison, 1962; Berrios, 1989; American Psychiatric Association, 1987; World Health Organisation, 1992). Such advancements in clinical identification were aided immeasurably in the mid 1880s by improvements in scientific equipment, particularly microscopes.

Citing Pick's work in Prague as a prime example, Berrios (1990) reports that the clinical descriptions of dementia started 'in earnest' during this period. Changes in brain pathology were singled out as important, such as cellular death and disintegration, and the existence of plaques and neurofibrils; however, the link between these processes was unknown. Thus, by the early 1900s, efforts were being made to: measure the symptoms and severity of dementia; ascertain the differential importance of senile and vascular

aetiology of dementia; and study the comparative prevalence of senile dementia in relation to other psychiatric conditions affecting older people. These enquiries were directly influenced by Marinesco (1900) whose theories on the ageing of brain tissue prompted Alois Alzheimer to explore brain pathology.

During his formative years Alzheimer studied medicine in Berlin, Tübingen and Würzburg before he joined Franz Nissl in 1888 at the psychiatric hospital in Frankfurt. Franz Nissl convinced Alzheimer that he should investigate the cerebral cortex in mental disorders, and apply Nissl's recently developed 'staining techniques' to the identification of nerve cells in the brain; a procedure through which the first reliable morphological assessment of nerve cells became possible. Indeed, it was Alzheimer (1897) who was to publish the first neurohistological study of schizophrenia, a feat he achieved before moving to Munich in 1903 to work with Emille Kraepelin. Here Alzheimer took up the joint post of Assistant Clinical Director of the Frankfurt am Main insane asylum and Director of the Anatomical Laboratory. It was in this position that Alzheimer conducted his seminal neurological and observational research on cognitive functioning and memory decline, eventually publishing his most influential paper *Über eine eigenartige Erkrankung der Hirnrinde*, literally translated as *Munich: On an Unusual Illness of the Cerebral Cortex* (Alzheimer, 1907). This paper was to change the course of medical and social understanding of dementia and consolidate the medical dominance of dementia for much of the remainder of the 20th century.

Interestingly, Alzheimer's disease, as it was to be eventually christened by his mentor Kraepelin (see: Berrios, 1990 p.358), was founded on the basis of one detailed case study on Auguste D, a 51 year old female resident of the Frankfurt am Main insane asylum. An English translation of Alzheimer's (1907) paper by Wilkins and Brody (1969) revealed that during her time in the asylum, Auguste D was completely disorientated in time and place, suffered from auditory hallucinations and expressed paranoid ideas. Alzheimer (1907) himself commented that due to her behaviour it was difficult to carry out detailed observations, although his written case study contained the following observation:

Her memory is seriously impaired. If objects are shown to her, she names them correctly, but almost immediately afterwards she has forgotten everything.

When reading a text, she skips from line to line or reads by spelling the words individually, or by making them meaningless through her pronunciation.
(translation in: Wilkins and Brody, 1969 p.109)

The same cognitive and linguistic deficits are clearly recognisable today in people with dementia and, in keeping with the times, the syndrome they came to represent was named 'pre-senile dementia' as the changes were seen as occurring before the person entered old age (see also: Perusini, 1909). What made Alzheimer's work so innovative was that, following the death of Auguste D and the anatomical dissection of her brain, he was able to link the diffuse cortical atrophy to the function and axonal spread of senile plaques and neurofibrillary tangles within the higher and dominant areas of the brain structure, particularly the limbic system (see also: Ball, 1978; Lishman, 1981). Alzheimer did not think this finding to be noteworthy at the time as cortical atrophy, and the existence of neurofibrillary tangles, had previously been reported (see: Marcé, 1863). Indeed, Alzheimer believed that the combination of anatomical signs that he recorded, simply represented an atypical form of senile psychosis and wanted instead to ascertain how the disease presented in similar cases in older people. However, for reasons that are still unclear, Kraepelin disagreed with this conclusion and encouraged Alzheimer to publish 'his new disease' in the *Journal of General Neurology and Psychiatry* (English translation from the German; see: Wilkins and Brody, 1969); a Journal which, co-incidentally, Alzheimer himself edited.

Whilst Alzheimer did not write a text detailing his observations, 'Alzheimer's disease' was christened on the basis of one clinical case. Following publication of his '*Unusual Illness*' and Kraepelin's later naming of the disease, arguments were put forward to suggest that the discovery was reported 'too hastily' and without proper scientific verification (see: Lugaro, 1916 cited in Berrios, 1990 p.362). Speculation persisted at the time that the rapid reporting and publication of the work was motivated by three reasons. Firstly, to compete with the work of Arnold Pick in Prague. Second, to prove that there were mental disorders that were organically based - a point of great contention with the emerging psychoanalytical theories of Sigmund Freud. Third, the financial pressures involved in running a research laboratory forced a need to 'discover something'; what better way to achieve this than by christening a new disease after one of the principal investigators at the laboratory. Whatever the real motivation, the clinical reporting of Alzheimer's disease as a 'pre-senile dementia' created a division

between dementias occurring in mid and later life; a diagnostic distinction that continues to the present (American Psychiatric Association, 1987; World Health Organisation, 1992).

Before leaving Alzheimer's contribution to the field of dementia, it is important to highlight one much overlooked fact; prior to taking up the post of Chair at the Psychiatry Department, University of Breslau, Alzheimer was also to discover the other cause of 'senile dementia', that attributed to cortical arteriosclerosis. In this additional research, Alzheimer was able to demonstrate that many patients with dementia had both types of brain pathology (what would later be termed 'mixed dementia'), but that, crucially, arteriosclerosis and nerve cell degeneration represented different disease entities (see: McMenemey, 1970).

For the remainder of the present century the medical profession has attempted systematically to define the characteristics of dementia and place them within a medical context, under the umbrella term of mental illness. However, it was not until the turn of the 1970s that the *ICD-10* (World Health Organisation, 1992) and *DSM-III-R* (American Psychiatric Association, 1987) converged and set agreed diagnostic criteria for dementia; even then discrepancies in category formation still existed, for instance in the reference to Multi-infarct dementia (American Psychiatric Association, 1987) and Vascular dementia (World Health Organisation, 1992) to broadly define the same set of signs and symptoms. What was clear, however, was that dementia had become medical territory, having been assigned to the broad domain of mental illness with the attendant implications for social policy and public perception that this term engenders.

1.3 Medical Definitions and Accounts of Dementia

Whilst there have been many attempts to provide a comprehensive medical definition of dementia, the following has been widely accepted:

Dementia is the global impairment of higher cortical functions, including memory, the capacity to solve problems of day to day living, the performance of learned perceptuo-motor skills, the correct use of social skills and control of emotional reactions in the absence of gross clouding of consciousness. The condition is often irreversible and progressive.

(World Health Organisation, 1986 cited in Arendt and Jones, 1992 p.9)

In keeping with the historical classification of dementia, both the *ICD-10* (World Health Organisation, 1992) and *DSM-III-R* (American Psychiatric Association, 1987) criteria divided the syndrome into two, on the basis of age of onset, with 65 years and under being referred to as 'early onset' dementia and anything later being referred to as 'late onset' dementia. The 'early onset' dementias encompass a diverse number of syndromes including: Alzheimer's disease; Vascular dementia; Pick's disease; Creutzfeldt-Jacob disease; Huntington's disease; and alcohol related dementia. Dementia may also rarely occur in children and young adolescents as a result of general medical conditions which include: head injury; brain tumours; strokes; and adrenoleukodystrophies (American Psychiatric Association, 1987 p.137). Moreover, as Stokes and Holden (1990 pp.26-27) state, and as is implied in the World Health Organisation (1986) definition, there are also potentially treatable causes of dementia, examples of which include:

- Deficiencies of vitamin B12, folate, niacin (pellagra), thiamine (Wernicke-Korsakoff syndrome);
- Zinc and/or copper deficiencies;
- Endocrine disorders (hypo or hyperthyroidism);
- Normal pressure hydrocephalus;
- Drug or medication induced disturbances;
- Subdural hematoma;
- Toxin exposure;
- Cerebral tumour.

As both Byrne (1987) and Jacques (1992) contend, it is also important to recognise that dementia has many different causes (see: Tables 1 and 2 respectively on the next page) and risk factors (for a review see: Dewey, Davidson and Copeland, 1988), and a correct diagnosis of dementia can only be made with about 80% certainty in any one instance (Lishman, 1981; Jacques, 1992).

Table 1: Causes of dementia with relatively rapid onset and course

Degenerative:	Diffuse Lewy Body disease, Alzheimer's disease (rare)
Vascular vasculitis:	Cerebral infarction and embolus, cerebral aneurism, cerebral vasculitis
Transmissible:	Creutzfeldt-Jakob disease, Gerstmann-Straussler syndrome dementias
Infection:	Encephalitis (especially herpes simplex), Whipple's disease
Miscellaneous:	Severe cerebral trauma (course may be prolonged), neuropsychiatric systemic lupus, rheumatoid, sarcoid, temporal arteritis

Adapted from: Byrne (1987 p.77)

Table 2: Causes of dementia with gradual onset and prolonged course

Degenerative:	Alzheimer's disease, Pick's disease, Wilson's disease, Huntington's Chorea, Diffuse Lewy Body disease, dementia of the frontal type, corticobasal degeneration, multi-system atrophies, multiple sclerosis, motor neurone disease, thalamic dementia
Vascular:	Binswanger's disease (subcortical arteriosclerotic encephalopathy)
Infections:	Neurosyphilis
Space Occupying:	Primary intracranial tumours, meningioma, astrocytoma, chronic sub-dural haematoma
Metabolic and Endocrine:	Uraemia, chronic hepatic encephalopathy, carcinomatosis, hypothyroidism, hypopituitarism
Miscellaneous:	Communicating hydrocephalus, Alcoholic dementia

Adapted from: Byrne (1987 p.78)

It is a sobering thought that as we approach the 21st century the only absolute means of confirming a diagnosis and type of dementia continues to be the performance of an autopsy (Jacques, 1992), much as it was with Alzheimer's (1907) original research.

The diverse nature of dementia challenges notions of diagnostic criteria. Even today consensus is lacking and the most recent copy of the *ICD-10* (World Health Organisation, 1992) lists dementia under 'Organic, including Symptomatic, Mental Disorders' and classifies it into nine categories; these range from 'Dementia in Alzheimer's disease' to 'Unspecified organic or symptomatic mental disorder'. Overall, in the nine *ICD-10* (World Health Organisation, 1992) classifications, there are a total of forty sub-categories which cover such familiar diagnoses as 'Multi-infarct dementia' to the more obscure, such as 'Dementia in Cruetzfelt-Jacob disease'. Confusingly, the *DSM-III-R* (American Psychiatric Association, 1987) separates the diagnosis of dementia into twelve categories, although consistent with the *ICD-10* definition (World Health Organisation, 1992), it tracks the diagnostic progression through mild, moderate and severe stages, as represented in Table 3:

Table 3: The *DSM-III-R* and *ICD-10* stages of dementia

<u>Stage</u>	<u>Property</u>
Mild	The decline in cognitive abilities causes impaired performance in daily living, but not to a degree that makes the individual dependent on others. Complicated daily tasks or recreational activities cannot be undertaken.
Moderate	The decline in cognitive abilities makes the individual unable to perform without the assistance of another in daily living, including shopping and handling money. Within the home, only simple chores can be performed. Activities are increasingly restricted and poorly sustained.
Severe	The decline is characterised by an absence, or virtual absence, of intelligible ideation.

Source: World Health Organisation (1992 p.12)

However, such staged definitions suggest that all dementias follow a uniform course once the diagnosis has been established, a conclusion, for Alzheimer's disease at least, that is currently being challenged in the literature (McDonald, 1969; Rosser *et al.*, 1984; Roth and Wischick, 1985; Christie and Wood, 1988). These studies seek to demonstrate that there are two distinctly separate forms of Alzheimer's disease, one acquired before the age of 72 years, the other after this time. Indeed, Roth and Wischick (1985) suggest that the 'early onset' label should be used to describe all dementias occurring before the age of 72. In broad support of this assertion, Christie and Wood (1988), in their experimental study, found that in the age group of over 75s with Alzheimer's disease (n=45) almost 70% of the disease progression could be managed at home with aid of appropriate community care and support. In contrast, for the under 75 population with Alzheimer's disease (n=38), Christie and Wood (1988) found the clinical picture to be different, with 'clinical problems', operationally defined as: confusion; wandering; restlessness (day and night); incontinence; poor self-care; and deluded and aggressive behaviour, leading to admission to hospital at a relatively early point in the trajectory of the dementia. Consequently, in the under 75 population, on average 50% of the total duration of the dementia is spent in hospital, compared with only 30% for the over 75 group (Christie and Wood, 1988). This study, therefore, may provide valuable insights into why family carers of younger people with dementia have an increased feeling of stress and burden in their role (Cox, 1991).

For an early diagnosis of dementia to be made it is essential that the individual is assessed as soon as possible during the mild stage of its progression (see: Table 3 p.22), although this is easier said than done. The *ICD-10* diagnostic criteria defines mild dementia as having the following properties:

The decline in cognitive abilities causes impaired performance in daily living, but not to a degree that makes the individual dependent on others. Complicated daily tasks or recreational activities cannot be undertaken.

(World Health Organisation, 1992 p.30)

However, the medical profession itself seem at odds over the relative merits of such diagnostic criteria as 'complicated daily tasks', when driving for example, can still be undertaken relatively competently by people with very mild Alzheimer's disease (Donnelly and Karlinsky, 1990; Parasuraman and Nestor, 1991).

Arguably, the diverse signs and symptoms applicable to the range of dementias (see: Lishman, 1981) has led to clinical dissatisfaction with overarching definitions. This has resulted in the development of seemingly more sensitive and personalised rating scales to grade the severity and impact of dementia. Examples of these rating scales include the Global Deterioration Scale (Reisberg *et al.*, 1982) and the Clinical Dementia Rating (CDR) (Hughes *et al.*, 1982), with both scales being frequently cited as admission criterion for inclusion in medical and psychological research. The CDR expands upon the three stages of dementia described in the *DSM-III-R* and the *ICD-10* (see: Table 3 p.22), and views dementia on a continuum ranging from: healthy (0); questionable dementia (0.5); mild dementia (1); moderate dementia (2); severe dementia (3). A weighting is then placed under each heading (indicated above in brackets) and criteria for inclusion placed under six domains covering: memory; orientation, judgement and problem solving; community affairs; homes and hobbies; personal care. For instance, people with questionable dementia - CDR (0.5) - under the memory domain experience mild consistent forgetfulness, partial recollection of events and 'benign' forgetfulness, whilst under the orientation domain are fully orientated.

There is a certain face validity and intuitive appeal in staging dementia, and evidence from qualitative studies suggests that these transitions are recognisable to carers (Chenoweth and Spencer, 1986; Wilson, 1989a,b; Clarke and Watson, 1991). Also an argument could be advanced that staging dementia in this way may help carers to shape their day-to-day decision-making, as well as indicate what the future may have in store (Barnes *et al.*, 1981; Fortinsky and Hathaway, 1990). Conversely, there is a certain insensitivity in forcing people with dementia into pre-determined categories, particularly when clinical judgement as to what constitutes mild dementia remains uncertain (Morris and Fulling, 1988), and where inclusion criteria themselves are still evolving, for instance in the recent 'discovery' and reporting of Lewy body dementia as an international disease classification (see: Yashimuro, 1983; Forno and Langston, 1988; Kosaka, 1990; Byrne, 1992a,b; McKeith, Perry and Fairbairn, 1992). This point is further reinforced by Rubin *et al.* (1989) who suggest that the CDR (0.5) stage of 'questionable cognitive impairment' actually represents very mild Alzheimer's disease.

For assessment and case identification of the early experience of dementia to improve, there is a need for a more complete understanding of its onset and progression. To

investigate this phenomenon Flicker, Ferris and Reisberg (1991) compared 32 elderly people with clinically identified mild cognitive impairment to a group of 32 age and education matched 'normal' subjects. In this study the mildly impaired subjects were found to perform more poorly on tests of recent memory, remote memory, language function, concept formation and visuospatial praxis. This finding was augmented by an individual case study undertaken on an 82 year old cognitively healthy man until very mild Alzheimer's disease was diagnosed some three years later (Morris and Fulling, 1988). The gentleman in their study had a high level of education and one of their key findings was that intellectual performance in selected older adults can be expected to 'hold' over time, and that brief cognitive scales for detecting the early signs of dementia may not have the necessary refinement and sensitivity to detect these changes; a finding consistent with other studies (see: Galasko *et al.*, 1990; Beardsall and Huppert, 1991). Morris and Fulling (1988) identified the need for 'an observant collateral source' (i.e. a close relative or friend) to aid accurate case identification. This finding was noted earlier by Huppert and Henderson (1984) who suggested that reliance on self reports by informant interview about cognitive performance was 'one of the most reliable methods of case identification' (p.10).

However, before this can happen, the person living with the early signs must recognise that these experiences are not simply signs of 'normal ageing' to be easily discounted (Bowers, 1987; Pollitt, O'Connor and Anderson, 1989). Similar considerations apply to family carers (Wilson, 1989a,b; Clarke and Watson, 1991) who, as Wood (1984) suggested, may even see significant memory failure as a normal part of ageing. This issue was explored further by Pollitt, O'Connor and Anderson (1989) in their study on perceptions and problems in mild dementia when they noted:

Until the carers or relatives make a conceptual leap from seeing the condition as normal to securing it as abnormal, it will be difficult to offer appropriate help to prevent the build-up of stress or crisis occurring. (p.273)

This is a contentious issue as studies have suggested that people living through the early signs of dementia actively engage in strategies to deny their failings and work to maintain a veneer of normality (Froggatt, 1988; Clarke and Watson, 1991). As the onset of dementia is usually an insidious process, it is at a point when the signs can no longer be easily discounted, or normalised, that professional opinion is sought (Wilson, 1989a,b), a

course of action that brings people with suspected cognitive impairment, and their carers, into contact with the assessment process.

1.4 Assessment: A Testing Situation?

Studies have repeatedly demonstrated that the first point of contact for formal confirmation of dementia is the primary health care team, and in particular the person's general practitioner (GP) (see: Wattis, 1988; Cooper, Bickel and Schäufele, 1992). However, even when such opinions are sought, the GPs ability to identify dementia (see: O'Connor *et al.*, 1988) and to distinguish between mild, or very mild, dementia and normal ageing, is limited (Hupport and Henderson, 1984; Pollitt, O'Connor and Anderson, 1989; Berg, 1990; Brayne and Calloway, 1990; Kay, 1991). Difficulties are heightened by the need to exclude other symptomology, such as: benign senescent forgetfulness (Kral, 1962); age associated memory impairment (Crook *et al.*, 1986); depressive pseudodementia (McAllister and Price, 1982); or some other underlying physical cause such as: normal pressure hydrocephalus; cerebral tumor; or drug toxicity (Byrne, 1987; Jacques, 1992).

In the current drive towards earlier diagnosis and support, such limitations have implications for health care providers and serve to maintain the present *status quo* whereby services to people with dementia, and their family carers, are usually accessed in the later stages and comprise mainly crisis intervention (see: Levin, Sinclair and Gorbach, 1989). This makes obtaining meaningful insights on service requirements from the person with dementia more challenging. Moreover, difficulty in establishing an early diagnosis of dementia are heightened for younger people when other factors, such as: parent bereavement; work or marriage difficulties; adjustment to the menopause and so on, can mask the underlying cause of the presenting memory impairment (Ron *et al.*, 1978; Cox, 1991; Furst and Sperlinger, 1992).

Diagnostic difficulties can lead to frustration in practice situations and result in over-reliance on cognitive/behavioural rating scales to identify areas of deficit and make a potential diagnosis. However, many such tests fail to take due account of the social context of the individual. For instance, there are a large number of screening measures for memory including: the Mini-Mental State Examination (Folstein *et al.*, 1975); the Middlesex Elderly Assessment of Mental State (Golding, 1988); the Manual of the

Clifton Assessment Procedures for the Elderly (CAPE) (Pattie and Gilleard, 1979); CAMDEX (Roth *et al.*, 1986); and The Kingston Standardized Cognitive Assessment (Rodenburg *et al.*, 1991) (for a comprehensive review of screening measures see: Twining, 1991; Beardsall and Huppert, 1991). All these measures rely heavily on establishing markers of: (a) time; (b) place; and (c) person. In other words, the measures include the expectation that the person being assessed should be oriented to the time of day, and the month, and that they can recite where they are, their own name and the names of famous people, such as the Prime Minister.

With reference to the above screening measures, the author will consider the social context and relevance of each of these markers in turn.

a) Time

Common questions on the screening measures include date and season with the assumption that a normally competent person knows the present date (see for example: Folstein *et al.*, 1975). These assumptions can be challenged and, at the very least, require empirical confirmation. The author would suggest that normally competent people, when asked the present or a future date, usually refer to their watch, or to a diary/calendar, and do not rely solely upon their memory. Moreover, most of us do not view time in a vacuum and have 'markers' to do with working life, social events and so on. For individuals who may lack such markers, for instance in residential care, time may be less relevant and knowing the actual date may be of little significance.

b) Place

One of the features of psychological assessment is that it often takes place away from the person's home (Coyne *et al.*, 1990), and they may, therefore, find themselves in a relatively unfamiliar environment. The situation can be further complicated by the person being assessed a number of times either within or between institutions. For instance, a person living alone with Alzheimer's disease who has suffered a fall can move through a local casualty department, to the district general hospital and on to the assessment/rehabilitation ward. It is highly questionable, the author would suggest, to compare the response of a person who has had such a sequence of relocation, to the question 'where are we now?' to that of an older person who has lived at the same address for a number of years.

c) Person

Both the literature and practice would suggest that very few people do not know their name (Jacques, 1992). Therefore, in memory screening tests, 'memory failure' is demonstrated by not knowing the name of the Prime Minister, or that of the President of the United States of America (USA). Although generally common knowledge, such information may not be of interest to everyone, particularly if a person becomes socially disengaged when they may have little motivation to update their knowledge of current events. A-priori, it is not clear why 'who is the Prime Minister?' is a particularly useful test of memory. For instance, there is a certain arbitrariness as to the name of people we each consider it important to remember. Therefore, it could be argued that present measures of memory confound the ability to memorise with levels of social engagement. Interestingly, if a person states that they have lost interest in politics, or what year it is, this behaviour is often construed as evidence of either depression, or a defence against actual memory loss; either way, its credibility as satisfactory explanation is discounted.

One final aspect of memory assessment deserves mention, namely the use of time limits for completion e.g. measures of verbal fluency as in the Kendrick Battery (Kendrick, 1985), or bonuses for time, as in the CAPE (Pattie and Gilleard, 1979). It is well established that anxiety and depression affect memory function (Murphy, 1986; Wattis and Hindmarch, 1988) and that depression negatively affects response time (Murphy, 1986). This being the case, it is hard to see why assessment techniques for confusion deliberately introduce or accept potentially contaminated measures.

However, even accepting the limitations of existing screening measures, for confirming, or suspecting, a diagnosis of dementia, professional nihilism may lead some GPs not to refer suspected cases to specialist support services (Glosser, Wexler and Balmelli, 1985). Furthermore, access to specialist diagnostic services, such as memory clinics, is largely dependent upon geographical location and local health authority priority, indicating the lack of a co-ordinated and integrated UK strategy. This is despite the fact that since their establishment in the UK in 1983 at St. Pancras' Hospital, such clinics have long been seen as an 'invaluable resource' (see: Philpot and Levy, 1987 p.199). However, without greater provision and instruments that can detect dementia earlier in its course, then the epidemiology of dementia remains uncertain.

1.5 Demographic and Epidemiological Trends

By the year 2000 the number of people aged 65 and over is expected to be about 423 million world-wide, with nearly 50% of this total living in developing countries (Prince, 1985). Prince further suggests that by the year 2025 there will be 34.1 million people with some form of dementia, 9.9 million situated in the developed world and 24.2 million in the developing countries. However, for the developed world, this may well be an under-estimate as Evans *et al.* (1989) contend that by the year 2040 there will be 9 million people with Alzheimer's disease living in the USA alone. This latter prediction does not include other known dementias which will undoubtedly push the projected figure to well over 10 million.

Ineichen (1987), in a detailed critique of existing prevalence and incidence studies of dementia, estimated that by the year 2001 there will be 56.4 million people living in the UK of whom 15.2% will be aged 65-74 years, 7.1% aged 75-84 years and a further 1.8% aged 85 years and over. In the absence of agreed criteria for mild dementia, and the tendency for previous estimates to be 'inconclusive', Ineichen (1987 p.198) concluded that a 'simple rule of thumb' to measure for the prevalence of dementia would be 1% of the population aged 65-74 years, and 10% of those aged 75 years and over. Whilst broadly agreeing with Ineichens' (1987) findings, Lindsay (1987 p.712) called this 'something of a guess' as the epidemiological knowledge on dementia relating to the oldest-old (85+) in society remains unknown; accordingly, any suggested prevalence must also be vague. With the present average life expectancy in the UK being around 78 years for men, and 82 years for women, with more than twice as many women surviving into old-old age than men (Arber and Ginn, 1991), Ineichens' (1987) calculation suggest a significant proportion of older people with dementia, mainly women, living in society.

More recently, Hofman *et al.* (1991) conducted an extensive multi-method prevalence study of dementia taking account of the detailed case analysis of samples of older people from twelve European countries; a study known as EURODEM. Investigating retrospective prevalence rates between 1980-1990, Hofman *et al.* (1991) detailed the age and gender-specific estimates of the prevalence of dementia using the *DSM-III-R* (American Psychiatric Association, 1987) and *ICD-10* (World Health Organisation, 1992)

standard diagnostic tools as entry criteria for the study. Of the twelve participating countries - which included the UK (although only sites in England were chosen), Finland, Italy, Spain and Sweden amongst others - it was found that general age and gender distribution was similar for all countries, with the overall European prevalence of dementia for the five year age groups from 60-94 years being: 1.0%, 1.4%, 4.1%, 5.7%, 13.0%, 21.6% and 32.2% respectively. In subjects aged under 75 years, the prevalence of dementia was slightly higher in men than in women, and in accordance with the findings of Prince (1985), of those aged 75 years and over the prevalence was higher in women. As Hofman *et al.* (1991 p.736) commented, the prevalence figures 'nearly doubled' with every five years of increase in age. The study did not research the prevalence rate of younger onset dementia within Europe, although one country, Holland, lowered its entry age to the study to 30 years. Unfortunately, the research pertaining to younger people with dementia has, so far, failed to report independently of the main study group.

In identifying the type of dementia, Gurland *et al.* (1983) found that Alzheimer's disease accounted for 60% of all diagnosed dementias in their over 75 sample (n=396), with a further 15% presenting with a mixed diagnosis of Multi-infarct (or Vascular) dementia and Alzheimer's disease. These findings are consistent with the figures proposed in a later study by Woods (1989 pp.18-19) who suggests that in a given population of people with dementia: 50% have Alzheimer's disease; 20% Multi-infarct (or Vascular) dementia; 20% Mixed dementia (i.e. a clinical presentation of both Alzheimer's disease and Multi-infarct dementia); and 10% 'other dementias'. However, cultural features may also be important, as in South-east Asia, particularly Japan, the prevalence of Multi-infarct (or Vascular) dementia is far higher than that of Alzheimer's disease (for a discussion see: Hashimoto, 1992).

Irrespective of the geography, the epidemiological literature relating to the prevalence of younger onset dementia is unclear (Sjögren, Sjögren and Lindgren, 1952; Nott and Fleming, 1975; Whalley *et al.*, 1982; Jörm and Körten, 1988; Cox, 1991). Such work requires a more concentrated focus as, whilst the genetic link with Huntington's Disease has been known for some time (for a review see: Folstein, 1989), there is emerging evidence of possible genetic inheritance of Alzheimer's disease, particularly for younger people (Kay, 1989; Whatley and Anderton, 1990; Mullan, 1991).

These, and the other demographic factors described above, have raised the profile of dementia as an area of social policy. However, the influence of the medical model is also apparent.

1.6 Policy Considerations

An illustration of the power of symbols and language in mental health care was provided as early as the 1950s in Thomson, Lowe and McKeown's (1951) influential report *The Care of the Ageing and Chronic Sick*. This report suggested that the stigmatising and homogenous term 'geriatrics' be abandoned as older people with mental illnesses were finding themselves placed in environments for the 'chronically sick' - populated by 'geriatrics' - rather than in the more appropriate (at the time) setting of the mental hospital. Moreover, in a thoughtful and far reaching assessment of the goals of public health, Vickers (1958) argued that society must remain responsive to the needs of the population, and provided a salutary reminder that 'the psychiatric literature is full of warnings against allowing our governing expectations to diverge too sharply from the realities of the world in which we live' (p.603).

Over thirty years later, policy and professional responses to people with dementia and their carers remains largely fragmented and poorly developed across the UK. This is exacerbated by two factors. Firstly, working with people with dementia has rarely been promoted positively for professional groups (Jones and Miesen, 1992), and second, working with older people, particularly those with dementia, has long been perceived as a negative choice for health care students (Åström, 1986). Furthermore, practising staff lack constructive opportunities for clinical supervision and specialised educational development (Firth, McKeown and McIntee, 1987).

This paucity of attention is despite the potential economic impact of dementia being recognised in the UK for some considerable time, with two reports issued at the beginning of the 1980s proving particularly influential, namely: *Organic Mental Impairment in the Elderly* (Royal College of Physicians, 1981) and *The Rising Tide* (Health Advisory Service, 1982). Both these reports signaled the importance of people with dementia and highlighted the need for well staffed resources in both community and residential settings. The potential contribution of nursing, in particular that of mental health nurses, figured

prominently within the context of the drive towards more effective multi-agency working. During this period the National Health Service (NHS) was the main service provider, resulting in its full scale commitment to the provision of continuing care facilities, even though they were usually located within the inappropriate setting of mental hospitals. For instance, in one of the few explicit policy reports addressing the needs of people with dementia and their carers, the Health Advisory Service (1982) set out the components of a comprehensive service and recommended that:

... the role in providing support, advice and relief at times of special difficulty to families and primary health and social services is an essential ingredient in a successful comprehensive service. (p.17)

Such an overt commitment to carers and people with dementia was later reinforced by the King's Fund Centre (1984) in a project paper detailing the principles of good service practice. By astutely avoiding exemplars of good practice, the report's authors were able to set out a challenge to service providers and policy makers. This was achieved by five key principles outlining philosophical beliefs about personal empowerment for people with dementia. The five principles (King's Fund Centre, 1984 pp.7-8 abridged) called for an acknowledgment that:

- People with dementia have the same human value as anyone else irrespective of their degree of disability or dependence;
- People with dementia have the same varied human needs as anyone else;
- People with dementia have the same rights as other citizens;
- Every person with dementia is an individual; and
- People with dementia have the right to forms of support which do not exploit family and friends.

As the decade wore on, government concern over the costs of funding the NHS stimulated a major debate over its purpose and priorities. A fundamental review led by Sir Roy Griffiths (see: Griffiths, 1988), and the publication of two White Papers: *Caring for People* (Department of Health, 1989a) and *Working for Patients* (Department of Health, 1989b) - which were to form the blue-print of the NHS and Community Care Act (Department of Health, 1990) - were to change the landscape of dementia care practice and assessment. In particular, the division of 'health' and 'social' care within the NHS

and Community Care Act (Department of Health, 1990) spelt out new challenges and responsibilities for case management, and transferred primary assessment responsibilities for the social care needs of older people to local authorities (Department of Health, 1991a,b).

In addition to the changing direction of service delivery and design, the 1980s also saw an early challenge to the medical domination of dementia. Beginning in the mid 1980s, Dr. Tom Kitwood and his colleagues at the Bradford Dementia Group conceptualised a new approach to the social understanding of people with dementia (see: Kitwood, 1988; 1989; 1990a,b; 1992; Kitwood and Bredin, 1992a,b). The basis for Kitwood's argument centred on the need to rebalance the 'technical framing' of dementia and complement it with a philosophy that was constructed from personhood and person-centred values (Kitwood, 1988). As Kitwood and his colleagues cogently argued, 'the dementia' is not the problem, it is 'our' (individual, carer, professional, society) inability to accommodate 'their' view of the world. This, Kitwood and Bredin (1992a) suggested, creates a 'them' and 'us' dialectic tension, a tension reinforced over the years by the devalued status of someone who is 'demented'.

Kitwood and Bredin (1992a p.10) argued that there had been 'no coherent theory of the process of care' for people who have dementia. Interestingly, as with Alzheimer (1907), the development of their social theory of personhood as applied to dementia was constructed from an individual case history, or psychobiography as it was named (see: Kitwood, 1990a). This psychobiography was conducted by Kitwood with a person called 'Rose' whose struggle to assert her personality through the mask of her confusion triggered Kitwoods' thoughts on the need to reconceptualise the experience of dementia. After attempting to agree a meaning to Rose's actions and behaviours with colleagues at the Bradford Dementia Group (see: Kitwood, 1990a for a fuller discussion), they constructed a multi-dimensional theory which outlined social and subjective influences as experienced by Rose. Whilst the emerging theory focused predominantly on the more 'severe' stages of dementia in residential care, mirroring Rose's personal situation, it nevertheless placed the person with dementia at the heart of the process.

Kitwood (1988) attempted to reconceptualise the dementing process along the following lines:

$$SD = P + B + H + NI + SP$$

In this equation SD refers to senile dementia and is viewed as a complex interaction between the remaining five elements of the equation:

- P = Personality, which includes coping styles and defences against anxiety;
- B = Biography, and responses to the vicissitudes of later life;
- H = Health status, including the acuity of the senses;
- NI = Neurological impairment, separated into its location, type and intensity;
- SP = Social psychology which constitutes the fabric of everyday life.

Kitwood (1988) suggested that the equation accounts for most of the phenomena associated with the range of dementias and explains the unique course of each person's dementia by combining 'structural' and 'conjunctural' means of explanation. This theory, which still requires full empirical testing, is Kitwood's (1990b) astute observation on the past failing of care environments and approaches to people with dementia, which, for Kitwood (1990b), amounted to the development of a 'malignant social psychology' that inhibited the full expression of people with dementia. Crucial to the emerging theory was the acceptance of the construct of 'personhood' and the recognition that a 'malignant social psychology' had been developed which 'beared down powerfully' on those with dementia (Kitwood and Bredin, 1992a). Kitwood (1990b) outlined ten components that illustrated the elements of this 'malignant social psychology' as involving:

- Treachery: The use of dishonest representation or deception in order to obtain compliance;
- Disempowerment: Doing for a dementia sufferer what he or she can still do, albeit clumsily or slowly;
- Infantilization: Implying that a dementia sufferer has the mentality or capability of a baby or young child;
- Condemnation: Blaming; the attribution of malicious or seditious motives, especially when the dementia sufferer is distressed;

Intimidation:	The use of threats, commands or physical assault; the abuse of power;
Stigmatization:	Turning a dementia sufferer into an alien, a diseased object, an outcast, especially through verbal labels;
Outpacing:	The delivery of information or instruction at a rate far beyond what can be processed;
Invalidation:	The ignoring or discounting of a dementia sufferer's subjective states; especially feelings of distress or bewilderment;
Banishment:	The removal of a dementia sufferer from the human milieu, either physically or psychologically;
Objectification:	Treating a person like a lump of dead matter; to be measured, pushed around, drained, filled and so on.

Underpinning these observations is the belief that if the elements of a 'malignant social psychology' can be identified, appraised and overcome, then care (both for family and professional carers) can be improved with the result that, for the person with dementia, a greater sense of personal 'well-being' can emerge. Indeed, a process of Dementia Care Mapping (Kitwood, 1990b; Kitwood and Bredin, 1992b) for evaluating the care process in formal settings has been established to operationalise the philosophy behind the theory. Moreover, Kitwood and Bredin (1992a) suggest that a positive change to the social environment will cause a reversal of the dementing process, or 'rementia' as they termed it, that actively challenges the medical stage theory of dementia (see: Table 3 p.22). Such a paradigm shift has implications for the caring professions as people with dementia are now seen to exert a sense of agency, an agency that can only be facilitated through a change of professional attitude and culture.

1.7 Summary

As this chapter has highlighted, the association of memory loss with ageing has been documented since ancient times. However, it was only in this century that medical advances have identified, and classified, the most common conditions. In European countries Alzheimer's disease is the most prevalent form of dementia, although clinical uncertainty over the characteristics of mild dementia has resulted in a criticism of present epidemiological studies. Despite these limitations it is acknowledged that

advancing age is directly correlated with dementia, with the oldest-old in society being most at risk. In contrast, the incidence and prevalence of younger onset dementia is less clear, with additional studies being required. In the UK significant developments in social policy relating to carers and people with dementia have been slow to emerge, although recent changes to community care legislation have implication for the funding, assessment and case management of people with dementia. Recently, there have been challenges to the medical dominance of dementia by constructing a social theory of dementia, one that views the 'problems' of dementia as located within societal attitudes, rather than the individual him or herself. This shift in the understanding of dementia has implications for the caring professions, challenging the bases for intervention.

The above represents the background to, and the context for, the author's understanding of dementia at the time that the study upon which this thesis is based began. The author, as a community psychiatric nurse, was influenced by the newly emerging policy frameworks and the alternative theoretical approaches to the experience of dementia. In particular, he was concerned with the needs of family carers as this formed a significant part of his clinical work. The next chapter turns attention to the literature on family care in dementia at the time the study commenced (late 1992) in order to highlight existing understanding and knowledge.

CHAPTER TWO

CAREGIVING AND DEMENTIA: A REVIEW OF THE LITERATURE

**Studies have not clarified how specific behaviors contribute to the burden of home care
(Zarit, Reever and Bach-Peterson, 1980 p.650)**

2.1 Introduction

Building on the seminal work of Zarit, Reever and Bach-Peterson (1980) the 1980s were a fertile period for the exploration of caregiver stress in dementia care. This extensive literature has been summarised in reviews such as those by: Morris, Morris and Britton (1988); Barer and Johnson (1990); Dhooper (1991); Kuhlman *et al.* (1991); and Vitaliano, Young and Russo (1991). This chapter identifies key aspects of this comprehensive literature and outlines the main research and practice trends in family caregiving for people with dementia, up to the start of the empirical component of the thesis.

The chapter begins by reviewing the theoretical underpinnings of caregiving research which has been informed largely by the transactional model of stress and coping (Lazarus, 1966), following which attention will be turned to gender and spousal caregiving. Next, an overview of the key transitions in care will be discussed, together with a consideration of the more diffuse aspects of providing care to people with dementia, including an exploration of meaning, reciprocity and existential issues in caregiving. Particular attention will be paid to the work of Hirschfield (1981; 1983) and the development of 'mutuality' as a concept to explore the underlying dynamics and motivating factors for caregiving in dementia. An outline of the potential satisfactions of care follows, before consideration is given to the emergence of temporal models of dementia, as constructed from the caregiver's perspective. Attention will centre mainly upon the eight stage model of dementia developed by Wilson (1989a,b), as this significantly influenced the context and direction of the study described in this thesis. The chapter includes a review of information and service needs for carers of people with dementia, and concludes with a rationale for the initial research question.

2.2 Context of Caregiving

In the UK, as Gilhooly (1986) suggested, the majority of people with dementia (five out of six) live in the community with the help of family, friends and the wider support network (see also: Bergmann *et al.*, 1978; Poulshock and Deimling, 1984). A similar situation is apparent in the USA (Shanas, 1979), with carers generally expressing their willingness to provide the type of support needed (Brody *et al.*, 1983). Reliance on family care to sustain people with chronic illness at home underpins community care policy in the UK (Department of Health, 1990; Social Services Inspectorate, 1991), with studies indicating that the caring role falls primarily on one person, usually a spouse or adult child (Green, 1988). Whilst most care is provided willingly, caring for a person with dementia can have a detrimental effect on the carer's emotional, social and physical well-being (see for instance studies by: Zarit, Reever and Bach-Peterson, 1980; Greene *et al.*, 1982; Thompson and Doll, 1982; Poulshock and Deimling, 1984; Zarit, Orr and Zarit, 1985; Chenoweth and Spencer, 1986; Haley *et al.*, 1987; Eagles *et al.*, 1987; O'Connor *et al.*, 1990a; Duijnste, 1992; Mace *et al.*, 1992). Moreover, in comparison to other caregiving groups, carers of people with dementia are at an increased risk of experiencing: depression (Coppel *et al.*, 1985; George and Gwyther, 1986; Haley *et al.*, 1987; Morris, Morris and Britton, 1988; Pruchno and Resch, 1989; Calder *et al.*, 1991; Baumgarten *et al.*, 1992; Given *et al.*, 1992); burnout, particularly for spouse carers (for a discussion see: Pagel, Becker and Coppel, 1985; Ekberg, Griffith and Foxhall, 1986); and erosion of their mental health status (Anthony-Bergstone, Zarit and Gatz, 1988).

Such findings first emerged in an early, and seminal, study by Grad and Sainsbury (1965). These authors measured the burden placed on carers caused by the discharge home of elderly psychiatric patients from an institutional setting. In so doing they distinguished between objective burden, that is, the behavioural dysfunctions and practical problems that were encountered by the carer, and subjective burden, the carer's emotional adjustment in terms of increased stress, lowered morale and so on. This conceptualisation of 'burden' can also be seen in a study by Sanford (1975), which was one of the first to explore stress and the experience of caring at home for a person with dementia. In this study the author interviewed fifty family carers whose relative was attending a 'geriatric unit' in one of three district general hospitals in London. The focus of the study was on carers whose dependent had experienced dementia for some time and the interviews explored the subjective and objective circumstances of care. His findings were that behavioural

disturbances, such as sleep disturbance (including: night wandering and shouting) and communication difficulties were poorly tolerated by carers and caused the greatest feelings of stress. On the other hand, attending to their dependent's activities of daily living caused comparatively little upset to the carer, particularly those tasks relating to the person's basic human needs such as feeding and washing.

Sanford (1975) also commented that services, in the guise of district nurses, intervened in areas of the carer's life where they felt best able to cope, but tended to overlook the more debilitating aspects of care as perceived by the carer. To improve this situation Panzarine (1985), in a later study, suggested that community practitioners might best intervene during the caregiver's period of anticipatory coping i.e. at the time when the carer is deciding what future action to take, thus helping to ameliorate the further build-up of stressors. This relationship between stress and coping has informed the majority of caregiving studies in dementia (see: Rabins, Mace and Lucas, 1982; Levine, Dastoor and Gendron, 1983; Pratt *et al.*, 1985; Quayhagen and Quayhagen, 1988; Harvis and Rabins, 1989; Mungas *et al.*, 1989; Pearlin *et al.*, 1990), and it is therefore important to have a more complete understanding of this area of the literature.

Early studies on coping tended to focus on the relationship between coping, the stressors of life and their effect on health status (see for instance: Janoff-Bolman and Marshall, 1982). In order to better understand this process, Morrissey, Becker and Rupert (1990) suggested that the context of stress is an important factor in determining coping and advocated that the transactional model of stress best characterizes this relationship. The transactional model builds on the work of Lazarus (1966) and, as the name suggests, views stress as resulting from a transaction between an individual and his/her environment. It is based upon a process of assessment, or appraisal, in which, initially, an individual considers the nature of an event and decides whether it poses a threat, harm or challenge. This period of consideration is known as the primary appraisal. If as a result of this appraisal a response is perceived as necessary, the potential response is compared to the individual's available coping resources (secondary appraisal). A coping response is selected and its effect on the original demand is then assessed (reappraisal). Stress is only said to result when there is a perceived mismatch between the nature of the demand and the individual's ability to respond effectively, by reducing the degree of perceived threat, harm or challenge. Using this approach the crucial determinant is not the objective nature

of the demand (stressor) itself, but its appraised impact. Hence carers in Sanford's (1975) study were able to tolerate the seemingly stressful event of their dependent's incontinence, but were less well able to manage the social embarrassment that such behaviours evoked. In other words, events only become stressors when the mind identifies them as such (see: Spaniol and Jung, 1987). This distinction is important as it allows for the possibility of the same event being differentially stressful for different people, or even for the same person at different points in time.

Using this transactional approach most of the caregiving research during the 1980s considered the relative importance of objective and subjective burden, with a number of differing models emerging (see for example: Zarit, Reever and Bach-Peterson, 1980; Cantor, 1983; Poulshock and Deimling, 1984; Deimling and Bass, 1986; George and Gwyther, 1986; Zarit, Todd and Zarit, 1986; Pearlin *et al.*, 1990). A significant study in establishing the burden of dementia caregiving utilising a transactional approach was undertaken by Zarit, Reever and Bach-Peterson (1980) and resulted in the development of a 29-item 'Burden Inventory' as the first well-validated instrument in this area (see: Greene *et al.*, 1982; Rabins, Mace and Lucas, 1982; Fitting *et al.*, 1986; Quayhagen and Quayhagen, 1989; Mathew, Mattocks and Slatt, 1990). Unwittingly, the study also promoted an approach to assessment that centred around the negative impact of dementia on the carer's life, with this emphasis influencing the direction of caregiver research for most of the 1980s.

Items on the 'Burden Inventory' were generated largely from the authors' collective research experience and addressed a number of areas of concern, namely: health; finances; social life; and interpersonal relations. Building on their subsequent interviews with carers (n=29) and administration of the 'Burden Inventory', Zarit, Reever and Bach-Peterson (1980) found that the perceived extent of burden was not related to the behavioural problems caused by dementia, but 'was associated with the social supports available, specifically the number of visitors to the household' (p.653). Their primary recommendation for practice was to review the informal support available for carers. This finding was later supported by Cantor (1983) who recommended that those visiting should have adequate training and support. However, Gilleard *et al.* (1984) suggested that the level of informal support available in home care was not significant, and that stress was age related (the higher the age the lower the perceived level of stress) and the

accumulation of problems, such as: not being able to go out; impaired hygiene; incontinence, and so forth. Interestingly, Greene *et al.* (1982) found that the greatest strain on carers was not the amount of instrumental care, but the 'apathetic inactivity' on the part of the person with dementia. In contrast, George and Gwyther (1986) suggested that the construct of burden was too limiting to describe the complexities of caregiving and recommended that the concept 'well-being' be used in its place.

As a result of such studies it quickly became evident that the changing nature of dementia resulted in shifting dependency needs which, for the carer, may cause stress at different points and times in the caring history. Moreover, as suggested earlier, how carers adjust and cope was seen to depend largely upon how such stressors are appraised. For instance, in the early stages of Alzheimer's disease, carers often have difficulty in adjusting the pattern of their lives to the unexplained behavioural and emotional shifts with which they are suddenly confronted. These may include: a newly found difficulty in holding a conversation; spatial and orientation problems; personality change(s); inappropriate dressing; and verbal repetition during conversation (see: Reed, Jagust and Seab, 1989; Morgan and Laing, 1991). For some carers, coping and adjusting to these new and, until the time of diagnosis, unexplained behaviours, is the most difficult and challenging part of the entire caregiving trajectory (Chenoweth and Spencer, 1986; Bowers, 1987; Clarke and Watson, 1991). Later incremental demands made by dementia are a consequence of its progressive but unpredictable nature, highlighting the need to consider how the disease develops over time as suggested by Rolland (1988). This highlights the importance of locating dementia within a temporal context, an issue that will be explored in greater detail later in this chapter. Prior to this, however, attention is turned to other aspects of variability in the experience of caring for a person with dementia, particularly that of gender and spousal caregiving.

2.3 Gender and Spousal Caregiving

Traditionally, caregiving has been seen as a female responsibility with wives and daughters undertaking the majority of formal and informal care (Cantor, 1983; Johnson and Catalano, 1983; Brody, 1985; Lewis and Meredith, 1988). However, Horowitz (1985) reported that the primary caregiver will usually be a spouse (where one exists), with Fengler and Goodrich (1979) describing the spousal caregiver as 'the hidden patient'

(p.175). This observation was reinforced by Cantor (1983) when she found that spouses were the most 'at risk' group of caregivers, whilst being (at the time of her study) the most overlooked.

Since Cantor's (1983) observation, studies have consistently documented the high level of stress associated with the spousal caregiving role (see for instance: Zarit, Reever and Bach-Peterson, 1980; Brody, 1981; Gilhooly, 1984; Lund, Pett and Caserta, 1985; Zarit, Todd and Zarit, 1986; Pruchno and Resch, 1989). Fitting *et al.* (1986) also reported that husband and wife caregivers of their spouse with dementia experienced similar degrees of objective burden, but that wives reported more depressive symptoms. Building on this finding, Pruchno and Resch (1989) contrasted the predictors of depression amongst spousal caregivers of people with Alzheimer's disease and found that for wives burden was associated with poorer health and less emotional involvement. However, the external validity of such studies can be questioned as they either focused on older caregivers (Zarit, Reever and Bach-Peterson, 1980; Zarit, Todd and Zarit, 1986; Fitting *et al.*, 1986; Barusch and Spaid, 1989; Pruchno and Resch, 1989), or younger spousal carers were not differentiated from older carers in reporting findings (see: Zarit, Reever and Bach-Peterson, 1980; Barusch and Spaid, 1989; Pruchno and Resch, 1989). For a fuller understanding, greater attention needs to be given to spousal caring and the younger person with dementia, an agenda that, as the study began, was only just beginning to emerge (Cox, 1991; Furst and Sperlinger, 1992).

A different orientation to the subject of gender and caregiving was adapted by Mathew, Mattocks and Slatt (1990) who explored the coping patterns of two groups of male carers. The first group (n=12) were caring at home for their female relatives, which included five spouse carers. The second group (n=8) were male carers who attended a support group having placed their dependent in nursing home care. Whilst the numbers in the sample were small, the authors found that men tended to approach their caring 'through a leadership role' (p.22) and were able to find moments of intense satisfaction. This was manifest by the men in the study through their ability to find and share humorous caregiving situations. Interestingly, Mathew, Mattocks and Slatt (1990) also commented that respondents in their sample were more likely to continue their caring role for longer than female carers, and would not consider institutionalization until the dementia became very severe. This finding supports that of Fitting *et al.* (1986) who found that a significant

percentage (25%) of men carers in their sample (n=28), as opposed to female carers (n=26) matched for age and caregiving characteristics, reported an improvement in their relationship with their spouse 'since assuming the caregiving role' (p.251). Consistent with the later study by Mathew, Mattocks and Slatt (1990), Fitting *et al.* (1986) suggested that this may be due to men being able to more successfully distance themselves from the caregiving situation and see their role predominately 'as a job'. However, Barusch and Spaid (1989) disputed these findings and suggested that the difference in perceived burden between men and women carers centred solely on the age of the carer (echoing the earlier work of Gilleard *et al.*, 1984) and not on other coping characteristics. Such findings do however raise the prospect of caregivers having satisfactions, an issue that will be explored more fully later.

Focusing on Alzheimer's disease, Lund, Pett and Caserta (1985) also found that the spouse was the caregiver most likely to anticipate the admission of their partner into continuing care. During their two year longitudinal study on subjective burden in spousal caregiving, Zarit, Todd and Zarit (1986) suggested that at the time of admitting their spouse to a continuing care environment, wives were assessed as having a greater burden in undertaking this task.

In a UK study based on 34 married couples mostly aged over 75, Pollitt, Anderson and O'Connor (1991) reviewed the experience of caring for an elderly spouse with dementia. The sample was further divided into groups which were differentiated by the diagnosed degree of dementia (see: Table 3 p.22) i.e. 'mild' group (n=16); 'moderate' group (n=14); and 'severe' group (n=4). Nineteen men and 15 women comprised the sample. Interestingly, in reporting this study, the 'mild' group received no visits from professional care staff and obtained their support, if any, via home support workers; in contrast, the 'moderate' group were reported as receiving the most professional service contact. However, transcending this finding, is that during each interview no one carer in the sample recognised the clinical staging of dementia, and they experienced considerable difficulty in attaching this (professionally) driven set of criteria to the person they were caring for. Instead, carers attached meaning to the actions of their spouse through the amount of 'problems', if any, they presented, and what resources they could call upon in order to generate solutions. From the perspective of a spouse carer of a person with dementia, what constituted a clinical definition of 'mild

dementia', for instance, was relatively meaningless in the context of their day-to-day life.

To address this imbalance in understanding, and to further their research inquiry, Pollitt, Anderson and O'Connor (1991) developed a new 3 stage classification which they considered may better represent the lives of carers. Group 1 now comprised carers that refused to accept that the person they were caring for had dementia; as the authors reported, this was especially evident in those caring for a person with 'mild' dementia. Group 2 was also described as denying the existence of dementia and viewed the physical disability as the area that required the most attention. Finally, the carers in the third group were perceived as accepting dementia as the main presenting 'problem' and were, from the operational definition, 'well adjusted' to their role. The development of this 'new staging' was reported in the study as reflecting more accurately the experiences of carers and, therefore, of being a more reliable method of data collection. As studies on the gender of carers suggest, there is considerable variation in how caregiving is experienced, with the role of gender being inconclusive. Perhaps one of the lessons to be learnt is that to better reflect the experiences of caring, it is first necessary to gain a carer's perspective on its meaning. It is to a consideration of this issue that the chapter will now turn.

2.4 Finding Meaning in Care

A significant contribution to advancing understanding on the meaning of care from the experiences of carers of people with dementia emerged from a study conducted in the USA by Hirschfield (1981; 1983). In this study the author interviewed 30 caregivers of people with dementia (the sample also including unstructured interviews with 7 people with mild cognitive impairment), and developed the concept of 'mutuality' as 'the most important variable' (p.26) to explain the social relationship between families and the person with dementia. In outlining the properties of 'mutuality', Hirschfield (1983) suggested that:

... it grew out of the caregiver's ability to find gratification in the relationship with the impaired person and meaning from the caregiving situation. Another important component to mutuality was the caregiver's ability to perceive the impaired person as reciprocating by virtue of his/her existence. (p.26)

Thus mutuality is based on the carer's ability to find meaning, gratification and reciprocity in their caregiving role (see also: Horowitz and Shindelman, 1983). According to Hirschfield (1981; 1983) varying degrees of mutuality could be identified:

- High mutuality from within the relationship (internally reinforced mutuality);
- High mutuality due to circumstances (externally reinforced mutuality);
- Low mutuality;
- No mutuality survived.

Feelings of low mutuality were synonymous with poor adjustment within the family and negative feelings towards the person with dementia. This negative adjustment was as likely to be present in those caring for a person with mild dementia as those caring in later stages. Hirschfield (1983) outlined three other variables which influenced the planned continuation of home care, these being: management ability; morale; and tension. Interestingly, the operational definition of tension included the feeling of 'being tied down', and this was conceptualised as the carer's restricted opportunity for free time and lack of individual privacy. Indeed, it was the combination of low/no mutuality coupled with 'severe tension' that Hirschfield (1983) believed to be the driving force for carers considering the person with dementia's admission into care, and thus predicting the breakdown of home care (for a validation of this assessment see later studies by: Hutton *et al.*, 1985; Gilhooly, 1986; Cohen, Tell and Wallack, 1986; Colerick and George, 1986; Lieberman and Kramer, 1991). Hirschfield (1983) illustrated the existence of this phenomenon via the following case example of 'no mutually existing':

I used to love my father; I used to love to see him come through the door. Now when he comes I hate it. It is like my emotions have changed. I hate to think that I hate my father now, but I just hate the disease he has. It's like I consider him dead three or four years ago ... some people say 'that's your father' but when you hear a door banging all night long you can't sleep. (p.28)

It's uncertain if it is the person with dementia or the disease that is being blamed in this case example, but it highlights the importance of establishing the nature and quality of the relationship during professional assessment of need (see also: Gilhooly, 1984; George and Gwyther, 1986; Bowers, 1988a; Morris, Morris and Britton, 1988).

With the son's description of the father being considered dead 'three or four years ago' Hirschfield's (1983) case illustration also identifies another significant concept in the literature, namely anticipatory grief and social death. Sweeting and Gilhooly (1990) have provided an authoritative overview of the literature of anticipatory grief with Aldrich (1974), drawing on his earlier work from the mid 1950s, defining the concept as 'any grief occurring prior to a loss, as distinguishable from the grief which occurs at, or after, a loss' (p.4). Sweeting (1991) pioneered the application of anticipatory grief to the process of caregiving and dementia, including in her application the notion of social death of the person with dementia. Kalish (1968 cited in Sweeting, 1991 p.6) defines the latter concept as one 'when people who once knew an individual as alive now think of him as being, for all practical purposes, dead or non-existent'. Indeed, Sweeting (1991) suggests that when relatives are eventually able to discuss the death of their dependent (real or imagined) they felt unburdened at the ability to share and confide their fears. This need to feel 'unburdened' again highlights the invisible work undertaken by carers in living with the experience of dementia.

A further study which discussed such existential issues in the provision of family care to people with dementia was conducted by Levine *et al.* (1984). Here, the authors used four existential themes to describe the act of providing family care for a person with dementia, these being: a sense of death; isolation; freedom; and meaning. Whilst the paper contained an overwhelmingly negative image of dementia, Levine *et al.* (1984) advised that meaning in the provision of family care was transitional in nature, and that the reality of living in the shadow of constant death suggested that choices had to be made 'in consideration to this context'. As Levine *et al.* (1984) succinctly described it:

The notion of the burden of supporting a demented relative is meaningful is the perception of the spouse, and not the health care professional. What is meaningful for governments and institutions is not necessarily meaningful for the wife of the demented patient. (p.222)

In other words, services are only likely to be accepted by the family carer if they are seen as being complementary, meaningful and facilitative within their own construction of dementia. As the 1980s progressed this message was reinforced as it became increasingly clear that to focus on the burdens of care alone, albeit from a subjective standpoint, was inadequate. Qualitative studies by researchers in the 1980s from the USA

and Canada began to make a significant contribution to understanding the motivating factors involved in providing home care to people with dementia (see: Hirschfield, 1981; 1983; Bowers, 1987; 1988a; Hasselkus, 1988). For example, following interviews with 32 adult child carers (predominately daughters) caring for their parent with varying degrees of dementia, Bowers (1987) developed a five stage temporal model of types of care: anticipatory; preventive; supervisory; instrumental; and protective. Bowers (1987) suggested that protective caregiving, i.e. protecting the self image of the parent with dementia was, for adult child carers, the most stressful part of providing home care, although later she substituted this category with 'preservative caregiving' when reporting the carer's emotional adjustment to the person with dementia following their move into institutional care (Bowers, 1988a).

Drawing attention to the work of Bowers (1987; 1988a) and using an ethnographic research design, Hasselkus (1988) explored the meaning of the caregiving experience and the carer's perspectives on their relationship with professional workers. Hasselkus (1988) interviewed 15 family carers (only one male carer was present in the sample) for one hour and visited each family in the sample four times. Analysis of the data revealed the existence of five 'themes of meaning', and these were reported as a sense of:

- Self
Concern for self;
Consideration of personal capabilities;
Increased sense of personal causation.
- Managing
Standards of care being judged by orderliness and cleanliness;
Getting enough activity;
Getting things done;
Devising and implementing elaborate routines.
- Future
A 'sense of doom' pervading the caregiving situation;
Showing concern about own health needs.
- Fear and risk
A fear of change, or anything that may cause a change of activities governed by the need to maintain safety.

- Change in role and responsibility Distancing and changed asymmetry in relationship;
Being in limbo in the relationship.

One of the most salient findings of the study was that the carer was uncertain over the professional's role in their life, and that there was a 'constant battle' over the ownership of care, particularly as carers believed they were in possession of 'special knowledge' about the individual and their care needs. This emphasis on ownership of care was illustrated in the text by one carer rejecting the hospital's management of her mother's incontinence as it did not fit in with what the carer considered to be best practice (see also: Stokes, 1987). Moreover, Hasselkus (1988) reported that examples of the professionals' sharing their expert knowledge were 'surprisingly rare' (p.689) which indicated to the carer that the role of professionals was more of a critical observer than that of helper. These five existential themes were consistent with the emphasis on discovering the invisible work conducted by carers, work which is often overlooked in assessment and intervention practice by professional workers.

Perhaps most significantly of all, the work of Hirschfield (1981; 1983) drew attention to the possible influence of satisfactions in caring, an issue that will now be considered further.

2.5 Exploring the Satisfactions of Care

As noted earlier, Hirschfield's (1983) concept of 'high mutuality' rested upon the premise that carers could find gratification and a source of meaning in their actions. It is important to highlight that exploring satisfactions in providing home care, either within the dementia-specific literature or the wider gerontological context, was, at the start of the present study, under-researched. There was, however, some evidence of the potential importance of satisfactions. For instance, in Zarit, Reever and Bach-Peterson's (1980) pioneering 29-item 'Burden Interview', three of the questions related directly to satisfactions within the caregiving relationship, namely:

Question 14: I feel pleased about my interactions with my spouse.

Question 16: I feel useful in my interactions with my spouse.

Question 20: I feel that I am contributing to the well-being of my spouse.

Whilst these questions could largely be seen as reflecting positive statements of self-worth and personal growth for the caregiver, the published work mainly concentrated on the burdens of care and the subsequent examination of stress. Whilst it would be unfair to attribute the dominance of stress and caregiving studies to one paper (see: Zarit, 1988), there is little doubt that the work of Zarit, Reever and Bach-Peterson (1980) had a major impact. Indeed, it was not until the end of the 1980s that Motenko (1989) called for practitioners and researchers in dementia care to begin to redress the balance and search for the positives within the caring relationship. In his study Motenko (1989) conducted semi-structured interviews with 50 older women who were caring at home for a husband with dementia. One of the major findings was that gratification was associated with greater well-being and that the ability to find meaning, and establish continuity in the caregiving relationship, were more important than the amount of care provided; a finding previously noted by Hirschfield (1981; 1983). As Motenko (1989) explained, spouses who experienced reciprocity within the relationship and viewed their caring as nurturing (i.e. providing tender loving care) were more likely to experience high gratification.

Similar findings were reported by Kinney and Stephens (1989) in their description of the 'uplifts' of family caring; in particular, the pleasure associated with the behaviour of the care receiver and support from the social network. Kinney and Stephens (1989) noted that carers who were more intensely involved in the experience of providing home care were more likely to appraise caregiving events as satisfying. This is an interesting finding and points to the experience of self-growth and expertise developed during caring, especially, but not exclusively, within spousal caregiving. For instance, by interpreting questionnaire data (n=289) and telephone conversations with 13 family carers of people with dementia, Chenoweth and Spencer (1986) found that the overwhelming response to providing home care was 'devastating'. The early experiences of dementia were also found to be amongst the most difficult to manage, however there were a few carers in the study who reported the experience of dementia 'had actually drawn the family closer together' (p.270). Although Chenoweth and Spencer (1986) did not discuss this finding further within their paper, it drew attention to a hitherto neglected area. In reviewing the findings of qualitative interviews with 41 co-resident daughter caregivers, Lewis and Meredith (1988) reported that most of the sample had positive feelings about having cared and had 'a deep seated desire to care'

(p.5). Associated with this motivation to provide care, Lewis and Meredith (1988) also suggested that the co-resident daughters had a binding loyalty to their mother and a desire to protect her from the impact of the illness. Whilst the sample in this study was not dementia-specific, the findings elaborate upon the experience of providing care and highlight the potential for finding meaning within the role.

A further advance in the understanding of caregiving satisfactions was made by Nolan and Grant (1992) and their development of the Carers' Assessment of Satisfactions Index. Emerging from a study on hospital respite care (Nolan and Grant, 1992), the Carers' Assessment of Satisfactions Index consists of 30 statements drawn directly from carer's expressions of satisfaction within their relationship, with the sample representing a broad range of caring experiences. Nolan and Grant (1992 p.123 slightly abridged) suggested that four major categories accounted for a significant percentage of all positive statements, these being:

- The act of giving care to the dependent;
- That there was no real alternative;
- That carers feel appreciated and valued for their efforts; and
- Caring met basic psychic needs such as the desire to feel needed and wanted; caring also provided life with a purpose.

Elaborating on the second point, Nolan and Grant (1992) highlighted an emerging tension in that carers who admitted their dependent into care, knowing that there was no real alternative, experienced feelings of extreme guilt over their decision, guilt that was very difficult to reconcile. Consequently, carers were reluctant to consider any such admission as they felt that no-one but themselves possessed the necessary knowledge 'that was required to provide adequate care' (p.124). This latter statement intimates that carers viewed themselves as having skills and expertise in their role, an expertise that they wanted to have recognised and acknowledged, as suggested by authors such as Hasselkus (1988).

The end of the 1980s and early 1990s witnessed a move away from an overtly stress-related model of caregiving towards a more holistic orientation. Another manifestation of this was the emergence of temporal models of the caregiving experience.

2.6 Temporal Models of Dementia Caregiving

Arguably, the enhanced understanding of the caregiving experience which emerged in the late 1980s is most clearly evident in the development of temporal models of care, and in studies which adopted a trajectory framework (Corbin and Strauss, 1988). Nursing was often at the forefront of developing interpretive models of the dementia process grounded in understanding a carer's reactions over time. Undoubtedly, the study by Wilson (1989a,b) exerted a major influence on thinking in this area, and the present study in particular. For this reason, Wilson's (1989a,b) findings will be explored in detail so that emergent concepts can be discussed and critically appraised.

Wilson (1989a,b) used a grounded theory method on a purposive sample of 20 family caregivers of people with dementia (14 female; 6 male), using interviews to explore the experience of living with dementia and to interpret the processes and coping patterns of family carers. Data were collected by a trained psychiatric nurse research team, in the carer's own home. The interviews lasted a minimum of two hours and the team analysed their data using *Ethnograph*, an approach to data analysis that is perhaps not wholly consistent with grounded theory research and application (for a discussion see: Glaser, 1978 pp.55-82). Wilson (1989a,b) adapted an analytical approach first described by Hutchinson (1986) to outline an eight stage model on the course of Alzheimer's disease as experienced by family members. In the first paper relating her findings, Wilson (1989a) stated that:

From an interaction perspective, the unfolding course of Alzheimer's Disease {original capitalisation} is experienced by family caregivers as insidious, progressive and deteriorative. It is characterised by uncertainty, fear of the unknown, speculation and reinterpretation of the meaning of behavioural and cognitive changes observed in the relative. (p.42)

Building upon this observation, the temporal model begins with the initial stage of 'noticing', where family carers gradually become more aware of the bizarre, or aberrant, behaviour of the person they live with. This stage was reported as only being recognised in retrospect and no particular cognitive deficit or behaviour was cited by family caregivers in this study as alerting them to the fact that something was wrong. Noticing, therefore, was as a result of cumulative behaviour which was initially discounted and normalised. The processes of 'discounting and normalising' formed

stage 2 of the model, and at this point the changes were mainly attributed to old age until two conditions emerged:

- The unusual behaviour worsened; and
- A particular event took place which was sufficiently serious to make discounting it very difficult.

Wilson (1989a) gives an example of one family noticing changes for three or four years until one behavioural cue made it impossible to discount. This led to stage 3 'suspecting'. Wilson (1989a) suggested that 'pervasive uncertainty' characterised this stage with family members speculating about what was going wrong. This suspicion formed an acknowledgement that something more serious was happening and prompted family carers to search for explanations. In stage 4 'searching for explanations' Wilson (1989a) suggests that the decision to seek confirmation of a diagnosis was undertaken 'reluctantly' as families were increasingly aware of the financial costs and stress involved. The discovery that the person had probable Alzheimer's disease led some families to avoid further medical investigations, fuelled by the belief that nothing could be done anyway.

Stage 5 'recasting' describes how, once the diagnosis had been tentatively confirmed, families described themselves as re-appraising, retrospectively, various experiences with their demented relative; that is, they reflected back on their experiences to date within the context of the diagnosis. In stage 6 'taking it on', 'recasting' provides the basis for making informed decisions about whether to 'take on' care. Wilson (1989a) describes this as being a decision taken without full knowledge of the likely demands and implications of the role. Rather, the decision to take on family care is motivated by a sense of moral duty. Stage 7 'going through it' describes how dementia presents the family caregiver with a 'seemingly unending list of problems' (Wilson, 1989a p.43) which require resolution. These are tackled on a trial and error basis, with little or no practical help, support or respite. The experience is characterised as 'living on the brink' of the family carer's tolerance, with carers being continually confronted by negative choices in which decisions must be made, but without desirable alternatives. Wilson suggests that most family caregivers then come to terms with the erosion of their own physical and emotional well-being and now start to consider institutionalisation.

This leads to stage 8 'turning it over'. At this point family caregivers consciously and reluctantly let go of the direct care of their relative and entrust that care to an institution. Wilson (1989a) suggests that carers continue their role in a less visible capacity by undertaking daily visits, taking care of financial management and 'being there' during crises and transfers in and out of institutions. Wilson (1989a) acknowledged that this study offered 'a beginning knowledge basic to interpreting the meaning associated with their (family carers) experience' (p.44).

In her second paper (Wilson, 1989b) described more fully her substantive theory and the sub processes involved in providing home care. This was largely constructed around the basic social process of 'surviving on the brink' and related particularly to the stages of: Taking it On (now re-labelled stage: 1); Going Through It (stage: 2); and Turning it Over (stage: 3), with differing coping strategies being apparent in each of these stages.

Stage 1: Taking it On. Building on the initial model, this stage is predominantly made up of: uncertainty; unpredictability; lack of resources and information; financial strain. Wilson (1989b) suggests that to manage these negative factors, three main coping strategies are used: (a) self dialogue i.e. talking to yourself to gain inner strength to take on care: (b) seeking spiritual solace i.e. turning to religious practices and rituals: (c) unburdening i.e. talking to others who are non-judgmental. Wilson (1989b) suggests that this latter coping strategy is used selectively.

Stage 2: Going Through It. As highlighted earlier, this stage is associated primarily with escalating problems. These are described as: illness ambiguity (see also: Boss, Caron and Horbal, 1988); breakdown of shared meanings; maintaining activities of daily living; disrupted household patterns; family conflicts; financial strain; active resistance; agitation; violence; constant supervision; depletion of the caregiver's energy and 'putting one's own life in suspension' (Wilson, 1989b p.96). The conflicting demands made of the family carer are seen as disrupting family relations and routines. Again, to begin to cope with this situation, Wilson (1989b) highlights three main strategies: (a) taking care of business i.e. resolving legal and financial issues, shaping the environment: (b) selective resourcing i.e. embarrassment is seen as inhibiting service uptake and those services that are provided e.g. day care, are largely seen as inadequate with instrumental help seen as the most important source of support as the caregiving

progresses: (c) protective governing, this strategy is used to sustain the energy and coping capacity of the caregiver. It is dependent on three forms:

- i) Situational positioning: Eliminating situations that present problems and opting for those that are manageable;
- ii) Guarding personal time: Caregiver places a priority on activities judged most likely to enhance their ability to go on - this leads to;
- iii) Recharging through personal diversions: Seeking personal time and space within the act of giving care.

Stage 3: Turning It Over. This is seen as a gradual, considered process and a reversal of formally held positions. As Wilson (1989b) herself explains:

Placing an Alzheimer's disease relative in a nursing home is a dreaded eventuality and the decision poses the *ultimate* (emphasis added) negative choice for caregivers. (p.98)

Quite why this decision should be the ultimate negative choice is not really explored in the paper. In developing her substantive theory, Wilson (1989a,b) constructed the experience of family care and dementia squarely around negative images, there is no mention anywhere of any positive dimensions to caring or caregiving. Nevertheless the model has a certain coherence and suggests the need to understand caregiving as an evolving dynamic. Wilson (personal communication, 1992) did not develop the model further, although she expressed a desire for further refinement of the model, empirical testing and practice evaluation.

Elements of Wilson's (1989a,b) model can be found in the earlier work of Teusink and Mahler (1984). In this qualitative study, the emotional reactions of family carers at different points of the caregiving trajectory were retrospectively examined. Teusink and Mahler (1984 pp.153-154 slightly abridged) constructed a five stage model to document this process of adjustment, which was seen to shift through:

- **Denial:** In this stage family members were seen to make excuses for the 'patient' and attribute changes to normal ageing, the consequences of stress and so on;
- **Over-involvement:** Family members attempted to compensate for the 'patient's' losses as his/her deterioration became more obvious;
- **Anger:** In this stage family members became angry owing to the physical burden of care, and the embarrassment and frustrations caused by the 'patient's' condition. Teusink and Mahler (1984) suggested that, at times, this feeling of anger was displaced to the caring professions;
- **Guilt:** Here, family carers feel a sense of guilt over their impatience, anger and difficulty in accommodating to 'patient's' illogical and unrealistic behaviour and demands;
- **Acceptance:** In this final stage of the model acceptance is seen to emerge slowly owing to the insidious and progressive nature of dementia, as well as to the 'patient's' relative presentation of normal physical vigour and appearance during the early stages of the illness. Following acceptance, family members were seen to go through a prolonged grief process (this was not reported as a separate stage in the model) because the psychological death of the 'patient' occurred 'long before the death of his/her body'.

This last finding can be integrated into the concepts of anticipatory grief and social death for carers of people with dementia as discussed earlier in the chapter. Moreover, the stages of Denial - Acceptance bear more than a passing resemblance to the five stage model of death and dying suggested by Kübler-Ross (1970) a model which, in itself, has been applied to carers of people with dementia to describe their cycle of loss (see: Gilliard, 1992). Indeed, these interpretative accounts may say more about the experience of living with a chronic illness than about the specific situations in family caregiving and dementia.

Building on the temporal approach Willoughby and Keating (1991) were critical of previous dementia research as it failed to 'identify common patterns or beginnings or

end points in the process' (p.31), with little being known about the 'pre-diagnostic phase' of family caregiving, and how carers constructed an awareness that 'something was wrong with their relative' (p.28). Again following a grounded theory methodology, using a retrospective design, the authors conducted multiple unstructured interviews with 10 caregivers who had placed their relative in institutional care (3 female spouse carers and 7 adult children: 4 female and 3 male) who had been caring for between 1½ - 15 years. By utilising this research design Willoughby and Keating (1991) aimed to generate hypotheses about the nature and the process of caring for a relative with Alzheimer's disease. Analyses of the transcribed interviews resulted in the generation of a five stage process of change during family caregiving. The five stages of change that emerged were sequential, although the length of time for each stage varied. The authors described cognitively driven 'turning points' emerging from the data which signalled changes in attitude and thought prior to some action by the caregiver which affected their perceived control over caregiving.

Whilst containing some relevant findings, Willoughby and Keating's (1991) study moves very quickly into considering institutional care (stage 2) and stage 4 of the model refers to the caregiver's adjustment to the psychiatric institution. The model does not fully explore the process of home care prior to considering admission into care and gives the impression of being somewhat forced in its construction, especially in the description of stage 5 'moving on' when family solidarity re-emerges and the carers are 'able to make new friends' through their social interactions. However, Willoughby and Keating (1991) recognised that this was a working model and might not be generalisable to other caregiving situations.

Although varying in their sophistication and emphasis, temporal models were important additions as they began to highlight the need to provide support for carers consistent with the stages of the caregiving history.

2.7 Service and Information Needs

Building on the transactional model of stress outlined earlier, it became increasingly clear that eligibility for services should not be based exclusively on dependency criteria i.e. activities of daily living and so on, nor, equally, should the focus be exclusively related to

relationships and the more diffuse aspects of caregiving. In a comprehensive assessment neither side should dominate, and dependency factors need to be considered within a transactional model of stress which allows the carer to rate the stressful nature of each event. Moreover, exploring the underlying dynamics of the caring relationship over time emerges as an essential component of any service model. Such a re-orientation is essential if services are to be seen as useful by carers, although studies suggest that this is often not the case.

Levin, Sinclair and Gorbach (1989) in a comprehensive review of service provision for carers of people with dementia, found that vital support such as domiciliary services and day care were under used by carers. Overall, such under use appeared to hinge on three factors. Firstly, professional staff simply did not offer access to the service. Second, professional staff either failed to respond to, or act upon, a referral. Third, professional staff arranged services, such as day care, where the kinship tie was so intense that the service was seen as worthless by the carer. Unfortunately, this discrepancy is not an isolated phenomenon as a comprehensive study in the USA by Coyne (1991) drew similar conclusions about poor service uptake. The necessity for services to be more client (carer) centered was noted by Badger, Cameron and Evers (1990a,b). These authors urged service providers to be more sensitive to the information needs of carers and to issues concerning the gender of the caregiver, as had been reported previously by Fitting *et al.* (1986) and contemporaneously by Askham and Thompson (1990). In the study by Badger, Cameron and Evers (1990a,b), wives caring for husbands were much less likely than male carers to receive community nursing services, or home help, and there was evidence that carers were seen more as a resource to be utilized rather than a true partner in care (see also: Nolan and Grant, 1989; Nolan, Grant and Ellis, 1990; Nolan and Grant, 1992). If a true partnership is to emerge it is also important that carers are well informed and can make decisions based upon appropriate information.

In the early stages of caring providing information to carers of people with dementia is essential in helping them adjust to their new role (Zarit, Orr and Zarit, 1985; Watkins, 1988). However, studies have repeatedly reported that a structured, personalised and systematic approach to the provision of information to carers is the exception rather than the rule (Fortinsky and Hathaway, 1990; Coyne, 1991), despite the fact that information-giving frameworks are predicated as supporting the caregiver throughout their decision-

making processes (Zarit, Orr and Zarit, 1985; Watkins, 1988). Watkins (1988), for example, with a focus primarily on nursing, argued that the existence of a shared framework allows community practitioners and caregivers to 'jointly assess each patients ability to carry out their activities of living and to define actual problems' (p.19). However, such an information-giving role assumes that reliable and valid research-based information is available and that carers are viewed as partners in the decision-making process.

The role of information is well documented with Fortinsky and Hathaway (1990), in a study on information and service need among both current and former carers of people with Alzheimer's disease, arguing that both groups rated information as 'extremely important'. In this study carers requested information about direct care issues, for example: behaviour management techniques and incontinence management; education issues; genetic factors; the stages of Alzheimer's disease; and advocacy issues, such as lobbying and raising money. Fortinsky and Hathaway (1990) drew attention to carers' perceived need for high quality educational material throughout their caregiving career and concluded that:

... although most direct services are clearly in a greater need during the active 'hands-on' phase of caregiving, information about Alzheimer's disease is likely to continue as a need even after the caregiver is no longer responsible for daily care and provision. (p.608)

Consistent information-giving calls for a forging of a much closer partnership with carers and a considerable re-orientation of existing practice.

The need for a structured approach to information-giving is also evident in the literature exploring the efficacy of educational support groups for carers of people with dementia, in a range of contexts including: time-limited support groups associated with the emotional adjustment to being a carer (Barnes *et al.*, 1981; Marples, 1986; Brodaty and Gresham, 1989; Chiverton and Caine, 1989; Greene and Monahan, 1989); improving the coping patterns of family carers through skills training and sharing (Lazarus *et al.*, 1981; Zarit, Orr and Zarit, 1985; Gendron *et al.*, 1986; Simank and Strickland, 1986; Dellasega, 1990); and the ability of carer support groups (when combined with an educational component) to delay the admission of a person with dementia into institutional care (Greene and

Monahan, 1987). However, whilst support groups are largely viewed in a positive light, an experimental study by Haley, Brown and Levine (1987) suggested that no reduction in the existence of stress emerged between the experimental (n=27) and control (n=27) groups. These authors contend that the primary reason for this was that whilst carers enjoyed the experience of being in a supportive environment, they were more concerned with improving their caregiving abilities rather than decreasing their subjective stress (see also: Zarit, Anthony and Boutselis, 1987).

However, whilst information and access to information remain important features, it is essential that the inter-relationship between the carer and person with dementia is placed at the centre of service and assessment frameworks. Without the carer deriving a sense of meaning and satisfaction from their role, then information and domiciliary support services in themselves are unlikely to be sufficient. Carers, and people with dementia, need real choices and alternatives if the quality of their lives is not to diminish.

2.8 Developing the Research Approach: A Rationale

As this consideration of the literature has highlighted, whilst the 1980s and early 1990s saw a burgeoning of studies describing the experiences of carers of people with dementia, these were in an early stage of development and rarely used to inform practice. As a consequence the help that carers received was often seen as inappropriate (Twigg and Atkin, 1991). Moreover, a more complete understanding was limited as much of the previous research considered only the carer's problems and did not include the potential sources of satisfaction to be gained from the caregiving experience (Motenko, 1989; Lawton *et al.*, 1989), despite the fact that carers who report some satisfaction in their role appear to be less stressed than those who report none (Hirschfield, 1981;1983; Motenko, 1989; Lawton *et al.*, 1989; Nolan and Grant, 1992). Moreover, while the literature suggested that carers of people with dementia are often particularly stressed (Gilleard, 1984; Morris, Morris and Britton, 1988), few studies had explored the types of coping methods carers employ and which they identified as being the most useful (Gilhooly, 1984; Pearlin *et al.*, 1990).

At this point the author considered it important to build on new and emerging concepts and to begin to develop a more rounded body of knowledge to help inform policy and

practice. The context and timing were appropriate, with the recent emphasis on community care and the forging of partnerships between services and users (Department of Health, 1990). However, despite the move away from a pathological view of caring and the challenge to the medical hegemony in the field of dementia, a more complete understanding of the carer experience over time and how coping strategies were developed was still required. It was the desire to elaborate upon the way carers coped with their changing role that prompted the author to begin the initial study upon which the remainder of this thesis is based.

In reflecting upon the choice of methodology to operationalise the study, the author was struck by the insights generated by using grounded theory approach both in dementia care research (see for instance: Bowers, 1987; 1988a; Wilson, 1989a,b; Clarke and Watson, 1991; Willoughby and Keating, 1991), and the broader context of chronic illness more generally (see for instance: Strauss, 1975; Corbin and Strauss, 1988; Charmaz, 1990). Furthermore, in a leading text on the grounded theory approach, Chenitz and Swanson (1986) suggested that grounded theory makes its greatest contribution 'in areas in which little research has been done' (p.7). Its application to the lives and experiences of carers of people with dementia was therefore considered appropriate, and the manner in which grounded theory was operationalised in the context of the present study forms the basis of the next chapter.

2.9 Summary

Over the last two decades (up until 1992), there has been an extensive literature exploring the stresses and burdens experienced by carers of people with dementia. Studies have been largely underpinned by the transactional model of stress, and recent attention has focused on the role of satisfactions in ameliorating caregiving burden, with carers who are able to find satisfaction, reciprocity and meaning being more likely to be well adjusted to their role, and to experience less stress. Deriving mainly from nursing research, recent attention has been paid to developing temporal models of care, constructing the experience of dementia from the perspective of family carers. Whilst adding significantly to the literature, such studies have mainly focused on a negative perception of dementia, and have generally failed to elaborate upon the experience of satisfaction within caregiving. The present study aims to add to current knowledge by

exploring the temporal processes of coping within dementia, grounding any emerging insights in the experience of family caregivers themselves.

CHAPTER THREE

GROUNDED THEORY METHODOLOGY AND STUDY DESIGN – PHASE 1

Generating grounded theory takes time Glaser (1978 p.19)

3.1 Introduction

As noted in the last chapter, although the two decades up until the early part of the 1990s had witnessed considerable research interest and activity in the field of caregiving in dementia, the vast majority of studies focused on aspects of stress with relatively little attention being given to a more holistic approach to family care. Despite this there was growing awareness of the potential importance of satisfactions, and an appreciation of the benefits of taking a temporal dimension which recognised how carer's needs changed over time. From a policy and practice perspective there was also emerging evidence to suggest that services were more likely to be appropriately and selectively targeted if they were matched to carers' perceived needs at a given point in time.

This more holistic orientation resonated with the author's experience as a clinician (community psychiatric nurse) and it was the desire to further understand how carers of people with dementia coped with their role that provided the initial motivation for the reported study. Given the relative paucity of previous empirical work and the hope of developing a theoretical model that could help inform practice, a decision was made to consider the use of a grounded theory methodology. The author's interpretation of grounded theory and how it was operationalised in the context of this thesis forms the substance of this chapter.

Drawing predominantly on the work of Glaser and Strauss (1967) and Glaser (1978), the chapter presents an overview of the grounded theory methodology that was used to underpin the empirical component of this thesis. The chapter begins with a review of symbolic interaction(ism) as the conceptual basis for grounded theory, a fact overlooked by many (see for instance: Kratz, 1978; Currie, 1988; Willoughby and Keating, 1991;

Wilson, 1989a,b;), but not all (see for instance: Phillips and Rempusheski, 1986; Charmaz, 1990; Cowley, 1991) published grounded theory studies. The review of symbolic interaction(ism) highlights the influence of Mead (1970; first published 1934) and Blumer (1953; 1956) on the thinking of Anselm Strauss during his time as a student and, later, as a lecturer (1952-1956) at the Department of Sociology at the University of Chicago where both George Herbert Mead (earlier) and Herbert Blumer (concurrently with Strauss) had residence. Subsequently, the central tenets of the grounded theory methodology will be presented, drawing primarily on Glaser and Strauss's (1967) seminal text *The Discovery Of Grounded Theory: Strategies for Qualitative Research* (henceforward shortened to the *Discovery book*) and developed further by Glaser (1978) to assimilate the notion of basic social processes within a grounded theory methodology. These two texts, elaborated upon by Strauss (1987) and Glaser (1992), form the cornerstones of the author's approach to a substantive grounded theory on the experience of dementia as described in chapters 4, 5 and 6.

The initial study design and its operationalisation will then be described, explaining three broad approaches. Firstly, an overview of the interview process will be presented. Second, preparation for fieldwork will be explored, including: gaining the support of key personnel; funding the project; designing the semi-structured interview guide; and gaining ethical permission to conduct the study. Third, the chapter will conclude with the properties of the interview schedule, totalling 74 interviewees, that comprised the study sample.

3.2 Symbolic Interaction(ism): Beliefs and Values

To appreciate the philosophical and ontological basis for the development of grounded theory, attention is best turned to the University of Chicago and its Department of Sociology which was at its most influential from the 1920s to the mid 1950s with the work of George Herbert Mead, John Dewey and Herbert Blumer. Fearful of the potential confining and restrictive properties of the printed word, Mead (1970; first published 1934) left much of his thoughts on symbolic interaction to be passed down in the form of class or lecture notes prepared by himself for his influential course in social psychology at the University of Chicago (1914-1931). Following Mead's death in 1931, these lecture notes were collated by Charles Morris, a former student, into the much

cited and influential body of work *Mind, Self and Society* (Mead, 1970; first published 1934; see also: Mead, 1982 (edited volume by David L. Miller)).

The first edition of the psychology lecture notes (Mead, 1970; first published 1934) were later to prove highly influential for both Anslem Strauss, and a fellow student of sociology at the Bureau of Applied Social Research at Columbia University, Barney Glaser (for a discussion see: Stern, Allen and Moxley, 1982). During his time at Columbia University, Glaser was a student of Robert K. Merton whose lectures on middle-range theory building and the cultures of organisations were to prove highly influential as Glaser's own academic career progressed. By the end of the 1950s, Glaser had explored further some of Merton's theories on organisational structures and augmented this original thinking by assimilating a study of professional careers (a transitionary process) within the structure of organisations (see: Glaser, 1964); a theme to which Glaser would later return to illustrate further the application of the grounded theory methodology (Glaser, 1968; 1972).

As has been well documented, the Department of Sociology at the University of Chicago developed the tradition of pragmatism where the interactive, dynamic and changing processes of social life were seen as the key to understanding human systems (see: Manis and Meltzer, 1978; Bulmer, 1984a; Bowers, 1988b). This approach was articulated most clearly by Mead (1970; first published 1934) and Blumer (1962; 1969) who both claimed that the four customary means for empirical validation, namely: proper research design; replication; hypothesis testing; and operational procedures were inadequate as they gave no assurance that premises, problems and data relations were empirically valid. Instead, Blumer (1969) argued that the only way to acquire this assurance was 'to go directly to the empirical social world' (p.35). As Huber (1978) noted later, direct familiarity with the social world was necessary as sociologists held their theoretical positions 'tenaciously' and 'gratuitously accepted concepts and beliefs as inherently true' (p.414). Thus, to understand and interpret the world in which we live, the Chicago School of Sociology believed it was important to participate in social settings and seek to understand actions within the context of an observed setting. However, an uncomfortable question remained: 'how do we develop and assign an agreed meaning to what we are seeing in a changing social world?'

To address this dilemma, Mead (1970; first published 1934) developed a social theory (or construction) of the mind. Breaking with the psychological tradition of the time which saw the human mind as simply being an extended function of the brain, Mead (1970; first published 1934) suggested that brains were necessary to the emergence of mind, but that the existence of brains in themselves did not make a mind. Instead, Mead (1970; first published 1934) contended that it is the inter-relationship between society-social integration-using brains that makes the mind, and that this inter-relationship is a socially constructed process. Undoubtedly, this development of a social theory of mind is best expressed by Mead (1970; first published 1934) himself:

In defending a social theory of mind we are defending a functional, as opposed to any form of substantive or entitative, view as to its nature. And in particular, we are opposing all intracranial or intraepidermal views as to its character and locus. For it follows from our social theory of mind that the field of mind must be co-extensive with, and include all the components of, the field the social process or experience and behavior: i.e., the matrix of social relations and interactions among individuals, which is presupposed by it, and out of which it arises or comes into being. If mind is socially constructed, then the field or locus of any given individual mind must extend as far as the social activity or apparatus of social relations which constitutes it extends; and hence that field cannot be bound by the skin of the individual organism to which it belongs. (p.223 - footnote)

In Mead's (1970; first published 1934) view, therefore, the world of science was composed of that which is common to, and true for, various observers; the world of common or social experience as symbolically formulated. For Mead (1970; first published 1934) intelligent human behaviour is 'essentially and fundamentally social' (p.118) with the transformation of the minded, biologic individual into 'the self' taking place through the use of language, with language in turn presupposing the existence of a certain kind of society and physiological capacities in the individual organism (Mead, 1970; first published 1934; see also: Morris, 1970). In developing his thoughts on social interaction, Mead (1970; first published 1934) viewed language as being central to the development of meaning within the human social process. For instance, if the premise is accepted that all human beings have intelligence, then intelligence takes place, or is demonstrated, through the act of communication. Mead (1970; first published 1934 p.75) saw this demonstration as evolving on two levels. Firstly, by gestures on the lower planes of human evolution. Second, by significant symbols (gestures which possess meanings and are more than mere substitute stimuli) on the

higher planes of human evolution. As Morris (1970) himself suggested during the Introduction to *Mind, Self and Society*, the experienced world was conceived by Mead as:

... a realm of natural events, emergent through the sensitivity of organisms, events no more a property of the organism than of the thing being observed. (p.xix)

This distinction is important as it suggests that experience has a social dimension as 'the self' (or organism). Blumer (1962 p.97) later contended that the statement that the human being 'has a self' was Mead's key contribution to the development of social psychology as it suggested that human beings can be the object of their own actions i.e. they can act towards themselves as they might act towards others. Blumer (1962) attempts to clarify this more simply when he states that the conscious life of the human being, from the time of waking to falling asleep, is 'a continual flow of self-indications-notions of things with which he deals and takes into account' (p.182). The central process in such adjustment is the understanding and exchange of meaning. According to Mead (1970; first published 1934) meaning arises and lies within the field of relation between the gesture of a given human organism and the subsequent behaviour of this organism to another human organism by that gesture. In other words, if that gesture indicates to another organism the subsequent (or resultant) behaviour of the given organism, then it has meaning. This is clarified further by Mead (1970; first published 1934) as follows:

Meaning is a development of something objectively there as a relation between certain phases of the social act; it is not a physical addition to that act and it is not an "idea" {original emphasis} as traditionally conceived. (p.76)

Meaning, therefore, is implicit in the relationship of the various phases of the social act to which it refers, and out of which it develops. The development of meaning takes place in terms of symbolisation at the human evolutionary level. For Mead (1970; first published 1934), symbolisation constitutes objects not constituted before, objects which would not exist except for the context of social relationships wherein symbolisation occurs. Language, therefore, does not simply symbolise a situation or object which is already there in advance, it makes possible the existence or the appearance of that situation or object, as it is seen as being part of the mechanism whereby that situation or

object is created. Through this process an exchange of meaning is to be understood on three levels as:

- A state of consciousness;
- A set of existing organised relations; and
- Continuing mentally outside the field of experience into which it enters.

From this symbolic standpoint, therefore, a common world exists only in so far as there is a common group experience of the world; naturally, this perspective has ramifications for the development of social research to explore subjective experience. Blumer (1954) argued that by accepting this premise, generating a precise procedure to yield a definitive empirical content, which relies solely on 'standardised techniques and mathematical categories', would not establish genuine concepts related to the natural social world. An alternative paradigm is to accept sociological concepts as sensitising rather than definitive, with concepts dependent upon faithful reportorial depiction and analytical probing. Moreover, it was seen as vital that such probing remained in close and continuous relation with the natural social world (Blumer, 1954 pp.9-10).

In adopting this stance theory emerges from direct observation, with understanding of the meaning attached to the social world (Mead, 1970; first published 1934) requiring acknowledgement of the perspectives of both 'actors' (researcher and subject). Mead's conceptualisation relies heavily on the concept of 'self' which is viewed as comprising two analytically distinct but related concepts, the 'I' and the 'Me'. In the symbolic interactionist tradition the processes of the 'I' and the 'Me' are the keys to unlocking an understanding of human behaviour and action. Mead (1970; first published 1934) viewed the 'I' as the impulsive tendency of the individual, the initial, spontaneous, unorganised aspects of the human experience. The 'I', therefore, represents the undisciplined, unrestrained and undirected tendencies of the individual, which take the form of diffuse and undifferentiated activity; an example would be an immediate impulse of retaliation after being hit by another. The 'Me', on the other hand, represents the 'generalised other' within the individual, comprising the organised set of attitudes and definitions prevailing within the group and in any given situation.

As the 'I' provides the propulsion, and the 'Me' provides direction to an act, human behaviour is viewed as an on-going series of initiations of incipient acts by impulses (the 'I') and of guidance of such acts (by the 'Me'). By being able to address oneself from the standpoint of the 'generalised other', the individual has a universe of discourse, a system of common symbols and meanings with which to address him/herself, which are presupposed as the context for 'minded behaviour' (Meltzer, 1978 p.21). Thus, both Mead (1970; first published 1934) and Blumer (1962) hold that mental activity is an activity that goes on in the experience of the person; the activity is that of the person responding to him/herself and indicating things to him/herself. From the symbolic interactionist viewpoint, therefore, human conduct is seen as a series of reactions which are continually defined and refined by a common understanding of shared meaning and symbols.

3.3 Symbolic Interactionism: A Change of Meaning

Whilst acknowledging the 'profound' contribution of Mead (1970; first published 1934) to the development of social psychology, Blumer (1962) also criticised him for failing to develop the methodological implications of symbolic interaction for sociological study. Based on an earlier essay (Blumer, 1962), Blumer sought to capture the essence of Mead's views on symbolic interaction i.e. as a peculiar and distinctive character of interaction taking place between human beings, and apply it in a new direction, symbolic interactionism. Underscored by the belief that interaction was more than simply observable phenomena, Blumer's addition of (ism) to the end of interaction reflects the dynamic processes of people and cultures as they continually strive to define, and re-define, the context and meaning of their actions.

The accepted empirical grounding for symbolic interactionism was rehearsed in the seminal text *Symbolic Interactionism: Perspective and Method* (Blumer, 1969) when Blumer (p.3) stated that the approach fundamentally rested upon three premises, namely:

- That human beings act towards things on the basis of the meaning that things have for them;
- That the meaning of such things derives from the social interaction one has with one's fellows; and
- That these meanings are handled in, and modified through, an interpretative process.

It is clear from these premises that Blumer was concerned with uncovering the nature of meaning in the context of progressing symbolic interactionism. Whilst Mead (1970; first published 1934) used meaning as a neutral link between the initiating factors and the subsequent behaviour, symbolic interactionism, in contrast, suggested that the meanings that things have for human beings are valid in their own right. As Blumer (1969) contended, to ignore the meaning of the things toward which people act results in 'falsifying the behaviour under study' (p.3). Consequently meaning has a prime position in the formation of human behaviour.

For Blumer (1969) meaning arose through the process of interaction between people and their actions, and operates to define 'the thing' for the person. As such, symbolic interactionism views meanings as social products, as creations that are formed in and through the defining activities of people as they interact. Naturally, this implies an interpretative process, and Blumer (1969 p.5 slightly abridged) suggests the process has two distinct steps:

- The actor indicates to him/herself the things toward which he is acting; s/he has to point out to him/herself the things that have meaning. The makings of such indications is an internalised social process in that the actor is interacting/communicating with him/herself; and
- By virtue of this process of communicating with him/herself, interpretation becomes a process of handling meanings. The actor selects, checks, suspends, regroupes and transforms the meanings in the light of the situation in which he is placed and the direction of his action. Accordingly, interpretation is a formative process in which the meanings are used and revised as instruments for the guidance and formation of action.

In symbolic interactionism it is vital that this quest for action and meaning is studied in the empirical world for, as Blumer (1969) contends, reality for empirical science exists only in the empirical world, can only be sought and found there and that 'nothing is known to human beings except in the form of something that they may indicate or refer to' (p.22). Empirical science, therefore, is viewed as an enterprise that seeks to develop images and conceptions that can successfully handle and accommodate the resistance offered by the empirical world under study. In this way, Blumer (1969) states the 'proper picture' of empirical science as a collective quest for answers to questions directed to the resistant character of the given empirical world under study. To achieve this it becomes necessary to inspect the 'obdurate character' of that empirical world, a position referred to by Blumer (1969) as the 'cardinal principle of empirical science' (p.23).

For Blumer (1969) empirical science pursues the quest by devising images through exacting scrutiny of the empirical world. In contrast, symbolic interactionism views the role of methodology as detailing the principles that underline and guide the full process of studying the 'obdurate character' of the given empirical world. Blumer (1969 pp.23-28 abridged) highlights three highly important areas detailed by this approach to understanding methodology:

- a) Methodology embraces the entire scientific quest and not merely some selected portion or aspect of that quest. This involves:
 - i) The possession and use of an a-priori picture or scheme of the empirical world under study;
 - ii) The asking of questions of the empirical world and the conversions of the questions into problems;
 - iii) Determination of the data to be sought and the means to be employed in getting the data;
 - iv) Determination of relations between the data;
 - v) Interpretation of the findings; and
 - vi) The use of concepts.

On this last point, Blumer (1969) argues that concepts are seen to play a central role in the act of scientific inquiry as they are likely to be the terms in which the problem is cast. Moreover, they are usually the categories for which the data are sought and into which the data are grouped. Concepts, therefore, are the chief means for establishing relations between data and are seen as the anchor points in the interpretation of findings.

- b) Each part of the scientific quest, as well as the complete scientific act itself, has to fit the obdurate character of the empirical world under study; therefore, methods of study are subservient to that world and should be subject to test by it; and
- c) The empirical world under study, and not some model of scientific inquiry, provides the ultimate and decisive answer to the test.

As a qualitative methodology, grounded theory (as originally formulated) was influenced by these three foundations, particularly the notion that methodology embraces the entire scientific quest (see: Glaser and Strauss, 1967) and the central part played by concepts in theory building (Glaser, 1978; 1992). However, Glaser and Strauss (1967 pp13-14) questioned aspects of Blumer's own qualitative research using symbolic interactionism (see for instance: chapter 6 '*The Polish Peasant*' in Blumer (1969) drawn from an earlier essay), as it produced rich biographical description, but its focus was upon theory verification rather than theory generation. Indeed, whilst Blumer's influence on Glaser and Strauss' approach to viewing the social world was profound, this criticism of Blumer's own use of symbolic interactionism in social research settings added fresh impetus to their need to view theory generation from data as 'a legitimate enterprise' (Glaser and Strauss, 1967 p.7). Paradoxically, whilst denouncing the concept of theory verification, Glaser and Strauss (1967) were keen to make their new and evolving methodology as rigorous in its construction as the traditional experimental methods. Indeed, peppered throughout the *Discovery book* (Glaser and Strauss, 1967), and one suspects Glaser's influence in particular, is the insertion and use of terminology associated predominantly with the quantitative approach. Indeed, it was of prime importance for Glaser and Strauss (1967) that their new qualitative methodology should have the conceptual power to explain and predict, and that, as analogous to the use of a control group in experimental research, prospective researchers should set up a series of qualitative interviews independent of

the subject under study to guide and test the independent nature of their data analysis - a position both Glaser (1978; 1992) and Strauss (1987) would later reject as unworkable.

It was these variations, amongst many others, that contributed towards the unique foothold of grounded theory within qualitative methodologies. However, following their initial seminal work, Glaser and Strauss did not produce a further co-authored text on advancing the grounded theory methodology, or jointly invest in updating the original *Discovery book* (Glaser and Strauss, 1967) having vigorously disagreed in the late 1980s over its future direction (see mainly: Strauss and Corbin, 1990; Glaser, 1992). This left grounded theory open to many subsequent interpretations, such as extending the dimensional nature of its analysis (see for instance: Schatzman, 1991), exploring the dramaturgical aspects (see for instance: Bowers, 1987; 1988a) or removing its creative analytical coding frame and replacing it with another, more formulaic, approach (see for instance: Strauss and Corbin, 1990). All these subsequent interpretations, are, however, underpinned by the methodology that was outlined in the *Discovery book* (Glaser and Strauss, 1967).

Before the subsequent fragmentation of the grounded theory methodology can be explored further, and the author's rationale for pursuing a modified Glaserian approach outlined, a consideration of the initial formulation of grounded theory as suggested by Glaser and Strauss (1967), and advanced by Glaser (1978), is necessary.

3.4 The Grounded Theory Methodology: Background Issues

In the Preface to their *Discovery book* Glaser and Strauss (1967) wrote the following:

Our book is directed toward improving social scientists' capacities for generating theory that will be relevant to their research. (pp.vii-viii)

This emphasis was influenced by Glaser and Strauss': academic backgrounds; their previous exposure to naturalistic enquiry; their individual set of beliefs; their view of the social world; and their determination to align research and theory generation with the experience of the individual and their perspective on the social world. Methodological disquiet began for Glaser and Strauss during their first tentative forays into the field of sociological research inquiry at the turn of the 1960s, which resulted in

a gross dissatisfaction with contemporary qualitative methodologies, particularly ethnographic studies which they saw as 'too impressionistic' (Glaser and Strauss, 1967 p.15).

An important early monograph (Glaser and Strauss, 1965) focused upon the individual experience of death and dying, carrying forward the University of Chicago's interest in this phenomenon (see for instance: Kübler-Ross, 1970). However, whilst Kübler-Ross (1970) largely used phenomenology to generate her five stage model of the adjustment to dying, Glaser and Strauss (1965) set about an inquiry that was 'not at all medical in character' (p.viii), and wrote a broad set of research aims which were process driven and grounded in sociological inquiry. Because this study (Glaser and Strauss, 1965) significantly influenced grounded theory methodology, its aims (see: p.viii) are repeated below:

- How do nurses and physicians manage themselves and their patients while the latter are dying in hospital?
- How is the hospital's organization capitalized upon in this process?
- What forms of social action, transitory or more permanent, arise while handling the dying of people?
- What are the social consequences for the hospital and its staff, as well as for the patients and their families?

Glaser and Strauss (1965) met these aims by integrating symbolic interactionism with the principles of both qualitative and quantitative research, with the intention of building a middle-range theory. The 'new methodology' (it was not called grounded theory at this stage) attempted to explain and predict human behaviour within a defined area of study, in this instance during social adjustment to dying in hospital. A focus upon the experience of death and dying in hospital was a logical extension, and integration, of Glaser and Strauss' own research interests. For Glaser, the hospital allowed for the systematic study of the dynamics of an organisation, whilst for Strauss the symbolic perspective is evident in investigating the 'taboo' subject of death and dying; the practice of informing people (or not) of their terminal illness; and then observing stages of reaction to such events. Despite the importance of the topic it was

not until the last eight pages of their monograph (Glaser and Strauss, 1965) that they documented their 'new methodology'. The early genesis of the 'grounded theory' methodology is clearly discernible within these pages, particularly in the approach of constantly comparing data to allow properties and categories to emerge and then testing and re-testing such phenomenon in the next set of research observations and analyses.

By employing this approach to theory generation, Glaser and Strauss (1965) did, indeed, 'discover' something new and 'awareness contexts' emerged from the study as a theoretical abstraction that served to illustrate the experience of dying in hospital. Awareness contexts were seen to have temporal dimensions, with the properties of the dimensions depending upon the social situation and beliefs of hospital staff, moving from: closed awareness - suspected awareness - mutual pretense awareness - open awareness. Glaser and Strauss (1965) then applied structural conditions to each transition which moved people from one stage to another or, alternatively, locked them 'within a specific stage' (p.29). After completing this analysis, the concept of an 'awareness context' was taken out of the 'substantive' area of inquiry and applied to other settings; this originally involved other patients, family members and hospital staff. In effect, based upon its predictive properties, Glaser and Strauss (1965) generated, or perhaps this is better described at the moment as elevated, the abstraction of an 'awareness context' to 'formal grounded theory'. 'Awareness contexts' were therefore seen to have the ability to explain and predict phenomenon in other social settings, outside of the field and scope of the original study. This placed the discovery of 'awareness contexts' on a new plateau in the realms of the applicability and power of explanation of qualitative research findings. A fuller discussion on the differences between substantive and formal grounded theory will be presented later in this thesis.

Encouraged by the positive reception to their study, during 1966 Glaser and Strauss set about documenting the rationale that lay behind the generation of their theory of 'awareness contexts', and applied these steps to the drafts of the *Discovery book*. In all probability, it was the re-tracing and documentation of these steps and the reaffirmation of their epistemological beliefs, that makes an initial reading of the *Discovery book* so difficult for the uninitiated reader. This is apparent in some of the present author's notes after first reading the book, as indicated below:

Some thoughts upon a first reading - the Discovery book:

- Introduced the conceptual basis for grounded theory and said it worked, because the authors did grounded theory and said so;
- Provided an outline of how to do grounded theory, but failed to expand upon certain key parts, in the field of analysis in particular;
- Provided the potential researcher with relevant predictions, explanations, interpretations and applications, but failed to provide a framework for understanding fully the integration of qualitative and quantitative research concepts;
- Introduced a new language of conceptual description and coding, such as constant comparative analysis and theoretical saturation, without providing an adequate understanding of when such coding should end;
- Provided unworkable guidance on the use of literature prior to engaging in grounded theory study;
- Left the emergence of theory to trust and confidence; and
- Provided very little guidance on how to undertake a qualitative research interview to support the approach to data collection and analysis.

However, what the author failed to appreciate at the time were the remarkable insights and sheer enthusiasm Glaser and Strauss brought to their writings, and the difficult nature of blending competing ideologies. The *Discovery book* was, of course, an initial formulation and there was a need to refine some of its claims, and to empirically test others. This did not fully happen however as Anselm Strauss gradually distanced himself from the text (as he did from his co-author) believing that the scope for the misinterpretation of theory as process, as originally conceived, was evident. Moreover, other users of the methodology as set out in the *Discovery book* also began to question the validity of some of the claims made in the text, and had difficulty implementing certain passages, particularly those to do with data analysis and the meaning of theoretical sampling (see: Brown, 1973; Stern, 1980; Turner, 1981). Notwithstanding these difficulties the initial methodology has merit and the basic canons of the approach are now discussed.

3.5 Grounded Theory: Concepts and Properties

Augmented by other interpretations, but with the writings of Glaser and Strauss (1967) at its core, a synthesis of the central concepts and properties of grounded theory is presented below under the sub-headings: a) theory as process; b) the constant comparative method; c) theoretical sampling; d) theoretical sensitivity; e) the use of supporting literature; and f) tests for credibility. Where Glaser and Strauss' later writings are used to illuminate the debate, these will be cited accordingly.

a) Theory as Process

The central ideas and philosophy delineated in the *Discovery book* (Glaser and Strauss, 1967) were only ever meant to be a beginning. This was especially evident in the development of 'theory as process' (p.9) and in the strategic method of comparative analysis, which Glaser and Strauss (1967) saw as a general approach 'just as statistics exist for the experimental methods' (p.21), with the addendum that both approaches use the logic of comparison. Grounded theories exist to 'take hard study of much data' and Glaser and Strauss (1967 p.3 slightly abridged) believed that the inter-related role of theory within sociology was to:

- Enable prediction and explanation of behaviour;
- Be useful in theoretical advance in sociology;
- Be usable in practical applications - prediction and explanation should be able to give the practitioner understanding and some control of situations;
- Provide a perspective on behaviour - a stance to be taken toward data; and
- Guide and provide a style for research on particular areas of behaviour.

As such, Glaser and Strauss (1967) saw the role of theory in sociology as a strategy for handling data in research which provided modes of conceptualisation for describing and explaining. Thus, in conducting grounded theory the researcher attempts to give the data a more general sociological meaning, as well as to account for, and interpret, what has been found.

Glaser and Strauss (1967) believed that by making theory generation a legitimate enterprise they would be able to free research from the 'rigorous rules' of objective verification, assimilating verification instead into the on-going process of generating

theory. Accordingly, the canons of the deductive approach exist in grounded theory not only as tests of the generalisability of the study, but also as a method for theory modification. Not surprisingly, such a paradigm shift did not find much favour with proponents of other qualitative methodologies, as Glaser and Strauss (1967) were effectively challenging the independent nature of qualitative inquiry and promoting the integration of both approaches (for a discussion on the criticisms of grounded theory aligning itself to qualitative approaches see: Lincoln and Guba, 1985 pp.207-208). However, whilst it is relatively easy to be dismissive of Glaser and Strauss' views, it should be remembered that qualitative research had traditionally been viewed as a 'soft-data' social science (see: Leininger, 1985 pp.1-25), and cast as an endeavour rich in description but lacking sufficient empirical basis for true theoretical development (Glaser and Strauss, 1967).

By aligning elements of grounded theory with the positivistic paradigm, it is the author's opinion that Glaser and Strauss (1967) were attempting to strengthen the scientific veracity of their approach so that proponents of the experimental approach would have difficulty in dismissing it as producing the 'soft-data' of other qualitative approaches. Put simply, Glaser and Strauss (1967) wanted to be seen as part of a qualitative tradition (their reliance on inductive data analysis demanded it), but did not want their developing and evolving methodology to be so lightly dismissed. This position was clarified further by Glaser and Strauss (1967) when they introduced the meaning of categories and properties in developing grounded theory, and described the need for an emerging grounded theory to 'fit and work' i.e. to have the ability to predict and explain the data under study. By 'fit', in the generation of grounded theory, Glaser and Strauss (1967) were alluding to the need for conceptual categories to be readily (not forcibly) applicable to, and indicated by, the data under study. Similarly, theory was seen to 'work' if it was meaningful, relevant and able to explain the behaviour under study. To achieve this required a new approach to qualitative data analysis that went beyond rich, faithful depiction of social situations, and one which Glaser and Strauss (1967) named, interchangeably, the constant comparative method and constant comparative analysis.

b) The Constant Comparative Method

The purpose of the constant comparative method, which underpinned the use of concepts, was to explain, predict and seek relationships within data, as Glaser (1992) himself stated in this straightforward, but perhaps optimistic, summary:

Using {the} constant comparison method gets the analyst to the desired “conceptual power” {original emphasis} quickly, with ease and joy. Categories emerge upon comparison and properties emerge upon more comparison. And that is all there is to it. (p.43)

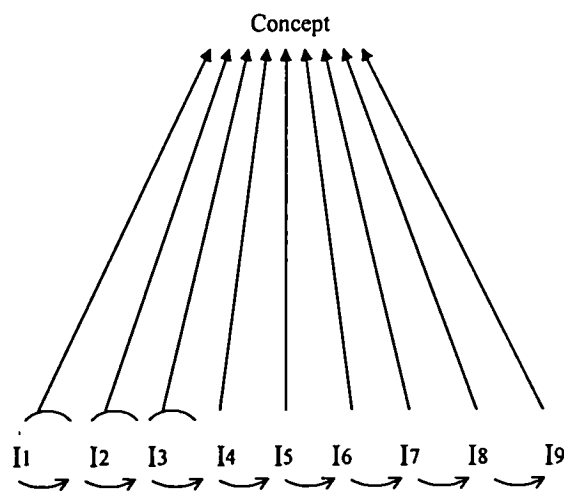
In grounded theory, theory and theory development are grounded in empirical data and in acts of everyday social life, although it is important to emphasise that in grounded theory development it is not the data which are important, but the conceptual category (or conceptual property of the category) that is generated from it. As Glaser and Strauss (1967) explain, a concept may be generated from one datum which then merely becomes one of a ‘universe of many possible diverse indicators for, and data on, the concept’ (p.23). Crucially, in grounded theory, it is the indicators that are then sought for comparative analysis, and there are seen to be four stages in this process:

- i) Comparing incidents applicable to each category;
- ii) Integrating categories and their properties;
- iii) Delimiting the theory; and
- iv) Writing the theory.

To discover these processes, it is envisaged in grounded theory that the researcher must interact with those being studied and strive to interpret their social world and meanings; the symbolic interactionist tradition in evidence as the ‘generalised other’. Consequently, conducting interviews, transcribing text and detailing, storing and referring to theoretical memos are central to the process of undertaking the grounded theory method; indeed, Glaser (1978) later viewed the writing of theoretical memos as the ‘core stage’ in the process of generating theory, with memos defined as ‘the theorizing write-up of ideas about codes and their relationships as they strike the analyst while coding’ (p.83).

Within the constant comparative method memoing is seen as a constant, unrestricted process that begins when first coding the data. This initial approach to finding relationships in data (however tenuous) enables the grounded theory analyst to reach levels of abstraction and ideation with an aim of developing theoretical ideas (codes). In developing such codes grounded theory is based on a concept-indicator model which directs the conceptual coding of a set of empirical indicators. The concept-indicator model provides 'the essential link' (Glaser, 1978 p.62) between data and concept which results in a theory generated from data. Diagrammatically, when undertaking grounded theory analysis via the constant comparative method, the concept-indicator model resembles the following process:

Figure 1: Concept-indicator model



Source: Glaser (1978 p. 62)

Crucially, the concept-indicator model is based upon constant comparison of:

- Indicator to indicator and when a conceptual code is generated; and
- Comparing indicators to the emerging concept.

The comparison of indicator to indicator forces the grounded theory analyst to confront the similarities, differences and degrees of consistency of meaning between indicators.

This generates an underlying uniformity, which, in turn, results in a coded category and the beginning of its properties. From the comparisons of further indicators to the conceptual codes, the code is sharpened to achieve its 'best fit', whilst further properties are generated until the code is verified and saturated (Glaser, 1978 p.62). In these steps, grounded theory is built upon multi-indicator concepts where it becomes possible to interchange the indicators to allow theory to apply to a less obvious area. Moreover, the 'memo fund' continues to be used to document tentative relationships and thoughts about the data, and its potential for linkage of indicators. The 'memo fund' is then sorted and used to develop the emerging theory and its properties further. Moreover, the transcribed data are continually coded, analysed and empirically tested using the constant comparative method with the aim of explaining the relationships within the data under study.

To discover theory using the constant comparative method, conceptual categories or properties are generated from evidence; then the evidence from which the category emerged is used to illustrate the concept. As Glaser and Strauss (1967) suggest, the evidence may not necessarily be accurate 'beyond a doubt' (p.23), but the concept is a relevant theoretical abstraction about what is happening in the area being studied (see previous discussion on the development of 'awareness contexts' pp.73-74). Moreover, within the grounded theory method, the concept itself will change. What remains central is that the researcher compares incident for incident until conceptual categories are generated which serve to explain the data under study. Theory, therefore, is developed by a process of induction and verification of this process, a process that can be refined during the time of writing (Glaser and Strauss, 1967; Glaser, 1978; Strauss, 1987), and will often change even after publication of the initial findings (Glaser, 1992). Once conceptual categories begin to emerge from the data, they are used to direct future data collection; a methodological approach described by Glaser and Strauss (1965) in their original study as:

One whereby the analyst jointly collects, codes and analyses his data and decides what data to collect next and where to find them in order to develop his theory as it emerges. (p.35)

Grounded theory therefore acts as a transactional system which 'allows one to examine the interactive nature of events' (Strauss and Corbin, 1990 p.59). Thus the generation of

theory through comparative analysis both subsumes and assumes verifications and accurate descriptions, but only to the extent that the latter are in the service of generation. As theory is derived from data, generation of comparative analysis requires a multitude of carefully selected cases, with the aim, for the analyst, not of generating a 'perfect description of an area' (Glaser and Strauss, 1967 p.28) but, instead, developing a theory that accounts for as much as possible of the relevant behaviour. This is an important issue as Glaser and Strauss (1965; 1967) were attempting to break away from the traditions of qualitative and, in particular, ethnographic research, to allow the grounded theory analyst creativity and freedom in the process of theory generation. Indeed, writing later, Glaser (1992) recommended that individuals with 'a low conceptual ability' should not commence a grounded theory study as they would experience difficulty in finding relationships and theoretical abstractions in the data. Theory, therefore, needs to be continually developed and not frozen, and deductions from the developing grounded theory are the method by which theoretical sampling is directed.

Before discussing the properties of theoretical sampling, it is important to emphasise that constant comparative analysis exists to develop two basic kinds of grounded theory: substantive and formal. Substantive theory is one that is developed for a particular or 'substantive' empirical area of sociological inquiry; Glaser and Strauss (1967) provided examples of substantive areas as: patient care; professional education; and race relations, amongst others. Formal theory, on the other hand, is assigned to a conceptual area of sociological inquiry, such as stigma or social mobility. Both approaches to theory generation are seen to be 'middle-range', but they exist on distinguishable levels of generality which differ in terms of degree (Glaser and Strauss, 1967). Therefore, in any grounded theory study, and this study is no exception, each type of theory can shade into one another, although Glaser and Strauss (1967) firmly indicated that the researcher begins a grounded theory study by focusing upon one or other specific level. In the present context, the substantive area of inquiry focused on the experience of family caregiving for a person with dementia which evolved, through theoretical sampling, into exploring dementia as experienced by those living with an early awareness of its impact - hence there were two study designs set two years apart (see: chapter 5 of the thesis). These inter-related perspectives were then integrated by the use of the comparative method. By following this process a formal area emerged from the data, a linking

scheme, which the author has named 'maintaining involvement', underpinned by the basic social process of 'working' (see: Introduction and developed further in chapter 6). This linking scheme helped to capture and distil the myriad of experiences and coping behaviours exhibited by people with dementia and, later, their family caregivers, over the trajectory of the illness. Maintaining involvement and its associated basic social processes only arose at the end of the study through constant comparative analysis of the substantive area of inquiry. As Glaser and Strauss (1967) suggested, the existence of a linking scheme does not, *de facto*, make any study a formal grounded theory as:

For substantive theory, the analyst is very likely to discover an integrating scheme within his data, since the data and the inter-relations of the theory lie so close together. (p.41)

However, 'maintaining involvement' has, the author would suggest, a level of theoretical abstraction that is applicable to other areas of the dementia care experience, e.g. how do professional workers maintain involvement with family carers of people with dementia?, and, potentially, has generalised application within the dynamics of other chronic illnesses and conditions, for instance how do those living and helping people with Parkinson's disease begin 'maintaining involvement' with such experiences? Conducting a study into the properties of 'maintaining involvement' in such settings could lead future researchers (if they were so interested) to the generation of formal grounded theory. The status of the grounded theory developed during the study will be discussed more fully in the concluding chapter.

c) Theoretical Sampling: Stages and Development

Within a grounded theory study, the process view of generating theory is led by data and interpretations of the data. As such, it is logical that the process of data collection is controlled by the emerging theory. Glaser and Strauss (1967) termed this process theoretical sampling and defined its properties as follows:

Theoretical sampling is the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges. (p.45)

Again, what Glaser and Strauss (1967) are specifying here is the need for subject recruitment to follow the needs of the study; however, they provided no practical guidance on how subjects were to be found and recruited into the study, rather it is simply assumed that subjects existed to serve the needs of the study and that, if found, they would consent to take part. This oversight apart, the two questions that Glaser and Strauss (1967 p.48) sought to address in theoretical sampling are:

- i) What groups or sub-groups are required in data collection?; and
- ii) For what theoretical purpose?

Glaser and Strauss (1967) viewed the response to these two questions as involving the criteria of 'purpose and relevance', a position whereby the analyst adjusts control of the data collection to ensure the data's relevance to the criteria of the emerging theory. Moreover, theoretical sampling is seen to vary in depth and scope and to be selectively applied. For instance, Glaser and Strauss (1967) did not see the need to theoretically sample a whole group, except at the very beginning of research study 'when the main categories are emerging' (p.69), and that this was only necessary when there was a need to collect data on categories for a specific purpose; namely, to generate properties and hypotheses. Within theoretical sampling more targeted collection is used for the development and identification of core theoretical categories i.e. those parts of the theory with the most explanatory power. This process continues until the categories and properties become 'saturated' through the use of constant comparative analysis using the concept-indicator model, i.e. until no new properties are seen to emerge for the subject under study. Through theoretical sampling, therefore, the theory gradually moves towards completion, with theoretical saturation providing the driving force for this process. Within grounded theory theoretical saturation is seen to be reached when no additional data are found, and where the analyst can develop the properties of the category no further. When the phenomenon is seen repeatedly in data analysis so that 'the researcher becomes empirically confident that a category is saturated' (p.61), then theoretical saturation can be said to have occurred. A general rule in grounded theory research is the need to sample until theoretical saturation of each category is reached, and, as synthesised by Strauss and Corbin (1990 p.188), this means until:

- No new relevant data seem to emerge regarding a category;
- The category development is dense, insofar as all of the main elements are accounted for, along with variation and process; and
- The relationship between categories is well established and validated.

Whilst, at a theoretical level, the concept of theoretical saturation appears straightforward, in practice and in close examination of the text (Glaser and Strauss, 1967 pp.61-61; and Strauss and Corbin's (1990) later clarification listed above) it becomes problematic. Firstly, this is because Glaser and Strauss (1967) gave no clear guidance on how, and when, it is known that a category has been exhausted. Second, no firm set of descriptors were ever presented to help in this process of decision-making; for instance, the indicator that changed the meaning of a formed category may be present in the next interview, so how do you decide not to conduct any more interviews?

In their defence, it must be remembered that the *Discovery book* (Glaser and Strauss, 1967) only illustrated the development of the grounded theory methodology based on the findings of previous study (Glaser and Strauss, 1965), and that this single case was used to illuminate the robustness of the entire methodology; as such, it is not surprising that omissions were made or concepts overlooked. Attention to the researcher's role in generating grounded theory may also have helped to provide additional insights into its operationalisation. However, the *Discovery book* failed to take this issue forward and viewed the theoretical sensitivity of the analyst to the subject under study as playing only a 'minor role' in the advancement of theory as process. Glaser (1978) would later revisit this oversight and place theoretical sensitivity at the heart of the advancement of the grounded theory methodology.

d) Theoretical Sensitivity

In their *Discovery book*, Glaser and Strauss (1967) incorporated theoretical sensitivity within the section on theoretical sampling (pp.46-47), and outlined its importance for the understanding and formulation of theory as it emerged from the data. Dissatisfied with the depth and clarity of the original text, Glaser (1978) later structured an entire monograph around advances in theoretical sensitivity (repeatedly using the pronoun 'we' when discussing his thoughts on advancing the methodology - obviously referring to Anselm Strauss - even though Glaser was writing as sole author).

As originally formulated, theoretical sensitivity was seen by Glaser and Strauss (1967) as developing 'over several years' (p.46) and it defined the relationship between the grounded theory analyst and their exposure to the research topic. However, this appeared an inadequate summary, as when the grounded theory approach is used, relationships between theory and methods become inseparable. Whilst theoretical sensitivity, as originally formulated, can assist in reaching a certain depth of analysis, the empirical relationships between the theory that is being constructed are, themselves, essential. For as Glaser (1978) himself suggested, a primary goal of grounded theory:

... is to generate a theory that accounts for a pattern of behavior which is relevant and problematic for those involved and that this goal is not reached by voluminous description, but by clever verification. (p.39)

As first intimated by Glaser and Strauss (1967), but later developed more fully by Glaser (1978), and explicitly supported by Strauss (1987 p.6), searching for patterns in the generation of theory revolves around a core category, as the absence of a core category compromises the relevance and workability of grounded theory.

To advance grounded theory methodology required an understanding of the stages leading to the identification of a core category(ies), a process Glaser (1978) re-named theoretical sensitivity. Thus, whilst searching for a core category(ies), the grounded theory analyst looks for a core variable in the data and then searches for the 'main theme', or problem for those in that setting, that sums up the substance of what is going on in the data. In this way core categories are given 'best fit' conceptual labels. The criteria to establish a core category were set out by Glaser (1978 p.95-96 slightly abridged) as follows:

- It must be central in that it relates to as many other categories and properties as possible. The criteria for centrality is a necessary condition to make it core;
- It must reoccur frequently in the data;
- It takes more time to saturate the core category than other categories;
- It relates meaningfully and easily with other categories;

- A core category in a substantive study has clear and grabbing implications for formal theory;
- The core category has considerable carry through in that it does not lead to dead ends in the theory;
- It is variable, in that it frequently relates to other categories making it highly variable in degree, dimension and type. It is readily modifiable through these dependent variations;
- A core category is also a dimension of the problem, thus in part it explains itself and its own variations; and
- The core category can be any kind of theoretical code: a process, a condition, two dimensions and so on.

The search for core categories are led by ‘basic social processes’, that are processural or, as suggested by Glaser (1978; 1992), they ‘process out’. Within grounded theory a process has temporal dimensions that have discernible breaking points i.e. they are discernible to the extent that stages can be perceived so that they can be treated as theoretical units in themselves. Basic social processes have temporal dimensions that move and change over time. Moreover, for the integration of a basic social process within grounded theory, a process must be seen to have at least two elements which are derived from the following list (Glaser, 1978 p.74): stages; staging; phases; phasings; progressions; passages; gradations; transitions; steps; ranks; careers; ordering; trajectories; chains; sequencings; temporalizing; shaping; and cycling.

Glaser (1978) viewed stages to be ‘perceivable’ as they sequenced with one another within certain temporal limits. The stages were seen to be to be either in vivo (generally perceivable by those involved) or heuristic (generally not perceivable by the persons involved, but demarcated by the researcher for theoretical reasons). Stages which are perceivable would probably be built into the social structure under study. The development into stages takes the staticity ordinarily found in most types of theory out of a basic social process theory and allows the analyst to follow changes over time, yet still grasp a theoretical ‘whole’ process, which has a natural beginning and an end. When the stages and their properties are integrated into the whole process, and when each stage’s relationship to the process and the other stages are integrated, then the

processes can be conceptually followed from stage to stage, with the change over time being theoretically accounted for without the imagery of the overall process being lost. From Glaser's (1978) assertions, therefore, it would appear that all grounded theories need to have a temporal dimension.

For Glaser (1978) stages, then, operate as an integrating scheme which tie together various sets of conditions and allow for theoretical tracing of, and accounting for, change over time. It follows, therefore, that stages have a time dimension i.e. a perceivable beginning and an end, and the length of time between these points may or may not be fixed and will depend upon what brings about the transition from one stage to another. The transition from one stage to another is ordinarily contingent upon one or more things happening and may be in the form of a critical juncture. Glaser (1978) explains that this may be influenced by the occurrence or non-occurrence of a particular critical event which will determine whether a new stage is entered, or skipped, or the previous stage maintained. An exact time of transition may be impossible (or arbitrary) to pin down, but the transition may be obvious later throughout the gradual occurrence and clarity of a set of indicators (see: Glaser, 1978 pp.98-100). Stages then are prime property of basic social process and are generated properties of process.

Given the exacting nature of basic social processes, it is uncertain, but possibly understandable, why Strauss abandoned them in developing his own approach to grounded theory. Glaser (1992 p.3) was scathing of Strauss and Corbin's (1990) reformulation of the grounded theory methodology stating that '90%' of the ideas coming from their original text (Glaser and Strauss, 1967) and its subsequent advancement (Glaser, 1978) were 'excluded' from the revision. Understanding this schism is important as it influenced the author's decision to follow a modified Glaserian approach.

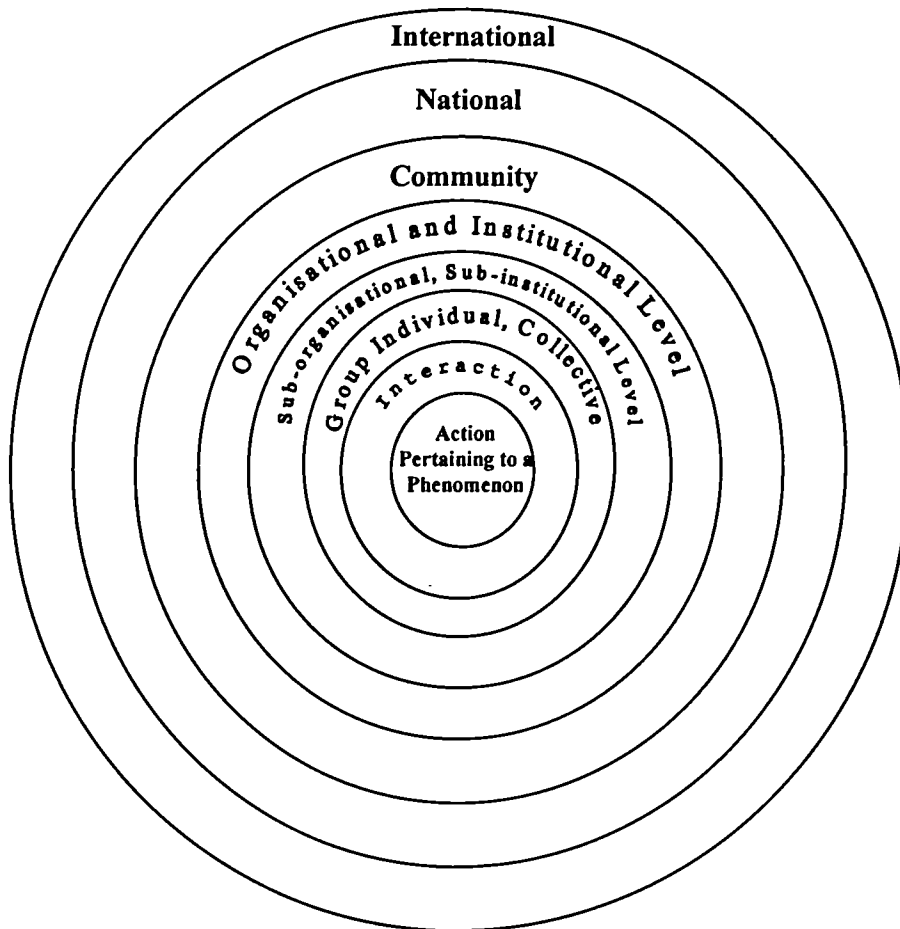
Grounded theory is not a quick fit solution, and is not an approach where latent content analysis can be applied to transcripts to quickly generate a series of findings (see: Fox, 1982 and Babbie, 1979 cited in Field and Morse, 1985 p.103). Whilst Strauss (1987) initially appeared to agree with Glaser (1978) about this assertion, the present author would suggest that Strauss and Corbin's (1990) later revisions to the grounded theory methodology was largely instigated by their impatience over the time it takes to generate

grounded theory via the constant comparative method. The creative tenets of the analyst evident in the *Discovery book* (Glaser and Strauss, 1967) in tracing theory as process were replaced with a more formulaic, step-by-step approach which was sequentially linked (see: Strauss and Corbin (1990) *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*). It could be argued of course that those who followed this approach would offer a more 'transparent' process, and this may well have been the motivation of Strauss and Corbin (1990).

According to Stern, Allen and Moxley (1982 p.201), it was Strauss' involvement with the Doctor of Nursing Science programme at the University of California, San Francisco that highlighted the inaccessibility of the method to students. Collaboration with Juliet Corbin, a lecturer at San Jose State University, California and a former student of Strauss, led to the emergence of a new external coding matrix into the process of conducting 'grounded theory' data analysis. This effectively removed any trace of constant comparative analysis from grounded theory research, and replaced it with axial and selective coding within the framework of a conditional matrix (pp.158-175) as shown in Figure 2 on the next page.

Perhaps driven by a vision of making grounded theory more accessible, Anselm Strauss decided to radically revisit his past for, as both Glaser and Strauss (1967) stated in the Introduction to the *Discovery book*, the text was only ever meant to be a beginning. However, a consequence of this revision was, according to Glaser, the imposition of 'forced, preconceived, full conceptual description' (Glaser, 1992 p.3) which negated grounded theory in the traditional meaning of the word. It appears that Anselm Strauss lost faith in the merits of, and trust in, the creativity of the researcher, and with the input of Juliet Corbin, constructed a methodology that he found to be more relevant to the rapidly changing world of social research.

Figure 2: The conditional matrix



Source: Strauss and Corbin (1990 p.163)

e) The Use of Supporting Literature

A mistaken assumption that has frequently arisen is that Glaser and Strauss (1967) advocated that literature should never be used to inform grounded theory analysis. Whilst Glaser and Strauss (1967) did not advocate its use in the early stages of the study, or in its planning stages for fear of 'contaminating' the researcher and their prospective approach to data analysis, they clearly stated that literature could be consulted later, as the process of theory generation evolved. This, the authors suggested, would allow the properties of the emerging concepts and their indicators to be assessed one against another. Whilst accepting, in academic terms, the purity of

Glaser and Strauss' (1967) arguments against the background use of literature, there remains the difficulty that, in the research process, formal research proposals and ethical submissions are required to both fund and guide emerging research projects. These require an understanding of the literature to formulate a study design and to convince others of the need for the study. It therefore appears rather naïve to believe that researchers will not consult the literature before stepping into the field.

In a later publication, Strauss and Corbin (1990) take a slightly more relaxed attitude towards literature searching prior to conducting a grounded theory study, although they still warn against the use of too much 'technical literature', again fearing that it would contaminate the analytical process. That said, there remains a certain clarity in Glaser and Strauss' (1967) original thoughts and the need for grounded theory analysis to remain focused only upon the data under study; it is however very difficult to achieve in practice. The author will return to this issue later in the chapter whilst outlining his rationale for modifying the grounded theory approach used in this study.

f) Tests for Credibility

Glaser and Strauss (1967 p.237 slightly abridged) outlined four inter-related properties for testing the practical application of grounded theory, these were that the theory must:

- i) Closely fit the area in which it will be applied;
- ii) Be readily understandable to laymen concerned with the area;
- iii) Be sufficiently general to be applicable to a multitude of diverse situations within the area of study, not to just a specific type of situation; and
- iv) Allow the user partial control over the structure and process of daily situations as they change through time.

Whilst additions have been made by other authors (see: Turner, 1981; Rennie, Phillips and Quartaro, 1988; Pidgeon, Turner and Blockley, 1991), particularly that of comparison with other methodologies (Wilson and Hutchinson, 1991), Glaser (1978) later suggested that these four properties best summarise the 'fit and grab' of a grounded theory study.

3.6 The Operationalisation of Grounded Theory

At this point it would be relatively easy to construct a 'post hoc' rationalisation of the author's approach to grounded theory based on a detailed analysis of the methodologies that has just been presented. In reality, of course, this more in-depth understanding emerged later, when the author was permitted a fuller reading of the various text. At the time data collection for this thesis began the main source of information was the *Discovery book*, some general modifications to the grounded theory methodology and the studies in the field that had used a grounded theory approach (see in particular: Bowers, 1987; 1988a; Wilson, 1989a,b). These sources, coupled with the author's sensitivity (theoretical or otherwise) to the experience of dementia from several year's practice, resulted in an intuitive appeal of the more general approach to grounded theory as initially formulated by Glaser and Strauss (1967) and updated by Glaser (1978). This desire to explore the temporal dimensions of dementia, and open up a potentially new field of study, further reinforced the value of grounded theory as described in the *Discovery book*.

Pragmatic considerations also applied as there was a limited window of opportunity during which study leave could be negotiated for the early stages of data collection, and this did not permit the luxury of an extended period of methodological reflection. Armed therefore with an adequate, but still emerging, grasp of the central tenets of grounded theory, the author sought data that would allow him to explore further the substantive area of interest. This, in turn, required certain modifications to be made to the grounded theory approach before entering the field, and these centred along four dimensions:

- a) Theoretically sampling subjects in advance of the interview. Whilst this may be seen as going against the grain of grounded theory, because Glaser and Strauss (1967) failed to give clear guidance on what constituted a theoretical sample the author felt justified in facilitating the recruitment of participants in advance, as long as their experience clearly related to the area under study. This pre-structuring of sample recruitment also helped clinical colleagues, particularly medical staff, to provide access to informants.

- b) The a-priori identification of a number of temporal stages likely to be influential in interpreting the experience of dementia. Glaser (1978) would probably have argued that this 'forced' the study, as it partially determined the study parameters before the process of data collection and constant comparison began. Strictly speaking, in grounded theory methodology, it is the data that should lead the level of theoretical coverage. However, this level of freedom was simply not available to the author given the requirement of well developed, and structured, research protocol by ethical and funding committees prior to engaging in field work. This will be returned to later when considering the design of the semi-structured interview guide.
- c) Closely related to the above is the use of background literature. Having undertaken a previous course of study the author was already familiar with the work of Wilson (1989a,b - see: chapter 2 pp.51-54), and it seemed inappropriate to try and forget that this existed. It was therefore decided to use the findings of this study, in particular, as a theoretical marker to help shape and guide the process of analysis and theory building (see also: Morse, 1986).
- d) Constant comparative method to be used, in part, retrospectively in the study. During the entire series of interviews that comprised this study, the author attempted, by hand, to transcribe each interview before proceeding to the next. However, at times, the full analysis of the data was undertaken the following day, together with the author's use of his theoretical memo book. The author needed this level of flexibility to allow the study to be completed within the time limitations on his secondment from the practice setting.

Having decided upon these modifications, it became apparent that in the grounded theory texts (Glaser and Strauss, 1967; Glaser, 1978) little time was spent outlining the method of data collection; it was assumed that the reader already had an ability to conduct research interviews and successfully design a research study. For instance, the original *Discovery book* (Glaser and Strauss, 1967) contained no reference at all to the mechanics of data collection. While the author would suggest that this omission by Glaser and Strauss (1967) was simply due to the exuberance of their writing and their rush to communicate a 'new' methodology, rather than any desire to leave the reader 'in

the dark' over how to conduct a research study, this seemingly trivial oversight increased the uncertainty associated with operationalising the 'new' methodology of grounded theory, and fuelled the ambiguity over the role of interviewing to probe for conceptual relationships and theoretical saturation within the data.

The remainder of this chapter makes explicit the methods the author followed in the present study.

3.7 The Interview Process

Whilst interviews are seen as being one of the most costly methods of data collection (Barker, 1991; Polgar and Thomas, 1991), they allow the opportunity for in-depth exploration of issues and facilitate variation in data collection. Interviews have been distinguished by their degree of structure, ranging from 'structured' to 'unstructured' formats, although the adoption of such terminology can itself be confusing as 'formal'; 'informal'; 'guided'; and 'open-ended' are often used interchangeably to describe the same technique (see: Field and Morse, 1985; Leininger, 1985). A structured interview involves reading a prepared questionnaire to an interviewee and then completing a response sheet on their behalf. Questions are presented in a pre-set order, which allows little, or no, deviation from the prepared instrument (Denzin, 1989). Structured interviews are used mainly in quantitative research when consistency of response is of central importance to the design of the study (see: Richardson, Dohrenwend and Klein, 1965; Carter, 1991). On the other hand, an unstructured interview may involve the interviewer asking no direct questions, but simply asking the interviewee to think reflexively on their current interests and concerns. However, this latter approach is open to uncertainty as the interviewer/interviewee situation requires a certain degree of structure to legitimate the researcher's presence; the unstructured interview, therefore, is seen by some as a misnomer (Whyte, 1982). In contrast a semi-structured interview allows areas of interest to the researcher to be probed, whilst permitting time and flexibility to explore further the interviewee's subjective interpretation of events. To this end, Polgar and Thomas (1991 pp.121-122 slightly abridged) provide a useful framework for facilitating the interview process, this includes:

Selection of interviewees. One of the interviewer's first tasks is to select the people to be interviewed. Polgar and Thomas (1991) call these the 'key players', although recruitment in a grounded theory study is underpinned by theoretical sampling (Glaser, 1978). In effect, the emerging theory becomes the 'key player' and the subjects are identified to explore and test it further. In the early stages interviewees are selected who are likely to have experience of the area under study.

Recruitment of the interviewees. Strategies for recruitment include explaining the purposes of the interview and making assurances about: confidentiality; anonymity; and time involvement of the interview. These issues will be elaborated upon later. In terms of study recruitment, Polgar and Thomas (1991) contend that a useful strategy is for the researcher to write to the potential interviewee first and then invite contact; this, it is suggested, will make the interview situation 'less confronting' (p.121).

The Interview. The interview should tap the interviewees' views, rather than reflecting those of the interviewer. This is central to the process of conducting qualitative research where the researcher's role is to explore the interviewee's subjective interpretation and meaning of events within the overall context of the area of study. This requires good conversational skills. Field and Morse (1985) suggest that this involves: the use of sensitive questions; the ability to be non-judgmental; to be alert at delivering and sequencing the questions; and to conduct the interview in a setting that is familiar and comfortable to the interviewee, which may well be the person's own home. A further advantage to undertaking an interview at the person's home is that the person can be visited in their domestic environment, helping to build a more complete picture of their day-to-day life.

An interview situation also allows the researcher to pick-up non verbal cues such as: tone of voice; eye contact; hand gestures and so on, cues that are not apparent in transcriptions or when utilising other qualitative methods, such as self-report questionnaires (Bulmer, 1984b). Contrasting the interview to self-report questionnaires, Barker (1991 p.213) listed the following advantages:

- People are more likely to discard questionnaires or leave sections blank; faced with an interview, a fuller response to all questions is more likely;
- Some subjects will be unable to complete self-report questionnaires through blindness, illiteracy, poor education, or limited comprehension or reasoning. Very young, older, or anxious people may also be put off by the demands of the self-report questionnaire;
- Areas of uncertainty or ambiguity can be clarified, avoiding the misinterpretations which might arise from a questionnaire;
- Some forms of interview allow the subject to expand on their response; this is rarely possible or likely in a self-report questionnaire. The subject may talk expansively where he/she would not write detailed or lengthy responses;
- The interviewer can control the circumstances of the response by his/her presence; it is not unknown for respondents to questionnaires to seek assistance from friends or colleagues, thereby contaminating results; and
- Additional data on the context of the interview can be collected by the interviewer. Such supplementary observations may be used to qualify final conclusions, or as preparation for the design of other interview schedules and research hypotheses.

Polgar and Thomas (1991) also suggest that interviewers may use a different means of recording interview data which range from written summary notes of the interview to an actual video or audio taping of the interview. With a tape-recorded interview the transcription can be open to independent scrutiny and, more importantly, to verification from the subject; a sequence of events that can assist in determining the validity of an emerging theory. For these reasons the author decided to seek permission to tape record interviews, whilst also keeping a detailed written summary of each interview within the study's theoretical memo book, an addition that is essential in conducting grounded theory research (Glaser, 1978).

3.8 Interviews: Limitations to the Method

Field and Morse (1985 pp.67-73 abridged) provide an overview of the common pitfalls and limitations of the interview process, these are:

Interruptions; such as telephones ringing during the interview, or the arrival of visitors to the home. Field and Morse (1985) suggest that the researcher could advise the interviewee to take the telephone 'off the hook', and thus preserve the flow of the interview. However, the author decided that this was inappropriate in the circumstances, as in certain situations the carer was interviewed when the person with dementia was in day or respite care. Taking the telephone 'off the hook' in such circumstances could have prevented any attempt by the residential facility to contact the carer. Similarly, there must be a certain acknowledgement that a research interview takes place in the real world. As such, it is inappropriate to expect the interviewee to make such changes, or to insinuate that they have not pre-empted such interruptions and made suitable arrangements.

Competing Distractions; Field and Morse (1985) contend that a 'high quality' interview will require concentrated energy on the part of the interviewer and interviewee. If there is inattention during the interview, then meaningful data may not be collected if distractions are considerable. The author did note some distractions, particularly if the person with dementia was present, but often rather than disrupt data collection these distractions provided an opportunity to explore new directions.

Stage Fright; stage fright can be said to occur when the research interview is being tape recorded, and the interviewee begins to feel uncomfortable. The strategies the author used to overcome 'stage fright' included: the use of a small, hand held tape recorder that was discretely placed between the interviewer/interviewee; checking the operational levels of the batteries prior to each interview; pre-loading and coding each C90 tape prior to commencing each interview; rehearsing the consent to tape record the interview at the start of each interview, and also committing this to tape.

Avoiding Awkward Questions; whilst the meaning of this statement is immediately apparent, Field and Morse (1985) suggest that this is one of the major drawbacks in undertaking a 'one-off' interview as the main source of data collection. The inability to

build a relationship over time makes the use of probing important, but delicate. The author rarely experienced this and it may well be that his background as a community psychiatric nurse, and the interviewees' awareness of this, made potentially awkward subjects legitimate.

Jumping; it is considered important for the interviewer to conduct the interview in a logical sequence, and not jump from one idea to, what Field and Morse (1985) term, 'a disconnected statement'. This requires concentration during the interview process, and the ability to actively listen and reflect the meaning of the conversation back to the person being interviewed. However, it is important that the person being interviewed does not feel that they are being forced to participate in any way, or that experiences that are important to them are not neglected in the researcher's push for theoretical relevance. Balancing these factors requires a careful, sensitive approach on behalf of the researcher, and an acknowledgement that the experiences of the person being interviewed are more important than the opportunity to validate emerging conceptual properties.

Teaching and Preaching; Field and Morse (1985) contend that switching roles in the interview is a particular trap for the health care researcher who, they argue, is conditioned for a helping relationship. As a practitioner and a researcher, knowing when to 'switch-off' from a professional, assessment mode of interaction, was something the author developed over time as experience in the role developed, although there were times when the practitioner/researcher roles became blurred. This will be returned to again during chapter 7 of this thesis when areas for future clarification for practitioners as qualitative researchers are discussed.

Counselling; at present a line of methodological inquiry is emerging that explores the positive dimensions to the use of counselling strategies between the nurse researcher and informant, particularly when the researcher is gathering interview data in a sensitive area and drawing upon their own clinical experiences to guide and clarify the interviewees subjective interpretation of events (Wilde, 1992). However, Field and Morse (1985) argue that the interviewer should guard against such situations occurring, and actively search for examples of counselling strategies in the transcripts so that they could be avoided in future interviews. Their arguments for adopting this position are

not made clear, but the author presumes that Field and Morse (1985) require a certain distance and objectivity from the interviewer for 'proper' data collection to occur, and that this distance cannot be accounted for within a counselling relationship. However, whilst there is broad support for this position within standard texts (see: Bulmer, 1984b; Denzin, 1989), it continues to be difficult to achieve when family carers are either undergoing stressful events such as feeling guilt over placing the person they cared for in an institutional environment, or have been through the bereavement process and wish to share their emotions over this event. It is the author's opinion, and experience, that a sensitive approach to such situations provides an opportunity for rich data collection, so long as the researcher is aware of the nature of this interaction and is able to close the relationship safely at the end of the visit.

3.9 Preparations for Entering the Field

Once the methodology and method had been decided upon, the next stage of the study involved its operationalisation. This was achieved via the following stages:

- a) Gaining support of key personnel;
- b) Funding the project;
- c) Designing the semi-structured interview guide; and
- d) Gaining ethical permission to conduct the study.

Each of these stages will be addressed in turn.

a) Gaining Support of Key Personnel

After completing a part-time post graduate Diploma in Advanced Community Studies (Gerontology) in June 1992 at the University of Wales, Bangor, the author received an offer of support from Dr. (now Professor) Mike Nolan to supervise and help facilitate the reported research study. Discussions on the shape of the original study centred on the need to address two aims, one primary and the other subsidiary. The primary aim was to explore the carer's subjective coping strategies throughout the trajectory of dementia, an area reviewed previously in chapter 2 and felt to be in need of further elaboration. This was seen as particularly relevant to the author's clinical orientation, where the identification of carer's coping patterns could help enhance assessment and

intervention. Second, the interviews provided a serendipitous opportunity to further explore the content validity and acceptability of the Carers' Assessment of Difficulties Index and the Carers' Assessment of Satisfaction Index (Nolan and Grant, 1992), instruments which had been developed following extensive postal survey work but had yet to be applied in an interview situation. Moreover, the instruments were developed in generic caregiving situations and had not, at this time, been applied specifically to carers of people with dementia. The second aim also provided the opportunity to secure some funding that would facilitate the primary aim through qualitative interviews.

As the author was still in clinical practice in a community dementia team in North Meirionnydd, Gwynedd at this time, it was crucial to negotiate some 'time out' for the study for a number of reasons. Firstly, to help the author adjust to the new role of researcher, with support from experienced research staff. Second, to allow time to implement a proposed grounded theory design that would, it was hoped, lead to an emerging account of carers coping with people with dementia. Third, to gain support for the study from key management and medical personnel in the Health Authority.

Consequently, in July, 1992 an initial approach was made by the author to his clinical nurse manager to discuss the preliminary thoughts on the research design, and to ascertain the viability of spending three months out of the clinical environment to begin the process of data collection. Fortunately, this approach received an enthusiastic response, and a meeting was held subsequently between the author, his clinical nurse manager and members of the community dementia team to discuss the project. This was necessary as the author's caseload had to be covered during any agreed period of secondment to the Health Studies Research Division at the University of Wales, Bangor. Fortunately, the community dementia team expressed support for the study and provisional arrangements were made to distribute the author's caseload amongst clinical colleagues. Once this agreement had been secured, a joint approach was then made by the author and his clinical nurse manager to meet with the Director of Nursing Services (Community) to gain approval for a three month secondment. Permission was duly given for a three month secondment to begin in October, 1992. In a letter confirming the secondment, two conditions were set by the Health Authority. Firstly, that the Health Authority would not be responsible for meeting any travel costs. Second, no support would be available to cover secretarial duties. Fortunately, the Health Authority

agreed to maintain the author's salary costs and employment conditions during the period of secondment which helped enormously in funding the research study. Agreement was also reached that the author would be based in Health Authority premises during the period of the secondment which was situated near to the Health Studies Research Division in Bangor.

During this period the author also contacted two Consultant Psychiatrists in Gwynedd as their support was crucial to the process of negotiating access to carers of people diagnosed with dementia. It was decided that only carers whose dependent had been diagnosed with dementia using *DSM-III-R* (American Psychiatric Association, 1987) criteria would be approached to be admitted into the study. This would minimise any need for the author to conduct additional psychological screening of a person with (suspected) dementia, although adopting this approach did result in carers who were not in receipt of services being automatically excluded from the study design.

Consultant A covered the entire county of Gwynedd (excluding Meirionnydd) for people with dementia, and Consultant B covered Meirionnydd, an extensive rural area in the south of the county. Personal appointments were made to discuss the outline of the project and permission was forthcoming from both Consultant A and B to help facilitate the study design. It was decided at this time that Consultant A would be main data collection source given the population covered. Consultant B consented to provide 'back-up' should it prove impracticable to gather the theoretical sample from Consultant A. However, as the author worked in North Meirionnydd as a community psychiatric nurse, it was agreed that he would not interview any carers from the North Meirionnydd or who, for whatever reason, were previously known to him.

b) Funding the Project

In preparing a research proposal, Bond (1991) argues that resources to conduct the study must be realistically appraised and accounted for within the overall study design. Over the summer of 1992 senior research staff at the Faculty of Health Studies and the School of Sociology and Social Policy, University of Wales, Bangor wrote a research proposal entitled 'Alzheimer's disease: extending the caregiving paradigm'. The monies were sought from the University of Wales, Bangor as part of their annual call to fund 'low budget' innovative research designs. The proposal requested an amount of £3000 to

fund a two-stage methodology. Briefly, monies for stage one sought cover for travel, interviewer, transcription and analysis costs for a series of detailed carer interviews, whilst stage two was to fund a large scale postal survey. The University of Wales, Bangor approved this research proposal in mid July, 1992 and committed a time-limited budget code to the Research Division at the Faculty of Health Studies in order to fund claims made on behalf of the project. Transcription of the study data was undertaken on behalf of the author by private agreement with secretarial staff. The transcripts were typed from hand-written accounts from each tape provided by the author, with anonymous codes already written onto the covering page. The inclusion of the Carers' Assessment of Difficulties Index and the Carers' Assessment of Satisfactions Index (Nolan and Grant, 1992) in the interview schedule, together with other quantitative collection techniques, were intended to provide a pilot for the larger postal survey, but were, as noted earlier, an adjunct to the interview itself.

c) Designing the Semi-Structured Interview Guide

The complete semi-structured interview guide, including quantitative elements, can be found in Appendix 1. The first sheet summarises the structure, and shape of the qualitative, semi-structured interview to explore the author's research question, as outlined at the end of chapter 2 (see: pp.59-60). As can be seen, and in agreement with Gilleard (1991 p.351), it was considered important in the context of the grounded theory study to allow the trajectory of caregiving and coping to be explored. The cover sheet also asked carers to share their perspectives on satisfaction with professional service staff and perceptions of their own expertise in managing the condition, an issue that was just beginning to be explored in the literature (Nolan and Grant, 1992). At the start of the semi-structured interview the author's background was also restated, as was the fact that all interviews would be confidential and coded anonymously.

The structured measures in the semi-structured interview guide incorporated the Carers' Assessment of Difficulties Index and the Carers' Assessment of Satisfactions Index (Nolan and Grant, 1992), with the scales extended to explore: how carers normally dealt with the situation; and the sources of support they normally received. Data were also collected on stress levels using the Malaise Inventory (Rutter, Graham and Yule, 1970), a well known measure which produces reliable data in a non-threatening form, together with dependency information (updating a scale on instrumental care developed by Nolan

(1991)) and basic demographic details. This more structured section was used throughout the carer's interviews, but always followed the open interview. As the data from the structured section were not involved in the grounded theory approach, these will not be referred to further. However, they did provide the basis for further work, including the construction of the Carers' Assessment of Managing Index (Nolan, Keady and Grant, 1995).

d) Gaining Ethical Permission to Conduct the Study

According to Schröck (1991 pp.37-38) the primary purpose of Ethical Committees operating at Area Health Authority level is the protection of the potential subjects of medical research. The necessary forms for the Gwynedd Ethical Committee were completed in early July, 1992 and forwarded to the chairman of the Ethical Committee. Following the usual protocol, the Gwynedd Ethical Committee required all forms comprising the study design to be available in full, together with the design of all letters/approaches to recruit into the study; with the addition of the semi-structured interview guide in Appendix 1, this information is displayed in Appendix 2. Initially, it was agreed that the author would access Consultant A's caseload and then seek permission to interview the carer at the venue of their choice.

Unfortunately, for reasons that were not made clear at the time, the August and September meetings of the Gwynedd Ethical Committee were cancelled, and the date for consideration of the submission was to be on the 1st October, 1992, the same date as the commencement of the author's three month secondment. After the evening presentation on the 1st October, approval was given to conduct the study by the Chairman of the Gwynedd Ethical Committee, with two caveats:

- i) That the first approach to the carer to recruit into the study was to be made by Consultant A (or Consultant B). Furthermore, the letter to recruit carers should be sent from Consultant A (or Consultant B) enclosing a consent form to be signed by the carer and returned in a provided stamp addressed envelope; and
- ii) That written consent for tape-recording the interview was to be obtained. The Gwynedd Ethical Committee placed a two year time limit on keeping the tape recording before it was to be destroyed.

The study could not proceed until copies of the re-designed bilingual letters were received by the Gwynedd Ethical Committee. The revised study design is shown in Appendix 3. It was also decided at the time of this revision that Consultant A would attempt to recruit into the study during clinical visits, as well as to undertake a self-selected screening process based on the needs of the study.

Overall, the amendments required by the Gwynedd Ethical Committee to the study design improved the ethical issues to be addressed in qualitative research, especially the element of patient confidentiality and their right not to participate (see also: Royal College of Nursing, 1977; Archbold, 1986). Whilst Norton (1975) suggests that the first duty of the researcher is to ensure that the research shall not do the subject any harm, retaining the word 'dementia' in the covering letter from Consultant A (or Consultant B) also ensured that the subject was 'out in the open' before the research interview took place.

The English version of the required amendments were forwarded to the Secretary to the Gwynedd Ethics Committee on the 8th October, 1992, with the documents being sent to the Welsh Translations of the University of Wales, Bangor on the same day. As this translation took up to two weeks, the start of the study was delayed until the 20th October, 1992.

3.10 Study Recruitment

Appendix 4 details the interviews conducted for the entire period of the study and includes a background to the person being interviewed, such as their: age; date the interview took place; transcription date of interview, and so on. For phase 1 of the study, 58 semi-structured interviews were undertaken by the author with family carers of people with dementia between October, 1992 and May, 1994 (represented by interviews: 1-58 in Appendix 4). During this first phase of the study, the author undertook 31 interviews (interviews: 1-31) during his time-limited secondment to the Health Studies Research Division (October, 1992-December, 1992), 13 interviews (interviews: 32-44) on his return to full-time clinical practice (January, 1993-June, 1993) and 14 interviews (interviews 45-58) during his time as Lecturer in Nursing

Studies at the University of Wales, Bangor (September, 1993-May, 1994), a position he was to hold for the remainder of the study. A further 11 interviews (interviews: 59-68) were completed by the author between August, 1994 and January, 1995, with the author returning to the home of one of the interviewees (interview: 66) in February, 1995 to conduct a further round of data collection. These interviews comprised the second phase of the study (see: chapter 5) involving people with the early experience of dementia and their carers. A final series of interviews, phase 3, was undertaken between June, 1995 and July, 1996 (interviews: 69-74) to test the linking scheme of 'maintaining involvement' with family carers. The manner in which these phases developed indicate the complex nature of a grounded theory study, the rationale for which is provided more fully in the relevant chapters.

During these three phases of the study, all but one interview was conducted at the carer's home and tape recorded (see: interview: 28). The interviews were undertaken in North Wales (phase 1); England (phase 2); and Mid Wales (phase 3) and, as outlined previously, admission into the study was provided via a diagnosis of dementia using *DSM-III-R* (American Psychiatric Association, 1987) or *DSM-IV* (American Psychiatric Association, 1994) criteria – depending upon the ensuing year of interview. None of the sample were known to the author before contact was made.

3.11 Data Analysis

The approach to data analysis in grounded theory was described in some detail earlier in the chapter, and the author followed this faithfully using a Glaserian approach. In particular, a hand-written transcription was always completed following each interview and prior to the next, with a preliminary analysis occurring in order to begin to identify key aspects. Concurrently, an extensive fund of theoretical memos were compiled and both these, and sections of the data, are cited as appropriate in subsequent chapters to illustrate the key points.

However, in developing a grounded theory, it is important to emphasise that such theories are not static, but rather they look for relationships within the data as they relate to the whole. Inter-relationships in the data, say in analysing the different coping styles between daughter and son caregivers, or between young and older carers, are not a specific requirement for the methodology. What transcends the data is the 'best fit'

processes by which care is approached, guided by theoretical sampling (as modified by the author) and sensitivity. Analysis is not led, for example, by the gender of the subject being interviewed, unless of course that is the expressed purpose of the study. The theory, therefore, needs to be understood in this context as grounded theory aims to capture the 'whole process' (Glaser, 1978) and not individual variables.

Using the modified grounded theory approach, the author relied on the conceptual power of the constant comparative method (see: pp.78-81) to help guide and shape the analysis of each interview. As previously explained, theoretical memos were kept by the author following each interview and their use helped to shape his process of data analysis, particularly in the search for basic social processes and their role in explaining relationships in the data.

In keeping with the general philosophy of the grounded theory approach, the author will document in text key passages from his theoretical memo fund in order to demonstrate the process of theory generation. This approach will facilitate the integration of theory verification as it emerged during the study. Furthermore, it is hoped that by placing data analysis within the development of the study findings, that a more transparent process can emerge and the author's conceptual thinking become more explicit. Moreover, rather than simply pay 'lip service' to symbolic interactionism in detailing a substantive grounded theory, the approach will be integrated into certain passages of the text in order to capture a sociological meaning to the encounter. Importantly, given the central role of temporality in grounded theory, the accounts provided in chapters 4, 5 and 6 mirrors as closely as possible the sequencing of data collection and analysis as they unfolded throughout the duration of the study.

3.12 Summary

This chapter began with a general description of symbolic interaction, including Blumer's (1969) additional development highlighting the mediating role of meaning in understanding human behaviour. The influence of symbolic interactionism on the formative thinking of Anselm Strauss and Barney Glaser was identified, the basic canons of the grounded theory methodology were introduced, and the limitations in its depiction explored. In particular, the original formulation of grounded theory failed to make explicit the meaning of some of its central concepts, such as theoretical saturation

and theoretical sensitivity. The ensuing schism in grounded theory was then outlined, with Strauss preferring a rigid conditional matrix as a more transparent process of generating grounded theory, whereas Glaser developed further the concept of theoretical sensitivity and continued to place a basic trust in the creativity of analyst. The approach of Glaser appealed to the author, but four modifications to the grounded theory methodology were necessary to operationalise the present study. Subsequently, methods of data collection were outlined with a focus on the interview process and the limitations of this method. The chapter concluded with an overview of the three phases that comprised the entire study, and a statement of the approach to data analysis adopted by the author.

The results of these empirical phases of the study are presented sequentially in chapters 4, 5 and 6, beginning with the 58 interviews conducted with carers of people with dementia in which the primary aim was to explore and develop a temporal model of coping strategies as they evolved over time.

CHAPTER FOUR

TRANSITIONS IN CARE: DEVELOPING A SIX STAGE TEMPORAL MODEL

**Alzheimer's disease you say? I've never heard of that.
I just look after my husband you see
(interview: 1)**

4.1 Introduction

Using the modified grounded theory approach outlined in chapter 3, this chapter describes the development of the stages, supporting processes, phases and critical junctures of a six stage temporal model of care developed from a carer's experience of dementia. This model was generated during 1992-1994 and involved interviews with 58 family carers who were at different points in their caregiving experience (see interviews: 1-58 in Appendix 4 for a complete breakdown of the interviews conducted). However, the main dimensions of the model emerged during the first six months of the study (October, 1992-March, 1993 - interviews: 1-38).

Following an overview of the emerging temporal model of care the chapter will introduce an exploratory nine stage model on the subjective experience of dementia (Keady and Nolan, 1994b). This exploratory model was developed during the 'carer-focused' interviews when four people with the early experience of dementia contributed during the interviews and shared their experience of living with memory loss. This was not anticipated in the original study design and required changes to the research protocol. However, the willingness of people with an early diagnosis of dementia to share their experience led the author to question the explanatory power of a model of dementia constructed solely from the experience of family carers. This resulted in a second phase of the study which involved the participation of people with the early experience of dementia, and their family carers; this is considered in chapter 5.

Consistent with a grounded theory model, data itself drove the direction of the study and this resulted in a relative change in emphasis away from a primary focus on coping towards the notion of transitions in care. This change in the direction was a result of data emerging from the opening series of six interviews (interviews: 1-6), which occurred between the 22nd October, 1992 and the 7th November, 1992. The chapter therefore begins by considering these data.

4.2 From Coping to Experiencing: Broadening the Research Context

The quotation at the start of this chapter was taken from an interview with an 82 year old woman who had cared for her husband for the past twelve years at their farm house on the Llyn Peninsula, North Wales. They constituted the first words committed to audio-tape in the opening series of interviews. The carer's remarks suggested a surprising lack of knowledge about a condition from which her husband had been diagnosed some six years previously. However, as far as could be ascertained during the interview, the carer had never been made aware of the specific name for her husband's condition (over and above 'senility'), its likely impact upon their lives, her husband's entitlement to care allowance or the name(s) of a service provider who might be of assistance. In short, a picture quickly emerged of poor service co-ordination, delivery and design. To the author, as a practitioner in the same Health Authority, it was also a revelation that highlighted a number of tensions with regard to his new research role.

However, as the interview progressed, it quickly became evident that the carer had built-up her own stock of interventions and explanations for her husband's Alzheimer's disease in order to persevere his identity, and normalise their relationship with the family. This introduction to the world of caregiving without a 'professional identity' highlighted to the author the limitations of a simple stress-burden model in capturing the dynamic context that is family care. As the carer explained it was far more important to her to continue to express her love towards her husband, and to achieve a semblance of normality by sticking to a well planned routine that had been finely tuned over the years. It also emerged that the language used to ascribe meanings by the carer was different to that used by professionals. For instance, what professional workers - the author included - construed as 'wandering behaviour' to describe her husband's nocturnal

activity, the carer called 'his get up and go'. Similarly, her husband's short and long term memory loss was understood as 'not being his fault' and of 'needing a bit of help here and there'. In the interview this was manifest by his wife representing her husband, and keeping his thoughts alive, and present, throughout the interview.

This initial insight into the subjective experience of caregiving in dementia, and the carer's obvious skill in successfully managing her husband's Alzheimer's disease, challenged profoundly the author's belief in the basis for professional interventions. Returning home later that evening, and before transcribing the interview by hand, the author jotted down the following set of observations in a newly acquired theoretical memo book:

- Consider how the carer had first recognised, understood and interacted with her husband's (undiagnosed) Alzheimer's disease - think about her entry into the caring relationship;
- What decision-making processes were used on a daily basis and how were they constructed? - there is a need to explore further in future interviews;
- Piece together the coping skills and practical interventions that the carer used and try to find out how their effectiveness, or otherwise, was evaluated;
- Their interactions and relationship changed over time, did the carer see this as a positive experience? - need to find out more;
- What was the carer's continuing motivation to deliver home care and what part did their past relationship play?;
- Did the carer see herself as a skilled person? I did. Find out more about these skills, how they are developed over time and what they may involve.

These were views that the author sought to explore further in the initial interviews (interviews: 1-6), and the transcripts and theoretical memos at the end of this period of data collection highlighted the varied dynamics of care. However, the data were particularly rich in documenting the carers' initial awareness of dementia and their transition to understanding the caregiving experience. This emphasis came about primarily from the design of the semi-structured interview guide (see: Appendix 1)

which focused on the carer's early adjustment, with each interview starting with the same question, namely:

Could you tell me what behaviour, or actions, in your *{insert relationship}* did you first notice that brought about your belief that something quite unusual was happening to your *{insert relationship}*?

Placing the word 'notice' in this opening question was purposeful and directly influenced by Wilson (1989a) and her description of 'noticing' as the first of eight stages of a temporal model of caregiving in Alzheimer's disease; the properties of which were more fully explored in chapter 2 (pp.51-54). The author discovered that the use of 'noticing' was meaningful to carers, and the phrase was used repeatedly in the course of our conversations to describe changes to their dependant's physical, psychological and/or social behaviour. Consequently, diverse examples of 'noticing' were provided during the course of these opening six interviews, as these data reveal:

- He began to write strangely and couldn't sign his name any more (interview: 1);
- His temper began to get worse (interview: 2);
- I couldn't understand what she was saying anymore (interview: 3);
- My mother suddenly stopped calling me on the telephone (interview: 4);
- He couldn't do electrical things anymore like fit a plug or things like that. I found that really strange because he was always really good with that type of thing (interview: 5);
- My father became distant with me and unapproachable (interview: 6).

The opening question also afforded carers the opportunity to explore a number of different dimensions in their caregiving experience. For instance, they were able to reflect upon the processes that changed a familiar person with recognisable personality traits and actions, to someone who was, at first, unfamiliar. In exploring this transition, carers would often spend some time discussing aspects of their life together before the onset of dementia (even though this word may not have been used), taking pleasure in sharing important memories, such as their wedding date (for spouse carers), birth of children, work experience, home life and so on. Such recollections, at times, proved an emotional experience, as with the fourth interviewee in the study (interview: 4) who revealed 'I had almost forgotten what my mother was like before all this started'.

Analysis of the interview transcripts from these opening six interviews revealed that the carer's use of 'noticing' went far beyond Wilson's (1989a) description of this as being a stage confined to the beginning of caregiving. Indeed, 'noticing' was a recurrent process that helped inform the act of caring. For example, on arriving at the home of one carer (interview: 5), the carer began the interview by speaking warmly of the close family support she had received during the past six years from her daughter. As the carer went on to explain, each Wednesday for the past two years her daughter 'had taken him {referring to her husband} out for a ride in the car'. Probing for the purpose behind this routine, it emerged that it was used to give the carer 'a break' whilst simultaneously acting to maintain the daughter's relationship with her father. On discussing the perceived benefits gained from receiving such a short break, the carer suddenly changed the direction of the conversation and said:

... isn't it funny. Just this morning I *noticed* {emphasis added} that he {her husband} didn't dry his face with the towel. He just sat there with it in his hands and looked at me - he didn't seem to know what to do. I always help him in the bathroom, with his shaving and that, but he has always dried his face afterwards. Normally, I just hand him the towel and he gets on with it. So this morning when he didn't do that I thought it was a little strange. I told my daughter about it when she arrived and she thought so too. I only wash his face properly in the morning, you know, but I might try again later when he comes home to see if he does it again.

(interview: 5)

As can be seen from this extract, the decision to act on the husband's change of routine was fuelled by the carer recognising a change in his usual pattern of behaviour; this recognition was prompted by a process of 'noticing'. Whilst a simple observation in itself, this use of 'noticing' by this carer challenged Wilson's (1989a) assumption that 'it was present only in retrospect' (p.42), and, *de facto*, a stage of caregiving to be quickly passed through. Recognising this subtle variation, the author began to search through the other transcripts to look for similar examples to support this more contemporaneous process of 'noticing'. In the final interview of this opening phase (interview: 6), the author retrieved the following data:

Researcher: You were telling me earlier that your father had been a kind and gentle man in the past. Did the dementia change him in any way?

Carer: At first it did, yes. He would do all sorts of things that would drive us mad, like fiddling with the video and putting all the lights on in the house. We couldn't leave him alone for a minute.

Researcher: Does your father still do such things now?

Carer: Oh no, not anymore. He just sits in his chair for most of the day and talks to himself. That makes it better for me. If you can stay a little longer you will soon hear him stop chattering away and start humming and tapping his leg with his hand. I *noticed* {emphasis added} he started doing that a few weeks ago. When he does that, it means he wants to go to the toilet. That's something new and it took me a little time to work out what was happening. But now I know it saves on the washing - well a bit anyway {laughs}.

These data clearly suggest that 'noticing' is not simply a first stage in caregiving, but rather a consistently occurring process that prompts the carer to act; in this case (interview: 6) causing the daughter to search for the cause of this newly exhibited behaviour. At the time the author recorded this more active functioning of 'noticing' in his theoretical memo book as follows:

The question posed by 'noticing' is not simply a retrospective one i.e. 'what have I seen?' More precisely, it starts a process of decision-making, challenging the carer to do something about its entry into their social world.

(theoretical memo book entry: 8.11.1992)

In such circumstances the carer's struggle to attach a symbolic context to the encounter as the symbols (objective meaning) of the exchange have not been understood. Thus 'noticing' is not passive in the previously suggested sense, but an active process that prompts the carer to address two inter-linked questions. Firstly, 'what am I seeing?' and second, 'now that I have seen it {the object} how can I understand and act on it?' Each carer's process of adjustment added to their understanding and knowledge of the context of care. This was particularly evident during the carer's early exposure to (undiagnosed) dementia, or when caring continued without active professional involvement and

support. For example, during the third interview (interview: 3), the author was at the home of a 78 year old spouse carer who had not received any meaningful professional support for the last two years. In the following extract from the interview transcript, the carer was responding to the author's question on how he best understood his wife's behaviour in the context of their day-to-day life together:

My wife doesn't do any housework now you know, she does nothing at all although she thinks she has done it. I just say 'oh yes, look how well you have cleaned the house'. Normally, in the morning, I will make her some toast and cornflakes and a cup of tea and bring her downstairs so she can sit and have them with me, and after she's finished she will normally say 'oh, I'm really tired now after making the breakfast for us'. And I will think 'what does she mean by this, I have done it all?' Sometimes with my help she will dust and she'll just touch the area she is trying to clean and then she thinks she has done it all. I mean you have to try and put her right at times, but without my help she hasn't used a duster properly in two and a half years, and she will sit in the front room and watch me finish it. I mean I will care but there again I've got nothing else to do have I? It's such a shame that she just can't carry on like she used to, but it's up to me to try and help her the best I can.

(interview: 3)

What emerged a little later in this interview was that to 'try and help her the best I can' the carer continually persuaded his wife to attempt domestic chores around the home. To achieve this the carer would tell his wife 'if you don't do what I want you to do, then our money will be stopped', and as the carer went on to explain 'money and being up-to-date with paying bills has always been a big thing with her'. This statement was 'a bluff' in that, as the carer admitted, he 'would never force her to do anything she didn't want to do'. To the author this prompted the question 'why use the strategy in the first place?' Exploring this question with the carer during the course of the interview, it emerged that he used 'the bluff' to get his wife 'moving and doing things again'. Thus its primary purpose was as a source of motivation utilised to maintain a past social role, thereby preserving (in the carer's wife) a sense of her identity. Over and above this function, 'the bluff' was constructed from an intimate knowledge of his wife's past.

Reflecting upon this interaction shortly after the interview, the author entered the following note in his theoretical memo book:

... in this interview the carer is attempting to maintain a past role within the context of their present (imbalanced) relationship - a relationship where the carer

feels a duty to act and for which he is undoubtedly taking a lead. However, the carer does not appear to want to be seen by his wife as having this lead, as it means taking over a previously valued social role (this protective/preservative dichotomy has been seen previously in the work of Bowers (1987; 1988a)). To motivate his wife to live positively through her experience of dementia, the carer is building upon the unique biographical knowledge in his possession to direct present caregiving efforts. For the carer the purpose attached to this motivational behaviour is clear (although invisible), but for the person with dementia its impact is more difficult to evaluate.

(theoretical memo book entry: 24.10.1992)

After recording this theoretical memo, the author searched through the interview transcripts for similar examples of the past influencing present caregiving efforts. From this constant comparative process, a further example emerged from the second interview (interview: 2) when the carer had forced herself to become interested in her husband's previous 'preoccupation' with motor cars. During this interview the carer explained that developing this interest was necessary as it allowed her to 'continue talking with him'. Moreover, the interest also helped distract her husband whenever he became 'uncertain of his whereabouts' {carer's words}. Whenever her husband became 'uncertain of his whereabouts', the carer would lead her husband out of the house and into their garage where she would ask him to 'get the car going so they could go out for a drive'. However, unbeknown to the person with dementia, and with the prior help of their son, the carer had had the car engine immobilised and ignition key removed from the set of car keys. The carer found that taking her husband to the garage, and then providing him with this challenge, would keep him occupied for many hours. This deceptive act (similar in purpose to 'the bluff' strategy seen in interview: 3), coupled to her husband's familiarity and ease with the environment, helped to focus his 'uncertainty' and assist in minimising levels of anxiety - both for the person with dementia and the carer.

Again, the author noted that this approach was made possible by an intimate knowledge of the person's past, and a desire to preserve a valued social role within the context of a changing reality. Attempting to make a theoretical connection between these similar experiences led the author to place the following entry in his theoretical memo book:

...by drawing upon intimate knowledge of the person, carers appear *to build on the past* {original emphasis} in order to shape the context of their day-to-day caring and decision-making.

(theoretical memo book entry: 26.10.1992)

Following this entry the author used the words 'to build on the past' as a pre-stage that might help explain the context of caregiving, although its properties clearly required further empirical development and refinement as the study progressed.

As the opening transcripts were continually read and the audio-tapes replayed, it became increasingly evident to the author that caregiving was not a passive activity and it occurred in the context of a relationship. Indeed, caregiving required a great deal of time, effort, ingenuity and, perhaps most important of all, an intimate knowledge of the person on the receiving end of care. Without this intimate knowledge and relationship attempts by the carer to find and attach meaning to their role would be very difficult. Moreover, from these opening six interviews, additional markers emerged to help explore the experience of dementia as viewed from the perspective of family carers, namely the:

- Importance of developing, managing and sustaining routines to help provide stability in the relationship;
- Use of adaptive, imaginative and skilled coping efforts to stabilise the uncertainty that resulted from living with a person with dementia;
- Attempts, led by the carer, to form a partnership in order to preserve a sense of normality within their lives and relationship;
- Experience of caregiving as socially isolating;
- 'Normalising' a behaviour exhibited by the person with (undiagnosed) dementia during their early awareness and process of adjustment; and
- Knowledge of dementia held by professionals may not be meaningful within the context of the carer's lived experience.

From this early phase of the research process, and consistent with a grounded theory approach, discovering how such dynamics interacted to structure the carer's experience of dementia shifted the emphasis away from a coping paradigm towards a more multi-dimensional and contextual focus. This was recognised by the author in a theoretical memo made just after listing the above additional markers:

... coping with caregiving is just one part of a multi-dimensional agenda faced by family carers. The emergence of a carer developed model of dementia, replete with signposts to mark this journey, would help to ground the caregiving

experience and assist professionals to build-up their intervention from this standpoint. It is becoming increasingly evident from the six carers interviewed to date that their awareness of dementia, and their skill at managing complex problems without reference to professional intervention, needs to be more fully understood if a more comprehensive and person-centred service is to be provided. I would suggest that this search becomes the main focus of the study. Without a broad framework from which to explore the dynamics of dementia, attempts to understand more fully such complex constructs as coping, satisfaction and stress could not be undertaken adequately, or else attempts at explaining such phenomenon would be taken out of the context in which they existed.

(theoretical memo book entry: 8.11.1992)

If a suitable temporal model could emerge from the study, then, it was thought, professional interventions could be constructed to complement the pace and understanding of dementia as experienced by the family carer - an area in the literature that was poorly developed. As highlighted in chapter 3, the author had access to Wilson's (1989a) study to act as a conceptual guide and to help recognise properties of an emerging model.

Discussing this revised research design with his supervisor shortly after completing these opening interviews, it was agreed to re-focus the study along the above lines. The remainder of this chapter, and thesis, focuses on the initial carer-led and subsequent dyadic model of the dementia experience that resulted from this change of emphasis.

4.3 Changing Emphasis: Focusing on the Early Transition to Care

In subsequent interviews the author had to determine how to identify a theoretical sample of informants. After considering the analysis of the initial data, the author decided to target the carer's early awareness and adjustment to caregiving tentatively named 'to build on the past'. By exploring the caregiver's early transition and awareness of 'dementia', the processes involved in 'noticing' could be explored further and its importance empirically tested.

In November, 1992 after discussing the revised research agenda with Consultant A, he began the process of identifying twenty carers from his clinical caseload, with this number being agreed for three reasons. Firstly, to identify a sufficient number of carers to ensure the necessary level of theoretical coverage of the phenomenon under study.

Second, to anticipate the possibility of some carers deciding not to take part in the study. Third, to enable the author to undertake as many interviews as possible before the completion of his secondment at the end of December, 1992. Consultant A wrote to each carer to invite their participation into the study, selecting a broad spectrum of carers (ranging from months to years) and from a wide geographical spread across Gwynedd.

Following Consultant A's approach, fifteen carers agreed to take part in the study (interviews: 7-21 – see: Appendix 4) with appointments then being made by the author to interview each carer at home. These interviews took place between 16th-30th November, 1992. The analysis of this series of interviews, which were integrated and compared to the findings of the first six, is presented below.

4.4 'Noticing': Shifting the Emphasis from Stage to Process

As a measure of consistency in data collection, each interview in this second series commenced by asking the carer the same opening question as in the first six (see: page 110). Subsequently, however, the interview focused on the carer's early awareness and adjustment to dementia, and explored the properties of the process that comprised the carer's 'noticing' behaviour.

After completing the series of interviews and constantly comparing experiences, an awareness of issues associated with driving emerged a number of times as an area where carers first 'noticed' a subtle change to the person's behaviour, particularly in their judgement and reaction times (expressed in interviews: 11, 12 and 14). However, it was not just difficulties with driving where the carer first 'noticed' a change of behaviour, as the following data from other interviews suggest:

- For some reason my father wasn't able to subtract the scores during our dart matches, something he had done well for years (interview: 8);
- We first noticed Dad's change of routine (interview: 13);
- He would get headaches and need to spend time away from us (interview: 16);
- I noticed there was things she was forgetting (interview: 17);

- My husband began to spend more time outside the house than he did with me (interview: 18);
- My wife started to burn all the pans when she was in the kitchen, and couldn't work the cooker properly (interview: 20).

Analysing these encounters from a symbolic interactionist perspective, the sudden entry into the social setting of these objects disrupted the agreed exchange of symbols existing between carers and people with (undiagnosed) dementia in the course of day-to-day social interaction. Consequently, carers were unable to place themselves in the position of the 'generalised other', a standpoint essential if meaningful interaction is to ensue. As carers were now unable to attach and agree a meaning to the object (encounter), such as a 'safe' driver suddenly being unable to handle the instructions on a traffic light (interview: 14, for instance), it prompted the carer to ask the question 'what am I seeing?' To address this uncertainty, a phenomenon seen in each interview throughout the study (interviews: 1-21) emerged in that carers implemented a cognitive coping strategy to 'normalise' the significance of the encounter. On each occasion this was achieved by generating a plausible explanation for occurrence of the unusual behaviour. The following data provide diverse examples of this 'normalising' process:

- I thought it was just a normal part of getting old (interviews: 1, 4, 5, 6, 9, 10, 12, 14, 16 and 21);
- Our mother died last year and we all put it down to him being sad and depressed about it all (interview: 13);
- I tried not to think about it, if you can understand that (interview: 15);
- I just believed my husband was getting ill, and he would get better again soon (interview code: 18);
- I thought he was depressed because of his retirement (interview: 19).

By utilising such a cognitive coping strategy carers had a social currency with which to contextualise the encounter, returning it to the safety of 'this is OK'. For the carer the ability to say 'this is OK' allowed life to return 'to normal', albeit within a newly defined construction of reality, as this carer's experience suggests (interview: 14):

Carer: The first thing I noticed? His {carer's husband} driving. My husband had always been such a careful driver and then he suddenly started to hit the kerb and drive too close to the car in front. He also didn't seem to understand traffic lights anymore. They would turn to green and I would be sitting there waiting to move off but he didn't go. He would just sit there and I would have to tell him to go in the end.

Researcher: What did you put this down to at the time?

Carer: I just thought he was getting on and that he couldn't see as well as he used to. That's what I told myself anyway, but I thought it was a little strange.

Wilson (1989a p.42) had previously identified this process and had labelled it 'discounting and normalizing' (her sequence), placing it as the second stage in her eight stage model. However, data from the present study would strongly suggest that there is both a sequence and division between 'normalising' and 'discounting' that reverses Wilson's original stage formation and also differentiates between the phenomena. Prompted by the question 'what am I seeing?' normalising and discounting are two separate processes that quickly follow each other in a cycle of decision-making. They also have two distinct roles. From the data the purpose of 'normalising' is to first locate the encounter within a symbolic (meaningful) context for the carer, one that is arrived at after thinking about what they were seeing i.e. 'I thought he was depressed because of his retirement' (interview: 19). On the other hand, the primary purpose of discounting is to return the entire encounter to the safety of 'this is OK', thus allowing the carer to preserve social interaction with the person with (undiagnosed) dementia.

However, as an example from interview: 14 illustrates, whilst the behaviour might be normalised, the encounter itself was not entirely discounted. Over time, and as the encounter (or the behaviour) was repeated, increased in severity or frequency, or new 'encounters' occurred, it became increasingly difficult to normalise events and carers suspected that something quite serious was happening. However, following the initial encounter, the carer was unable to grasp fully the significance of what they were seeing and thus found it easier to discount it temporarily.

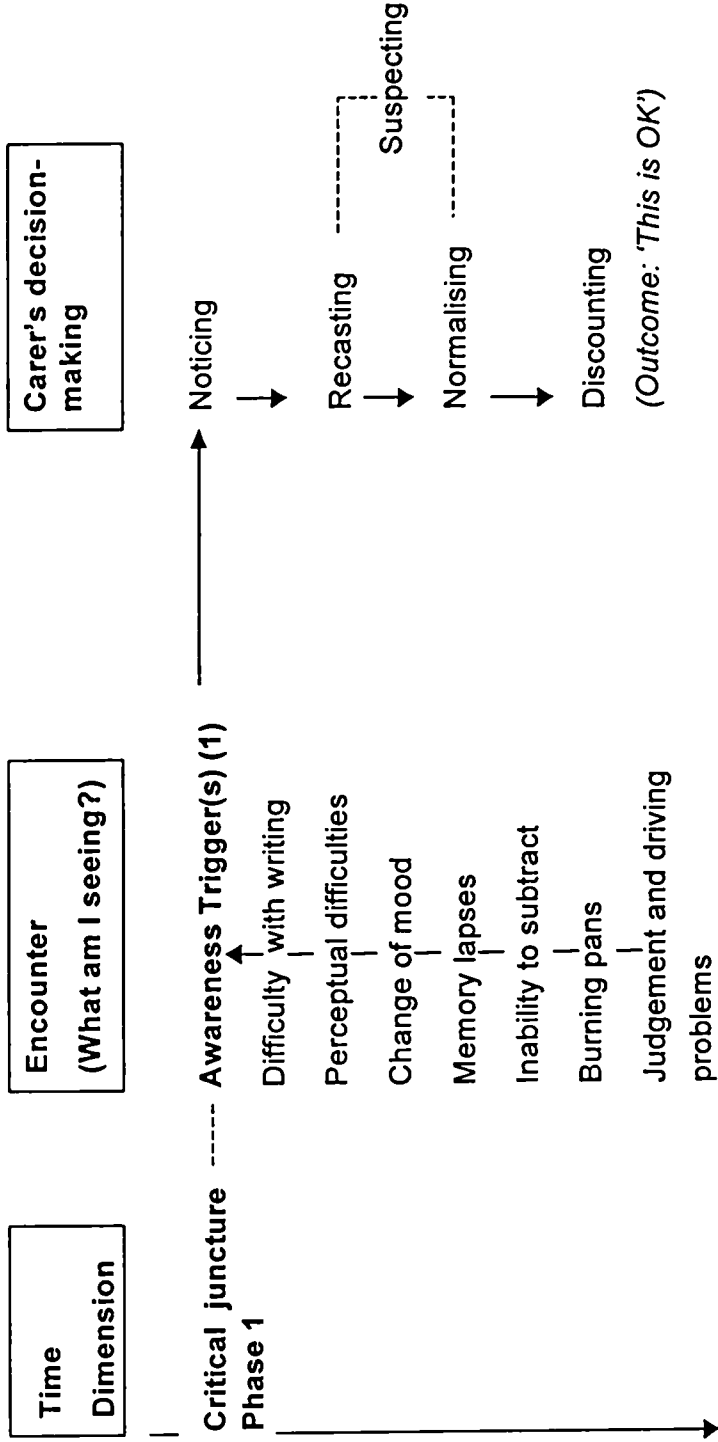
Writing in his theoretical memo book on the 1st December, 1992, the author attempted to represent this early dynamic as part of a decision-making process employed by each carer in the study, as Figure 3 (next page) reveals.

In this decision-making process, the carer has their first encounter with the ‘unusual behaviour/action’ (represented in Figure 3 as an awareness trigger(s)), recasts it (tries to find a symbolic context to attach to the meaning of the encounter), is unable to do so, therefore normalises the encounter by implementing a cognitive coping effort (‘it’s probably due to age/stress/retirement’); thus the final outcome of the encounter is one of discounting it as something not to be worried about. As highlighted earlier, whilst the awareness trigger(s) is discounted, it is still considered an unusual occurrence, hence the entry of ‘suspecting’ into the decision-making process, which becomes stronger and more influential as the behaviour is repeated.

This model of early recognition and discounting was applied to the data set (interviews: 1-21), and was seen to be a universally occurring phenomenon that symbolised the carer’s first encounter with the experience of dementia. However, it is important to place a time dimension against the processes involved in generating a perception of ‘this is OK’, because for all the carers both normalising and discounting could only be temporary phenomenon on the road to a formal diagnosis of dementia provided by Consultant A. What the author wanted to explore was how the perception ‘this is OK’ shifted to a recognition that ‘this is (or might be) serious’.

Drawing on two interviews conducted during the second series of interviews, the following cases illustrate the decision-making processes involved in Figure 3, and help to identify the awareness triggers necessary to begin questioning the initial belief structure that ‘this is OK’.

Figure 3 'This is OK': Discounting the noticed awareness trigger



Theoretical memo book entry: 1.12.92

Note: The awareness trigger(s) in Phase 1 are illustrative

Case Illustration 1 (interview: 9)

During this interview, when recounting his transition to care some six years ago, an 82 year old spouse vividly recollected being called in from the garden to be presented for lunch with potatoes, carrots and cat food. As he recalled the first time this happened both he and his wife passed it off as a normal part of getting old. The second time it happened it was 'as something simply to laugh about', but on the third occurrence, for the husband, it signaled something to be concerned about. Significantly, in acting upon this suspicion, help was not sought immediately from the GP but, as is so often the case, from close family members; in this case, the only son. The solution to this dilemma was a family decision (which excluded the person with (undiagnosed) dementia) that the son would provide all meals for his parents, and the rationalisation that the 'odd behaviour' remained one of the inevitable consequences of 'getting old'. It was a further two years before the concerned spouse sought the advice of their GP, and this was prompted by an article he read in a Sunday newspaper on the clinical signs of Alzheimer's disease. This article, the carer explained, 'was all about my wife'. However, because she refused to attend the surgery to confirm his suspicions, it proved to be a further eighteen months before she was seen at home and additional support arranged.

As can be seen from this first case illustration, the awareness trigger that turned the carer's belief that 'this is OK' to a new belief that 'this might be serious' was the continuation of his wife's 'unusual' behaviour, and the secondary (informal) confirmation of events between father and son. The fact that the encounter was subsequently 'normalised' and 'discounted' again by the family unit illustrates the strength of such perceptions. Indeed, it took the introduction of an additional awareness trigger - in this instance a newspaper article on the clinical presentation of Alzheimer's disease - to rekindle the properties of the 'suspecting' process to challenge the belief that 'this is OK'. However, this time, instead of seeking a secondary (informal) confirmation of events between family members, the carer chose to seek a more formal confirmation from an alternative route, namely a medical opinion provided by his GP. Unfortunately, for the carer and the person with (undiagnosed) dementia, in attempting once again to act upon his suspicions, the response of the primary health care team was far from accommodating and failed to provide the necessary support and action. This caused a dilemma as the carer was unable to return to a

phase 1 perception of 'this is OK' (Figure 3), as he believed (from an independent report that apparently explained his observations and experience) that his wife was medically unwell. Consequently, the carer entered a period of uncertainty that was to last a further eighteen months where the routines and behaviour constructed to support his wife's (undiagnosed) dementia were continued, only this time they also involved the carer becoming increasingly vigilant.

For the carer this experience of living with uncertainty was only resolved through his 'pestering' (carer's words) the surgery until his own GP came out to see him at home; this visit triggered a referral to Consultant A and the start of the formal diagnostic process. Crucially, it also validated the carer's concerns about the seriousness of the situation he faced and, just as importantly, the situation faced by his wife. Indeed, once Consultant A became involved, the carer's wife was admitted for a short time to a dementia assessment ward and a diagnosis of Alzheimer's disease (moderate stage) made and communicated to the carer.

The interface with professional care staff raises a number of important questions, particularly as the provision of a diagnosis marks a critical juncture for carers who can, legitimately, leave the state of uncertainty and take on a more formal, and recognised role, of carer. In this case the diagnosis propelled the carer into a new phase of caregiving, one that was to last several more years and see his care evolve into tending to his wife's physical needs; a task, the carer admitted, that was 'a pleasure to perform'.

Case Illustration 2 (interview: 17)

Answering the author's opening question in the research interview, the carer provided the following response:

What did I first notice about Mum? Well, the first nine months I was down there {her mother's house situated a short walk away} virtually from the time I got up in the morning to the time I went to bed. I'd run home, get a quick snack, and I would have to spend more and more time down there because ... I think it really started that we noticed ... I mean I noticed there was things she was forgetting and I put it down to old age and she, I mean my sister, she came up once a year for a week. So the first year she came up she was fine, the second year she started to say that 'Mum is definitely forgetful, isn't she?', and the third year she came up I said 'yes she is'.

In this second case illustration the awareness trigger that moved the carer's discounting process to one of suspecting that 'this might be serious' occurred one morning when she went to the house and found her mother washing her underwear in the kitchen sink. Normally this would not have been a problem, but on this occasion her mother was washing her underwear in the same water, and at the same time, as her breakfast bowl. Having spent a lifetime being meticulous about washing her clothes, the carer could find no rational explanation for this turn of events. Indeed, as the carer explained in the interview 'it suddenly struck me that my mother really wasn't right'.

However, as with case illustration 1, to confirm this suspicion the carer did not turn immediately to professional advice. Instead, a complex caring routine was initiated that saw the carer's increasing vigilance of the situation. At the beginning, this increasing vigilance centred on a 'surveillance' of her mother's house, without her mother being aware of the context in which the surveillance was taking place. This period of surveillance involved the carer and her husband driving, or walking past, her mother's house at different times of the day and evening. The purpose of this was to look for her mother's movements in the home and, in the evening, to see how many lights were switched on. For the carer, the more lights that were switched on in the house, especially those upstairs, the more 'unusual' she believed her mother's behaviour to be and the more anxious she became over her safety. This, in turn, prompted further action by the carer, such as raising the general level of awareness of her mother's 'unusual' behaviour with the local community, as well as taking charge of her mother's financial affairs and more practical necessities, such as shopping for groceries and cleaning the house.

As time went by and her mother's forgetfulness did not improve, the carer began to look for alternative ways of 'catching her mother out'. As the carer explained, whilst still attempting to nurture her mother's independence, she would call each morning and leave her mother with four slices of bread for the day. This was done for two reasons. Firstly, to make sure that her mother did not eat a whole loaf of bread, as she had always enjoyed her 'bechdan jam' (jam sandwich). Second, if the slices of bread were then found hidden in the house (as they invariably were) then this confirmed to the daughter that her suspicions were justified, and that an increased level of surveillance was, indeed, necessary. Consequently, the meaning and purpose of the carer's action subtly

shifted, from one of a more passive noticing of events to a more watchful activity that involved confirming the seriousness of the situation without the person with (undiagnosed) dementia being aware of what was happening. This finding is similar in context to that of supervisory care as reported previously by Bowers (1987). However, as both these case illustrations have demonstrated, seeking a secondary (informal) confirmation of the encounter was also crucial.

Paradoxically, during the carer's initial adjustment to the belief 'this might be serious', the carer did not give up hope that things may return 'to normal' as she went on to explain:

In the early days I wanted my Mum to be better. I knew it was not getting any better, but I wanted her to, if that makes any sense to you. She was so forgetful by then. Calling me the wrong name all the time, not doing the shopping and the like. It was so unlike her. And her temper! I knew then I had to do something, but early on I always hoped that she would come back and be my Mum again.

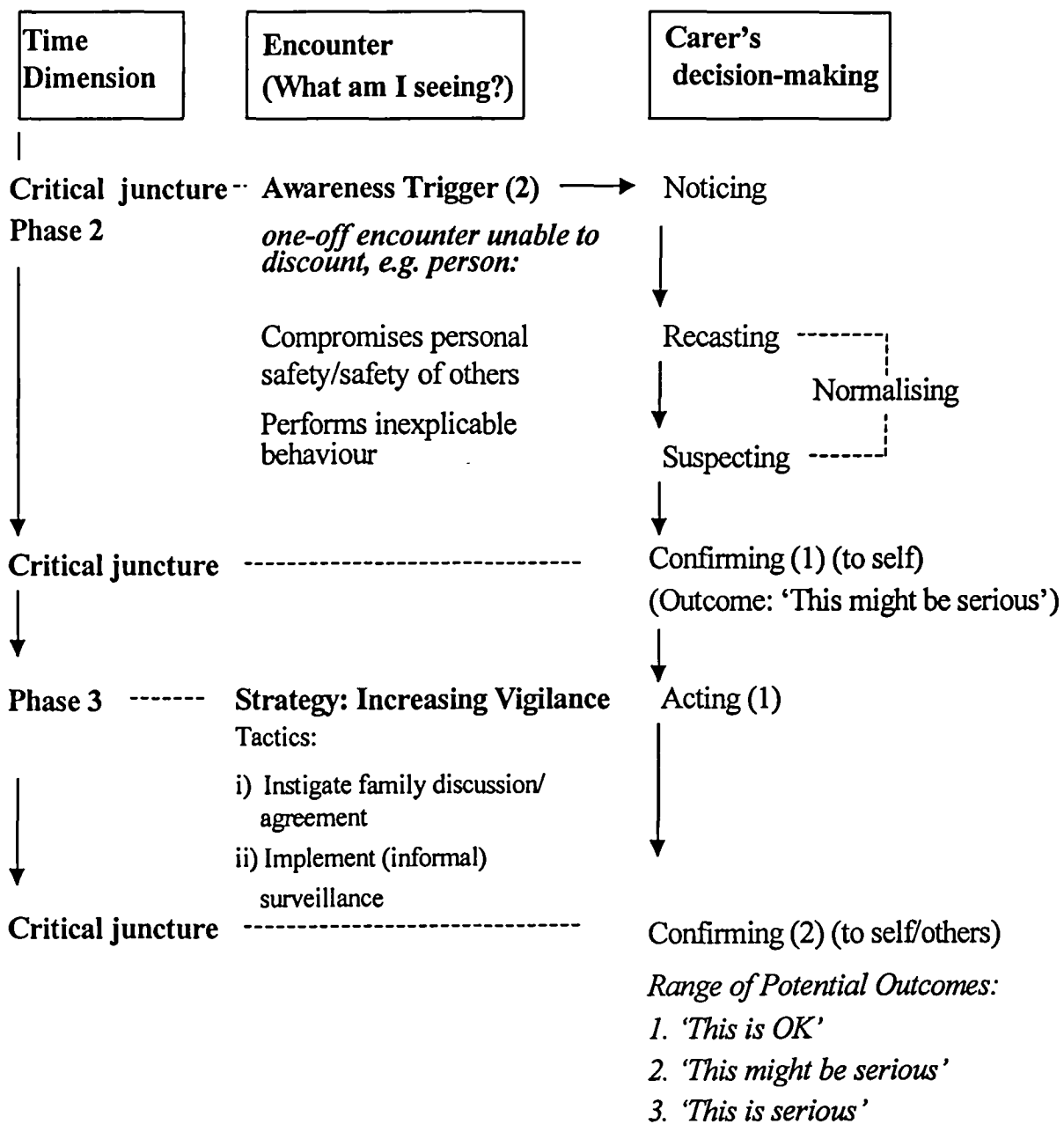
(interview: 17)

Whether this is a positive coping response is debatable, but the ability to normalise the reality of 'dementia' gradually diminished over time and the person did not return to her former self. However, as the data suggested, carers initially acted upon their suspicion that 'this might be serious' by informally 'checking out' their observations with close family members, and/or by increasing the level of surveillance to confirm what they were seeing. This process of (informal) confirmation between family members on the 'seriousness' of the situation was repeated throughout the data set and could last several months, or years, with the time dimension attached to this phase of caregiving depending largely upon the support structures of the carer, and/or their belief structures that allowed them to minimise the significance of what they were seeing.

4.5 Steps to 'This is Serious': Searching for Conceptual Links

Building on this growing understanding of the carer's decision-making processes, Figure 4 (next page) is taken from a theoretical memo entry written in early December, 1992. Figure 4 attempts to illustrate this more active period in the decision-making process when the carer was no longer able to discount the significance of the encounter,

Figure 4: 'This is Serious': Steps in the carer's decision-making process



Theoretical memo book entry: 2.12.1992

and begins to believe that 'this might be serious'. However, as seen in case illustration 1, the outcome of this concern can still be to return to a phase of 'this is OK', or it can be moved, over time, to holding a belief that 'this is serious', thus prompting further action by the carer.

In figure 4 it is important to highlight that it is the introduction of the second awareness trigger in phase 2 that prompts the questioning of a belief that 'this is OK', and that this occurs against the backdrop of the accumulation, and diversity, of the phase 1 awareness trigger(s). In turn, the carer's increasing vigilance gradually confirms their suspicions.

In phase 2, then, substituting 'discounting' and replacing it with 'confirming'(1) (to self) was the result of the second awareness trigger which could not be discounted. In case illustration 2 this was seen when the daughter found her mother washing her clothes and breakfast dishes in the same bowl and could find 'no rational explanation' to contextualise this occurrence.

The initial process of confirming (to the carer/self) that 'this might be serious' negated the belief that 'this is OK'. Once this cognitive shift had been made, the carer then acted upon his/her suspicions through increasing vigilance and by implementing the two tactics outlined in phase 3. Significantly, such actions were not revealed to the person with (undiagnosed) dementia, and they were not asked at the time to explain their behaviour. From the data it would appear that the second awareness trigger served to confirm the seriousness of what the carer was seeing. However, as carers doubted their own judgement, they 'hid' their raised level of concern from the person with (undiagnosed) dementia and engaged in strategies to either confirm (for a second time), or deny, the reality of what they were seeing; this is represented by the phase 3 actions outlined in Figure 4 and the potential range of outcomes associated with this process.

4.6 'Where do I go Next?': Strategies Leading to a Medical Diagnosis

Taken from the tenth interview in the study (interview: 10), this following example provides an elegant account of the time dimension attached to the processes outlined in Figure 4, and the carer's need to continually act upon their suspicions:

Researcher: You said you've been caring for your husband for eighteen years?

Carer: Yes, eighteen years. That's right. The first thing I noticed was his loss of memory, though thinking back the first thing I noticed was that he would show me the same book reference day after day and I eventually thought this was rather odd, but it was basically a loss of memory.

Researcher: What did you put this down to at the time?

Carer: At first I just thought it was a bit odd, but as time went by I realised that it was more than this and that something more serious was coming on.

Researcher: How did you understand your husband's behaviour at the time?

Carer: He {her husband} was rather slow to start with at the time. I wouldn't have called it dementia until I heard Consultant A say the word 'dementia' many years later. I didn't really understand what it was. All I knew was that he would do funny things and fiddle with things in the house. It was when he started to put the gas on and forget to light it, that I knew something had to be done. We discussed it as a family and we all agreed.

Researcher: When you say you discussed it as a family, did the discussion include your husband?

Carer: No.

Researcher: So it was when your husband began to be unsafe in the house you felt you had to do something?

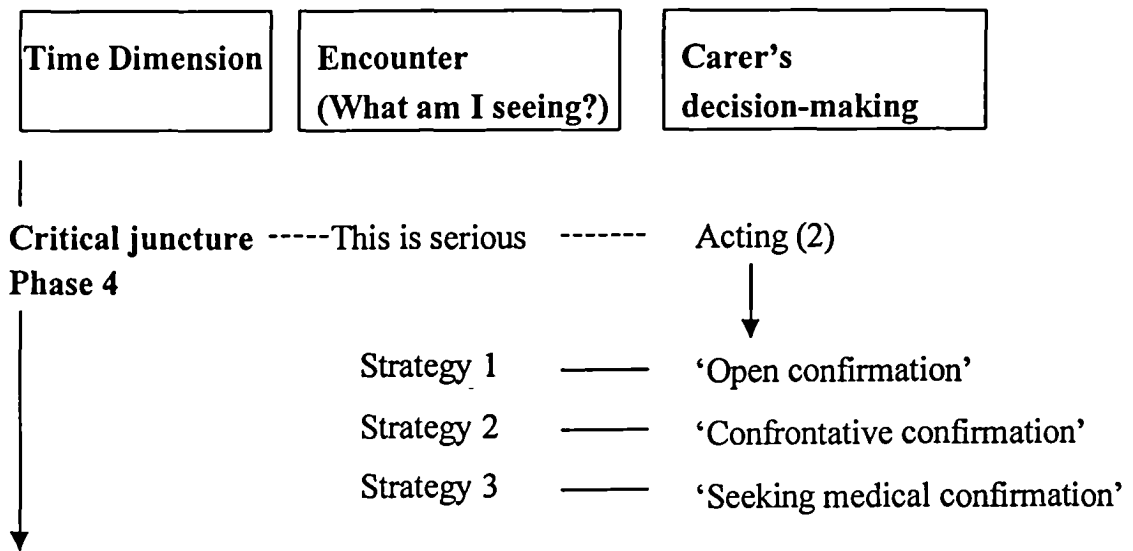
Carer: Yes, that's it. I went to the doctor then and he gave me a booklet - one with a black cover. He asked me to read it and come back again if I was having trouble managing. He also gave me a booklet telling me who to contact and, you know, that's just about it until I went back again to see him.

Researcher: So how long did you live with this knowledge, and your husband, before you returned again to your doctor to ask for more help?

Carer: About two years.

As can be seen in this interview, the GP took no steps to confirm a clinical diagnosis of dementia, apparently reaching the decision by relying solely on the carer's account. The fact that his professional response was to hand the carer the 'Who Cares?' booklet (Health Education Council, 1986) and return her home armed with a little more information, hardly portrays an image of proactive assessment and intervention. However, whilst the professional response was, in this case, inadequate, by presenting herself to the surgery the carer had come to a decision that her husband's behaviour was 'serious', and she was seeking a formal (medical) confirmation of this belief. As the data revealed, carers approached this phase by using one, or a combination, of three strategies as illustrated in Figure 5:

Figure 5: Strategies to 'open up' the illness behaviour



Theoretical memo book entry : 4.12.1992

Supported by the data an illustration of each of these strategies will now be presented.

Strategy 1: Open confirmation

For carers and people with dementia in this initial sample (interviews: 1-21), a shared decision to seek an explanation for the awareness trigger(s) exhibited in phases 1, 2 or 3

simply did not happen. Instead, attempts at facilitating open disclosure between the family and the person with (undiagnosed) dementia resulted in a denial that anything was wrong by the person with (undiagnosed) dementia. Therefore, when open confirmation was initiated by the carer, the result was conflict. This seemed to be because the person with (undiagnosed) dementia was still discounting the significance of the encounter, as one daughter in the study explained:

I tried to tell my mother about what she was doing and ask her if she recognised it too, but she didn't want to know. I thought I had done all the right things, you know, planned what I was going to say and I waited until there was no-one else in the house. She seemed happy enough at first but I couldn't get through to her. She just stopped me stone dead and said there was nothing wrong with her... {pause}, but I knew there was.

(interview: 17)

This situation presents the carer with a particular dilemma and was managed either by carrying on with the 'surveillance' and accumulating additional confirmatory evidence (as in this interview), or in seeking an explanation from a formal (medical) source from their GP - an issue that will be discussed shortly under strategy 3.

Strategy 2: Confrontative confirmation

Confrontative confirmation was seen to occur in the heat of the moment and was normally triggered when the carer's patience finally 'snapped'. However, unlike the phase 2 awareness trigger which the carer kept to themselves, this time the encounter was verbally, and often aggressively, communicated to the person with (undiagnosed) dementia. For instance, one female spouse carer (interview: 14) remembered screaming at her husband that he 'really was mad' after he had forgotten (again) to turn off the gas taps after heating a tin of beans on the stove. This verbal outburst was then followed by a stream of other concerns that the carer had noticed over the preceding years, but had kept to herself, as illustrated on the next page:

Carer: I remember coming home from the shops to find my husband on his knees trying to put soiled toilet paper into a plant pot. At the time I felt sick and disgusted, I was just so tired of having to chase after him all the time. I remember shouting at him 'why don't you flush it down the toilet like everyone else!' I then said something like 'you're a grown man' and that 'you're not normal'.

Researcher: What happened after you said those things?

Carer: Nothing much, he just sort of looked at me strangely and started to walk away.

Researcher: Did you chase after him?

Carer: Yes. I went running after him. I remember I was still shouting at him, things like 'you've ruined my life', that sort of thing. I feel terrible telling you all about this now because he {carer's husband} really isn't well. But it is what happened. When he didn't answer me I told him 'I was going to do something about it', so I remember leaving him by himself and I went straight to the doctors. I couldn't cope any more. I felt so angry and I knew something had to be done.

As in this example, the breaking point for the carer was a 'one-off' incident at the end of a long line of (secret) concerns stretching back several years where the carer had gradually worked through the awareness levels attached to phases 1, 2 and 3 of the decision-making process; processes that started when the carer first 'noticed' her husband's poor driving skills. Whilst not attempting to defend the verbal onslaught hurled at the person with (undiagnosed) dementia, for the carer her action and her husband's lack of response set in motion a chain of events that was to lead to the eventual diagnosis of her husband's dementia; it was then that the real cause of the behaviour became apparent and its meaning placed in context. It was also at this later time that the carer herself regretted her actions and felt guilty about her response. However, without this confrontative confirmation, the carer would have remained 'at

boiling point' uncertain of her husband's motivations for his behaviour and continually questioning what she was seeing.

A number of other carers in this first and second series of interviews also reported that their confrontative outburst brought no meaningful response from the person they were concerned about, other than silence (expressed in interviews: 4, 12, 14 and 19). It is possible that in this group, the person with (undiagnosed) dementia was able to cope with such an outburst having already anticipated such an event. This area will be returned to again later in the thesis.

Strategy 3: Seeking medical confirmation

For some carers the decision to seek a medical opinion was described as a breach of confidence towards the cared-for person, as one male spouse carer explained 'she's my wife for God's sake, I didn't want to sound like I was telling tales about her' (interview: 3). However, whilst the carer was now certain that 'this is serious' the decision to seek medical help to confirm this belief had an uncertain outcome. One of the major stumbling blocks was that the GP consulted was often the carer's and not the person with (undiagnosed) dementia. This presented the GP with an ethical dilemma as they felt unable to help without the direct consent of the person being discussed, but this was not always understood by the carer as they now wanted an expert opinion to confirm the seriousness of what they were seeing.

For carers, this seeming intransigence and insensitivity to their situation led to an increasing uncertainty over the role of the GP in the process of confirming that 'this is serious'. This is graphically illustrated in the following quotation:

I went to the doctor because my wife was doing things that I just did not understand. I knew she was ill but nobody would believe me - she couldn't go with me you see and they had to go on what I said. All the doctor said to me was 'come back again in six months if things have not improved'. Some help that was.

(interview: 7)

Even when arrangements were made for the GP to see the person with (undiagnosed) dementia, reaching a diagnosis was not always the first priority. GPs often seemed content to give unsupported explanations such as: natural ageing process; depression;

menopause; and worry over work. In many ways, this failure to take the reported signs and symptoms seriously mirrored the carer's 'normalising' and 'discounting' processes seen previously in Figure 3. This lack of investigation, and medical confirmation that 'this is OK', caused the carer to return to their situation and the strategies employed during phase 2 of their decision-making process (see: Figure 4). However, this time, it was much more difficult for the carer to return to their phase 1 belief of 'this is OK'. As such, the strategies of 'surveillance' and containment were entered into once again. However, the dismissal of the carer's concerns was not the end of the road. For some carers, their firm belief that 'this is serious' led them to explore other avenues for medical advice, such as seeking a private medical consultation (if their means allowed) to provide confirmation.

The levels of stress carers experienced in seeking a formal (medical) confirmation of events should not be underestimated. The period surrounding diagnosis was an important and traumatic one. The data suggest that far greater thought should be given as to how information is conveyed at this time. Once the diagnosis was provided the usual practice was to inform the close family of the suspected diagnosis and leave it to their discretion when, and if, the diagnosis was given to the person concerned. However, by this time, carers felt a personal ownership of the diagnosis and that the diagnosis existed solely to validate their assertion that 'this is serious'. Thus one partner in the process of dementia had the necessary level of confirmation, but the person with dementia themselves appeared a lost voice in this process of disclosure.

4.7 Transcending the Data: Theorising the Early Stages of Care

Up until the 5th December, 1992 the author had 'worked the data' so that the phases, underlying processes and strategies that illuminated the carer's awareness and transition to the diagnosis of dementia had emerged, but, as yet, these processes had not been adequately elaborated into inter-linked stages. In grounded theory stages can only be attained by the analyst transcending the data in order for such links to emerge. On approaching this part of the study, therefore, one of the first acts the author undertook was to return to the work of Glaser (1978) to be certain that he did not 'drift away' from the task in hand (the meaning of 'stages' in the generation of grounded theory is

discussed more fully in chapter 3 pp.86-87). Briefly, however, Glaser defined the constituent properties of a stage as follows:

Stages allow one to follow changes over time, yet remain in grasp of a theoretical whole process - which has a beginning and an end. When the properties and so forth are integrated into the whole process, when each stage's relationship to the process and the other stages - how they affect it, shape it and so on - are integrated, then the process can be conceptually followed from stage to stage, the change over time being conceptually accounted for without the imagery of the whole being lost.

(Glaser, 1978 p.99)

In grounded theory, therefore, stages act as an integrating scheme and account for changes over time. Moreover, the transition from one stage to another is contingent upon the existence of a 'critical juncture'. As such the occurrence or non-occurrence of a critical juncture will determine whether a new stage is entered, or the previous stage maintained.

Armed again with this knowledge the author returned to the data and started to read and re-read the interview transcripts (interviews: 1-21), beginning the time-consuming process of listening again to the audio-tapes of each interview and consulting his theoretical memo fund. Whilst undertaking this exercise the author centred his attention, initially, on a theoretical memo (dated: 26.10.1992) which concerned the potential development of 'to build on the past' as the name of a possible 'pre-stage' of caring. At the time, the author had suggested that the properties involved in 'to build on the past' influenced the carer's adjustment, motivation and belief structures that were present in the delivery and meaning of care. Under the working title assigned to the name of the 'pre-stage' the author attempted to test out the properties of the stage and assimilate data emerging from the study under this heading.

4.8 From 'To Build on the Past' to 'Building on the Past': Exploring the Context of Care

Whilst analysing the data, the author was reminded again of the power of the past to help understand the context of care. This was articulated most clearly during the twelfth interview in the study:

Our {personal} relationship has always been bad, no worse than that, dreadful. I mean he was away all the time and even when he came home he acted as if he never wanted to be here. I began to dread him coming home and I only put up with it for the sake of children. They kept us together. You see I got used to leading my own life and since this started {the dementia} he's around the house all the time relying on me for things, like finding out the times of the bus or demanding to know where I've hidden his car keys. Well I just don't want to do anything for him but he is ill, forgetful and that. Everyone would expect me to be there for him but he was never there for me. I feel so trapped and on my own.
(interview: 12)

This feeling of being 'trapped' proved a powerful image and was significant in determining the outcome of care and quality of life for the carer. Alternatively, when previous relationships had been good there was no such reticence, and there was a willingness, indeed even a strong desire, to take on a caring role, as this 82 year old man caring for his wife with Alzheimer's disease attests:

We've been married over 60 years. I took her on for life and we made vows to each other. That meant everything to me and no-one is going to take her away from me. I would have to be dead first. I'll put up with all this because I love her and she's my wife. I take everything day-by-day and I thank God for everyday we are alive. As long as I get someone to help me with a bath for her, I don't need anything else. Ever.

(interview: 11)

Naturally, not all caregiving relationships are entered into in such a way. For some spouse and adult child carers the relationship was also considered to be poor coming into the caring role, but a measure of meaning and satisfaction could be found in the act of caring, ameliorating previous feelings of anger and resentment. For others, there was also the opportunity to gain control over a relationship which had previously been outside their control, an issue which was particularly prevalent in adult child and female spouse carers. Moreover, the meaning attributed to the marital vows of 'for better and for worse' was constantly cited by spouse carers as a reason for entering into, and continuing to deliver, home care (interviews: 1, 2, 9, 10, 14, 15, 19 and 20).

Synthesising these experiences, and applying them to others in the series of interviews, ascertained that the quality of previous relationships was crucial, and caution was needed when there had always been a poor relationship (as in interview: 12), or previously good relationship had been spoiled by the carer not fully grasping the reason for the change of behaviour (as in interview: 17, for example). In this respect 'to build

on the past', whilst accurate in its context, sounded rather passive in tone and did not convey the depth of biography and personal relationships found at the heart of such experiences. Whilst thinking about this, the author amended the prefix from 'to build on the past' to 'building on the past'. This subtle change of emphasis gave the model a more authentic feel and provided a theoretical foundation that allowed a conceptual link, and integration, with future developed stages of care.

Stage 1 of the emerging model, therefore, was named 'Building on the Past' and the author began to search through the data for further examples to support its properties and explanatory power. The result of this search confirmed that to understand caring requires a consideration of the nature and quality of past interactions. This is relevant in all caregiving situations, although the emphasis varies as people with dementia and their carers bring their individual biography and personality into the illness/relationship reflecting their unique history and life events. As theoretical sensitivity to the data increased, it became apparent that in supporting the stage of Building on the Past the following properties of process were important to identify, namely the:

- Nature, quality and degree of reciprocity in the past relationship;
- Nature, quality and degree of reciprocity in the present relationship;
- Proximity of formal and informal support network;
- Availability of and access to community support;
- Previous experience of managing illness;
- Carer belief structures, including marital vows and religious beliefs; and
- Geographical location.

Geographical location was an important feature in this sample as the majority of carers were drawn from a rural population and specialist services were, at times, located many miles away. For instance, hospital based services for people with dementia living in South Gwynedd were situated over sixty miles away, and the area contained no private or NHS funded continuing care facilities for people with dementia. However, whilst this undoubtedly complicated the picture, carers developed other types of support and had limited expectations of help. In such cases, establishing the nature and quality of the previous relationship became an important factor, and identifying these processes gave subtle clues as to the motivating factors involved in continuing to provide care.

4.9 'Recognising the Need': Steps to Stage Formation

As well as being central to the understanding of the antecedents of care, Building on the Past also plays a critical role throughout the natural history of caring relationships. Whilst from a heuristic stance caregiving could be seen to start in Building on the Past, in reality it starts when the carer becomes aware of the change to their social world brought about by their encounter with the first awareness trigger(s), as illustrated in Figure 3. The entry of this encounter into the social world of the carer marked a critical juncture, theoretically speaking, which led the carer out of Building on the Past and into a new stage of caregiving; one that chartered their course through the experience of dementia and is underpinned by time and adaptation to many new encounters

Once this first critical juncture was identified from the data, the author returned to his theoretical memo fund and interview transcripts to begin the task of discovering the next stage(s) of caregiving, and its accompanying critical juncture. In many ways this process was a little easier to analyse as the carer's gradual awareness and adjustment to dementia ran the following course:

- What am I seeing?;
- This is OK;
- This might be serious;
- This is serious.

This transition has been illustrated previously in Figures 3; 4 and 5, and whilst the speed of decision-making and awareness differed from one carer to another, a medical diagnosis of dementia cemented the seriousness of what the carer was seeing and validated their right to be concerned about the situation. Certainly, what these combined experiences appeared to be saying, was that until a diagnosis of dementia was reached carers remained in a continual state of uncertainty and could not formally take on the caring role and, theoretically at least, make an informed decision over their future involvement in care.

Whilst considering the critical junctures and experiences that brought the carer to this outcome, the author wrote down the heading 'Recognising the Need' as a summary of these experiences. Thus, from the critical juncture which first saw the carer 'noticing' the awareness trigger(s) (see: Figure 3) to the time of reaching the diagnosis of dementia (as illustrated through implementing strategy 3 of Figure 5), carers would be in a continual cycle of Recognising the Need. Only when the diagnosis was reached could carers leave the stage of Recognising the Need and progress to another stage, one that acknowledged the more formal role of carer.

Applying the 'discovery' of Recognising the Need to the data appeared to make conceptual sense, as it was evident in each story and flowed logically from the first stage of Building on the Past. Recognising the Need, therefore, became stage 2 of the emerging model and was supported by the properties of process outlined in Figures 3; 4 and 5. The provision, or omission, of the diagnosis, therefore, became the critical juncture that dictated whether carers remained in the stage of Recognising the Need or left it.

4.10 'Taking it On': A Point of Agreement in Stage Formation

The decision-making processes involved in choosing to become or not to become a 'carer' at the time of the diagnosis constituted the next stage of care, one Wilson (1989a) had previously named 'Taking it On'. Whilst the time dimension for this stage of care is brief, it is, nonetheless, a crucial phase of the caregiving experience. The data suggested that this stage was not particularly well understood by carers, and it was a period in which professional intervention played a major role in the life of both the person with dementia and also the carer. As already highlighted in Figure 5, a formal (medical) explanation of the cause of the person's behaviour/actions marked a critical juncture leading the carer out of Recognising the Need and into a stage that propels the carer towards the more formally recognised role of 'carer'. The data would suggest that this period of further decision-making confronts the carer with a number of questions, such as:

- Is this for me?;
- Can I do it?;

- What will it mean?;
- Should I 'go through with it'?

For carers, providing a response to such questions was set within a broad recognition of the context of care, as outlined in the properties of Building on the Past. Drawn from one interview (interview: 12), the following exchange helps illustrate this point further:

Researcher: You say you never really loved your husband. What, then, made you decide to care for him during the early days?

Carer: Duty mainly, and I couldn't lose face in front of the neighbours and the children. I hated those times. It didn't help that our marriage had been going through another bad patch.

Researcher: So you believed it was your duty to care, even though you would have preferred not to. How, then, did you approach your caregiving being aware of these feelings?

Carer: Well, I'd been told he was ill and would need help, so I thought I would just shut everyone away so it was just me and him. I thought that would make it easier. I didn't want to know too much about 'dementia' as I thought that if I had him on my own, I could cope better. That sounds a bit naïve now, but that's how I felt - it was down to me, so I would deal with it. I went through it all until I couldn't cope any more and then I went back to the doctor for help.

The decision to take on the caring role is a result of a number of complex dynamics, which are related directly to the context of previous relationships and to the opportunities provided by professional care agencies. How carers weigh up the options at this time is crucial, and yet there was not one carer in the sample (interviews: 1-21) that had been made aware of potential alternatives to them 'taking on' the caring role. From the perspective of helping agencies, it was expected that caregiving would continue and that, when offered, professional support would simply assist in this process; it was through this narrow and circumscribed view of the world that carers took

on their role. From the data it appeared to the author that Wilson (1989a) had accurately represented and named this stage as Taking it On, and it seemed inappropriate to change the title simply for cosmetic purposes.

Stage 3 of the carers model, therefore, was named 'Taking it On', although its supporting properties required further elaboration as the formal caring role was 'taken on' with differing expectations. To a significant extent, these were shaped by the properties of process identified in Building on the Past and the length of time it had taken to work through the stage of Recognising the Need. For some carers, reaching the point of a diagnosis was a relief as it validated their concerns over the person and put their future into some form of context. Conversely, other carers approached Taking it On with misgivings, uncertain about the future and their relationship with the person with dementia.

In attempting to gain a more complete understanding of Taking it On, the author returned to the transcripts and theoretical memo fund for further interrogation. From the data, it appeared that those carers who approached Taking it On in a positive light were more likely to attach meaning to their role, as the following extracts suggest:

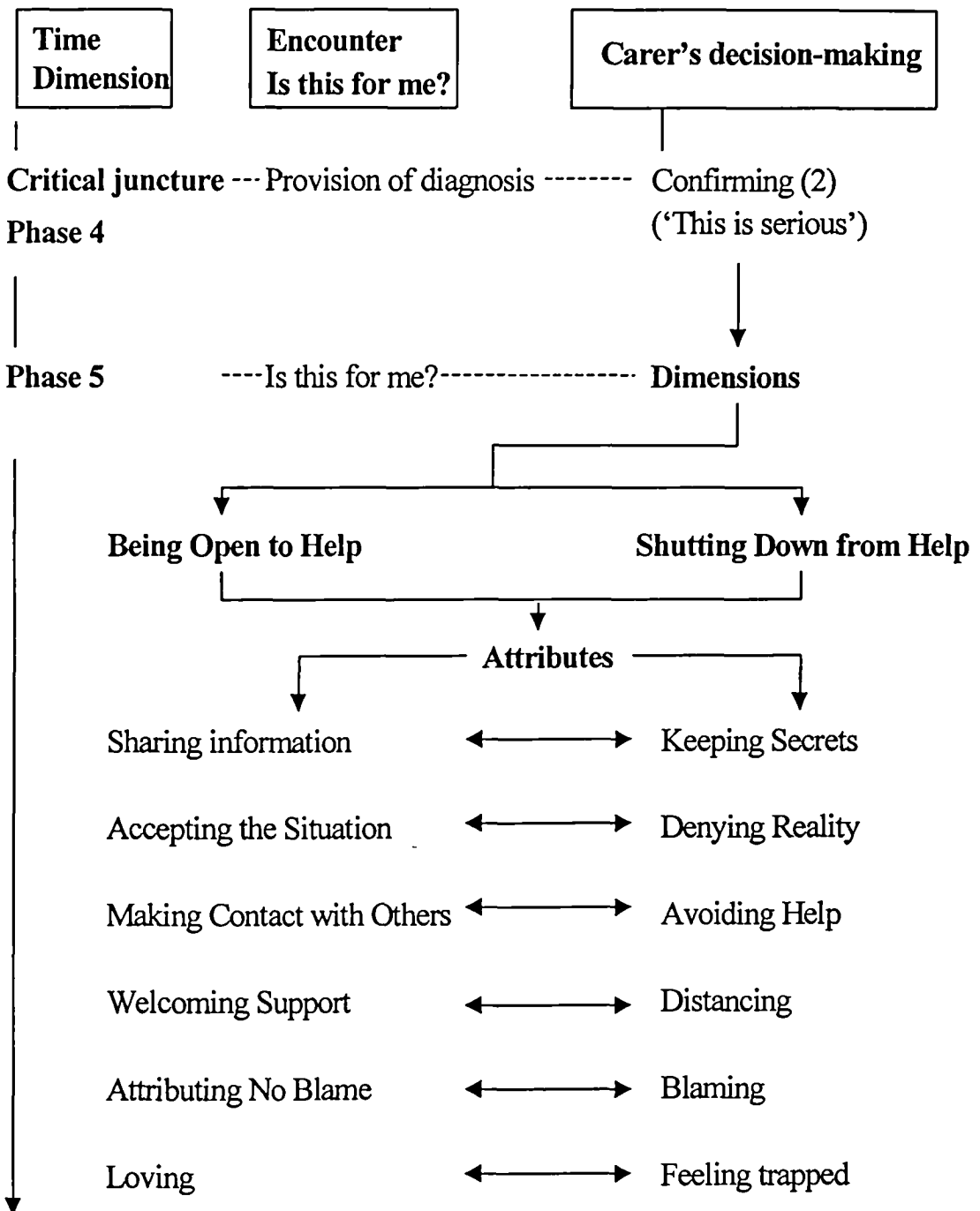
The diagnosis was something I was expecting, to be honest. It was a relief in some ways to know that it had a name and that we were not on our own.
(interview: 8)

As soon as I heard it was Alzheimer's disease, and learnt more about it, I knew my father didn't mean the things he'd been saying. That was a great relief, to know it was not his fault.
(interview: 13)

When the diagnosis was made, I didn't want to keep it to myself. I thought it was important that others should know so that they could understanding why my father was behaving this way.
(interview: 16)

On the basis of such positive dimensions, the author began to construct a typology which is represented in Figure 6 (next page), providing a 'best fit' description of the competing interpersonal attributes, beliefs and dimensions that carers bring with them as they attempt to negotiate Taking it On.

Figure 6: 'Taking It On': A typology of carer's decision-making



Theoretical memo book entry: 7.12.1992

The Figure comprises a series of continua depicting a positive (Being Open to Help) as opposed to more negative (Shutting Down from Help) dimension involved in Taking it On. As represented in the dimension 'Shutting Down from Help', when carers 'took on' the caring role by initially attaching feelings of blame to the person, or by expressing feelings of being trapped, then it was highly likely that limited feelings of satisfaction would be experienced during care, with the carer struggling to attach meaning and purpose to their role even at this early stage of the caregiving career.

With the provision of a diagnosis, carers would then have to decide relatively quickly what they were going to do next, and if caring was for them; hence the time dimension attached to phase 5 was rapid. Naturally, a decision to continue to provide care would mark a critical juncture and lead the carer out of the stage of Taking it On. However, the data indicated that carers were having to decide against a background of an expectation to care - from themselves, the community and professional care agencies - thereby all but negating the exercise of a genuinely informed choice, and making it highly unlikely that they could choose not to care. Therefore, while all of the informants in this study had 'taken it on', some had done so in a more positive frame than others. This raises a number of questions about whether or not all carers should be expected to 'take it on', an issue that will be returned to later in the thesis.

Given that all carers had 'taken it on', often for many years, it seemed necessary to understand further how care was subsequently experienced. It is to this area that attention is now turned.

4.11 Moving Care Beyond the Diagnosis: Background Issues

As previously indicated, Wilson (1989a) had named the more instrumental and 'hands-on' stage of caregiving as 'going through it', and that, for the carer, the stage presented a 'seemingly unending list of problems' (p.43). According to Wilson (1989a) this stage was 'endured' until the carer had no other option but to 'turn it over' i.e. decide when to have the person with dementia admitted into continuing care.

On the surface at least, Wilson's (1989a) coupling of 'going through it' to an 'unending list of problems' and 'turning it over' left carers little scope for any satisfaction in the

caregiving experience, and failed to account for carers who positively chose to care for the person with dementia at home until the time of that person's death. The potential satisfactions attached to caregiving were illustrated during the eleventh interview in the study. In this interview an 82 year old spouse carer spoke movingly of the love he felt towards his wife, and described how the last twelve years of caring had been 'amongst our best together'. The carer was proud that his wife, now in the terminal stages of Alzheimer's disease, had not required the support of any outside agency and that he had fulfilled the obligations of his marital vows. For this carer the reciprocal elements embedded in the stage of Building on the Past had been a strong, and perhaps dominant, motivating force throughout his caregiving experience. In this interview the carer's physical care of his bed-bound wife was, in the author's (nursing) opinion, of the highest standard and he drew great comfort from the fact that 'she had never developed a sore in the last two years'. Indeed, during the hour-and-a-half interview, the carer left the living room on ten occasions to go to the adjacent room and check that his wife was 'OK'.

Towards the end of this interview the carer asked the author if he would like to meet his wife. Naturally, the author agreed, and in making the short walk from the living room to the sitting room, where the person with dementia was lying in bed, it was immediately apparent that the carer had attempted to place as many familiar and personal possessions as possible within her eyesight. This included: a favourite dress (hung from a wardrobe door); framed photographs of themselves at various times of their lives together; a wedding photograph; and a photograph of the carer's parents. These photographs were given a prominent position by his wife's bedside. In the room a half-opened copy of 'Cysgod Ddoe' (a well known Welsh text) lay face down at the bottom of the bed. The carer explained that when he had finished 'his caring' he would pick up the book and read pages of it to her, making sure to start from the last sentence he had read. On enquiring how many times he had read the book in the last few years, the carer replied 'this is the tenth'. For the carer it was enough to know that the book had given his wife pleasure during her lifetime, and therefore he saw no reason why this should now be denied.

Whilst this example was a further illustration of the continued influence of Building on the Past, of far more consequence was to understand how, over the years, the carer had

developed skills in managing his wife's dementia, and how had he come to know what worked and what did not in the provision of personal care.

In listening again to the interview and recalling the experience of being at the couples' home, there was little doubt that this carer built his approach to caregiving upon a platform of altruism. In the instrumental act of caregiving, the primary purpose appeared to be to maximise the positive whilst seeking to minimise the negative. Other data suggested that in achieving this balance carers appeared to gain satisfaction from their role. Providing simple pleasures, maintaining dignity and ensuring that needs are tended were all integral to the successful delivery of care. This appeared to be an important phenomenon for helping carers go through the active process of adjusting to their role and the demands that it placed upon them.

Whilst the data from the first twenty-one interviews partially supported Wilson's (1989a) finding that carers initially solved their problems on a 'trial and error basis', there were elements in care which were instinctive, intuitive and built upon a history of knowing a person intimately over time. In this way, by the time the carer had been caring for many years at home with a person with dementia, there was demonstrable expertise in the care they were providing and in what they were striving to achieve.

To continue to explore this more active period of caregiving, the author worked closely with Consultant A over the next sixteen months (December 1992 - May 1994) to theoretically sample carers whose experiences would reflect this phase of caregiving. Focusing on this more 'instrumental' phase of caregiving would also allow the decision-making processes evident in Figures 3; 4; 5; and 6, and the three emergent stages of caregiving: Building on the Past (1); Recognising the Need (2); and Taking it On (3), to be empirically tested.

Starting in December, 1992 and ending in May, 1994 Consultant A wrote to 50 carers known to him from his clinical caseload. From this approach, 29 carers responded positively to the request to interview (interviews: 22-50) with 9 carers (interviews: 27, 31, 37, 38, 39, 42, 44, 47 and 50) consenting to an interview who had placed the person with dementia into full-time residential care, and one carer (interview: 41) who had been widowed. This latter carer was well-known to Consultant A and was interviewed a

little over a year after her husband's death. However, to theoretically sample the experience of bereavement following caring for a person with dementia, the author conducted a further 8 interviews (interview codes 51-58; see: Appendix 4) between March-June, 1994. This sample was gained through contact with an Alzheimer's Disease Society bereavement support group situated in North-East Wales.

The author conducted the first ten of these interviews in December, 1992 (interviews: 22-31) before returning to his full-time employment as a community psychiatric nurse on the 3rd January, 1993; indeed, the author was to remain in full-time employment for the remainder of the study although his move to a lecturing position at the University of Wales, Bangor in the summer of 1993 provided space to allow the study to develop. In January 1993, after his return to the position of community psychiatric nurse, the author conducted seven interviews during this and the following month. The interviews were significant in that they completed the development of the six stages of the temporal model prior to additional theoretical testing (Keady and Nolan, 1993a,b,c), with the remaining interviews in the series used to test its properties, as well as to theoretically sample the experience of bereavement and loss in dementia (Keady and Nolan, 1994c,d,e). However, to retain consistency in recording the development of theory as process, the model will be reported in the sequence in which it emerged.

4.12 From 'Going Through It' to 'Working Through It': Exploring the Dynamics of Care

To retain consistency with earlier interviews the author began this series of interviews with same initial question, but subsequently explored both the elements of the model developed to date and adjustment post-diagnosis.

The first interview in this next series (interview: 22), involved a woman who explained that eight years ago she had given up a successful career in Manchester to return to North Wales to care permanently for her mother. Prior to making this decision, the informant recounted that she had travelled back and forth to North Wales from Manchester most week-ends to increasingly tend for her mother's needs, particularly the shopping and sorting out her affairs. Initially, the carer put her mother's failing abilities down to the natural consequences of her age, and the adjustments needed following the

death of her (mother's) husband. However, as time went by, and the behaviours continued, the daughter called in her mother's GP who eventually arranged for some additional investigations to be conducted at the local community hospital. It was at this time that Consultant A became involved and a diagnosis of Vascular dementia was made. As the daughter explained, the decision involved in Taking it On was 'the only thing I could do' when faced with the diagnosis and the realisation that, in all likelihood and with the best intentions, her father had been 'compensating' for the onset of her mother's dementia for several years. As the carer revealed, Consultant A informed her that her mother would require more intensive support if she was to remain in the community with a degree of personal safety.

Once the carer had made the decision to 'take it on' the following exchange highlights her process of adjustment:

Researcher: Did you ever regret your decision to take on the caring role?

Carer: Regret it? No, but at first I had difficulty getting to know my mother. When I first moved in with her and saw how much help she needed, that's probably the only time I ever 'regretted' it, as you say. But I could see how much she needed me and I had given up my job and everything to be with her, so I knew I had to get on with it and do the best I could. What I wasn't really prepared for, though, was the change of routine and how I would have to turn night into day. At the beginning Mum was so restless in the evening, always on the go. I tried all sorts of things to help calm her down a little and found the only thing that worked was to be with her and hold her hand. Somehow that helped. So I put a baby-listening system in her room so that I could hear her at night, and I also tied a bell to the door handle of her bedroom so that when she opened it, I knew she was up and about. It didn't take me long to figure out that nights are the worst time for her.

Researcher: Once you had figured this out, how did you cope with it?

Carer: I spent night after night in bed with her so that she would feel safe and know someone was there and caring for her. She didn't always recognise me, but that didn't matter so much.

Researcher: Do you still do that now?

Carer: You mean sleep in the same bed as my Mum? Yes, I don't really need to do that any more, but I like to be close to her, and if she does wake up she knows that someone is around. I often try and imagine what it must be like for her. For me it's become easier in some ways as there aren't so many surprises anymore. I've had to sacrifice a lot mind you to be able to say this to you, and I sometimes think of the life I left behind, but I couldn't imagine not being here with her.

In this short exchange so many of the complex dynamics involved in caring for a person with dementia are revealed, including the:

- Motivation to continue to provide care;
- Importance of maintaining and establishing routines;
- Implementation of problem-solving techniques, including a 'trial and error approach';
- Time dimension attached to caring, especially surrounding 'Recognising the Need'; and
- Coping with anticipatory loss associated with caring, witnessed in the expression of 'the other life' that could have existed if dementia had not intervened.

This need to consider 'the other life' also continued once a carer was no longer involved in the 'formal' role of carer. For example, in December, 1992 the author completed his first interview with a carer who had worked through the caregiving role, and had decided to admit the person with dementia into residential care (interview: 27). This interview was long and protracted, with the author helping the carer to explore her feelings of guilt about the placement and her belief that she had somehow 'failed' her husband. As the carer explained, the admission of her husband into a local authority residential home was made after many years of them being at home together, but

towards the end she felt unable to manage his continence difficulties, especially as he was a 'very strong and well-built man'. From this interview the author quickly became aware of the sense of guilt that the carer felt, and of her constant need to 'check-out' her belief that she had acted in the best interests of all concerned, as the following exchange illustrates:

Researcher: How long do you think you actually worked through your experience of care before you decided that something had to change?

Carer: Well, it was about seven years. I tried so hard to be with him to the end. It feels as though I have let him down so badly after all this time together. I couldn't carry on with it all you see. I just got so tired towards the end. He would need changing five or six times a day and he was such a big man. I have a photograph of him if you would like to see it? {interview interrupted for a few minutes whilst the carer went to retrieve a photograph}. See what I mean. He would let me change him at first, but towards the end he started to become a little aggressive with me and wouldn't let me take his trousers down. He was calling me by his mother's name then, so I suppose he felt a bit embarrassed about it all. Anyway, I tried to put him in those, em, jogging pants, but he didn't like them and kept taking them off. I didn't mind but it wasn't very dignified for him to be walking around in his underpants, or nothing at all. I had to tell my doctor I couldn't cope with him anymore and that's how it happened that he saw Consultant A again. After that he went to the local hospital and from there he went to the home and didn't come back.

Researcher: How long ago was this?

Carer: Three years this August.

Whilst this experience involved the withdrawal of services to the carer as soon as the person with dementia was admitted into care, an illustration of the carer's 'expertise' in

managing her husband's dementia was also apparent, as the author noted at the time in his theoretical memo book:

The carer's decision to put her husband in 'jogging pants' was the result of her own problem-solving approach. Presumably if it had worked then the carer's husband would still be living at home. However, what is more important here is not so much the negative outcome attached to this approach (in the carer's eyes), but that the carer had attempted it in the first place in the absence of any (meaningful) service involvement to help shape her decision-making.

(theoretical memo book entry: 11.12.1992)

This appreciation of the skills carers acquired led the author to consider further the demonstration and exercise of expertise within caregiving, and also how this was often associated with finding meaning and satisfaction in their role. As described earlier, carers who were able to attach meaning and satisfaction to their act of caregiving at the point of Taking it On were more like to continue to deliver home care to people with dementia, as these data attest:

- I just want to look back in the years to come and for people to say 'she did the best she could'. I wouldn't be doing my best if he wasn't here (interview: 18);
- As long as I can get a quiet five minutes every day, I'll keep on going (interview: 25);
- I started this job and I want to see it through (interview: 26);
- My father could never go to a home, I just wouldn't allow it (interview: 33);
- My wife helped pay for this house, so she is not leaving it (interview: 34);
- How could I not go on? I love my husband and I just want to care for him (interview: 35).

The data revealed other similar examples of how meaning and satisfactions could motivate and underpin the ways in which carers managed their situation. Certainly, within this active phase of caregiving, carers were faced with many challenging and competing situations ranging from frustration at their inability to have a conversation, to the need to provide total nursing care to a person in the terminal stages of dementia. However, many carers transcended and overcame such difficulties and, in so doing, can be seen as the genuine 'experts' in their role.

The carer's ability to face and overcome such challenges counters the negativity that Wilson (1989a) associated with 'going through it', a position the author later recorded in the following theoretical memo book entry:

Carers are not 'going through it' in the passive sense that this conveys. More specifically, they are *working through care* {original emphasis} and this image of care as 'work' better represents the stage of caregiving experienced at this time. The longer the carer is able to remain in control of their situation, and find some expression of meaning in the act itself, the more likely it is that they begin to demonstrate 'expert' caring practice which could be found in the domains of linguistic interpretation, needs anticipation and problem-solving skills.

(theoretical memo book entry: 27.3.1993)

Thus by transcending the data, the next stage of the model, stage 4, became 'Working Through It'. Working Through It started once the carer had been through the decision-making involved in Taking it On and ended once the active process of care at home concluded.

Applying the new stage formation of Working Through It to the data, suggested that carers were still noticing and acting on signs and adjusting to subsequent behaviour, but following the diagnosis, were now able to attribute meaning to aberrant acts. Where once all had been uncertainty and confusion, carers, if they were able, or so desired, began to manage the experience of dementia by taking charge of events and tailoring support to the needs of the person with dementia, as the following example helps illustrate:

A lot of the time you can't work out what she's trying to say, but when she get things back-to-front like cold, then she obviously means she's hot; and she will call a dog a horse and I know she means our dog here. {pats dog} Some of them are difficult but there are a few things you can work out - you just need patience. People who have been here have lacked this and haven't known Mum very well.

(interview: 32)

The author reflected on this process and considered that to reach such an intimate knowledge of a person requires a commitment to translate the meaning of the experience, and a willingness to spend time uncovering the process. However, whilst carers continued to 'notice' changes in people with dementia, the provision of the diagnosis had changed the context in which this noticing behaviour occurred. By this

time, carers had accepted that something was wrong and were actively trying to generate solutions to the problems that they encountered, such as the earlier examples of the carer placing a baby-listening system into her mother's bedroom so that she could hear her at night (interview: 22); the carer who had 'worked out' the meaning of her father starting to hum and tap his leg with his hand in that it was a sign that he wanted to use the toilet (interview: 6); the carer placing her husband 'in jogging pants' to help support his continence needs (interview: 27); and expertly tending to physical needs in the terminal stages of dementia (interview: 11).

Moreover, these outcomes allowed carers to continually question 'what am I seeing?' and develop a response appropriate to the dynamic context of caring. Reflecting on this process, the author considered that when faced with new challenges, carers were novices and gradually became more expert in generating solutions as time went by, much along the lines described by Benner (1984) and Eraut (1994) as relating to professional carers. From examples already shown from the data, the carer's progression from 'novice' appeared to turn on their ability to anticipate events, and how informed they were at this time. An illustration of informed anticipation was seen in an extract from the interview cited earlier (interview: 32), in which the carer began to anticipate and interpret the meaning of her mother's behaviour. Demonstrating and applying this level of informed anticipation appeared vital in enabling carers to progress to a level of caregiving expertise.

To help explain this evolving problem-solving approach, the author developed the A-E of caring to try and capture the dynamics of care and place it in a transactional framework (Keady and Nolan, 1993a). The A-E of caring was developed through the author's theoretical sensitivity to the data and comprised the following framework:

Acknowledging the challenge

Here the carer recognises that a situation has arisen that requires a response and determines whether this poses a threat, harm or challenge. This equates with the primary appraisal within stress theory. This is followed by:

Balancing the books

Where the carer considers the range of resources that they have at their disposal, resulting in:

Clarifying the alternatives

When a range of possible courses of action are identified leading to a process of:

Deciding what to do.

Together these processes would constitute the secondary appraisal in the transactional model of stress and coping. After taking action the carer begins:

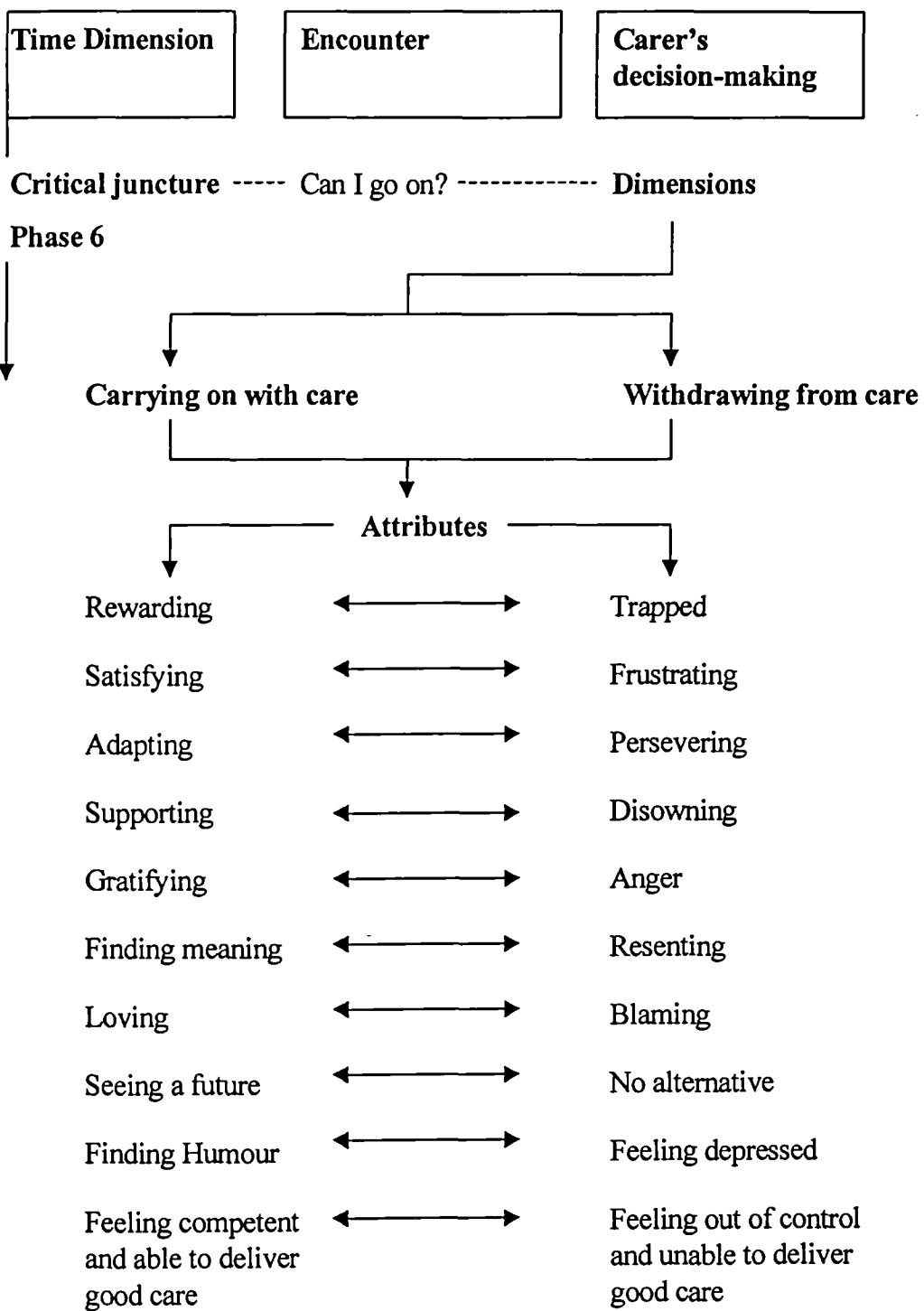
Evaluating the consequences

Or reappraises the effectiveness of what they have done.

Thus, in interview: 22, the failure of the baby-listening system to control fully the mother's nocturnal restlessness, provoked another solution by the carer which involved her remaining with her mother at night to allay fears and uncertainty. The 'success' of this strategy meant that the carer continued to undertake the activity for the duration of her caregiving career.

By following an approach consistent with the A-E of caring, carers gradually built-up a stock of caregiving solutions which, in themselves, became demonstrations of 'expert' practice. On the other hand, the A-E of caring could only be successful if carers continued to find satisfaction and meaning in the role they were undertaking and were not looking for ways to withdraw from care. As such, the typology which was evident at the onset of Taking it On (see: Figure 6 p.141) continued into the active part of caregiving, but required modification to reflect the more complex, and competing, demands faced by carers as they continue to 'work through it'. Drawn from the data (interviews: 1-38), and a theoretical memo book entry, Figure 7 (next page) attempts to capture this more complex dynamic along a typology of varied experiences which help to explain situations in which carers may no longer continue to care, or at least experience it as difficult and stressful.

Figure 7: 'Working Through It': Dimensions, attributes and approaches to decision-making



Theoretical memo book entry: 26.2.1993

As illustrated in this Figure, working through care is a complex dynamic whereby experiencing the properties of one, or a combination, of attributes shown on the right-hand side of the typology, may lead the carer to consider their future options. For 'expert' caregiving to continue to evolve, therefore, it is essential that carers locate themselves on the dimensions evident on the left-hand side of the typology of Figure 7, and be able to balance the more negative components of care with meaning and satisfactions. Understanding the context of Building on the Past becomes crucial at this time, as the previous relationships between carer and cared-for help shape the carer's perception of their role and the meaning they attach to it. For instance, although some of the more negative attributes that may be associated with the feelings of being 'trapped', 'depressed' or 'persevering' with care may be ameliorated by the provision of social support, such as day, respite or sitting services, and/or the continued involvement in care from other members of the family; however, this support is only helpful if the carer is motivated to remain in their caring relationship.

As long as carers can identify themselves with the positive elements, then they are more likely to continue in their role, only reaching the end of their caregiving experience when some external factor, such as their own death, personal injury/ill health or death of the person with dementia, intervenes. This on-going process of identification, therefore, becomes central to the carer's efforts at delivering care to people with dementia, and provides some measure of theoretical explanation as to why carers do, or do not, continue to deliver care at home.

In terms of coping, the data indicated that carers develop routines and try different tactics in a constant endeavour to maximise the positive aspects of care and test out the A-E of caring. As has been noted in the literature and in the study to this time (interviews: 1-38), the longer care continues, the less stressful it may become; and the more competent carers feel in their role, the less likely they are to be stressed or burdened. However, this is a delicate balance, as caring can only become less stressful if the carer is able to identify with the positive attributes of care as listed on Figure 7 and find ways of overcoming the myriad of challenges that people with dementia pose.

On the other hand, there comes a time when the instrumental act of caregiving comes to an end and understanding why carers reach the end of care is also a complex issue.

However, the author would suggest that ‘withdrawing from care’ (as illustrated in Figure 7) is the result of the carer being faced with one, or a combination of, the attributes expressed on the right-hand side of the typology, together with an inability to generate a solution to the problem(s) facing them. The example given earlier of carer faced with an aggressive spouse who would not allow the carer to take off his clothes or dress him in ‘jogging pants’ is an example of reaching the end of care following this theoretical rationale. In this instance, the carer began to become *frustrated* in her actions, felt *anger*, started to *blame* her husband for the aggression and began to *resent* the caring act. The carer’s inability to clarify a meaningful alternative to the situation meant that she was *persevering* with a solution that was simply not acceptable by her own standards. The result was *feeling out of control* of the situation and an inability to cope. This, in turn, prompted a need to withdraw from caregiving, handing over responsibility to someone else who, in the carer’s opinion, would be better able to manage the situation.

In essence it was the motivation attached to ‘withdrawing from care’ that led the stage of Working Through It to end. If carers did not want care to end and could still attach meaning and satisfaction to their role, then they would not be faced with this critical juncture, and would continue in their role for as long as their health, or the health status of the person with dementia, permitted.

In this decision-making process, ‘withdrawing from care’ does not necessarily mean that carers no longer care, rather that another form of care is substituted, and carers need to resolve the issues before deciding what to do next. To move on successfully carers have to create a balanced perception of what they have achieved during caring, to recognise the value of their efforts over several years and to come to the realisation that a choice to place the cared-for person in alternative care was the right and the best one to make.

4.13 ‘Reaching the End’: Entering the Later Stages of the Caregiving Experience

During the development of the carer’s model, at the end of the first interview conducted with a person who had given up the formal caregiving role (interview: 27), the author placed the following entry in his theoretical memo book:

In this interview the carer has *reached the end of care* {original emphasis} and has embarked upon *a new beginning* {original emphasis} in terms of her life adjustment and responsibilities following caregiving. This was an important interview to conduct as it placed the caregiving experience in context in terms of its transition from initial awareness to the final stages of the act itself. Without an adequate explanation of why carers seek to give up care and the circumstance surrounding their adjustment following this decision, the model will be incomplete.

(theoretical memo book entry: 12.12.1992)

On concluding the third series of interviews (interview: 22-38), the author drew out the words 'Reaching the End' (stage 5) and 'A New Beginning' (stage 6) to tentatively describe the final stages of the carer's model, aware that further empirical study was necessary to conclude the properties of process attached to such stage formation (Keady and Nolan, 1993a).

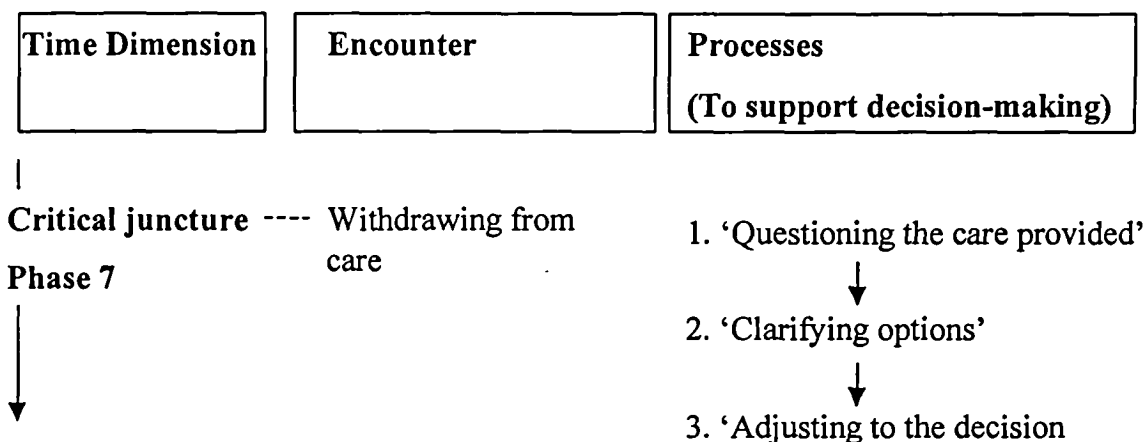
As stated earlier, during the first 38 interviews, the author interviewed four carers (interviews: 27, 31, 37 and 38) whose dependent had been admitted to residential care and the name of the stage had been documented following the first interview (interview: 27). This was elaborated upon further with an additional five interviews (interviews: 42, 44, 47, 49 and 50) and an additional nine interviews with carers who had been through the bereavement process (interviews: 41, 51, 52, 53, 54, 55, 56, 57 and 58). These interviews came to an end in May, 1994 when the author was able to identify and test the supporting processes involved in Reaching the End (stage 5) and A New Beginning (stage 6).

Although the majority of carers wished to continue in their role for as long as possible there came a point when for many it was either not in their best interests, or those of the cared-for person. In describing this as Reaching the End the author is not necessarily suggesting that carers cease to care. Rather that, the end of instrumental care is reached and generally, at least as far as service providers are concerned, carers are no longer seen to need their support. The stage of instrumental care ended through bereavement or the admission of the person with dementia into a nursing or residential home, and both these outcomes will now be considered.

From the series of interviews that comprised the stage of Reaching the End, carers spoke of gradually being 'ground down' by the weight and responsibility of caring. This

was not the result of one factor but a combination of circumstances, with the absence of satisfactions in providing care being crucial to the decision to contemplate 'wanting out' (see: Figure 7). For some carers, reaching this decision was a relatively easy process and they rationalised that they had done everything possible and that it was time to move on. Such a decision was informed by 3 processes, illustrated in Figure 8.

Figure 8: 'Reaching the End': Supporting processes



Theoretical memo book entry: 16.3.1993

Supported by the data each of these processes will now be addressed in turn.

Process 1: Questioning the care provided

This first process was to question the care required and raised concerns about whether the carer could necessarily carry on and deliver the quality of care they wanted to. This often engendered feelings of anger and frustration, but carers could now reconcile this decision as the following example illustrates:

I knew Dad had to go somewhere. I've tried to balance work, family and care for the last six years. I love him but it's time to move on. I wish I could go on but it's come to the end. Someone else will have to do it now.

(interview: 42)

The process of 'questioning the care', therefore, also had a beneficial component if there was a recognition and awareness that all that could be done had been done. As such Reaching the End and going into care was not always seen as a failure, but as an achievement in keeping the person at home for as long as possible. This realisation led to a search for help to identify a suitable alternative and included consultation with other family members, and/or discussion with a professional or voluntary agency who had been intimately involved in supporting the carer. Thus 'questioning the care' often shifted the carer from the right-hand side of the typology on Figure 7 (p.153), to the left-hand side.

Process 2: Clarifying options

Once the decision to relinquish care had been made it was vitally important that placement was perceived as being an acceptable alternative. However, more often than not, a degree of compromise was needed as it was not always possible to get a place in the home of first choice. Financial considerations were also important and some carers were shocked to discover that their personal savings would have to be used to pay for care. This reality could cause considerable personal resentment which further impacted on the quality of their caregiving relationship, with potentially far more negative perceptions emerging.

Unfortunately, the above was often compounded as carers frequently did not contemplate the end of care until crisis point was reached and, consequently, had made few, if any, plans. This example from an 80 year old spouse carer helps to illustrate this point (interview: 44):

Researcher: What made you decide to stop caring for your wife?

Carer: I just couldn't go on any more you see. I have trouble with my heart {rubs his chest}, and I had to go to the hospital for tests. She {referring to his wife} had to go into a home when I was there because she couldn't be left on her own. After the tests they told me I wouldn't be well enough to look after her, so she had to stay there. I go when I can.

With few exceptions carers received minimal help during this difficult period and generally considered that they were left to 'sink or swim'. A range of emotional reactions were described, including: guilt; anger; relief; and helplessness. As on the first interview (interview: 1) this was a revelation to the author and also a source of serious concern. It was not easy to leave people at home knowing that they were in a degree of emotional turmoil, with no visible means of support to help redress the guilt over the lack of options. Indeed, carers would often describe guilt that had persisted unabated with the passage of time, and highlighted the lack of support they received once they had made the decision, or the decision had been made for the carer, to withdraw from care.

Process 3: Adjusting to the decision

This process involved a reflection on the past and recent events. There was a need to 'check-out' that other people in the family, or friends, also agreed that the placement had been legitimate and in everyone's best interests. It was important to counter the perception that other people within a community, or within the family, would see the decision as an indication of failure and of 'giving up' on the person with dementia.

Placement decisions meant placing trust in others and carers stated that this was one of the most difficult periods, as this meant relinquishing control to those outside the immediate relationship. Opening up in this way exposed the person with dementia and the family to the outside world, and this was often a shock. Adjusting to the belief that the person they cared for was, in their words, 'the same as others' brought about a range of emotions and coping strategies. Consequently, there was a need to protect themselves from the effects of their decision, with, in many cases, guilt at the decision to institutionalise the cared-for person gradually diminishing over time, leading to an acceptance of the decision. However, this adaptation could occur quickly or might take several years.

After having selected a home carers also have to live with the consequences and adjust to the decision. Lewis and Meredith (1989) described the grief, guilt and loss experienced by many family carers following admission to a residential or nursing home, but noted that professional carers tended to treat them as if their problems were over; indeed, the interviews conducted by the author for this part of the study proved to

be the most time-consuming, with carers wanting to share their knowledge of the person in care, and seek reassurance that they had 'done the right thing'. Over and above this carers also needed support to deal with the conflicting emotions that many still felt. Without this it was difficult to move on to 'a new-beginning'.

Alternatively, caregiving may reach the end following the death of the person with dementia, although in this study this was most likely to occur following admission into care, as in the following example:

My husband died several years ago now. Such a nice man, apart for the few years towards the end when he had to go to the home. It's a shame you couldn't have met him when he was alive. As you can see, I have kept his bed downstairs all this time. I don't have the heart, or the energy, to take it back upstairs {laughs}. I think of him when I am sitting here. Especially at night. All the times I was up with him, giving him drinks and just talking to him through those long hours. I miss his company but I don't miss that {his dementia}. He was such a kind man.

(interview: 57)

Supported by the experiences of other carers in the study, a sense of release was apparent in a variety of ways and combinations, which included:

- An escape for the person with dementia from their dementia;
- The release of the carer from their responsibilities;
- The release from financial penalties involved in paying for support (ranging from home care to the spending of substantial sums in supporting nursing/residential home placement); and
- A way of escaping from the experience of dementia.

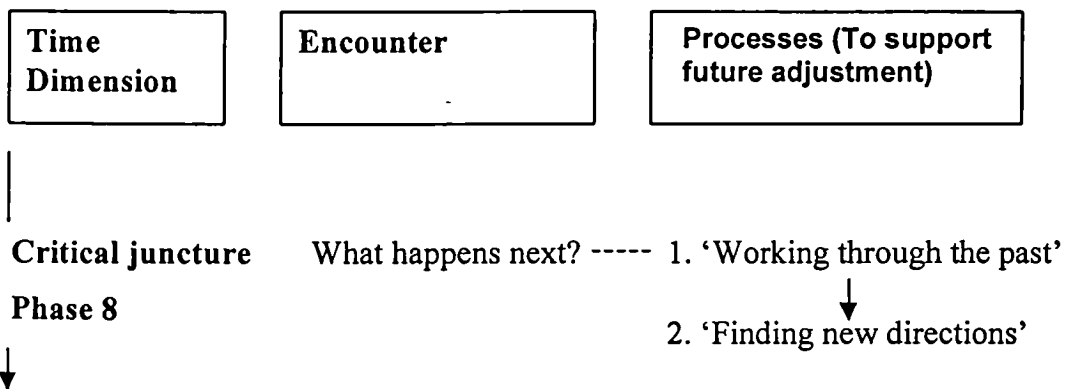
This release also allowed carers to move on with their lives into a search for A New Beginning, although the legacy of caring left its mark on all those interviewed. For instance, fear over the genetic transmission of dementia to surviving members of the carer's family (including adult child carers themselves); the signs that might indicate that this was happening; and the firm belief that they would not want their children to provide support to them should they 'develop dementia'. The critical juncture then that led the carer into this final stage of the caregiving experience, 'A New Beginning' was

the loss of the person with dementia - either through their admission to a care home or through their death

4.14 'A New Beginning': The Final Stage of the Carer's Model

Creating 'a new beginning' is a challenge at the best of times, but for a family carer, particularly one who may have done little else for several years and for whom caring may have constituted both a role and a sense of identity, it can be virtually impossible. Withdrawing professional support at such a time in the belief that 'problems are all over' (Lewis and Meredith, 1989) is simply not sanctionable. Arguably, most carers are ill-prepared for a life after caring and this may be exacerbated for those who have been caring for the longest period. Indeed, the way in which caring was discontinued significantly influenced the way in which carers could resolve issues and move forward. From the study, there would appear to be two inter-linked and sequential processes to support this new direction of care, as illustrated in Figure 9:

Figure 9: 'A New Beginning': Adjustment processes



Theoretical memo book entry: 16.5.1994

Supported by the data, each of these processes will be explored further.

Process 1: Working through the past

Here carers continue to strive to find meaning in their caregiving role. It is analogous to the 'recasting' function described in the opening decision-making model (Figure 3), but extends to cover the whole process of caregiving, not just discrete events. This is also an active strategy and involves rehearsing events and resolving, and confirming, decisions as this example illustrates (interview: 56):

Researcher: Your husband died a few years ago now, do you still think of him?

Carer: Oh yes, hardly a day goes by when I don't think of him. I was with him all the time you see, and I was there when he died.

Researcher: Did your husband change very much over the years?

Carer: Well, how can I put it, I'm convinced he still knew me so that helped a lot. When I wasn't washing linen and things I would spend my time just sitting here with him {carer's front-room}. Towards the end, I had to feed him all his drinks and food and I spent ages mashing it all together so that he could swallow it. My neighbour told me that bananas are good for you when you can't eat properly, so I mashed them up and mixed them with milk. I still can't look at a banana now without thinking of ... {names her husband}.

Researcher: When you look back at your experience of caring for your husband, how does it make you feel?

Carer: I, em {pause}, I feel that I did the best I could for him. I could have done more, mind you, and there was times when I wished he had never got this thing. But he was a good man, you see, a good husband.

Researcher: Do you miss him?

Carer: Oh yes, I miss him. As time has passed {carer was bereaved four years ago} I think more and more of our time together when we were young.

Mind you, I'm quite old myself so maybe it's good for me to think that way! We were married before the second war, you see, and I had to live without him for all those years. Sometimes I never thought I would see him again, so when he came back, that was the best feeling, everything else was just a bonus.

Researcher: And does that include the time spent caring for your husband?

Carer: Yes.

Whilst not readily apparent in the above extract, guilt was a feature during this period, a degree of which remained with all carers interviewed. Interestingly, dreams about the person with dementia also were in evidence during the interviews. Some were comforting, but others were more psychologically disturbing and hampered the carers' ability to work through the past and commence a new beginning with their life. Interestingly, this representation of the 'past' impacting upon the (present) reality of carers living through this transition, illustrates the dynamic movement and functioning of Building on the Past; this central role of the 'past' and its theoretical 'placement' as the first stage of caring in the six stage temporal model will be returned to again in chapter 6.

Process 2: Finding new directions

Carers could only enter this second process once they were able to place the experience of dementia in context, 'working through the past' in order to reach a level of acceptance. Only then, the data would suggest, could carers embark upon finding new directions in their lives. For instance, following institutionalisation or the death of the person with dementia, carers expressed the need to find this new direction whilst also preserving their unique contribution to the care of the person with dementia. This was not an easy process. Restructuring family systems following the loss of the person with dementia was extremely stressful. Some carers felt that they were at a loose end and that suddenly, after a number of years of caring and investing in the person with dementia, they were no longer useful. Where the person with dementia was in institutional care, family carers believed that their lives were on hold and could not

progress; this was especially true of the younger carers who felt they were unable to move on as their spouse was still alive. As one 58 year old spouse stated:

How long will this carry on? He's been in the home for four years now and I want to get on with my life.

(interview: 47)

Other carers wanted to leave dementia 'as far behind them as possible' and re-establish networks and interests that existed before the onset of dementia and their transition into care.

The ability to find new directions became an important for carers who had progressed through each of the identified stages of care. In many ways, it was one of the most challenging as they attempted to resolve their feelings about the experience of dementia and begin the difficult process of constructing a new reality for themselves, a reality that had been dominated in the recent past through their exposure to dementia. Whilst these processes become signposts, the circumstances and adjustments of 'ex-carers' is an area that remains under-researched and where additional investigation would help understanding.

Certainly, some carers in this study wanted to re-invest in the experience of dementia, and share their processes of adjustment and coping with others. Indeed, one carer whose wife was in residential care, described himself as the 'local exchange bureau' (interview: 37), as he was constantly receiving calls from other carers asking him what to do in certain situations. Thus, an important new direction for this carer emerged, where he continued to be engaged with the process of dementia whilst also receiving an acknowledgement from other carers of his (past) skills and expertise. This certainly breaks with the tradition of viewing carers as passive recipients of information, and will be returned to again in the final chapter of the thesis when discussing the practice implications of the study.

4.15 An Emerging Focus on People with Dementia

Having considered the key stages and supporting processes of the six stage temporal model of care from a carer's perspective, the chapter will now briefly outline an exploratory nine stage model detailing the subjective experience of dementia (Keady and Nolan, 1994b). The impetus for this model emerged during the accounts of four people with mild, or very mild, dementia who were present during the 'carer-focused' series interviews and wanted to briefly contribute towards the discussion (interviews: 40, 43, 45 and 48). This was not envisaged in the original study design, or during the letters of introduction and response that confirmed the carer's consent to interview.

Following the first 'joint' interview (interview: 40), where the person with the early experience of dementia remained in the interview for ten minutes, the author wrote to the Chairman of the Gwynedd Ethics Committee to ask for advice. Although the author received an acknowledgement of his letter, no additional guidance was given by the Ethical Committee on how to handle this situation, over and above a restatement of the conditions attached to tape recording interviews and the need to ensure informed consent. Whilst this was helpful, in the sense that future interview(s) could be conducted if similar circumstances arose, this experience led the author to consider what to do if such an opportunity presented itself in the future.

After first discussing the situation with his supervisor, 'consent to participate' guidelines were drafted by the author to ensure, if the situation arose, that something approaching 'informed consent' of a person with the early experience of dementia could be obtained; a situation that was to occur again during interviews: 43, 45 and 48. These 'consent to participate' guidelines consisted of:

- Confirming with the person with dementia the purpose of the interview, and asking them to repeat their understanding at the end of the explanation. A spare 'consent to interview' schedule was also to be signed in the presence of the carer and author;
- Repeating the same procedure with regard to 'consent to tape record' interview; and
- Reaffirming at the outset that the interview could be terminated at any time should the person become upset or distressed in any way.

The involvement of the person with dementia in each of the four interviews (interviews: 40, 43, 45 and 48) was relatively brief, totalling 45 minutes in all, but their contribution raised striking similarities in terms of living with the early experience of dementia. For instance, during interview: 43, the following exchange ensued:

Researcher: {directed to the couple} Thank you for agreeing to take part in this interview. {person with dementia and carer both smile} Could I start by asking what you first noticed about your condition? {directed to the person with dementia}

Person: It, em, was my memory really. I couldn't think of things quickly. That's what is was.

Carer: {to researcher} I didn't really know at the start, to be honest. It was only last year did I think that something was up with him.

Researcher: {to person with dementia} So what sort of things were happening to you at the very beginning?

Person: I would just forget simple things really, things I had always taken for granted. I didn't think it was serious then {pause} I just thought it would stop so I didn't tell anybody about it.

At the onset of dementia a similar process was also exhibited by the other interviewees and, for the author, it started to place in context the time dimension attached to the carer's 'noticing' behaviour, particularly as set out in Figure 3 (p.121).

Whilst this contact with people with the early experience of dementia was brief, the author used his theoretical sensitivity to the accounts in order to construct a theoretical nine stage exploratory model of the subjective experience of dementia (Keady and Nolan, 1994b). This was the author's first attempt to provide an account of dementia from the perspective of the person with memory loss, and although informed by the data from the above four interviews, had relatively little empirical support. Nevertheless, it reflected the emerging trend in the literature to focus on aspects of dementia previously

ignored. The model was therefore published (Keady and Nolan, 1994b pp.666-667) and, as it was to have a profound effect on the future direction of the study, a summary account is given below. An early attempt was also made to look for points of overlap with the carer model.

a) Slipping

The process of dementia was seen to begin with a stage of slipping where the person gradually became aware of minor and seemingly trivial 'slips and lapses' in their memory and/or behaviour. These 'slips and lapses' were initially ignored, but as they became more frequent could no longer be so easily dismissed. At this time emotion-focused coping behaviours such as 'discounting' and the 'normalising of events' were used to deny the significance of the symptoms. The stage was then seen to shade into:

b) Suspecting

Here the incidences occurred with greater frequency/severity so that they could no longer be rationalised or ignored. The 'discounting' and 'normalising of events' became less successful coping strategies and the individual began to suspect that something could be quite seriously amiss.

c) Covering Up

This strategy was employed when the person made a conscious and deliberate effort to compensate for their difficulties and to actively hide them from family members, friends and colleagues. As the condition progressed and covering up became more problematic, the person began to restrict activities in certain areas where their competence was difficult to sustain. If they had not noticed before, it was often at this point that the individual's partner/family may begin to notice changes in the behaviour of their relative.

d) Revealing

A stage of revealing is then reached where the individual's difficulties are revealed to those closest to him/her. This may be as a result of a conscious decision, or as a result of being confronted with patterns of loss. At this point shared knowledge might still be kept within the immediate family and a formal confirmation of suspicions may be

delayed. Although not immediately apparent at the time of publication, this was seen to be a point of overlap with the strategies in Figure 5 (p.129) of confirmation.

e) Confirming

Next is a stage of Confirming where open acknowledgement of the problem is made and the process of diagnostic conformation begins, this is usually the first point of contact with formal services.

f) Surviving

Following this process a stage of surviving is reached where the person continued to adjust to their dementia via the use of adaptive coping techniques to compensate for cumulating losses.

g) Disorganisation

Eventually a stage of disorganisation is experienced where cognitive difficulties and associated behavioural problems become an increasingly dominant feature. There is diminishing decision-making ability and awareness of actions may become more difficult to express.

h) Decline

Decline then follows where any semblance of a normal and overtly reciprocal relationship becomes clouded and uncertain. The instrumental demands of care become a more prominent feature of the caregiving relationship together with increased dependency needs. At some point along this road decisions on the person's admission into continuing care may be taken by the carer.

i) Death

Finally, the person with dementia is presented with the ultimate phase, and transition, their own death.

Developing this early exploratory model challenged profoundly the author's belief in the previous direction of his research process, particularly the decision to capture only one perspective, that is the carer's, in the process of dementia. The desire to gain a further and more complete understanding of the early experience of dementia, and discovering

how this integrated with the carer's perception, opened up a new line of research inquiry, one that potentially provided a more complete account of the experience of dementia. This led to a second phase of the study, which involved trying to gain new insights into dementia as experienced by the person directly affected. This new direction forms the substance of the next chapter.

4.16 Summary

This chapter has described the research process and findings of the first series of interviews that comprised the study, highlighting in particular the dynamic processes of conducting a grounded theory study. It began with a review of the first six interviews in the study which shifted the author's attention away from a specific emphasis on coping, towards a process of uncovering the temporal dimensions of caregiving. In developing this approach, the carer's first awareness of 'dementia' was seen through a process of 'noticing' and accompanying processes of 'normalising' and 'discounting'. When this perception could no longer be sustained the carer became increasingly vigilant, with a growing recognition that 'this might be serious' and 'this is serious'. In the phase of 'this is serious', carers would seek a medical opinion on the cause of the 'noticed' behaviour, and a diagnosis of dementia was identified as a critical juncture in putting past behaviour into context. Working within a modified grounded theory approach, using both constant comparison and theoretical sampling, the author constructed a six stage temporal model of care to account for developments over time, the stages being named as: Building on the Past; Recognising the Need; Taking it On; Working Through It; Reaching the End; and A New Beginning. Critical junctures were applied to each stage to either lock the carer in, or move them through, the model. The chapter concluded with an overview of a nine stage model of the subjective experience of dementia. This model was generated through the author's theoretical sensitivity to the data, and the brief contribution of four people with the early experience of dementia who wanted to take part in the interview process. This initial, largely theoretical model, opened up tensions with the initial research question and forced the author to reconsider future data collection. This required a fundamental re-orientation in order that the voice of the person with dementia be reflected more fully. This is the substance of the next chapter.

CHAPTER FIVE

THE EARLY EXPERIENCE OF DEMENTIA: A REVIEW, STUDY DESIGN AND FINDINGS – PHASE 2

**You've forgotten the spoon to stir John's tea
(interview: 60)**

5.1 Introduction

This chapter introduces the second phase of the study by briefly reviewing the literature on the early experience of dementia, with an emphasis on recent social research advances, and subsequently by introducing the method used to explore the subjective experience of dementia. The chapter will then outline the author's first three research interviews in this series (interviews: 59-61) as these experiences were a salient reminder of the need for both sensitivity and clinical judgement in conducting research interviews with people with dementia. Next, the text traces the steps that led the author to identify two stages to help explain the person's transition to dementia and ways of managing this experience, namely: Keeping it Hidden (1) and Sharing the Load (2). Keeping it Hidden is explored more fully through its three associated strategies: Closing Down; Regrouping; and Covering your Tacks. As in the carer's model, it was necessary to attach a time dimension to the development of each stage if the stages were to help explain the movement of the person from living with the feelings of anxiety at the onset of dementia, to taking part in a diagnostic procedure. The chapter then highlights the development and properties of two dimensions which were seen to link the stages of Keeping it Hidden and Sharing the Load; these dimensions were identified as Taking the Initiative and Responding to Events. Finally, the properties of 'maintaining involvement' as a linking scheme to explain the dynamics of dementia will be introduced, and developed further in the following chapter.

5.2 The Early Experience of Dementia: A Review of the Literature

a) Background

With the social research focus of the 1980s being firmly centred on carers and the dominant medical ideology of dementia, it is easy to see how people with dementia gradually became distanced from their own experience, portrayed as the instigator of this 'devastating process' (Orona, 1990 p.1247) and cast in a role of a 'patient' who is 'physically there but psychologically absent' (Boss, Caron and Horbal, 1988 p.123). Whilst service, policy and academic interest in carers flourished, the 1970s and 1980s, on the whole, saw services for people with dementia developed along homogeneous lines (see: Shah and Ames, 1994) with little attempt being made to involve people with dementia in the design of support services, such as day, respite or continuing care.

In the UK a catalyst for change emerged, in part, due to the introduction of the NHS and Community Care Act (Department of Health, 1990) and its emphasis upon user consultation and the negotiation of a mutually agreed package of care. Winner (1993), commenting upon the direction of the community care reforms, suggested that people with the early experience of dementia required on-going assessment, relationships and commitment if their empowerment and sense of involvement with care agencies was to develop in any meaningful way (see also: Chapman, 1993), arguing that the skills needed by professional staff 'were at a very early stage of their development' (p.7).

If the foundations for a heightened sensitivity to the individual being assessed were laid in the NHS and Community Care Act (Department of Health, 1990), they were cemented in subsequent policy initiatives, such as the mental illness targets set out in the White Paper *The Health of a Nation: A Strategy for Health in England* (Department of Health, 1992), and the right for information on a diagnosis as part of the Patient's Charter (Welsh Office, 1991). This emerging momentum for social inclusion was carried forward on a number of fronts. Prime amongst these was the creative work of the Bradford Dementia Group in the UK and its emphasis on person-centred values (Kitwood, 1988; 1993; Kitwood and Bredin, 1992a,b). As reviewed in chapter 1 (pp.33-35), the persuasive arguments forwarded by Kitwood and his colleagues to see the person first and the dementia second, did much to raise awareness and stimulate an agenda for change, particularly on the need to challenge the 'malignant social psychology' that has

surrounded the experience of dementia (Kitwood, 1988; 1992; Kitwood and Bredin, 1992a; Kitwood, 1993). This paradigm shift has seen the person with dementia moved to the forefront of practice, research and policy attention, with service providers being challenged to address inadequate care practices.

On this issue, recent practice innovations have validated the development of support groups for people with the early experience of dementia, similar in design to carer support groups (for a review see: Miller and Morris, 1993), and studies have demonstrated the benefits of such an approach in the teaching of: adaptive coping skills (Jackson and Wonson, 1987; McAfee, Ruh and Bell, 1989; Duff and Peach, 1994); sharing of information (Van-Wylen and Dykema-Lamse, 1990; David, 1991; Yale, 1991; Burningham, 1992); and the provision of cognitive markers about how to live within the shifting realities of the diagnosis (Thompson *et al.*, 1990; Woods; 1994). Indeed, the value of both memory training (for a review see: Scogin, 1992) and psychotherapy for people with the early experience of Alzheimer's disease has been known for some time (Teri and Gallagher-Thompson, 1991; Sutton, 1994). However, these advances have still not permeated routine practice (Malcolm, 1993; Department of Health, 1994) where a focus on the more traditional approaches to working with dementia, for instance through reality orientation, resolution or validation therapy (see respectively: Holden and Woods, 1988; Stokes and Goudie, 1990; Feil, 1992a,b), remains dominant. However, the increasing emphasis placed upon understanding and responding to the early experience of dementia may well provide a re-orientation of intervention, skills and preparation for practice, as a recent study for advancing cognitive screening by nurse practitioners in primary health care teams has demonstrated (Seymour *et al.*, 1994). If such approaches are to develop there is a need for a greater understanding of dementia as it is personally experienced, and it is to this area that attention is now turned.

b) Personal Perspectives

Prophetically, Pollitt, O'Connor and Anderson (1989) identified that little had been written about the early stage of dementia, in particular those aspects involving 'day-to-day activities and social relationships' (p.262). Cotrell and Schulz (1993) later picked up on this deficit challenging policy makers, service providers and social scientists to redress the balance. They argued against the uni-dimensional focus of social research conducted in the 1980s that had primarily explored and evaluated the impact of dementia upon family

caregivers, a contention confirmed by extensive literature reviews conducted in the last few years (Barer and Johnson, 1990; Kuhlman *et al.*, 1991; Dhooper, 1991; Knight, Lutzky and Macofsky-Urban, 1993; Downs, 1994; Hadfield and Watson, 1994). Cotrell and Schulz (1993) were severely critical of this carer-focused agenda which, in their opinion, subjugated the person with Alzheimer's disease to:

... an entity to be studied rather than someone who can directly contribute to an understanding of the illness and its course. (p.205)

Whilst not collecting data themselves Cotrell and Schulz (1993) did outline a broad framework for further research. This is clearly needed as existing literature is sparse.

Studies that have sought personal perspectives on the early experience of dementia have been confined to relatively small samples (Froggatt, 1988; Goldsmith, 1994; Wuest, Ericson and Stern, 1994), with thinking in this area being informed mainly by proxy from the experience of carers. For instance, La Rue, Watson and Plotkin (1993) found that carer's reported forgetfulness as by far the most common early indicator of dementia, followed by: confusion; depression; agitation; inattention; getting lost; language; and motor problems. Whilst such data are potentially useful, they are still a second-hand account. For Cotrell and Schulz (1993) such a perspective is severely limited as it does not adequately capture the personal meaning and experience of dementia.

Stemming from the USA, two books published four years apart provided new insights. The first publication was a relatively short book entitled *My Journey Into Alzheimer's Disease* by the Reverend Robert Davis (see: Davis, 1989) who was aged 54 at the time of the onset of Alzheimer's disease. Underpinned by his Christian faith, pages 21-82 of this publication were written by the Reverend Davis and articulated a seven month transition and adjustment to the onset of Alzheimer's disease. The remainder of the publication was an interpretation of the later experience of dementia written by Reverend Davis' wife. This moving account portrayed the fear and uncertainty which accompanied Reverend Davis' journey into Alzheimer's disease, as captured below:

I can no longer speak in public, and I shatter psychologically in any pressure situation. Mental and emotional fatigue leave me exhausted and confused. Mental alertness comes now only in waves at random hours of either the day and night.

(Davis, 1989 p.24)

The book also reveals that the couple's close marital relationship held them together during the onset and progression of dementia, particularly during the early months when Davis (1989) was struggling to make sense of his accumulating losses. This was particularly evident during his inability to come to terms with the loss of his fluent reading ability which evoked the following coping efforts:

- Implement a strategy of self assessment - of the loss;
- Instigate a compensatory coping response - such as reading slower; and
- Engage in a reassessment of (the hoped for) improvement.

Despite his best efforts at overcoming the loss, the inability to correct the situation was personally devastating to Davis (1989) as he had 'read a book a day from seventh grade on' (p.29). Indeed, it was his inability to resolve this situation that eventually led Reverend Davis and his wife to seek medical help; although their diagnostic quest was to prove to be a traumatic experience. Davis (1989) continually cites his reliance on existential coping techniques to make sense of this experience (see also: Cromwell, 1994), with the dementia 'part of God's plan' (p.80) to test his faith, reconcile his past and affirm the durability of his marital relationship. There was also the belief expressed both during his account, and later by his wife, that Alzheimer's disease had brought the couple closer together and that they were able to 'work through it' as a partnership once there was an awareness of the name and prognosis of the condition. It was this overriding combination of Christian belief, love and partnership that best summarised Reverend Davis' (1989) journey into Alzheimer's disease and one that appeared to continue until the time of his death.

Another younger person with dementia living in the USA, Diana Friel McGowin, also provided a lucid account of being 'dragged' into Alzheimer's disease. McGowin (1993) describes the emotional, physical, social and sexual turmoil that this process had upon her life and that of her family. However, in contrast to the account provided by Reverend Davis and his wife, for McGowin (1993) the early transition into Alzheimer's

disease was marked by the denial of events by her husband, and his reticence to acknowledge that she was failing in any way, as this extract from the book highlights:

The electric bill was higher than usual because my clothes dryer was not shutting off automatically. I frequently forgot to remove the clothes from the dryer and there were many days when the laundry load tumble-dried all day. Jack was furious, emphasising how much current the clothes drier used. All I had to do was remember to take the clothes out, he said.

(McGowin, 1993 p.82)

For McGowin (1993) such an exchange placed an additional layer of stress upon an already difficult situation, a process that led to an ever increasing cycle of blame and recrimination. In this instance, McGowin's husband was using denial as a coping strategy which, whilst useful as a temporary coping effort in the early adjustment to a traumatic event, giving the person time-out to consider future options (see: Kübler-Ross, 1970; Cohen, Kennedy and Eisdorfer, 1984; Conner, 1986; Forchuk and Westwell, 1987; Lazarus and Folkman, 1984; Handron, 1993), is unhelpful in the longer term (Lazarus and Folkman, 1984). Indeed, McGowin (1993) reveals that her husband continued to deny the reality of events for several years, which placed responsibility for responding to the symptoms directly with herself and led to severe tension in their marital relationship. Over time McGowin's husband accepted the seriousness of the situation, concluding that things would not get back 'to normal'. This acceptance allowed the 'opening up' of the condition, and was pivotal in helping the family learn to live with the impact of Alzheimer's disease. Reflecting later in the book on this traumatic experience, McGowin (1993) wrote the following:

My most troublesome fears revolved around the same theme. Would my husband of over twenty years protect and take care of me should I decline further? He is a stalwart, a stoic, and we had only recently regained a state of grace in our marriage, after many troubled years. What if he should tire of a wife without her senses about her, should that be my future? (p.114)

Similar to the experiences captured by Yale (1991), McGowin (1993) was actively expressing her fears for the future, whilst also anticipating her own prospective care needs. By the end of the book the couple had moved forward together to finding meaning in the experience of Alzheimer's disease, and it was this evolving partnership that was to give McGowin (1993) hope and 'the courage to face the day' (p.130).

It is interesting that professional interventions are mentioned only rarely in both these publications, and when they are, it is usually to reflect feelings of frustration and hostility. More specifically both Davis (1989) and McGowin (1993) expressed their distress at:

- The time it took to establish a diagnosis;
- Being kept in the dark over the outcome of assessment and investigations;
- The lack of dedicated support services, especially support groups to facilitate discussion;
- The inadequate supply of information; and the
- Lack of support for memory training.

Following this growing trend towards personal accounts of dementia, the Alzheimer's Disease Society in the UK, via its monthly *Newsletter*, printed brief segments of a diary written by Hall (1994) which gave an insight into his experience of Alzheimer's disease. Hall (1994) outlines memory loss and the breakdown of old routines as early indicators of his failings, and describes the emotional trauma of being an ex-Methodist minister who found himself 'at all sorts of times and places with my flies undone' (p.3). On an international platform, and in an effort to raise awareness of dementia, on the 5th November, 1994 Ronald Reagan, the former President of the USA, disclosed to the world in an emotional statement that he was in the early stages of Alzheimer's disease.

Prior to these personal accounts, Froggatt (1988) produced an interesting chapter for an Open University publication/study course on *Mental Health Problems in Old Age* which focused on self-awareness in early dementia. Whilst the research methodology and sample size were not made explicit, the research design involved interviews and non-participant observation. The aim of this study was to explore how the person with the early experience of dementia perceived themselves, and how they could be helped to retain a sense of identity. In this study the early experience of dementia was seen as a complex interplay of social, psychological and biological factors with memory failure quickly resulting in social isolation. The social construction of memory failure was seen as an episodic mixture of forgetfulness over recent events, absentmindedness and internal preoccupation with thoughts and day dreams. Froggatt (1988) also looked at the 'retained social skills repertoire', such as the person's ability to continue to express

politeness, be friendly to strangers and give a good presentation of self. Memory failure itself was found to be masked by confabulation, with the skill of creating and maintaining trust seen as crucial in gaining entry into the world of the person with dementia. As Froggatt (1988) suggested:

Unless some effort is made to piece together clues about the inner realities of people with dementia, all decisions about 'their' {original emphasis} future care and treatment will be made by others on their behalf, thus marginalising and objectifying sufferers even more. (p.132)

Other attempts at interpreting the experience of dementia can be found in a number of temporal models (see for instance: Hirschfield, 1981; 1983; Clarke and Watson, 1991; Willoughby and Keating, 1991; Kobayashi, Masaki and Noguchi, 1993; Taraborrelli, 1993; Collins, Given and Given, 1994; Garwick, Detzner and Boss, 1994; Harvath, 1994; Wuest, Ericson and Stern, 1994), although only a few have used the experience of people with dementia as part of the study and not all used this data. For instance, Hirschfield (1983) failed to report on the data collected from people with dementia (n=7) and, instead, focused exclusively upon generating a temporal model of care from the carers' perspective. Moreover, in the study by Wuest, Ericson and Stern (1994), the model suggests that after an initial 'dawning' stage, family caregivers and people with Alzheimer's disease 'pair up' and move on a continuum from a state of intimacy to alienation. In the context of their study, this is described as an universal phenomenon where caregivers detach themselves from the 'victim' the person has become and move towards 'becoming strangers'.

This rather negative image of family care and the experience of dementia may have been a feature of the sample under study, but it is not fully indicative of the experience of personal growth and satisfaction that is the feature of other caregiving studies in dementia (see: Motenko, 1989; Kobayashi, Masaki and Noguchi, 1993; Cohen *et al.*, 1994) and, indeed, in developing caregiving expertise as outlined in the previous chapter. As a further illustration, the grounded theory study by Kobayashi, Masaki and Noguchi (1993) was conducted with 49 family carers of people with dementia and outlined a seven stage model of this experience. The model placed an heightened emphasis upon the experience of personal growth and evolving expertise enjoyed by family carers throughout the continuum of care. Whilst there may be cultural influences

at play, the authors' conclusions certainly appear to provide a more balanced account of the experience of dementia. Moreover, the study drew attention to the importance of recognising non verbal communication within the caregiving relationship, highlighting that this form of interaction continues even though there may be no meaningful conversation between participants. In contrast to the description of cumulative losses, Kobayashi, Masaki and Noguchi (1993) saw that after working through a period of uncertainty, carers described a feeling of empathy and understanding for the person with dementia, and 'begin to feel sorry for them'. Thus, carers learn to appreciate aspects of the person with dementia and to find other methods of communication. The experience of dementia, therefore, is not inevitably the devastating picture that had been painted previously (Pitt, 1982), and more recent literature provides insights into the person's own adaptation to the process, their choices, views and wishes (Froggatt, 1988; Davis, 1989; Yale, 1989; Cotrell and Schulz, 1993; McGowin, 1993).

It was the desire to understand the perspective further that was the main impetus for the second phase of the study.

5.3 Study Design - Phase 2

a) Background Issues

As the first six stages of the early temporal model exploring the subjective experience of dementia (Keady and Nolan, 1994b) had been generated from people who had been diagnosed at an early point in their dementia, and were able to articulate this experience, it appeared salient to continue with this approach. This standpoint was reinforced by Cotrell and Schulz (1993) who, whilst not wishing to discount the importance of the later experience of dementia (see: Floyd, 1988; Kitwood and Bredin, 1992a,b), cogently stated that:

The most valuable insights regarding the psychological and experiential responses of persons with dementia are likely to be obtained during the mild to moderate levels of impairment when the individual is still able to verbalize an effective span of attention. (p.208)

Additionally, Cotrell and Schulz (1993) emphasised the need to explore further how people with the early experience of dementia respond and adjust to their experience, and argued that the only way to achieve this was to seek their opinion. Gaining this opinion is necessary as, on the whole, people with the early experience of dementia have been continually excluded from social research studies as researchers considered their accounts to be unreliable (Cotrell and Schulz, 1993). This was not the author's experience in either practice or research contexts. However, designing a study that specifically included people with the early experience of dementia was not an easy task. Approaching the subject for the first time, the author jotted down the following list of notes in his theoretical memo book:

How do you:

- Find a theoretical sample that were diagnosed early in their dementia?
- Go about gaining ethical consent to undertake such a study?

How can you make sure:

- Consent is informed and the purpose of the research study made clear?
- People with the early experience of dementia want to talk about their dementia?
- That any research interview is meaningful for the person?

(theoretical memo book entry: 4.2.1994)

By this stage in the research process the author was more confident in his ability to undertake grounded theory research, particularly using the constant comparative method (Glaser and Strauss, 1967; Glaser, 1978). Therefore, in planning this second phase of the study, the only real certainties were that the use of the grounded theory approach would continue, and that interviews would be the main method of data collection. The next step was to consult the literature in order to gain further assistance in designing the study, although, as Floyd (1988) insightfully observed, there were 'no easy solutions in enlisting demented clients as research subjects' (p.17).

b) The Study Design

Despite an exhaustive search by the author at the time of preparing the study design (early 1994), little guidance could be found on how to conduct the study, or to assist in

the approach to data collection. Texts which, on the surface at least, appeared to claim the perspective of the person with dementia, for instance those by Orona (1990) and Cotrell and Lien (1993), were, on closer examination, accounts provided by carers on their perception of coping with the early experience of dementia. On the whole, there were few studies that had actively sought out the perspective of the person with dementia as an integral part of the research design. Of those that were available four texts emerged which proved invaluable in shaping the research design and the interview process, these were: Froggatt (1988); Pollitt and Anderson (1991); Cotrell and Schulz (1993); and Lee (1993). The contribution and salient points of each of these texts will now be considered in turn.

In her pioneering study Froggatt (1988) outlined 'formidable obstacles' (p.134) to undertaking qualitative research with people known to experience early dementia, embracing ethical, methodological and psychological considerations. Drawing on her own research methodology Froggatt (1988 p.134 slightly abridged) listed nine areas to consider in conducting qualitative research with people with the early experience of dementia, namely:

- i. The underlying morality of asking those who are already mentally precarious about aspects of themselves which it may be painful to contemplate;
- ii. Gaining access to sufferers can only be through a general practitioner, psychogeriatrician, community psychiatric nurse or social worker;
- iii. Research probably needs to be conducted using a variety of methods: semi-structured conversations with the sufferer, additional interviews with key relatives and principal carer, and consulting records (with consent), to build-up a psychobiography;
- iv. Researchers/interviewers need to be experienced and/or trained, as interviews are likely to be emotionally difficult;
- v. Funding may be difficult to obtain, in the light of prevailing ageism;
- vi. Gaining consent from the sufferer to talk about his/her current life. If a person withholds consent because of anxiety this must be respected. Building trust, warmth and empathy into the encounter can reduce the anxiety for those who do consent;

- vii. There is reticence about conducting research in this area for fear of increasing anxiety (see also: Gilhooly, 1984). To legitimate the anxiety could be a way of strengthening the person's hold on reality;
- viii. Interviews with sufferers may need to be relatively short and, if conducted more than once, spaced close together to benefit memory; and
- ix. Interviews with relatives may need to be lengthy as they struggle to understand the minutiae of observed behaviour, trying instinctively to make sense of it.

Froggatt (1988) acknowledged that it may be a positive step in the interview to ask the person with the early experience of dementia to go on taking risks, facing up to new experiences and 'to cope with the anxiety' (p.135). Moreover, Froggatt (1988) suggested that the researcher should engage in lateral thinking and feeling; implicitly, this acknowledges that the interview will have an emotional impact upon the interviewer and that this should be recognised in any prospective study design.

A second rich source in planning the study was provided through a selection of the papers resulting from the Hughes Hall Project for Later Life (Pollitt, O'Connor and Anderson, 1989; Pollitt and Anderson, 1991; Pollitt, Anderson and O'Connor, 1991; and Pollitt, 1994), particularly Pollitt and Anderson's (1991) commendable honesty in admitting that during the study 'they did not always ask the right questions, or ask them to the right person' (p.30). Synthesising the 'methods' section of each of the papers stemming from the Hughes Hall Project for Later Life, the author was able to identify a number of issues emerging from their overall study design. Prime amongst these were that: interviews with people with the early experience of dementia could be undertaken both conjointly and individually; relatives largely controlled their dependants' entry into the study, and placed their own meaning upon the value of the research process; satisfactions in caregiving were present at the early experience of dementia; and at the beginning of an interview, it was crucial to build rapport and ask the right questions.

Third, the paper by Cotrell and Schulz (1993) was instrumental, and timely, in providing a theoretical framework of relevance to the proposed study. This contribution also proved helpful whilst attempting to negotiate access to the research subjects. Similar to the suggestion made by Froggatt (1988), Cotrell and Schulz (1993)

highlighted a number of strategies in developing a study design for people with the early experience of dementia. These included:

- Small sample sizes were appropriate;
- People with dementia may feel less threatened if the study is undertaken in their own home;
- The timing of the interview should be set by the person with the early experience of dementia, to enhance their feelings of control over the research process;
- The perspective of the caregiver is a valuable source of information; and
- People with the early experience of dementia may welcome the opportunity to discuss their experiences.

The importance of this last statement should not be under-estimated as it serves as a reminder over ownership of 'the dementia', and the need to be able to explore the subjective meaning of dementia and the ways of adapting to this experience (Yale, 1991).

Fourth, Lee (1993) published a practical text on *Doing research on sensitive subjects*, and whilst the main thrust of the book was on studying deviant populations, chapter 6 of the text covered the process of asking sensitive questions during interviews. Much of this chapter proved to be relevant to the prospective study, particularly Lee's (1993) recommendation that the interview should have a 'one-off' character (see also: Brannen, 1988) so that informants 'can disclose their experience safe in the knowledge that the paths of the interviewer and interviewee will not cross again' (p.112).

c) Formulating the Study Aims

The primary aim of the second phase was to provide a better understanding of how people with the early experience of dementia coped with their situation, specifically the key areas of the 'Slipping' to 'Surviving' stages (Keady and Nolan, 1994b). The questions to be addressed included:

- i. What are the experiences and coping behaviour of individuals with the early experience of dementia?
- ii. When, how and why are decisions made to seek professional help and support?

- iii. What are the stresses and coping behaviours used by carers supporting a person with the early experience of dementia?
- iv. How do people with the early experience of dementia and their carers view the effectiveness and availability of specialist services in responding to early stage memory impairment?

Exploring the subjective experience of dementia was placed purposively as the first study aim as it was considered important to obtain this perspective, despite the difficulties this might pose. What was now required was a strategy to operationalise the study aims by locating a theoretical sample and obtaining ethical approval to conduct the study. Both of these issues will now be addressed.

d) Accessing the Sample and Gaining Ethical Approval

Following the methodological advice outlined earlier, it was crucial that those recruited into the study had an early, confirmed, diagnosis of dementia. To achieve this a number of options were considered. The first strategy was to continue recruitment from the caseload of Consultant Psychiatrists A and B who had been crucial in facilitating the successful phase 1 of the study design. However, after meeting with Consultants A and B to explore this option, a number of problems emerged, including:

- Referrals from primary care were usually at a later stage of the dementia process;
- When referrals from people with the earlier stage of dementia were made, it was usually 'at a point of crisis' when multiple physical and cognitive assessments were required. Understandably, Consultants A and B were reticent about committing such people to potential entry into an exploratory project;
- Consultants A and B could not 'confidently predict' that a sample to meet the study aims could be found.

A second option was to consider subject recruitment from a memory clinic, as one of the specific purposes of a memory clinic is the early diagnosis of cognitive impairments, including that of dementia (Philpot and Levy, 1987). After discussion with the author's supervisor, it was decided to go for this option, although North Wales did not have a memory clinic of its own.

However, the author was aware of a memory clinic in another part of the UK and had an existing working relationship with a social worker based at the clinic (Social Worker A) who was, herself, researching interventions with carers of people with dementia. She was therefore approached at the end of February, 1994 to discuss the exploratory study aims and emerging ideas on gaining access to the sample. These aims were enthusiastically received, and Social Worker A arranged a meeting at the memory clinic with senior members of the staff, including the medical director, Professor A, in May, 1994 when the research aims and provisional plan could be discussed further.

To prepare for this meeting, consideration was given as to how to ensure the informed consent of the person with the early experience of dementia could be obtained. Whalley (1992) suggests that a person with dementia is able to give consent to participate in a research study if 'he/she understands what is being asked and feels free to refuse' (p.18). Moreover, for people with the early experience of dementia, the issue of competence to make such a decision is easier to discern than for someone in the later stages where competence is considered more elusive (Gilhooly, 1984; Cotrell and Schulz, 1993; Department of Health, 1993a,b). As Gilhooly (1992) argues, a diagnosis of dementia should not automatically disqualify a person from taking part in a study, especially if they wish to do so.

In the present study, it was considered crucial that consent was freely given and that the person having recently been through a diagnostic process - a time-consuming and stressful event in itself - was not in denial of their situation (Handron, 1993), or unduly depressed (Portalska and Bernstein, 1988; O'Connor *et al.*, 1990b; Flicker, Ferris and Reisberg, 1991; Loreck and Folstein, 1993; Verhey *et al.*, 1993; Barker, Carter and Jones, 1994). In reaching an early diagnosis of dementia it is the practice of most memory clinics to adopt a longitudinal approach where the person under assessment initially undergoes a battery of psychological and cognitive tests over a period of months (Philpot and Levy, 1987). This was the practice at the memory clinic where it was planned to conduct the study. As a matter of routine, following an early diagnosis, the person (and their carer if one existed) would receive a six monthly appointment to return to the memory clinic to check the reliability of the diagnostic procedure and explore personal coping responses. It was during this visit that the person, and their carer, could be approached to be interviewed as part of the study.

However, it would have been inappropriate for the author to 'sit in' on the appointment, and it was therefore agreed that the decision on whether subjects would be approached to take part in the study would be made by the member of staff responsible for providing the diagnosis and the follow-up visit. This was either the clinical neuropsychologist attached to the memory clinic, or the doctor in charge of the case, including Professor A. It was felt that this approach would have two benefits. Firstly, an early, and uniform, diagnosis of dementia using *DSM-IV* criteria (American Psychiatric Association, 1994) would have been reached. Second, a further clinical judgement would be made to assess the person's:

- i. Awareness of the procedure they had been through;
- ii. Adjustment and level of acceptance of their memory loss;
- iii. Level of competence and ability to give informed consent to a procedure; and
- iv. Retained verbal fluency and level of concentration.

It was considered essential that each of these four criteria were met before a person could be approached for recruitment into the study. If they were, the responsible clinical staff at the time of the follow-up visit would verbally introduce the aims of the study and then present the person (and their carer if present) with a previously scripted letter of introduction, and supporting information (see: Appendix 5). Assuming participation, a pre-paid envelope for return of the completed and signed documentation was also included and addressed to the author. The letter also invited the participation of relatives as part of the interview process. This was based upon the experience of Pollitt and Anderson (1991) and the presumption that:

- Carers act as a gatekeeper to the person with the early experience of dementia;
- Protective caregiving would be evident at this time (see: Bowers, 1987); and
- The early adjustment to dementia could be seen as a system of personal and family adaptation with both perspectives being important to consider, particularly for further understanding of the 'working through it' stage of the carer's model.

However, the introductory letter (Appendix 5) emphasised that the person living with the early experience of memory loss was to be the main focus of the interview. It was also decided to use a largely unstructured approach to help put the informant at ease.

Lee (1993) suggests that conducting sensitive interviews requires an open and flexible approach where the development of trust is essential:

Disclosure of sensitive or confidential information is usually only possible in these situations once trust has been established between the fieldworker and the people being studied. (p.103)

The timing of the interview therefore was designed to suit individual needs, with permission to tape record the interview received from both the person with the early experience of dementia and their carer. After some deliberation, it was decided that this request be included in the initial pack sent before any visit. This, it was anticipated, would ensure the person with the early experience of dementia had time to consider the request. As in the phase 1 interviews, it was also planned that the tape recording would be retained for a maximum of two years, anonymously coded, stored on University premises, with access to the data strictly reserved for the author and his supervisor. The transcription also allowed the opportunity for a synopsis of the interview to be returned to the participants to check for accuracy; this was always returned to the person with the early experience of dementia and marked for their attention. It was proposed that the conversation with the person with the early experience of dementia would be limited to a maximum of 45 minutes, with the interview closed earlier if there were signs of distress. Finally, the letter of introduction did not mention the word 'dementia' as it was the procedure of the memory clinic only to inform the carer of the diagnosis. Indeed, it was an explicit request by staff of the memory clinic that the term 'dementia' was not used by the author, unless it was first mentioned by the person themselves and/or their carer.

The meeting with key members of the memory clinic, including Social Worker A and Professor A, to share the study aims and proposed research design, was held on the 4th March, 1994, with the memory clinic staff agreeing in principle to support the project. Social Worker A and Professor A became the key contacts as their enthusiasm and local knowledge were central to furthering the project planning. Social Worker A in particular liaised closely with the author and continued to champion the research study at the regular team meetings of the memory clinic. This ensured that all staff in the memory clinic were clear about the purpose of the study before its commencement. Having negotiated access it was as essential to obtain ethical approval.

The local Area Health Authority Ethical Committee forms were completed during April, 1994 with the support of Professor A of the memory clinic being crucial. The study was given Ethical Committee approval, subject to one minor addition; namely, that on the request to interview form a sentence be inserted stating 'the person would not be prejudiced in any way should they decide not take part in the study'. This change was duly made and the revised form was returned to Ethical Committee (Appendix 6). Verbal consent was then provided by the Chairman of the Ethical Committee to Professor A that subject recruitment could be started.

5.4 Subject Recruitment: Sample Characteristics

Using this approach fifty requests for interviews were handed to attendees of the memory clinic (who met the agreed recruitment criteria) over a six month period, starting at the end of June, 1994. The requests for interview were handed separately to the person with dementia and their supporter by the responsible clinic staff. This approach resulted in 20 replies from 10 couples (9 married couples and 1 daughter and her mother) which resulted in 11 family interviews (one married couple were interviewed again later in the study) – see interviews: 59-68 in Appendix 4. Each interview was tape recorded and conducted in the person's own home. Consistent with phase 1, field notes and theoretical memos were kept during the active part of data collection, and all tapes were transcribed by hand and coded on the day of the interview. Whilst ethical approval, and the author's own considerations for a robust study design, restricted the formal length of each interview to 45 minutes, on five occasions the family supporter and person with the early experience of dementia asked if the author wanted to stay 'for a cup of tea' after the formal interview had concluded. This provided an additional opportunity for incidental data collection which were recorded in the author's theoretical memo book. From the medical notes held at the memory clinic it was found that seven people in the sample had a diagnosis of mild Alzheimer's disease (age range 67-82), two had Vascular dementia (ages 74 and 78) and one had Frontal Lobe dementia (aged 73).

On arriving at the home of one interviewee (interview: 64), the person was clearly in a state of denial of her symptoms and the interview did not proceed. Following the

research design, this incident was immediately reported to senior staff of the memory clinic. The interviewee was then contacted with a telephone call from the memory clinic to the carer and person concerned to enquire if any additional help was required at this time. In this particular instance, this offer was welcomed but declined. Further, on all but one occasion, the family carer of each person with the early experience of dementia wanted to be present at some time during the interview, highlighting the protective nature of the caring act (Bowers, 1987) and the 'gatekeeper' role suggested earlier (Pollitt and Anderson, 1991). It was the analysis of these interview data that facilitated the emergence of a model of the early experience of dementia outlined in the next section.

5.5 A Focus on People with Dementia: Beginning the Research Process

The author undertook the first interview of this series (interview: 59) on the 22nd August, 1994. Following personal introductions, the carer asked if the author would like to be left alone with her husband for a few minutes whilst she went to make a cup of tea. The author thanked the carer for this invitation and went into the living room to sit close to the person with dementia. Immediately, the author noted that her husband appeared rather ill at ease and kept looking over the author's shoulder to see if his wife were returning. The author attempted to lower the perception of 'threat' posed by himself by engaging in 'non-threatening' conversation, maintaining eye contact and adopting an open body posture. However, it was clear that the person with dementia was constantly 'thought blocking' and expressing his anger over his inability to link more than a few words together. This was particularly frustrating for the person as he told the author he had been a headmaster at a local school in the area, reinforcing this information with aggressive hand-rubbing and gnashing of teeth.

The person with dementia was pleased when the carer returned to the room some ten minutes later and sat next to him on the sofa. The security brought about by her return appeared to give the person with dementia an added feeling of safety, and the author sensed that he was addressing 'a partnership' rather than a vulnerable person. Indeed, as the interview progressed, the carer began to take the initiative more and more, and the person with dementia appeared increasingly at ease. However, a few minutes into the interview, the person with dementia interrupted the conversation by catching the

author's eye and pointing to a picture on the wall. Reaching over and tugging at the author's sleeve, the person with dementia said:

Person: What do that?

Carer: What my husband is asking is 'what does that remind you of?'

The carer's ability to interpret her husband's half-formed question and her role in minimising the frustration felt by her husband in his inability to fully contextualise a question, was evident. It became clear that the person with dementia was now having real difficulty following the conversation and asked the author 'what we doing?', and then 'if he could go out'. Naturally, the author had no objection to this, and after a short time away, the carer returned alone saying that her husband was now happy 'pottering around in the garden'. However, the carer said that she would have to return to her husband soon, and that we could only spend a few more minutes together.

Näively, perhaps, the person's inability to take a full part in the interview had not been anticipated, as it was thought that the study design would help to 'screen out' people who were unable to provide consent to interview. In the few minutes alone with the carer, the time was spent discussing the carer's early progression through the stage of Working Through It. The carer appeared genuinely pleased to be able to share her experiences and to have someone to listen to her. In particular, she wanted to share her distress at the actions of their grand children (aged six and five) who, on each visit, would 'laugh' at her husband's inability to form sentences and to 'play properly' with them. The carer also spoke of her husband's diminishing social world in that he no longer answered the telephone because 'he couldn't trust himself to speak properly any more'. Moreover, the carer explained that her husband now studiously avoided anything to do with money or the upkeep of the home for fear of 'making things worse'.

Whilst sharing these experiences, the carer became tearful and, in attempting to 'carry on', gave an additional insight into the emotional experience of caregiving:

I don't want to make him feel he is being supervised. There's a very fine line, you know. That's what people don't understand, we are just happy together. I only hope that he doesn't change his personality too much. If he does, I suppose I will just have to accept it.

The interview then concluded as the carer made her way out to the garden to see her husband. After leaving the home of the person with the dementia and returning to his temporary base at the memory clinic, the author took time to reflect upon the interview, both in terms of its content and direction, and made the following entry in his theoretical memo book:

It appeared important, certainly in this opening interview, to involve the carer in the research design as it provided a security to the person with dementia that was not evident without her presence. Without an opportunity to be personally involved in subject recruitment perhaps I am being over ambitious about involving people with dementia in the research process; their voice is vitally important to capture, but I am running a fine line with issues of informed consent and ensuring their understanding of why I am at their home. I felt it was important to (formally) terminate this interview once the person with dementia began to show distress at my presence and uncertainty over the aims of the study. It was also noticeable (cross refer to interviews: 40, 43, 45 and 48) that the carer was tearful and taking the full weight of responsibility for the consequences of the dementia without access to support herself. The position of young children and their understanding of the experience of dementia also requires consideration - however, this may well be beyond the scope of this study. It also became easy to sideline the person with dementia (alarmingly so) during the course of the conversation as he was not able to converse fluently and (quite rightly) because of the time limited contact. Within the restrictions and boundaries of the present study design, I do not have the opportunity to further build trust between myself, the person with dementia and the carer. In future it is important that I remember the focus of each interview, and not to see this series as simply an extension of the carer's data.

(theoretical memo book entry: 22.8.1994)

However, during the second interview in this series (interview: 60), conducted the following day, the author spent thirty minutes alone with the person with dementia, and was able to converse more fully about her awareness and feelings. In this situation the diagnosis of Alzheimer's disease had been made some six month's previous and, as was the practice of the memory clinic, had been communicated only to the carer. However, on returning home the same afternoon as he received the diagnosis, the carer had immediately informed his wife that she had Alzheimer's disease and would need his support. During the first few minutes of meeting the couple, the carer explained in a matter-of-fact way that they had 'never had any secrets between them' and could see no reason for discontinuing this life-long practice. Moreover, as the person with dementia

herself maintained 'I knew something was wrong, and that it had been coming on for two years - I was thankful in a way that it had a name'.

During this frank interview the person with dementia recounted her early memories of the condition and how she had worked hard to hide her failing abilities from her husband. The formal diagnosis had paved the way for a more open discussion of their actual fears, and the couple could now cope with the situation discussing the use of humour to help make sense of their circumstances. The person with dementia also took a proactive approach to her condition, engaging in a number of tactics to help retain her mental capacities, especially the use of cognitively challenging activities such as completing crosswords and using lists to augment her memory. Moreover, it was obvious from this interview that they were a very close, loving couple, who had a positive view of the world and a comfort that comes with the knowledge that they had done the best for each other and their family during their years together. However, despite their close relationship, the person with dementia admitted that she still concealed the full extent of her memory loss from her husband as she 'didn't want to see him hurt any more'. This admission brought about a 'hurt' response from the carer as he wished to be part of the experience of memory loss, rather than excluded from it. This concealment gave the author his first real insight into the 'ownership' of dementia, with in this case the person still controlling the flow of information.

Returning to the author's work base a little later that afternoon, he set about transcribing the interview by hand and open coding the data, searching for conceptual links to shape the line of inquiry as the next interview in the series was to be conducted later that afternoon. As the transcription and analysis progressed, the author jotted down the following substantive areas for subsequent comparative analysis in his theoretical memo book (entry dated: 23.8.1994):

In future interviews compare and contrast the:

- Emerging sense of partnership in managing the early experience of dementia (evident in this and the previous interview);
- Hidden and secretive nature of dementia at its onset - this interviewee did not ascribe any real significance to the first noticed sign, normalising ('pressure of

work’) and then discounting (‘just the work getting me down’) the process. Their early appearance is strikingly similar to the carer’s initial decision-making/discounting process. If possible, test out the features of this model in future interviews with people with dementia;

- Finding that concealment activity (in this case of the memory loss) continued into the present, even in a relationship that was very loving and close. There could be an emerging struggle over ownership of dementia and control of events - how does this influence the perception of being cared-for?;
- Feeling that ‘we can manage best’ and that the partnership consciously ‘hid’ the dementia from professional services once they had agreed between themselves that ‘this is serious’. It is at this point where the subjective experience of dementia and the transition into caregiving appear to meet;
- Explore further the range of cognitive coping resources that are used to give the early experience of dementia a sense of meaning; these included: finding humour in the memory loss; feeling others are worse off than yourself; and feeling ‘pity’ for others in their failure to grasp the significance of what they were seeing. Search for other examples and document the context in which they are seen to occur;
- Range of problem-solving approaches, such as ‘writing lists’ and documenting important events ‘on a calendar’ to aid memory performance. Note that this activity is ‘out in the open’ and shared between the couple - links into the partnership approach used to manage the early experience of dementia. Explore other problem-solving approaches that may be concealed from the carer - either in the present or during the past. In this instance, the person with dementia’s ability to engage in crosswords appears to have a dual function, in that it served to both test the degree of memory loss and also to provide hope. In this interview hope was expressed in the belief that ‘things cannot get any worse’ if the person with dementia is able to complete tasks which *they believe they have the ability to perform* {original emphasis in memo book}. This prompts a question ‘what happens when the person no longer has this belief?’ As seen in the previous interview (interview: 59) the person with dementia consciously withdrew from situations he found stressful and relied on his wife to ‘keep their reality going’. This tilted the axis of the partnership and control towards the carer. Is this a common process? Return to the previous data set for comparison and test out this observation in future interviews;

- Information needs of people with dementia - this is an unexplored area of research and practice and one which was not considered whilst devising the original study aims.

The next interview (interview: 61) provided a stark contrast to that which occurred earlier in the day as rather than the close relationship that had been seen previously, there was a sense of considerable tension. It was apparent that the carer did not (or did not want to) understand his wife's efforts to manage her dementia and, instead, purposively tried to impose his own way of coping. The husband in this case recounted how he had always been a 'problem-solver', describing himself as a 'trouble-shooters trouble-shooter', and he tried to insist that his wife adopt a similar approach.

In order to avoid potential conflict the person with dementia would walk as much as possible, and get out of the house in order not to be under her husband's feet. She had a locket around her neck which had her name and address in it in case she got lost and had to make her own way home. As with the previous interview, the person with dementia kept things hidden from her husband, although the motivation was different. In the first case it was to protect her husband from potentially painful knowledge of her failing abilities, while in the latter it was so as not to provoke anger. These two interviews provided telling insights into the potentially diverse reasons for apparently similar behaviour, and that this was to emerge and develop as the interviews progressed.

Throughout the interviews the author continued to document the person with dementia's first encounter with the experience of dementia. This provided a variety of responses, as displayed in Table 4 on the next page.

Upon experiencing one, or a combination, of these phenomenon, the data revealed that no one in the sample associated their 'slips and lapses' with the onset of dementia. Concentration difficulties in particular were perceived as a nuisance, a problem, the effects of growing older: 'I thought it was to be expected' as one gentleman described it (interview: 68). Others believed that their feelings of depression, or anger, were

Table 4: The first ‘noticed’ signs of dementia: Subjective recollections

Head feeling fuzzy (interview: 59)
Memory loss (interview: 60)
Writing block (interview: 61)
Problem-solving difficulties (interview: 62)
Heightened sense of taste and smell (interview: 62)
Inability to quickly recall names (interview: 63)
Losing track of conversations (interviews: 63 and 67)
Thought block (interview: 64)
Tearfulness (interview: 65)
Becoming sad and depressed (interviews: 65 and 66)
Being unable to concentrate for prolonged periods (interview: 67)
Feeling unduly angry (interview: 67)
Feeling disassociated from reality (interview: 68)
Feeling and becoming lost in familiar surroundings (interview: 68)

Note: some people recalled more than one first encounter

extensions of life-long personality traits; a reaction to their retirement, or the retirement of their spouse. As such the decision-making model outlined previously in Figure 3 appeared relevant to the experience of dementia. Only when the signs continued, increased in severity or new ‘lapses’ occurred, did people with dementia begin to experience varying degrees of uncertainty, gradually suspecting that something quite serious was happening to them. However, as noted earlier, generally people kept their fears hidden:

At the beginning it was so dark. I couldn’t believe I was doing these things. I felt so stupid and didn’t want to share it with anyone else. I had trouble getting the right word out and forgetting people’s names. It was awful.

(interview: 67)

Therefore none of these early experiences were shared or openly communicated to others, and reaching a decision that 'this might be serious' was a secretive process whereby the person with dementia was constantly trying to 'test' their memory performance in the hope that it would return to 'normal'. The following exchange (interview: 66) helps to illustrate this feature:

Researcher: Could you tell me how you first managed your memory loss?

Person: I am, er, it's hard to say, I did go through various stages where I thought 'well, what do I do about so and so?' and 'what do I do about this?'

Researcher: Were you still working when this was happening?

Person: Er, yes, I think so. {carer nods his head in agreement} I was at the local council, but there again I was in a job and it took me a while to get things OK and I'd say to people 'I'd never used to do it that way'.

Researcher: And you were able to get by this way?

Person: Yes.

Researcher: When you were suffering these lapses, did you tell your husband?

Person: Er, ... {shakes her head}

Researcher: If you didn't share it, how were you explaining things to yourself?

Person: I was very frightened. I wasn't sure what was happening to me. I felt very alone.

Researcher: So how did your husband find out?

Person: We had a big argument about it and he went to get help. I didn't want him to.

Researcher: So how long ago was this?

Carer: In January this year.

For this interviewee, therefore, she had been able to manage the onset of (undiagnosed) dementia for some three years before her husband engaged in a strategy of confrontative confirmation, described earlier in the carer's model. As the interview progressed, the person with dementia stated that once she had accepted (to herself) that the memory impairment was 'permanent', she engaged in strategies to help minimise its impact on her life and minimise the fear of getting 'found out' by her husband and work colleagues. As the person with dementia explained, this was achieved in a number of ways, including:

- Keeping fears and feelings secret;
- Secretly using lists and other memory aids - lists were stored in her handbag and included the names and addresses of important people in her life (including their children), and their dates of birth; and
- Constantly repeating things to herself to help her remember.

It was clear that she had worked very hard to maintain a veneer of normality, having accepted that 'things were not going to return to normal'. This acceptance formed a critical juncture in the life of the person with dementia as the function of the compensatory coping strategies had subtly shifted from one of 'testing out' the level of loss, to another level whereby they were used to actively 'cover up' its existence.

After completing this interview (66), a picture was beginning to emerge of the subjective experience of dementia. The time dimension seen in the carers model was evident for the person in coming to terms with the onset of 'dementia' (although it was not understood in this way). The cognitive decision-making processes at this time appeared very similar to those emerging from the carer's model (Figure 3 p.121) in that people with dementia would also normalise the symbolic nature of the encounter (i.e. memory loss, for instance), recast it (think about it) and then discount its significance by attaching a rational explanation for its occurrence (i.e. 'pressure of work'/'effect of

retirement'). However, as with the carer's decision-making model, the encounter was also monitored at an intuitive level as its entry into their social world was seen as an unusual occurrence and, potentially, something to be worried about. For the person with dementia, the critical juncture that turned a belief that 'this is OK' to one of 'this might be serious' was, first and foremost, time, the continuation of the encounter, its accumulation and/or the introduction of new encounters.

As the interviews progressed, the author was able to test out this observation on the next interview in the study (interview: 67). During this interview, the person also revealed that the onset of their dementia was concealed from the person closest to them, and that this was maintained until they felt they were losing control. As such, people with dementia spent this time confirming (to themselves) the seriousness of the situation, and then engaged in strategies to help minimise its impact on their life. At this juncture, the author wrote his impressions over the direction of the research process in his theoretical memo book, as the following record reveals:

Having completed eight interviews, what is beginning to emerge is that people with dementia go through a process of 'closing down' before being able to face the reality of what they are seeing. The main purpose of 'closing down' appears to be to confirm the seriousness of what is happening to them. From the experiences gathered to date, this process of 'closing down' can last for some time until an acknowledgement is made (to the self) that things are not going to return to normal. People with dementia then engage in strategies to minimise the impact of the encounter(s) upon their lives and that of others close to them. This aim to '*keep it hidden*' {original emphasis} also extended to employers when people with dementia found themselves in this environment (interviews: 60 and 66). This is a critical point in the lives of people with (undiagnosed) dementia as they have acknowledged the seriousness of what is happening to them and are now engaging in strategies to 'keep it hidden' from others. How long this concealment activity can continue is dependent upon a number of factors, such as: their skills in covering their tracks; the suspicion their behaviour/actions engender in others; and their mental desire to keep the uncertain behaviour to themselves. Hence, the meaning of their action has now changed to a more purposeful activity based on a strategy of concealment. It is vitally important to reflect this process in any exploratory model, and give due regard to the enormous mental effort that such activity takes for the person with (undiagnosed) dementia.

(theoretical memo book entry: 16.11.1994)

From this theoretical memo book entry, the author extrapolated the words 'Closing Down' to describe the strategy engaged by carers in their transition to dementia. From

the author's theoretical sensitivity to the data, and as intimated in the above theoretical memo book entry, the author considered that 'Keeping it Hidden' was more descriptive of an overarching process, possibly forming a stage, to explain the journey from the first subtle encounter with the experience of dementia to a decision to 'open up' the uncertain behaviour/action to others. As seen in this series of interviews, and from the carer's data, this occurs out of choice, confrontation or from the covert action of the carer who is becoming suspicious of what they are seeing.

In the final interview of this series (interview: 68), the author turned his attention to the properties of process that formed the opening strategy of Closing Down, and also searched through the data to begin to support its functioning. The results of this exercise are outlined below.

5.6 'Closing Down': A Strategy to Manage the Early Experience of Dementia

As the slices of data were retrieved from the existing set (interviews: 59-67), and compared to existing data collection (interview: 68), it became evident that Closing Down was, itself, a protracted process that could go on for many months. The properties involved in Closing Down were the result of the person with (undiagnosed) dementia trying to explain away - to themselves - the impact of the encounters displayed earlier in Table 4 (p.194). Thus in interpreting the early experience of dementia, it would appear that the original Slipping, Suspecting and Covering Up themes (Keady and Nolan, 1994b) had empirical validity, but only accounted superficially for the role and life transitions experienced by people with dementia. Indeed, it was the frequency, duration, and concern posed by the encounters that become the marker to employing the strategy of Closing Down.

As the data were constantly compared, the strategy of Closing Down was employed by each person in the study, for two main reasons; it allowed the person with undiagnosed dementia:

- Time to adjust to their new found reality; and
- Space to re-frame existing events.

In effect Closing Down was identified as a self protective strategy aimed at maintaining the person's integrity and sense of 'who they are'. From the data the strategy of Closing Down was an intensely private experience, and when people with dementia spoke retrospectively of using it, it was expressed via feelings of fear, anxiety, bewilderment, puzzlement, uncertainty and loss. Moreover, in sharing this strategy the body language of people with dementia also altered significantly and there was a great deal of comfort rubbing and clenching of fists/rubbing of hands. Eye contact also diminished rapidly giving life to the described feelings of fear and anxiety. Again the act of Closing Down was not shared, even in relationships which were obviously very loving and close (interview: 60, for instance), as articulated in the following coping strategies:

- Keeping my real fears and feelings secret (interview: 66);
- Withdrawing from conversations (interview: 65);
- Remaining in familiar surroundings (interview: 60);
- Constantly repeating things to myself to aid memory and recall (interview: 66);
- Keeping as active as possible by concentrating on familiar tasks (interviews: 61 and 67);
- Engaging in mentally challenging activities such as puzzles and crosswords (interviews: 60 and 67);
- Trying to avoid new situations as far as possible (interviews: 60, 65 and 68);
- Relying on myself to find answers to the problems (interviews: 66 and 68);
- Taking things one day at a time (interviews: 60, 62, 64, 67 and 68).

With the intensely private and secretive nature of these coping strategies, it is little wonder that people with (undiagnosed) dementia experienced depression and a lowering of mood. The awareness and secrecy of these behaviours, coupled with a rapidly shrinking social world, without an explanation of why it was happening, was a shattering blow to the individual. Moreover, the impact of employing restrictive coping strategies was magnified enormously as they led to sources of conflict within a relationship, with spouses/their adult children being confronted with 'new' behaviours which made little, if any, sense. These 'new' behaviours included their partner: suddenly starting to keep quiet during conversations; not following favourite television programmes; not wanting to go out of the home; restricting any driving activities to the local area; becoming argumentative for no obvious reason, and so on. These conflicts

often led the carer to expressions of guilt and self-directed anger later in the caregiving trajectory once the full impact of dementia was apparent.

The transition into Closing Down also began a voyage of self-discovery in which strands of the individual's personality were being lost and mourned by the person themselves; indeed, the author would argue that it is a process of saying 'good-bye' to parts of the self, and everyday functioning, that had previously been taken for granted. It is tempting to align this phenomenon to the bargaining stage of Kübler-Ross' (1970) five stage model of death and dying, but people in this sample were not dying in the accepted meaning of the word. Their philosophical bargaining with loss was more of a functional mechanism which allowed the person time to draw on other compensatory coping behaviours, rationalise their meaning and 'construct a new me' from within a shifting reality.

This exchange in the last interview in the series (interview: 68) attempts to illustrate this evolving process of loss and adaptation:

Person: ... I get muddled now. I get a bit better as the day goes on.

Researcher: Do you ever think of the time when you were not so muddled?

Person: Sometimes I do, yes. I used to think more about it at the beginning when I was trying to work out what was wrong with me.

Researcher: At this time, what sort of things were you trying to work out?

Person: Well, it was the simple things really. I couldn't remember where the shopping went in the cupboards so I said something to {my wife} and would let her do it. She used to get angry with me about that. I also got scared driving as I couldn't work out the way to the shops, so I told her my eyesight wasn't good and I stopped.

Carer: {to researcher} That's true. I used to think he was doing it on purpose. I never stopped at the beginning to think that something was wrong with

him. I just thought he was trying to annoy me all the time, and that he had lost his confidence.

Person: But I know what it is now, she {referring to his wife} told me. What's the name of it again? Begins with 'v'.

Carer: Vascular dementia.

Person: That's it. I've got Vascular dementia. Terrible name, isn't it? I don't worry too much about it, as long as I get by. One day at a time.

The dialogue reveals a personal acceptance of the impact of dementia, its process of rationalisation and the fact that the person has seemingly come to terms with its impact upon his life. Moreover, it was noticeable that people with (undiagnosed) dementia would look to take one day at a time and not look to plan too far in advance.

Within the strategy of Closing Down it is the eventual acceptance that 'things are not going to return to normal' that triggers the next strategy. In a theoretical memo book entry dated 17th November, 1994 the author named this strategy 'Regrouping'. As a strategy Regrouping best summarises the person's acceptance that things were not going to return to normal and through comparison of the data the author attached the following properties to its formation.

5.7 'Regrouping': The Next Steps in Keeping it Hidden

Regrouping is a time limited strategy aimed at providing the person with the confidence and resilience to 'keep going'. Regrouping involves an acceptance of the purpose of Closing Down and that the shifting reality cannot be returned to normal. In order to regroup people with dementia drew upon a diverse set of coping behaviours, including self-belief, and whilst it was not verbalised at the time, drew comfort from the familiarity of their surroundings and the support received from family and friends. From one set of field notes made at this time, this process was described as 'reciprocity without visible exchange' (theoretical memo book entry: 15.11.1994), but the exchange was evident in the compensatory feelings of comfort that familiar surroundings and

people bring. Moreover, in supporting the strategy of Regrouping, people with dementia stated that they talked to themselves a great deal, in effect giving themselves confidence to prepare for their future, whatever this may hold, as the following exchange illustrates (interview: 67):

Researcher: When you had come to terms with your memory loss, how did you start to adapt to it?

Person: I told myself I had to carry on.

Researcher: When you say 'you told yourself', does that mean you talked to yourself?

Person: Yes.

Researcher: What sort of things did you say?

Person: I told myself I had to keep going and that I couldn't let myself down.

The function and meaning of engaging in self-dialogue was an interesting feature and the author termed this process 'tacit collusion' i.e. colluding with yourself to maintain a veneer of normality (Keady and Nolan, 1995a). Through tacit collusion people with the early experience of dementia drew the inner strength to enter a more proactive, yet stoically secretive strategy, one that defines how long the person with (undiagnosed) dementia could, or wanted to, live out their condition without being found out.

Through the constant comparative analysis of the data, the following coping strategies were identified as being useful in controlling the progression of (undiagnosed) dementia:

- Taking things one day at a time (interviews: 60, 62, 64, 65, 67 and 68);
- Keeping any further memory loss to myself for as long as possible (interviews: 60, 66 and 67);
- Engaging in mentally challenging activities such as puzzles and crossword (interviews: 60 and 67);

- Using lists and other memory aids (interviews: 60, 66 and 68);
- Constantly repeating things to myself to help me remember (interviews: 63, 65 and 66);
- Keeping my real fears and feelings secret (interviews: 63 and 66);
- Trying to keep calm and relaxed at all times (interview: 65);
- Making up stories to fill in the gaps (interview: 66);
- Fighting the memory loss and trying not to let it get the better of me (interview: 68).

There is some overlap in the range of coping strategies above with those in Closing Down, such as engaging in mentally challenging activities (interviews: 60 and 67), but it is the meaning and purpose of the strategy that has altered. For instance, 'engaging in mentally challenging activities' was first used in Closing Down as a 'self administered test' for determining the extent of memory failure. However, by the time it was used within the next strategy, its purpose was now either to 'hold' the degree of cognitive loss or, in some instances, to actively challenge it.

Thus the next strategy required adaptive and imaginative coping patterns, this included writing down significant matters of concern such as: important birthdays, ages of (your) children, date of (your) anniversary, directions to the local shop, where important keys are kept and what they are for, a pictorial representation of the value of money and so on. These lists were usually secreted in places of as near absolute safety as possible where their chances of discovery were minimal; although, even in this scenario, there was an associated fear that their discovery could reveal the depths of an individuals' loss and perceived sense of failing. Interestingly, in carrying out this adaptive coping strategy, there were gender differences in places of concealment. For men a common hiding place for the lists was usually outside the house in places such as the garden shed or inside the car, whilst for women inside a handbag or inside clothes hanging in a wardrobe were frequently cited as 'secret places'. However, the purpose of the list was to perpetuate the veneer of normality and to preserve feelings of self-worth, identity and control.

Whilst considering the meaning of this activity and consulting his theoretical memo fund, the author was struck by the mental energy that was required to maintain this level of concealment. Searching for a descriptive term that would summarise this experience,

the author returned to a theoretical memo written on the 16th November, 1994 when he had noted the person with (undiagnosed) dementia's 'skills at covering their tracks'. Changing the words slightly, 'Covering your Tracks' captured the essence of this action, and the author therefore used this heading to describe this experience; it also became the third strategy attached to this stage of concealment, one that the author had named Keeping it Hidden (theoretical memo book entry: 16.11.1994).

As suggested, the physical and emotional energy invested in Covering your Tracks should not be underestimated, and could extend over a period stretching from months to years. Moreover, in some families, sources of conflict gradually diminished as the new behaviours began to be questioned less and less and became assimilated into daily living routines - it was 'Dad being difficult again' (interview: 62), or as one family carer stated:

After a while I began to think what he {her husband} was doing wasn't a problem. He wasn't doing any harm, you know. I got frustrated at first not being able to go out as often as I would have liked, to get the shopping mainly, but I just thought he had gone off the idea of driving. That's what he told me anyway, and there are worse things in this life than not going out in the car, don't you think? I picked up some old interests of mine and life just went on.

(interview: 68)

How long Covering your Tracks could be tolerated, and its surface meaning interpreted by others, was the hinge upon which the success and longevity of the strategy turned. Carers unwittingly began to collude with the stories and behaviours of their partner, thus twisting their meaning and making a seemingly abnormal situation 'normal' again.

Eventually, however, Covering your Tracks became an increasingly fraught and difficult process to manage. In time people with dementia started to react to events and not to shape them, with others eventually beginning to notice the 'slips and lapses' and note their frequency. For the individual with dementia, long held coping mechanisms aimed at concealment also began to break down and their cognitive skills were not sufficient to successfully re-shape them. At this point Covering your Tracks began to shade into a new phase of experiencing dementia, as this quotation from a 71 year old gentleman with Alzheimer's disease illustrates:

You see I couldn't carry on pretending anymore. I knew others knew, you could tell it in their eyes - they were watching me more, asking me questions, things I should have known but didn't. In the end I wanted them to know. It's a relief now.

(interview: 62)

Theoretically, this desire to 'open up' marked an end to the three strategies of Closing Down; Regrouping and Covering your Tracks. The critical juncture attached to Keeping it Hidden commenced at the point of the first encounter with the experience of dementia (as illustrated in Table 4) and ended once the person with undiagnosed dementia 'opened up' and sought confirmation of the cause of their concealment activity, or they were confronted with their behaviour by the carer. In reality, it becomes linked to the Taking it On strategy seen in the carer's model and the provision of a diagnosis.

From the interview data (interviews: 59-68) this opening up of the experience of (undiagnosed) dementia brought about a variety of responses, and similar to the experiences gathered from family carers of people with dementia, no person in this study sought an independent explanation of their changing cognitive and emotional behaviour direct from their GP, or other member of the primary health care team. Steps to the diagnosis were either taken by the carer (x 3), or jointly by the family member and the person with (undiagnosed) dementia (x 7).

No matter how this stage was reached, for all the individuals concerned this period of confronting their new found reality was a cathartic experience. For instance, on two occasions during the interviews when initially approached by the person with dementia, the carer denied firmly the existence of the exhibited signs and symptoms, suggesting instead that 'things would get better' (interview: 63), or that the behaviour was simply 'due to their retirement' (interview: 66). This denial placed enormous additional pressure on the person with (undiagnosed) dementia and often resulted in feelings of self-doubt and depression. Indeed, as seen in the carer's data, on the majority of occasions, how this process of informal confirmation was handled between the partners had a significant impact upon the future direction of care and the mutual seeking of a diagnosis. Obviously, in this part of the study, people with dementia and their carers were, on the whole, more willing to openly discuss and share their thoughts, feelings and experiences. As suggested in the carer's model this 'open disclosure' between partners may not be representative and this is a phenomenon where additional research

inquiry is necessary. However, from this study, a mutual acceptance of the existence of loss and adaptation moved the coping behaviours into a different domain, and people with dementia were able to feel a weight taken off their shoulders, as the following experience suggests:

I know I have Alzheimer's disease, but what can anyone do about it? I do silly things now but we just try and laugh about it. We have a saying 'pick up the pieces and start again'. It's the only way we manage.

(interview: 67)

Reaching this level of acceptance and intimation of 'partnership' led the author to consider the next stage of the subjective experience of dementia, and set this out in the following (brief) theoretical memo book entry on the 18th November, 1994:

People with dementia now embarked upon a stage of 'Sharing the Load' where they may form a 'partnership' with carers to jointly negotiate a path through dementia. This path includes efforts to take one day at a time and to implement routines to manage their day-to-day life together.

(theoretical memo book entry: 18.11.1994)

At the beginning the forming of 'partnerships' allowed people with dementia to 'share the load' via thoughts and actions of:

- Relying on the support of the person closest to me (interviews: 59, 60, 62 and 66);
- Being thankful for the close support of family and others around me (interviews: 60, 64, 66 and 68);
- Talking over my memory loss with people I trust (interviews: 63 and 67);
- Trying to keep calm and relaxed at all times (interviews: 65 and 68).

Alternatively, in the interview where support was more difficult to ascertain (interview: 61), a culture of blame and animosity pervaded the relationship and the person with dementia felt isolated within the caring relationship; as such, it proved much more difficult to Share the Load in any meaningful sense as both the carer and person with dementia were trapped in their experience.

However, during the stage of Sharing the Load, it would be a mistake to believe that cognitive and behavioural concealment activities just vanished. They didn't. Perhaps the most moving experience encountered during the entire set of interviews was when people with dementia admitted to their carer, at times to their utter astonishment (interviews: 60 and 67, for instance), that they were continuing to conceal further memory loss from them. As it emerged the purpose of this concealment activity was to protect the carer from evidence of further loss, thus covertly maintaining the strategy of Covering your Tracks, only this time its purpose was to retain control of their situation and protect the carer from the experience of loss.

For those who had moved to this point there was also a general feeling of satisfaction that no-one else knew, or had suspected, their earlier attempts at Keeping it Hidden, in particular the deployment of the strategy of Covering your Tracks; a reaction which the author had not anticipated. In all likelihood this points towards people with dementia developing a sense of mastery over their situation, a mastery which is grounded in an intimate knowledge of adapting to cumulative and consistent losses. Within this experience lies an untapped pool of knowledge and, the author would suggest, what is needed to reveal its properties is a professional mechanism and partnership able to dip into this reservoir of experience and use this knowledge as a means of building upon past coping patterns to shape future events.

Within Sharing the Load this professional partnership also extends to the task of sharing the diagnosis. This is a nettle which must be grasped, and 'sharing the load' is a responsibility that professional services also must bear. From the study data, and bearing in mind the practice of the memory clinic only to disclose the diagnosis to the supporter, some relatives believed that informing the person with dementia of their diagnosis was their duty, and they preferred to do this at a time, and in a place, which suited them (interviews: 60, 65 and 66).

For carers in this study provision of the diagnosis helped to place events, both retrospective and present, in context. For people with dementia this process appeared to follow the same course. Despite the best efforts of service providers to deny them the knowledge, armed with information about their diagnosis people with dementia no longer appeared frustrated when they forgot simple points, or dropped something which

could, otherwise, be construed as being clumsy. They could explain it to their family and friends, and most importantly, to themselves. Providing the diagnosis also helped people with dementia to make sense of their evolving behaviours, actions and feelings.

In the author's opinion, the majority of people interviewed in the second phase of the study had been ready to hear the truth, having worked through earlier feelings of shock and distress via the strategies identified in the stage of Keeping it Hidden. The diagnosis was, at times, a relief and a confirmation that 'they were not going mad' (interview: 66). On this same issue another woman in the study said 'well, it's there now and we can't change that, so I just have to make the best of it' (interview: 67). Sharing the Load was not an admission of defeat, but rather an acknowledgement that relationships and the meaning of illness could be restructured and rediscovered.

5.8 Theorising from the Data: Developing Temporal Dimensions and a Linking Scheme

On the 18th January, 1995 whilst discussing the data analysis with his supervisor, the author was describing the properties of process that formed the stages Keeping it Hidden and Sharing the Load. Whilst finding that each of these stages and supporting strategies had the 'fit and grab' that was necessary in the generation of substantive grounded theory, the author was looking to transcend the data to conceptualise a linking scheme. This was undertaken much along the lines of Glaser and Strauss (1965) and their generation of an 'awareness context' to conceptually link the experience of dying in hospital. Whilst using the author's theoretical sensitivity to the data to discuss the subjective experience of dementia, the author hit upon the idea that what we were really seeing were people continually attempting to 'maintain involvement' in their lives, in the variety of meanings that this wording suggests. During the supervision session, the concept of 'maintaining involvement' was written on the white board above the previously identified stages and strategies. Immediately, a link became apparent, in that people with dementia were attempting to 'maintain involvement' at a variety of levels. For instance, during their initial encounter with the signs of dementia (see: Table 4 p.194) people with (undiagnosed) dementia were attempting to maintain involvement in their day-to-day life by discounting the significance of the encounter. This process of 'maintaining involvement' then progressed and shifted in its meaning along the time

dimensions attached to the stages of Keeping it Hidden and Sharing the Load. Therefore, conceptually speaking, people with the early experience of dementia would implement coping strategies, such as taking things one day at a time, or keeping their real fears and feelings secret, in order to 'maintain involvement' in their shifting reality.

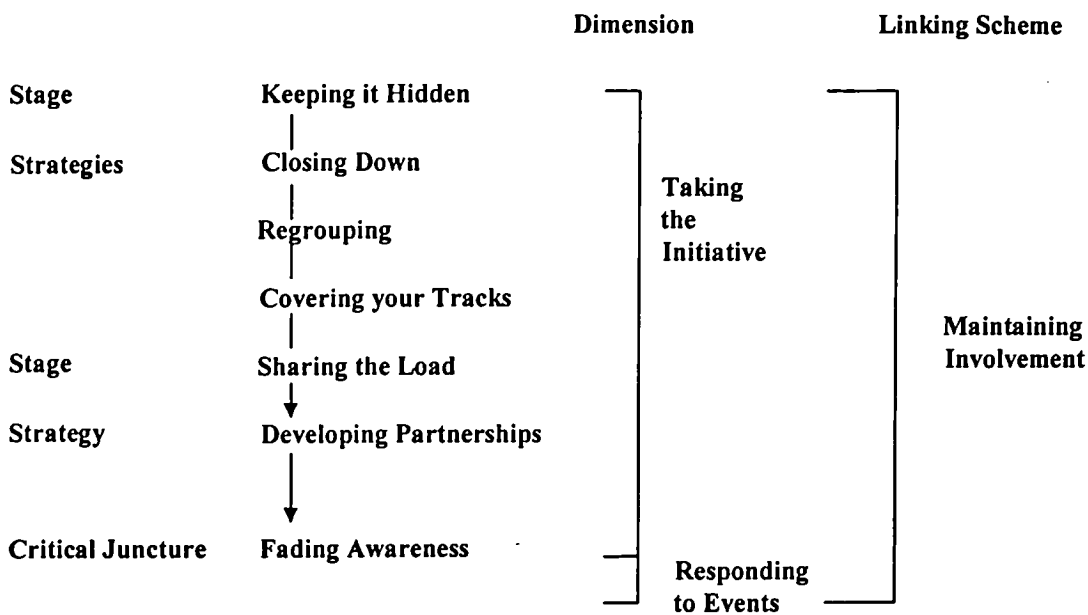
As this idea was pursued, it also became clear that both Keeping it Hidden and Sharing the Load were dynamic stages in living with the experience of dementia and far removed from the 'surviving' concept, initially described by the author, to explain the subjective experience of living through dementia (Keady and Nolan, 1994b). As such both Keeping it Hidden and Sharing the Load, whilst seemingly accurate in their descriptive functioning, could still, because of their naming, be seen as being passive stages in describing a person's adjustment to the onset of dementia. Such an outcome did not do justice to the lives and experiences of the people in this part of the study.

As the author continued to discuss this dilemma within the supervision session, theoretical sensitivity to the data suggested that at the time of working through these stages, people with the early experience of dementia were, in fact, 'Taking the Initiative' during the onset, progression and adjustment to their dementia. Only when people with dementia were no longer able to 'take the initiative' did they begin 'Responding to Events', and this was marked by reaching a (heuristic) critical juncture of Fading Awareness; this will be returned to again in chapter 6. Responding to Events was seen in the first interview of this series (interview: 59) when the person had passed through the activity described in the stage of Keeping it Hidden. Here, whilst the person with dementia was still attempting to respond to his environment and social cues, it was achieved through a withdrawal from situations so that his dementia could be 'controlled' within the familiarity and security of his home and his wife. Thus the act of Responding to Events represented a further dimension in the process of adjustment brought about by the on-going progression of dementia

In terms of developing theory as process following the modified grounded theory approach, the identified headings of Taking the Initiative and Responding to Events became dimensions which integrated the stages of Keeping it Hidden and Sharing the Load, together with their supporting strategies. Thus, as Figure 10 (next page) reveals,

theoretically at least, the early experience of dementia could be explained in the following way:

Figure 10: A theoretical integration of the early experience of dementia



Theoretical memo book entry: 18.1.1995

With the discovery of the linking scheme, dimensions, stages and strategies, it became important to test their validity with a person with dementia and their carer to see if the author's analysis of their experience made sense. The author decided to return to the person with dementia interviewed early on in the second phase of the study (interview: 60) as she appeared, on this first visit, to have accepted her dementia and was willing to discuss its impact on her life. Indeed, after the author had returned to North Wales shortly after this first visit, the person with dementia had sent the author a 'Thank you' letter for conducting the interview, and expressed a desire to help the author in any way 'should a need arise in the future' (personal communication). The author decided to take advantage of this offer and wrote to the person with dementia and their carer on the 4th February, 1995. A second interview date was agreed for later in the month, and the author prepared to return to the locality of the memory clinic to conduct the interview, but with the expressed intention of sharing and testing the results of the on-going process of theory development.

Whilst planning this interview, the author was mindful of the limitations placed on him by the Ethics Committee and that the formal contact with the person with dementia was to last no longer than forty-five minutes. Moreover, this time limit may, in itself, have been a little ambitious as the first interview was discontinued after thirty minutes as the person with dementia became tired and began to repeat the gist of the conversation. Therefore, to make the most of the time available, the author decided to send a short record of the findings to the person with dementia and the carer in advance of the meeting, together with a note that any clarification in the findings could be discussed during the interview. It was hoped that by providing the findings in advance, both the person with dementia and the carer could consider their scope and relevance.

On arriving at the home of the person with dementia and the carer at the agreed time on the 24th February, 1995 the author spent a little over thirty minutes talking to the person with dementia, and their carer, about the findings of the study. As the following exchange reveals, the identified linking scheme, dimensions, stages and strategies made sense, and the person with dementia herself was particularly pleased with the finding of 'maintaining involvement':

Researcher: Thank you for having me back. I'm really pleased to be here. Did you receive my letter all right?

Person: Oh yes, it arrived a while ago. {to husband} We enjoyed reading it, didn't we?

Carer: Very good, yes.

Researcher: {to person with dementia} Could you recognise yourself in it?

Person: Yes, very much so. I wouldn't have put it that way, mind you, but I certainly agreed with the covered one, what did you say again?

Researcher: Covering your tracks.

Person: Yes, I certainly did that. I didn't want him to find out you see. Once it was out in the open, mind you, we faced it together.

Researcher: So you felt you were sharing the load of your dementia?

Person: Yes. I don't know how I would manage without him. {laughs}

Carer: I often say that I am her brain and she keeps me on the straight and narrow. That's how we get on day-by-day.

Researcher: {to person with dementia} And what do you think of maintaining involvement - does that mean anything to you?

Person: Oh yes, marvellous. I try all the time to do that. All the time. We still go out you see, so we do a lot of what we did before only we do it different.

Researcher: So you could say you were trying to maintain involvement in all aspects of your life.

Person: Yes.

Carer: {to researcher} Yes, I liked that too. I think it explains a lot to me. Ever since we got your letter I have been thinking about it and it's true. I am trying to maintain involvement in my wife's memory loss and we are trying to do that together. I liked that bit of it.

Researcher: You told me on my last visit that you coped with your memory loss by always putting things in the same place. Are you still doing this?

Person: Yes, I was always taught that there was a place for everything and everything in its place. {person with the early experience of dementia and carer both laugh}.

Researcher: Is this the best way you have found to maintain involvement with your dementia and organise your life?

Person: Oh yes, it's much simpler if I do things this way.

Carer I agree. I had to take over so many things, like the money. She hasn't got a clue. Money was disappearing and there was no accounting for it.

As the interview progressed, the person with dementia eventually returned to the stories that came about earlier in the interview. For the author it was enough that the concepts made sense to both the person with dementia and the carer, a reflection that the author recorded in a theoretical memo book entry written immediately after the conclusion to the interview:

Whilst the dimensions, stages and strategies were recognised by the person with dementia, the linking scheme of maintaining involvement was also recognisable to the carer in this situation. This may form the final direction to the study as the carer (interview: 60) could also identify with the concept, and this was something that I had not really considered. It may be that maintaining involvement can be applied to the dynamics of dementia across the data set and this will need testing out. This may result in an additional set of carer-centred interviews to gain this level of understanding and agreement to its meaning.

(theoretical memo book entry: 24.2.1995)

The theoretical and practical relevance of 'maintaining involvement' to explain the experienced transitions was an exciting discovery that required additional empirical investigation. The results of this exercise will be reported in the next chapter, together with a theoretical integration of the models that emerged from this study.

5.9 Summary

This chapter began with a review of the literature on the early experience of dementia, highlighting the limited research and policy attention that has been paid to this area. The need to better understand the subjective experience of dementia was then raised in two moving texts, both written by people in the early stage of Alzheimer's disease. The social research agenda had just started to explore this subjective experience, and Cotrell and Schulz (1993) provided a cogent, and persuasive, set of arguments as to why they

should continue. The chapter then explored the study design that comprised the second phase of the study, drawing lessons from the limited literature available, particularly the importance of informed consent and flexible interviewing style. Subsequently the operationalisation of the study was discussed. This comprised 11 interviews with 10 people with the early experience of dementia and their family carers, using the modified grounded theory methodology with its constant comparative method. Two stages emerged from the data that help explain the person's transition through the experience of dementia, these being Keeping it Hidden and Sharing the Load. Keeping it Hidden was seen to have three supporting strategies. However, both Keeping it Hidden and Sharing the Load were inter-dependent and were seen to function under the dimensions Taking the Initiative and Responding to Events. Finally the discovery of the properties of the linking scheme of maintaining involvement was introduced, and its theoretical and practical relevance to the lives of people with dementia and their family carers briefly considered.

CHAPTER SIX

A THEORETICAL INTEGRATION OF THE DEVELOPED MODELS – PHASE 3

**The credibility of the theory should be won by its integration
(Glaser, 1978 p.134)**

6.1 Introduction

As discussed in chapter 3, grounded theory aims to produce theories of ‘fit and grab’, driven by properties of process, that make sense to the lay person. So far, the author has outlined the properties of process attached to the models of the dementia experience generated, separately, from the perspectives of the carer and the person with the early experience of dementia. This chapter aims to add a further conceptual layer to this process by theoretically integrating the models at different phases in their trajectory adopting the linking scheme, dimensions, stages, strategies and tactics as already outlined. This process results in some realignment of these properties, together with the addition of new critical junctures and sequencing. Importantly, in improving understanding of the shared experience of dementia, the integration of the models resulted in the identification of three basic social processes, namely: Working Apart; Working Together; and Working Alone.

This integration will utilise three case vignettes each representing, diagrammatically, different journeys through the trajectory of dementia. The first is drawn from interview: 53 and focuses upon a situation where a person with (undiagnosed) dementia openly shared their concerns with their carer. Subsequent processes will then be tracked through to the time of the person’s death, with the carer ‘maintaining involvement’ with Alzheimer’s disease via the local Alzheimer’s Disease Society network of support services. This case vignette will also (theoretically) ‘map out’ the person with

dementia's transition through the critical junctures of the early experience of dementia (see: chapter 5 and interviews: 59-68).

The next case vignette (interview: 50) represents the most common experience in the data, and relates to circumstances in which the diagnosis was sought independently by the carer from the carer's GP without the knowledge, or consent, of the person with (undiagnosed) dementia. The delays experienced in this process are illustrated and the differences in trajectory as compared to the first vignette are noted. The natural history of the experience of dementia will be traced up until the time of admission to care.

The final case vignette is taken from interview: 12 where a diagnosis of dementia was made early in its trajectory, but the carer was already expressing feelings of being 'trapped' in the role and finding little, if any, satisfaction. Primarily, these data will be used to illustrate the basic social process of Working Alone and to demonstrate the importance of the previous relationship (expressed through Building on the Past) in determining the experience of caring for a person with dementia.

Before the integration process is described more fully, a brief review of the final six interviews conducted by the author between June 1995 and July 1996 (interviews: 69-74) is presented. These interviews comprised phase 3 of the study and were undertaken to theoretically sample and empirically test the properties of the linking scheme of 'maintaining involvement' with family carers of people with dementia. These interviews were undertaken by the author in liaison with Consultant B and conducted in mid-Wales. They were considered important for, as Glaser (1978) himself argued, conducting grounded theory research requires the analyst to go back to the field 'for data *for and by* {original emphasis} conceptual elaboration' (p.41). It is therefore to a consideration of the evolving development of 'maintaining involvement' that the chapter will now turn.

6.2 'Maintaining Involvement': Applying the Linking Scheme to Carers

In its original conceptualisation 'maintaining involvement' was seen as a linking scheme between the dimensions of Taking the Initiative and Responding to Events in the model relating to the early experience of dementia (see: Figure 10 p.210), whereby

the person with the early experience of dementia was constantly trying to ‘maintain involvement’ in his/her changing social reality in order to preserve a sense of self and personal identity. This action was initially undertaken covertly. After briefly exploring the relevance of ‘maintaining involvement’ with a person with dementia and their carer (interview: 60 - second interview), it emerged that ‘maintaining involvement’ had potential for wider applicability. Indeed, as both the carer and person with dementia suggested (interview: 60 - second interview), efforts to ‘maintain involvement’ were relevant to them both and manifest in a number of ways, including their:

- Approach to looking out for one another;
- Interaction with the dementia itself;
- Relationship(s) with the community; and
- Interactions with other members of the family.

This prompted the author to return to his theoretical memo fund and transcripts, where ‘maintaining involvement’ could be seen to exist in a variety of forms in each of the stories being told, helping to illuminate the changing perspectives and dynamics of dementia. For instance, ‘maintaining involvement’ could be discerned in the first words committed to audio-tape at the beginning of the study, as noted in chapter 4:

Alzheimer’s disease you say? I’ve never heard of that. I just look after my husband you see.

(interview: 1)

In first considering the meaning of these words, they were seen by the author as suggesting:

- An uncertainty over the (clinical) meaning of Alzheimer’s disease;
- A lack of medical understanding on her husband’s condition; and
- The carer’s ‘hands-on’ approach to caregiving.

However, they may also be taken as examples of the carer attempting to ‘maintain involvement’ with her husband. As the author sought further indicators of ‘maintaining involvement’, it was seen potentially to shift in time, purpose and meaning, and to underpin adjustment and coping behaviours.

It seemed possible therefore that the desire to 'maintain involvement' could be applied at a number of levels and might provide both a motivation for, and the purpose of, caregiving. This appeared to be initially linked with the quality of the previous relationship and the carer's biographical knowledge of the person with dementia. Therefore, at one level, 'maintaining involvement' is about the desire to continue a previous relationship despite the fact that the nature of the relationship was changing. This provides one of the motivations for caregiving. Importantly, however, it is not only about the continuation of the relationship but, in the best caregiving circumstances, it is about the work needed to keep the person with dementia actively engaged, to maintain their involvement as a 'person' for as long as possible. This is initially an active part of the caregiving process and when this is no longer possible, in an objective sense, it is about maintaining the person's perception of self-identity, as for instance in the case of the husband noted earlier in chapter 4 (interview: 11 pp.143-144) who surrounded his wife with her favourite possessions and momentos.

Decisions about, and strategies for, 'maintaining involvement' appeared to be made at various critical junctures in the carer's model, for instance when Taking it On, and indeed it could be argued that even after the end of instrumental care, that carers sought to 'maintain involvement' by their participation in care following placement in a nursing or residential home.

Therefore, after identifying the presence of 'maintaining involvement' in the existing data, the author conducted six additional interviews (interviews: 69-74) to empirically test these findings. By working closely with Consultant B over a thirteen month period (June, 1995 to July, 1996), the author was able to theoretically sample carers who were actively engaged in the stages of: Working Through It (x3); Reaching the End (x2); and A New Beginning (x1). Unfortunately, due to prior ethical restrictions, the author was unable to return to the memory clinic to conduct further joint interviews on the meaning of 'maintaining involvement'.

This final series of interviews (interviews: 69-74) confirmed that 'maintaining involvement' as a concept was recognisable to carers at different points in the trajectory of dementia, indeed even transcending the end of caring. For example, in the final interview of the series (interview: 74), and indeed the study, the author was interviewing

a carer whose wife had died and who was now trying to 'get things together again'; in effect, considering the options available to him in commencing A New Beginning (see: Figure 9, p.161). Whilst discussing some of the issues involved in the process of 'working through the past', the carer explained that he 'maintained involvement' with his wife by 'keeping her memory alive in many different ways'. Whilst discussing the meaning of this reply, the carer explained that he often went, alone, for long walks to try and remember their time together, both during the period of active caregiving and before, while they were still untouched by the experience of dementia. Continuing the general thrust of the conversation, the carer explained that:

... I have spent the last ten years being so involved with my wife and that, that I just don't know what to do with my time anymore. I just miss seeing her so much.

(interview: 74)

After the death of his wife, the carer movingly explained that he first saw the dementia 'as being dead', but as time moved on he came to recognise that it was not the dementia that 'had died', but his wife. Reflecting on this account, and the carer's experience of 'maintaining involvement' with his wife via the past perception of his role and feelings of loss, the author placed the following entry in his theoretical memo book:

The carer in this interview has tracked the progression of 'maintaining involvement' throughout his caregiving experience. The struggle to 'hold on' to care during the stage of Working Through It was particularly difficult for this carer as he had great difficulty in tending to his wife's physical needs, particularly that of personal care. As he explained during the interview, he was able to overcome this by 'pretending I'm doing that to someone else', thus managing to 'maintain involvement' in his caregiving and in his wife's need for care. Writing this note, it has become apparent to me that I was also 'maintaining involvement' in this carer's life by acting as a 'sounding board' during the conversation, thus enabling the carer to share his emotional and physical experience of loss and, perhaps, come to terms a little more with some of the real conflicts he has faced. A new way forward for the study could be to explore how professional carers 'maintain involvement' in the life of carers and people with dementia, exploring both their knowledge base for constructing this involvement and how they go about managing intervention(s) in the delivery of care. Arguably, such a study would help to support a new direction of research based attention built from the social values and experiences of people with the real insight into dementia.

(theoretical memo book entry: 27.7.1996)

In many ways, it was fitting to end the series of interviews on this note as this carers' experience (interview: 74) captured the meaning of 'maintaining involvement' as a linking scheme both throughout, and beyond, the lived experience of dementia. For this carer, and others who had reached the end of caregiving and embarked upon A New Beginning, 'maintaining involvement' in the experience of dementia would continue for as long as they searched for new directions in their life and needed to resolve past experiences and emotional conflicts.

Beginning to describe the properties of the linking scheme of 'maintaining involvement' validated Glaser's (1978) assertion, built on the notion of trust, that the analyst's theoretical sensitivity is the crucial factor in generating substantive grounded theory, and helps to explain why developing grounded theory is such a potentially time-consuming process. On the other hand, this seemed like time well spent, and the relevance of 'maintaining involvement' to both the carer and the person with dementia suggested that a theoretical integration of the two models might add yet further insights. It is to this area that attention is now turned.

6.3 Integrating the Models: Generating a Process of Realignment

As seen in chapters 4 and 5 respectively, carers and people with the early experience of dementia journey through progressive stages and critical junctures in their lives in their attempt to adjust, and adapt, to their unfolding experience. Working through a modified grounded theory approach, but largely following the work of Glaser (1978), this study has, so far, outlined the properties of two trajectory frameworks to help explain this movement and transition. At present, however, the trajectory frameworks remain separate entities which, whilst offering a 'best fit' conceptual description of the individual experience of dementia, do not capture fully the complex dynamics surrounding dementia as a collective experience i.e. that seen, lived and negotiated between people with dementia and their carers. That said, the author has attempted to make some tentative conceptual links towards a more integrated model when outlining the stages relating to the early experience of dementia, particularly surrounding the time of the diagnosis and in the approach (for some carers and people with dementia in the sample) to develop a partnership and 'work together' to jointly manage this process.

In order to continue to build theory as process, the author will now theoretically integrate the generated models to produce a more complete trajectory of dementia. This integration will be illustrated diagrammatically using three Figures that help to 'give life' to the properties of process, and the dynamic context that is dementia. While it is not possible to capture all the nuances of the experience of dementia through the use of three case vignettes and accompanying Figures, they do nevertheless highlight the major transitions using critical junctures to predict movement within, and between, continua. To assist in this process the author will provide a commentary against each of the Figures to help contextualise their development and descriptive properties, particularly as they relate to the relevant case vignette.

In interpreting the Figures the following key provides an indication of important dimensions:

- Blue text refer to the person with dementia;
- Green text refer to the carer;
- Orange markings represent stages in the data;
- Brown line (dotted or continuous) represents the basic social processes of: Working Apart; Working Together; and Working Alone;
- The red line charts the (theoretical) course of 'maintaining involvement';
- Critical junctures are colour coded and numbered sequentially according to the person(s) involved, with the black vertical line illustrating the diagnosis of dementia;
- The vertical axis represents the person's and carer's attempts to 'maintaining involvement', ranging from 'high' to 'low';
- The horizontal axis represents the progression through time and the properties of process first identified in the stage of Building on the Past - the theoretical rationale behind this pairing will be explained shortly; and
- The spacing between the critical juncture are predominantly representative and not to be interpreted as to scale.

Case Vignette 1 (interview: 53)

Mrs. Jones cared for her husband at home from the time of his diagnosis of Alzheimer's disease in 1984 until his death in January, 1994. Throughout her caregiving, Mrs. Jones described her relationship with her husband as 'very loving and close', and whilst she made use of a local respite service, she would frequently visit him. It was clear to all those that met Mrs. Jones that she wanted to care for her husband at home for as long as possible.

Mr. Jones' diagnosis was made early on in the dementia following a joint approach to the GP and subsequent visits to 'out-patients' at the district general hospital. The diagnosis of Alzheimer's disease came 'as a shock' to them both, and Mrs. Jones described the first few years after diagnosis as 'getting used to one another all over again'. As the years went by and her husband required more physical care, she found tending his toileting needs the most stressful experience, as she suffered back pain whilst lifting him to a sitting position.

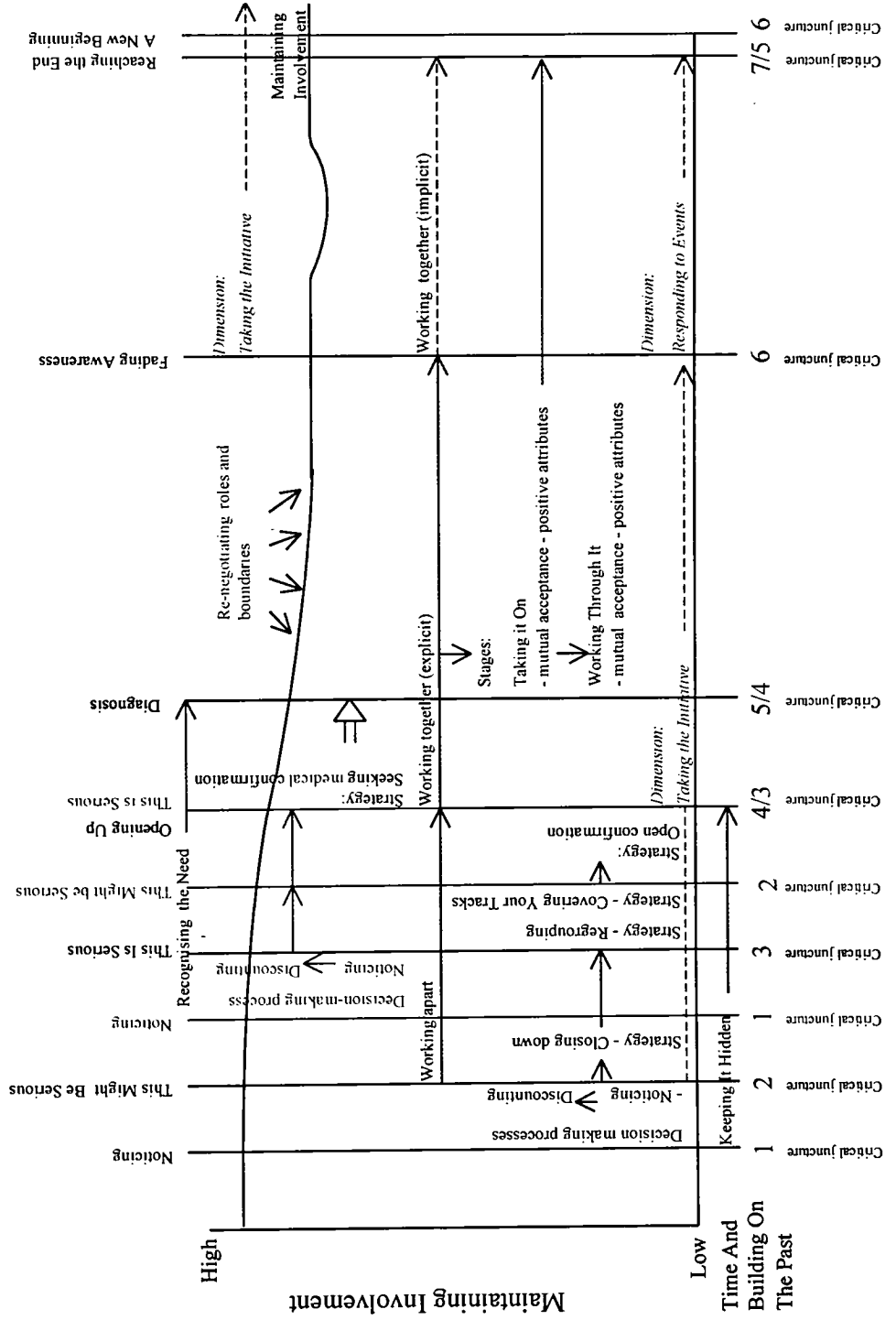
A home help was provided between 1990 and 1994 to assist Mrs. Jones with practical tasks, particularly shopping. This apart she largely coped day-by-day on her own, grateful for the respite care her husband received between 1991 and 1993. Mrs. Jones stated that this regular respite care helped her 'recharge her batteries'. Mr. Jones died of pneumonia in 1994 after being bed-bound for a little over 15 months. At the end of the interview, Mrs. Jones spoke lovingly of her husband, and was grateful that she had remained physically well during her caregiving career and that she had had the strength (both physical and emotional) to care for him. After his death, Mrs. Jones remained in contact with the local branch of the Alzheimer's Disease Society, wanting to 'give back something to others'. Mrs. Jones also started to attend a monthly bereavement support group established by her local Alzheimer's Disease Society branch.

Figure 11: A Commentary on its Properties

Figure 11 (next page) attempts to capture the complete trajectory of dementia as experienced by Mr. and Mrs. Jones. As can be seen in this case vignette, and in the

Figure 11 / Case Vignette 1:

Maintaining Involvement: early diagnosis, bereavement process and an example of working together (explicit and implicit)



supporting Figure, the first 7 critical junctures (5 for the person with the early experience of dementia and 4 for the carer) reflect the early diagnosis of Alzheimer's disease.

Moving through the Figure, the entry of critical juncture 1 (blue) represents Mr. Jones' first encounter with the experience of Alzheimer's disease. Naturally, his own account could not be obtained, but Mrs. Jones remembered that, at the beginning, her husband mentioned 'becoming forgetful for no good reason'. If the previous analysis in chapter 5 has utility, then this awareness trigger initiated (for Mr. Jones) decision-making processes attached to noticing-discounting the significance of the encounter (as displayed previously in Figure 3 p.121 relating to carers). Hypothetically, the continuation of 'forgetfulness', coupled with a rising severity and/or onset of new awareness triggers, would have led Mr. Jones to reach critical juncture 2 (blue), and a belief that 'this might be serious'. This, in turn, would have triggered the strategies of: Closing Down; Regrouping; and Covering your Tracks (illustrated in the movement between critical junctures 3 and 4 (blue)) in order for Mr. Jones to continue to exert control over his life.

During the interview with Mrs. Jones, she recalled that, in 'the early days', her husband 'began to lose interest in things' and 'became more distant from me'. For the carer, this prompted the entry of 'noticing' into the trajectory of dementia, illustrated by critical juncture 1 (green), as Mrs. Jones' own decision-making processes led her, initially, to discount the significance of what she was seeing but still 'suspect' that things were not quite right. This 'suspicion' eventually led her to a belief that 'this might be serious' (critical juncture 2 - green) and an increasing vigilance of the situation.

As shown in Figure 11, these early independent, and initially covert responses, by both Mr. and Mrs. Jones illustrates, conceptually, the start of a process which the author has named 'Working Apart'. Within grounded theory Working Apart (and also Working Together (explicit and implicit) as shown in Figure 11) are considered basic social processes as they have temporal dimensions with a discernible breaking point that still allow stages to be perceived as a theoretical whole (Glaser, 1978; see also: chapter 3 pp.85-87).

The basic social process of Working Apart emerged from the data and captures the dynamic that exists in managing the early process of adjustment as (subjective) attempts are made by both parties to understand a changing reality. As discussed in the properties of process relating to the stages Keeping it Hidden and Recognising the Need, this can take some time and Working Apart will continue until a shared agreement is reached that 'this is (might be) serious'. For instance, during the phase 2 interviews, even in relationships which were described as 'loving and close', at times people with the early experience of dementia went to considerable lengths to 'cover their tracks' for fear that 'opening up' would expose them as failing in some way and no longer in control of events. Similarly, carers may believe that this behaviour was a 'normal' part of ageing and fail to act, or conversely see this as 'serious', seek a medical confirmation of this belief, and encounter professional nihilism (as in interview: 7 for example - see: p.132). In any event, this lack of mutual agreement in acknowledging the 'seriousness' of what is happening continues the potentially divisive, but definitely covert, element that constitutes Working Apart.

From the data what appears crucial in heralding an end to the process of Working Apart is an agreement between the parties that 'things are not right', and a mutual decision to seek help. This could be reached through an 'open confirmation', or following a 'confrontative confirmation' of events, whereby behaviours and actions are directly challenged (see: Figure 5 p.129). In either case it is likely that the steps leading to an 'opening up' of the situation will be rooted in the properties of process attached to Building on the Past. Drawing on the data, the author would suggest that one, or a combination, of the following elements play a significant part in determining the end of Working Apart and the start of a new phase of Working Together (see: Figure 11):

- Personal belief structures;
- Geographical location; and
- The closeness of inter-personal relationship.

For Mr. and Mrs. Jones it was the closeness of their relationship that led to this early, open confirmation and consequent shared level of understanding, which accounts for the 'high' level of 'maintaining involvement' in Figure 11. Indeed, for Mr. and Mrs. Jones their joint response to Mr. Jones' memory difficulties was to seek help, and in this case

they went together to see their GP. The GP took Mr. Jones' signs seriously, and after 'a few tests to do with numbers', referred Mr. Jones to Consultant A's out-patient's clinic. Within a few months and without hospital admission for assessment, a diagnosis of 'mild dementia (probable Alzheimer's type)' was made, with its implications and prognosis communicated to both Mr. and Mrs. Jones. The communication and sharing of this diagnosis is represented by critical juncture 5 (blue) and 4 (green) in Figure 11. From the point of 'opening up' the critical junctures for both the person with the early experience of dementia and the carer became shared (illustrated heuristically by the blue/green text) as an explicit phase of Working Together.

Armed with the diagnosis, and service support (in terms of an application for 'attendance allowance' and an offer of future help from the day hospital social worker should they 'have difficulty managing'), Mr. and Mrs. Jones 'took it on' by deciding to 'manage the best we can', building on the positive dimensions of the typology presented previously in Figure 6. This allowed Mr. and Mrs. Jones time to re-negotiate their roles, compensating for one another's strengths and feelings of loss. On a practical footing, and as part of this re-negotiation, Mrs. Jones said she remained 'in charge' of the domestic chores, although they both 'worked together' on other tasks, such as shopping and so on. Mr. and Mrs. Jones also told their children about the diagnosis (and through them their grand-children), and received additional social support from this network as a result. Mrs. Jones joined the local branch of the Alzheimer's Disease Society and sought information from the Society on Alzheimer's disease. Moreover, they both decided to 'inform others in the community' about Mr. Jones's diagnosis as they felt that this was the best way to keep them socially engaged. This decision was influenced by the longevity of their community relationships, and their belief that others would be more understanding of Mr. Jones if they were informed of his dementia.

The transitions from critical juncture 1 can be placed in the context of Building on the Past and the ways in which people habitually cope, and adjust to, stressful/uncertain/threatening experiences during their lifetime. Whilst Building on the Past was first identified in the carer's model, its theoretical application to the lives of people with (undiagnosed) dementia is equally relevant. Just as carers brought their past experiences to bear, people encountering the first sign(s) of dementia (but not recognising them as such) also bring 'their past' and concept of self identity into

understanding and living with this (anticipated) transient uncertainty. The person's relationships, age, where they live, who they live with, their personality type, employment status, coping styles and environment, become important in understanding and adjusting to this uncertain experience. However, as the data revealed, the level of subjective awareness attached to these early encounters is kept hidden from others, with the person's attempts at monitoring its impact upon their life becoming crucial dimensions to their experience.

By employing a range of monitoring and coping efforts in an attempt to overcome, and minimise, these encounters, and to keep their existence hidden from others, the person drew upon knowledge of their past to help make sense of their new found reality. For instance, in interview: 65, whilst the person with dementia was describing her first encounter with memory loss, she believed it was simply 'a sign of having worked too hard', and that it was necessary to 'slow down a little' in order for things to get back to normal. To cope with the 'niggling' memory loss, the person with dementia then described how she took more breaks than usual, and began to delegate tasks to other colleagues, something she had done previously when she felt under pressure at work.

The role of Building on the Past in helping to adjust to the early experience of dementia calls into question its status as a 'stage' of caregiving. As already discussed, in grounded theory stages require fixed entry and exits points which are marked by reaching, and passing through, a critical juncture (Glaser, 1978). However, by its very nature, the past can represent a lifetime's experience or an event that happened just a moment ago. As such, it becomes much more difficult to say with any degree of certainty that people pass through a critical juncture in order to leave behind, or enter, the stage of Building on the Past. For such reasons it is more appropriate to see Building on the Past as a fluid, consistent and dynamic influence integral to the process of adaptation and adjustment. In this way Building on the Past can be seen as a core category. This level of flexibility is necessary for people, both individually and collectively, to learn to cope with the changing demands brought about by the experience of dementia. In other words, the past cannot be seen to be tied in time to a period before the onset of caregiving or the experience of illness.

This new interpretation of Building on the Past first emerged in chapter 4, for instance, when the author was describing the carer's problem-solving techniques. For example in interview: 2 (p.114), one of the carer's approaches to managing her husband's confusion and disorientation was to call upon her intimate knowledge of his past; in this case, her husband's life-long love of motor cars. The carer was dipping into her reservoir of knowledge about her husband in order to help solve a present day problem.

This coping strategy is similar to that used by people with (undiagnosed) dementia during their efforts at managing sustained uncertainty, particularly during the strategy of Covering your Tracks (see: pp.204-207). Accordingly, Building on the Past is seen to be an on-going process rather than a discrete stage. This requires a modification to the six stage model of care outlined in chapter 4. Consequently, the carer's model (and integrated scheme) now commences with Recognising the Need (stage 1) before progressing through: Taking it On (stage 2); Working Through It (stage 3); Reaching the End (stage 4); and A New Beginning (stage 5).

Returning to the case vignette supporting Figure 11, Mr. and Mrs. Jones' approach to Working Together through the process of dementia continued until critical juncture 6 (blue) was reached, and Mr. Jones experienced a 'fading awareness' of his reality. The introduction of critical juncture 6 (blue) in Figure 11 is a theoretical abstraction of this experience, and, as its name suggests, represents the time when self-awareness and control over behaviour/actions begins to diminish. Quite how this diminishing level of awareness is experienced and how much the person is, indeed, aware of this process, remains speculative and requires further empirical research, although evidence from this study suggests that people with dementia are, initially at least, aware of this change.

Theoretically, critical juncture 6 (blue) in this case vignette (Figure 11) marks the beginning of the end of the carer and person actively Working Together, as the carer gradually takes increasing responsibility. This is revealed in the Figure in the change from an 'explicit' focus in Working Together, to an 'implicit' one. During the interview Mrs. Jones became quite tearful when describing this period as she felt she had to start doing 'a lot of things on my own', although what was most upsetting to her was the change to her husband's temper, and that 'he began to shout at me about nothing at all'.

In sharing this experience, it can be seen from Figure 11 that the carer now implicitly begins Working Together, identified by the dotted line, as this conveys Mrs. Jones' attempts to find meaning and reciprocity in her role. It was this investment and satisfaction in the role that stopped the carer being, and thereby 'working', alone. In other words, Mrs. Jones continued to find meaning in what she was doing and saw it as important for Mr. Jones to 'maintain involvement' in the local community.

Critical juncture 6 (blue) marks the time when the carer begins Taking the Initiative, whilst the person with dementia begins Responding to Events. This change in the dynamic of the relationship, and the more uncertain response of her husband to 'simple requests', prompted Mrs. Jones to re-contact the day hospital social worker. This approach resulted in the start of social services day care and, as the instrumental demands increased, regular respite care. This level of social support meant that Mrs. Jones did not work entirely 'alone' during the (remaining) trajectory of dementia, and she said that 'she didn't know how she would have managed' without this additional help.

Between critical junctures 4/3-5(green), Mrs. Jones and her husband (initially together) and Mrs. Jones (later alone) implemented the A-E transactional framework to find new ways of managing their situation, such as going out more together. It was here that Mrs. Jones acted as a 'safety blanket', and this feeling of security enabled the couple to maintain a pattern of Working Together before the dementia progressed beyond critical juncture 6 (blue).

Eventually, 'managing' Mr. Jones' continence problems proved a difficulty, and Mrs. Jones admitted that she had thought of 'wanting out' of the relationship - hence the 'dip' in the line of 'maintaining involvement' in Figure 11. However, Mrs. Jones successfully negotiated this by constructing a routine where she would sit her husband on the toilet 'for ten minutes every hour' in order to minimise 'any chance of 'accidents', and to help preserve a measure of self-respect for her husband.

Thus, Mrs. Jones' ability to attach a positive meaning to her role, and the support she received, enabled her to continue caring at home until the time of her husband's death (marked by critical juncture 5 (green) on Figure 11). According to Mrs. Jones the 'later

years' were the easiest (in terms of the mental stress involved in caring) as she was able to build her caregiving around a set routine. This continued up until the time of her husband's death (marked by critical juncture 7 (blue) and 5 (green) on Figure 11). However, the fact that she still found satisfaction from her role is analogous to Hirschfield's (1981; 1983) description of high mutuality, in which the person with dementia still reciprocated by virtue of their existence. After her husband's death, Mrs. Jones continued to 'maintain involvement' in the experience of dementia through her attendance at the Alzheimer's Disease Society branch, and the bereavement support group (as represented in critical juncture 6 (green)).

As can be seen from Figure 11 the red line denoting 'maintaining involvement' remained high and this signalled the ability of the carer and the person with dementia to work together (both explicitly and implicitly) throughout the experience of dementia. Based on the case vignette and similar examples in the data, for this to occur the author identified the following potential conditions:

- A good prior relationship;
- A willingness by the person with (undiagnosed) dementia to openly disclose their fears, concerns and coping behaviours with a trusted person;
- A willingness by the trusted person (carer) to hear these concerns, validate and act upon them;
- A mutual decision to do something about it, where both parties recognise and agree that 'this is (might be) serious';
- A reasonably quick decision to seek a medical opinion on the cause of the experienced signs;
- Primary health care teams taking the reported signs and symptoms seriously, and having the necessary knowledge and skills to facilitate an early diagnosis of dementia. Alternatively, the primary health care team response may be to refer the person/couple to more specialised support services, such as a memory clinic, for a more detailed assessment;
- An early diagnosis being made and the person with dementia and the carer being informed of the diagnosis and prognosis;
- The person and carer understanding the implications of the diagnosis;

- An explicit willingness by the person/carer/family to work through the processes involved in living with the experience of dementia in a supportive manner;
- Specialist services being available on a continual basis to help support 'the partnership' - and the family - through this transition; and
- Ability of the carer to 'maintain involvement' even when the person with dementia had reached the dimension of Responding to Events i.e. the carer was able to gain satisfaction and meaning from the act of caring itself.

These conditions require further testing, but their occurrence seems important if support, and a diagnosis of dementia, are to occur at an earlier point. It is therefore possible to hypothesise that if each (or most) of the conditions were met, then the person with dementia and the carer would be more likely to Work Together with the aim of minimising the impact of dementia upon their lives, whilst maximising 'maintaining involvement'. This development adds a further layer of conceptual refinement to the grounded theory and begins to endow it with the properties of explanation and prediction.

The integration attempted in Figure 11 provides a more overt fusion of the experience of dementia, whereby Taking it On and Working Through It, whilst initially constructed from the carer's data, become a shared experience in which the carer and person with dementia work in tandem to compensate for deficits, jointly implementing the A-E decision-making framework to determine what works and what does not. Here Working Together is built on a mutual decision to 'share the load' and 'work through it'. As such, the properties of process initially attached to the stage of Sharing the Load in the model relating to the early experience of dementia (see: pp.206-208), are more naturally subsumed under these modified attributes of Taking it On and Working Through It.

Although at this point the integration above is partly theoretical (as the direct experience of the person with dementia is lacking), there was some empirical support from the study. Therefore, this process of Working Together was seen most vividly in some of the phase 2 interviews involving people with the early experience of dementia and their family carers (interviews: 59-68) when the carer reported that 'they were their memory' (interviews: 59, 60, 62 and 66), and the person with the early experience of dementia had no real difficulty accepting the reality of this statement. A common feature uniting

these experiences was the good inter-personal relationship between the carer and person with dementia prior to, and after, the diagnosis. It was evident that in the one phase 2 interview where a good relationship was clearly lacking (interview: 61), there was considerable tension and hostility between the carer and person with the early experience of dementia with each visibly Working Alone throughout their experience.

Case Vignette 2 (interview: 50)

Mr. Green first 'noticed' a change in his wife's behaviour some nine years before the interview when she would put things down and forget their whereabouts. Mr. Green became more concerned about his wife's behaviour when she stopped going out as 'she had always been such a sociable person'. Mr. Green went to see his doctor two years after he first noticed the signs, but it took a further eighteen months for his wife to attend the surgery and an additional eight months for a diagnosis of dementia to be made. The diagnosis of dementia was not communicated to Mrs. Green as it was felt that she would be unable to understand its implications.

At the time of the interview, Mr. Green had been caring for his wife for seven years at home until he came to the decision, earlier in the year, that he could no longer carry on. Mr. and Mrs. Green had been married for forty years, and his 'wanting out' of the caring role 'hurt a lot' as he felt he had let his wife down. However, the decision to admit his wife to a nursing home was prompted by Mr. Green's physical inability to continue to lift his wife, and the stress that this was causing him. As he could no longer lift her into bed and into the bath, Mr. Green believed he could no longer 'look after her properly', and a social worker was called in to help with the placement. According to Mr. Green, this was only his fifth contact with the statutory services during the course of his caregiving career. This is consistent with a shift from the left-hand side of the continua in Figure 7 (p.153) to the right-hand side, initiated by a belief that the quality of care was improved.

Following admission Mr. Green visited his wife at the nursing home whenever possible, and it was important for him that his wife lived nearby, so that he could feel close to her and spend as much time as possible with her, particularly at mealtimes. Whilst Mr. Green was grateful to the staff for changing and toileting his

wife, he continued to want to play a part in her care, and gained pleasure in helping his wife to eat, as well as simply sitting with her during the day.

Figure 12: A Commentary on its Properties

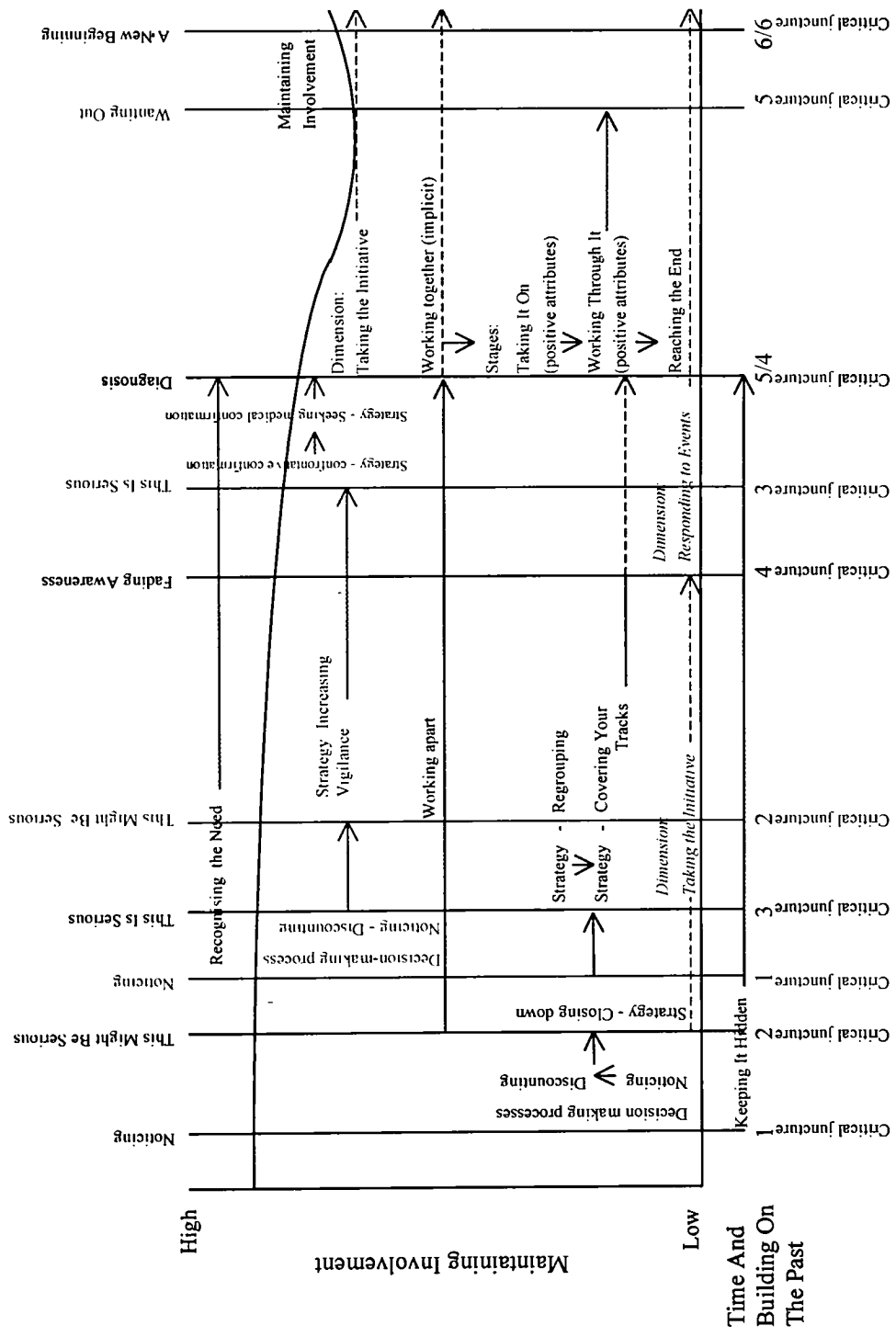
As seen in Figure 12 (next page), in contrast to Figure 11, the ordering of many of the critical junctures has changed as they differ in their relative timing. This change primarily reflects the time it took to obtain Mrs. Green's diagnosis of dementia and the circumstances surrounding this process, particularly the role of the GP.

In the early stages the critical junctures match those in Figure 12, but over a more prolonged time-scale. However, the absence of an 'open confirmation' at an early stage and the continued covert activity of Working Apart resulted in Mr. Green implementing the strategy of 'increasing vigilance' when his wife began to constantly mislay her glasses and he would find them 'in all sorts of strange places'. For Mr. Green, this 'vigilance' took the form of noting the time of day and excuse for which the glasses being 'mislaid'. The shift in belief structures from 'this might be serious' to 'this is serious', was made some time later (critical juncture 3 (green)) when Mr. Green's wife had passed through critical juncture 4 (blue), and entered the dimension of Responding to Events. Due to Mrs. Green's continuing, but less successful attempts, at 'covering her tracks', her 'unusual' behaviour became more difficult to discount, particularly her poor memory performance and levels of orientation. As Mr. Green stated at interview, his wife 'completely lost track of time' and 'couldn't really remember things we'd {just} talked about'.

It was Mrs. Green's transition beyond critical juncture 4 (blue), and her increasing inability to account for her memory performance, that eventually prompted her husband to place this behaviour within an 'illness context' and seek a more formal confirmation of this belief from his GP. However, as the case vignette revealed, Mrs. Green refused to attend the surgery for a 'check up' as she was convinced, according to her husband, that 'there was nothing wrong with her'. Accordingly, it was to be a further 18 months before a domicilliary visit was arranged by the GP for Consultant A, and an eventual diagnosis of dementia made; a turn of events that highlights the process of Working Apart that pervaded the first few years of this experience.

Figure 12 / Case Vignette 2:

Maintaining Involvement: later diagnosis, admission into care and an example of the carer working together (implicit)



The relatively late diagnosis denied Mr. and Mrs. Green an opportunity to explicitly Work Together during the experience of dementia. However, following the diagnosis, Mr. Green said that he began the stage of Working Through It (critical juncture 5 (blue) and 4 (green)) with 'the best intentions' (hence the dotted line attached to Working Together), and drew on his wife's past interests to frame his caregiving interventions. During this time Mr. Green found it particularly helpful to involve his family and he developed a fixed routine to manage care, a routine that he honed to the point of being able to anticipate future needs. Moreover, following the diagnosis, Mrs. Green was offered a place at day care in the area. However, this was attended only once as Mr. Green prevented his wife from returning as he felt 'she came home worse than when she went in'. Professional involvement and support was largely discontinued after this, and Mr. Green continued with his 'routine' to help him get by.

From critical juncture 4 (green), therefore, and the start of the A-E decision-making process, Mr. Green worked hard to maintain his wife's involvement. However, over time, his physical and mental health began to suffer and the negative dimensions attached to Figure 7 (see: p.153) started to dominate his perception of caregiving, thus subsuming previously held feelings of reciprocity. During the latter stages of Working Through It, Mr. Green's inability to lift his wife from a supine position, and his lack of alternative strategies, led him to experience a feeling of frustration and being out of control, which in turn, led to a process of 'wanting out' of care (as shown in critical juncture 5 (green)). However, as revealed in the case vignette, Mr. Green continued to 'maintain involvement' in caring for his wife. Thus, the decision to admit his wife into care, whilst forced by circumstances, was a largely positive choice, and this is reflected by the rising curve at the point of critical juncture 6 signifying Mr. Green's desire to 'maintain involvement'.

In contrast to case vignette 1 and Figure 11, while many of the conditions for a more explicit process of Working Together were in place, the failure to have an 'open confirmation' and an early diagnosis effectively precluded Mr. and Mrs. Green being able to Work Together explicitly.

Case Vignette 3 (interview: 12)

Mr. Evans was diagnosed with mild Alzheimer's disease six months prior to interview. At the time of the diagnosis he was 57 years of age. Prior to the diagnosis, Mr. Evans had been a long distance lorry driver and spent considerable periods of time away from home. Mr. Evans had been married for 30 years and had two children, the youngest of which (Mary) still lived at home. During the interview Mrs. Evans called their life together 'hell', and stated that her husband had never really cared for her during their marriage. Mrs. Evans particularly looked forward to the times when her husband would do 'the continental run' as this meant he was away for several months on end. Mrs. Evans stated that they had remained together 'for the sake of the children', but had led mainly separate lives and had very little in common.

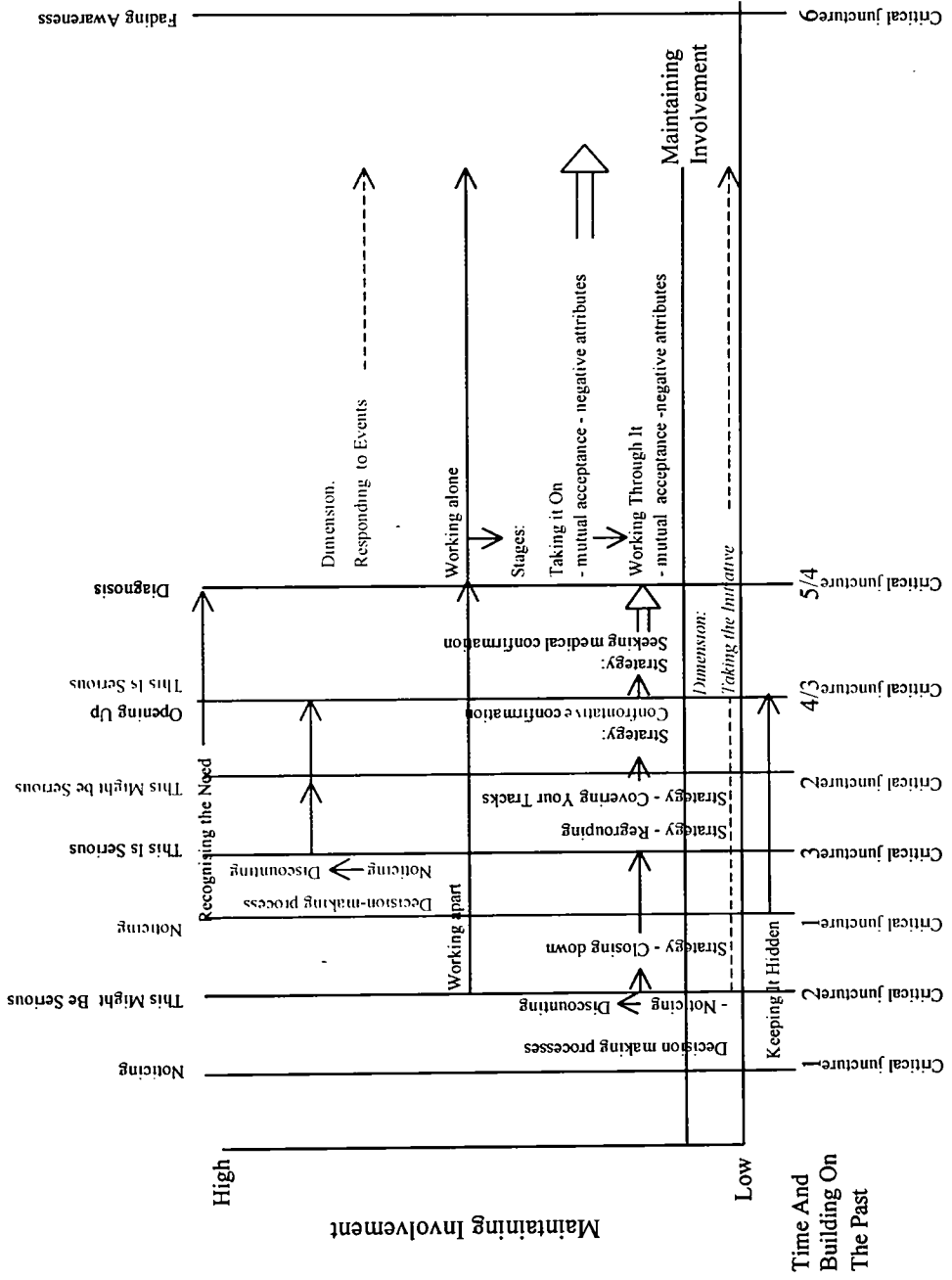
The early diagnosis was the result of a 'shouting match' when Mrs. Evans confronted her husband about his poor recollection of names, something she noticed had 'become worse' in the last year. Mrs. Evans challenged her husband to 'do something about it', and was surprised when he agreed and went (alone) to see his GP. As a result of this consultation a series of psychological tests and physical examinations were conducted that eventually led to a referral to Consultant A and a diagnosis of mild Alzheimer's disease. For both parties the diagnosis was a 'bolt from the blue' as it meant that Mr. Evans had to stop working, and this caused a considerable financial strain on the household. More importantly, Mrs. Evans 'detested' having her husband 'under her feet' every day, as he would make demands on her time and would repeatedly ask her to find the keys to the car so that 'he could go out'. To cope with the situation, Mrs. Evans had hidden the car keys in the garden and would leave the house as often as possible. The recent diagnosis of dementia left Mrs. Evans fearful and depressed about the future.

Figure 13: A Commentary on its Properties

Figure 13 (next page) illustrates the process of Working Alone that summarises the experience of dementia in this vignette. Owing to the previous poor relationship, 'maintaining involvement' was 'low' both entering the experience of dementia, and

Figure 13 / Case Vignette 3:

Maintaining Involvement: early diagnosis and an example of the carer working alone



following the diagnosis, with the carer feeling trapped and resenting her role. Moreover, as illustrated in Figure 13 the diagnosis (critical juncture 5 (blue) and 4 (green)) was reached following a process of Working Alone, and a confrontative confirmation with no positive attributes to Taking it On. For Mrs. Evans this meant that 'care' was taken on within the framework of a negative set of attributes attached to Figure 6 (p.141), a process that continued through the stage of Working Through It (see: Figure 7 p.153). These negative attributes provide a context for the carer's continuous Working Alone as there was no satisfaction to be gained from the role. Accordingly, care was taken on with limited (or no) expectation of its success, and following the diagnosis the dynamic was characterised by each partner Working Alone throughout their experience.

For the carer, Working Alone was expressed through a mixture of blame and anger (directed towards her husband) and despair (directed towards herself). This negative perception was compounded by the formal diagnosis as Mrs. Evans felt it was now 'too late to do anything about it' by leaving her husband. Despite her temptation to do so, Mrs. Evans did not want to be seen by others as 'abandoning him', and this need to 'keep face' with others effectively tied her to an unwanted caring situation. There was, therefore, no sense of Working Together, either implicitly or explicitly, as the necessary conditions to provide reciprocity and meaning were missing. This further demonstrates the importance of Building on the Past, as in this instance the past relationship was very poor and therefore one of the necessary conditions for Working Together was absent.

The negative features of this experience were compounded by the relative absence of (meaningful) service involvement, with the emphasis being placed on Mr. Evans' needs. The comments below made by Mrs. Evans following a visit by a social worker reflect this:

... she was only here five minutes and interested in him {referring to her husband}, how he was getting on and that. He said he was fine and that he was getting around. She {referring to the social worker} was pleased about that. She never spent any time with me.

Interestingly, and as Figure 13 illustrates, one of the outcomes of an early diagnosis in this case was that Mr. Evans was able to make informed decisions and choices about his actions, and whilst he was not interviewed as part of the study, from accounts provided by his wife he was still able to use public transport safely and regularly visited a local 'club' where he had been a member for a number of years. Therefore, Mr. Evans was still able to Take the Initiative through his dementia, although he 'worked alone' in doing so; this, however, left Mrs. Evans feeling increasingly powerless.

At the time of completing this interview the future was uncertain, but, the author would suggest, the relationship had potentially abusive dimensions that required urgent, and skilled, help. However, no one was taking a lead in this process, and for the author as a practitioner, leaving this interview was one of the most difficult parts of the entire research process. The author will return to the research/practitioner dilemma in the next chapter.

6.4 Summary

This chapter commenced with an account of the third phase of the study and the application of the linking scheme 'maintaining involvement' to a theoretical sample of carers of people with dementia. The linking scheme was seen to be meaningful and have the 'fit and grab' necessary to fulfil the criteria for a substantive grounded theory. Next, the chapter outlined three case vignettes that were drawn from the interview data to illustrate a theoretical integration of the developed models. This exercise resulted in the emergence of three basic social processes, namely: Working Apart; Working Together; and Working Alone, that underpinned the overall aim of 'maintaining involvement'. A set of conditions were identified, the presence of which it was hypothesised would result in the basic social process of Working Together. These were illustrated primarily in Figure 11 (case vignette 1). Subsequently, the following two case vignettes illustrated how differing trajectories emerged when some, or all, of the conditions were either absent or present. It is suggested here that the identification of these three basic social processes and the conditions which support them add an element of explanation and prediction that raises the status of the emerging grounded theory in line with the original formulation as suggested by Glaser and Strauss (1967), and updated by Glaser (1978).

The final chapter will further consider the status of the grounded theory, and identify some of its limitations. Tensions encountered during the research process, and the challenges of conducting a grounded theory study, will be considered. Potential areas for further study will also be suggested, and the policy and practice implications of the study will be rehearsed briefly.

CHAPTER SEVEN

DISCUSSION AND CONCLUSIONS

Do you think our chat will help others? (interview: 68)

7.1 Introduction

As noted in the *Preface* the author began the initial study which comprised this thesis while still practising as a community psychiatric nurse in a dementia team. He was motivated to do so by a desire for a better understanding of the experience of caring for someone with dementia in order that practice might improve. Importantly, it was also hoped that a more creative and personalised service response be developed. Consistent with a grounded theory approach the aims of this study evolved, underpinned by the notion of theoretical sampling and the constant comparative method. Informed by the data, the emphasis therefore shifted away from its early orientation on the coping patterns of carers, towards a more temporal and processural account that took cognisance of changes over time. The fortuitous presence of four people with the early experience of dementia during the later stages of the (phase 1) interviews, signalled another re-orientation by highlighting the importance of incorporating their perspectives into the dementia experience. Subsequent data collection resulted in the development of two models of living with the experience of dementia, and their eventual theoretical integration, which elaborated upon the stages, dimensions, processes and critical junctures that underpinned the basic social processes of 'working' i.e. Working Apart; Working Together; Working Alone, and the linking scheme of 'maintaining involvement'. Although still in need of further empirical testing, refinement and elaboration, the theory is considered to have utility at a number of levels adding to knowledge and understanding of dementia, while also having the potential to inform policy and practice in dementia care. It is the purpose of this final chapter to begin to

briefly pull together some of the many threads that have informed this thesis, and to reflect upon the theoretical, methodological and policy/practice issues that it raises.

7.2 Shape of the Chapter

This final chapter of the thesis draws upon a variety of sources in its construction. Given the breadth of experiences covered in the text, it was decided to predominantly structure the chapter around the publications arising from the study (see: Appendix 7). This approach, it is anticipated, will help place the findings of the study into a practice relevant setting, as well as allowing its implications for education and training to emerge.

The rationale for adopting a Glaserian approach to grounded theory, as interpreted and slightly modified by the author, were rehearsed in chapter 3 and it is not intended to replay those arguments here. Having taken this decision, however, it seems appropriate that the resulting product, the grounded theory, be viewed in the light of some of the criteria outlined by Glaser (1978; 1992), and that the challenges of using such an approach to generating grounded theory also be considered. It must be remembered that although viewed predominantly as a qualitative method, the aim of grounded theory is both to develop and test theory in order to be able to explain and predict human behaviour within a defined area of study; aims that are more often associated with a quantitative paradigm. However, grounded theory has its own criteria for judging the quality and robustness of its explanations. Here, theory as process is one of the main underpinnings of a Glaserian approach to grounded theory, whereby theory should not only be seen to explain and predict behaviour, but also have practical utility. Therefore, it is considered important that the grounded theory is 'useful' and applicable to practice, while still being of more generalised sociological relevance. Essentially, as Glaser (1978) states, the theory should 'fit and grab' the area under study so that the temporal nature of the phenomena are immediately apparent. This chapter will apply this criterion to the grounded theory which resulted from the studies described in this thesis, initially by drawing parallels with existing and emergent literature in the field in order to allow a judgement about the extent to which an addition to knowledge has been made.

Following this consideration the chapter then provides an indication of how to raise the status of the presented grounded theory from a substantive to formal level, before exploring its policy and practice implications. This latter focus is achieved by dividing the study implications in two, focusing first on people with dementia and second on family carers. During the discussion on people with dementia, the author's previously published accounts are used to illuminate the debate and this includes the presentation of: a values-based assessment approach; an empowerment framework; a coping-assessment index; and a range of (untested) information needs. This focus on information-giving is continued in the carer's section, when four main areas are presented in order to demonstrate a need to develop practice. The chapter will then give a resume of methodological reflections and the complex area surrounding practitioners who also act as researchers. Finally, the chapter highlights the main study limitations before providing a brief personal conclusion.

7.3 Addition to Knowledge

As already discussed, grounded theory by definition requires a temporal dimension and the identification of processes, phases, stages, dimensions, strategies and tactics (together with the properties of a liking scheme) that explain movement over time. Although a grounded theorist should enter the field with as few pre-conceptions as possible, the author's approach to the use of the literature and the initial debt owed to the work of Wilson (1989a,b) have been fully acknowledged, as have the ways in which the carer's model built upon and added to Wilson's original ideas (publications/presentations resulting from this study are displayed in Appendix 7 and see for example: Keady and Nolan, 1993a,b,c; 1994c,d). Given the temporal properties of a grounded theory it seems appropriate to consider how the model described in this thesis has added to knowledge by comparison with existing theories, in both dementia and the wider literature on chronic illness. This serves not only to explore additions to knowledge, but also the wider sociological relevance of the study. The temporal analysis begins with a consideration of issues in the pre-diagnostic phase.

a) Pre-diagnosis: A Phase of Managing Uncertainty

As seen in chapters 5 and 6, and highlighted in the carer's decision-making model presented in Figure 3 (p.121), a process of 'noticing' captures the first subjective

encounter with the experience of dementia. The concept of 'noticing' has been seen in other literature such as that exploring experiences and perceptions about the early recognition of Parkinson's disease (see: Abudi *et al.*, 1997), and in appraising delays in seeking a diagnosis of cancer (Andersen and Cacioppo, 1995). Therefore, in many insidious chronic conditions, it seems that 'noticing' (or an analogous process) is a first step in illness recognition. This was observed by Morse and Johnson (1991) who developed the four stage 'Illness-Constellation Model' in an attempt to socially construct the experience of illness recognition for 'self' and 'others' (see: Table 5 on the next page).

Morse and Johnson (1991) contend that the first stage of the illness experience commences 'as the individual begins to *suspect* {original emphasis} that something is wrong' (p.319) and that such 'suspecting' is simultaneously engaged in by the 'significant other', a process that was described as 'dawning' and 'pairing up' in the study by Wuest, Ericson and Stern (1994).

Whilst Morse and Johnson's (1991) model was developed to account for generic illness experiences, it has consistency with the author's work, particularly during the second stage of 'disruption' and the carer's notion of 'being vigilant'. As a response to uncertainty, 'vigilance' was also identified in this study (see: Figure 4 p.126) and the carer's reaction to their belief that 'this might be serious'. However, whilst there is some overlap in the models and supporting processes, on closer examination Morse and Johnson's (1991) model does not seek to describe how people move between the stages, and assumes there is a linear relationship between 'sufferer' and 'significant other' in reacting to their experiences. The findings from this study suggest that this is not the case. Rather, during the phase of pre-diagnostic uncertainty, people with (undiagnosed) dementia and their carers were at different levels of understanding and adjustment to the experiences being encountered, as illustrated by critical junctures 1-5 in the integrated models (see: Figures 11; 12; and 13 on pp.223; 234; and 237 respectively).

Table 5: Stages and focus of the Illness-Constellation Model

Self	Others
<i>Stage 1: The Stage of Uncertainty</i>	
Suspecting	Suspecting
Reading the body	Monitoring
Being overwhelmed	Being overwhelmed
<i>Stage 2: The Stage of Disruption</i>	
Relinquishing control	Accepting responsibility
Distancing oneself	Being vigilant
<i>Stage 3: Striving to Regain Self</i>	
Making sense	Committing to the struggle
Preserving self	Buffering
Renegotiating roles	Renegotiating roles
Seeking goals	Monitoring activities
Seeking reassurance	Supporting
<i>Stage 4: Regaining Wellness</i>	
Taking charge	Relinquishing control
Attaining mastery	Making it through
Seeking closure	Seeking closure

Source: Morse and Johnson (1991 p.321)

In the present study, the skills and ingenuity exhibited by people with (undiagnosed) dementia during the strategy of Covering your Tracks seemed likely to keep the initial experience of dementia secret, and even when the carer suspected something was wrong there was usually a period of Working Apart, which was often prolonged, until the person's transition through the (heuristic) critical juncture of Fading Awareness made it likely that the 'secret' could no longer be contained.

It is only when there was shared acknowledgement that the 'unusual' experiences were something to be worried about, and these concerns were acted on and taken seriously by the medical profession, that Working Together could begin and the shared approach suggested by Morse and Johnson (1991) be achieved. It may be that the secretive nature of this early experience to dementia is characteristic of the condition itself, and that Morse and Johnson's model applies in other situations. This is an area for further empirical study and more detailed attempts to integrate existing models. For example, although Morse and Johnson's (1991) model may have more general utility, the final stage of 'Regaining Wellness' would not apply in many chronic conditions, including dementia.

b) Adjustment to the Diagnosis

In developing her three stage model of the caregiving experience in dementia, Lindgren (1993) described the first stage as an 'encounter' whereby carers 'adjusted to the impact of the diagnosis' (p.215). Whilst the model did not outline the steps necessary to reach this point, consistent with other studies (Clarke, 1995; Fearnley, McLennan and Weaks, 1997), notably Taraborrelli (1993), the provision of the diagnosis was seen as a 'turning point' enabling past inexplicable behaviours to be located within an illness context. The diagnosis served a similar function in the present study being seen as a critical juncture which 'opened up' the dementia and formalised the role of carer, in the integrated scheme. This marked the transition from Recognising the Need to Taking it On. Interestingly, Lindgren (1993) noted that some carers in her sample experienced 'diagnostic shock' following disclosure of the diagnosis, whilst other carers were able to take such news 'in their stride'. This finding was also mirrored in the present study. For instance, one account detailing the experience of a younger carer (interview code: 41) of a younger person with dementia (Williams, Keady and Nolan, 1995), the carer stated that, for the first six months, she had difficulty recalling how she got through the

day as 'it was all black' (p.34). In contrast, other carers (and people with dementia) appeared better able to cope with the news. This diversity of reaction may be due to a variety of factors, such as their belief structures, past relationship, coping patterns and so on, properties that make the process of Building on the Past crucial to understanding and interpreting on-going adjustment patterns, and establish its status as a core category.

This is consistent with the work of Morgan and Laing (1991) who, in a study exploring the impact of the diagnosis of Alzheimer's disease soon after the diagnosis, suggested that the central determining factor to predicting successful adjustment was 'the quality of each couple's previous relationship' (p.370) (see also: Phillips and Rempusheski, 1986; Nolan, 1993). Morgan and Laing (1991) differentiated spouses following diagnosis into two groups. The first was named the 'grief group' who were seen as having a close, loving relationship prior to diagnosis, with the diagnosis acting as a trigger for anticipatory grief, until the carer 'came to terms' with the diagnosis. This group was seen as having a strong motivation to continue caring. In contrast, the 'role strain' group was characterised by carers whose relationship had been 'less intimate and stable' and where the diagnosis created a 'high degree of tension and distress', to the extent that carers were 'hanging on' during the process of care. Whilst the timing of diagnosis and the sharing of this with the person concerned were not discussed, Morgan and Laing's (1991) study has resonance with the 'typology of attributes' presented in this study (Figure 6 p.141), particularly during the stage of Taking it On when the carer either 'opened up' or 'shut down' from help. Negative perceptions at the time of Taking it On had a detrimental effect on the carer's adjustment and perception of their role resulting in them feeling 'trapped'; Aneshensel, Pearlin and Schuler (1993) and Aneshensel *et al.* (1995) later described a similar process as 'role captivity' and suggested that the carer's continued experience of 'role captivity' was often the reason for a breakdown of caregiving relationships.

However, despite the importance of early support, relatively little attention has been given to the way in which carers adopt or 'take on' their role (Given and Given, 1991; Nolan and Grant, 1992; Stewart *et al.*, 1993). For example, carers who feel that they have been able to exercise a genuine choice of whether to become a carer or not report less subsequent burden (Nolan and Grant, 1992), and Opie (1994) strongly advocates that all carers, no matter how willing they are to adopt the role, should be encouraged to

explore fully the implications of their decision. Yet, as reported in this study, genuine choice is often all but absent because assumptions are made about the willingness and ability of family members to take responsibility for care. For practice to improve, such assertions need to be challenged.

Parallels can be drawn here with the work of Lewis and Meredith (1988; 1989) who described a period of 'semi-care' and 'part-time full care' as preceding care proper. They concluded that most of the daughters in their study drifted into the caring role, rather than being thrust into it, as is often the case where increased dependency is an insidious process. As seen in this thesis, the experience of people with dementia and their carers illustrates this point well, particularly the difficulty in obtaining a diagnosis. During the interviews both carers and people with dementia voiced their anger at this turn of events, as this was considered to have 'robbed' them of valuable time when cognitive abilities were still relatively intact. Such a 'diagnostic quest' has been identified as one of the crucial periods both for people with chronic illness and their carers (Corbin and Strauss, 1988; 1992). The more prolonged the 'diagnostic limbo' between suspicion and confirmation of dementia, the greater the stress. In certain situations the 'diagnostic limbo' can be extremely lengthy, heightening both the ambiguity and unpredictability of caring, making it even more stressful.

Fundamentally, decisions around the time of Taking it On are crucial and the author would agree with Opie (1994) that all carers should actively be encouraged to explore their decision and its implications. In circumstances where there has been a poor previous relationship, or when carers voice doubts about their abilities to care, then questions must be asked about the advisability of initiating a caring situation. For those carers who are willing to 'take it on', reasonable boundaries and expectations should be established including setting limits on care (see also: Pratt, Schmall and Wright, 1987; Bell, Gibbons and Pinchen, 1987; Fotrell, 1988; Bell and Gibbons, 1989; Beach, 1993; Nolan *et al.*, 1994).

c) Working Through It

The concept of 'work' is a central component of this thesis, as seen, primarily, through the stage of Working Through It and the supporting basic social processes of Working

Apart; Working Together; and Working Alone, processes that provide a conceptual link to explain the paradoxical experience of separation and togetherness that often underlie the dynamics of dementia. However, in this context, the term 'work' does not necessarily indicate that carers or people with dementia treat their role like a job, although a number may well do. Rather, 'work' is indicative of the active nature of living with and managing a condition that is characterised by a varied and uncertain trajectory.

The metaphor of 'work' was adopted by Corbin and Strauss (1988; 1992) to capture the dynamics of chronic illness. These authors took 'work' to mean the day-to-day struggle of people with chronic illness and their carers to give balance and meaning to their situation. They describe a number of types of 'work' and their associated tasks. Such 'work' includes: biographical work (defining and maintaining an identity); occupational work; marital work and so on. The manner and type of 'work' varies according to the illness trajectory (Corbin and Strauss, 1988; 1992). The typologies of care presented in this thesis and the varying stages of the caring trajectory follow a similar logic.

As rehearsed in chapter 4, the primary purpose in Working Through It and, indeed, 'maintaining involvement', is to maximise the positive elements whilst seeking to minimise the negative. During the basic social process of Working Together, in its explicit and implicit conceptualisation (see: Figure 11 p.223), this is often the primary dynamic whereby carers and people with dementia (initially) gain many of their satisfactions. So, for instance, for carers who are Working Together (implicitly), providing simple pleasures, maintaining dignity and ensuring that needs are tended to are all integral to the successful delivery of care. In themselves these are not new findings (see: Hirschfield, 1981; 1983; Motenko, 1989; Nolan and Grant, 1992; Cartwright *et al.*, 1994; Cohen *et al.*, 1994; Carruth *et al.*, 1997; Grant *et al.*, 1998; Fearon *et al.*, 1998), however the author has attempted to capture these positive dimensions and link the processes of 'work' to the development of the A-E transactional framework during the stage of Working Through It (see: pp.151-152). During this phase of caregiving carers, over time, become 'experts' in the day-to-day aspects of their role. Similarly, the elements of 'work' are found in the stage of Keeping it Hidden, when people with the early experience of dementia, particularly during the strategy of Covering your Tracks, developed skills at concealment and living through

shifting reality. As previously noted, it is essential that those working with carers and people with the early experience of dementia acknowledge and act upon this expertise (see: Nolan, Grant and Keady, 1996; Keady and Gilliard, 1999). In terms of coping, once the person with dementia had passed the transition through the (heuristic) critical juncture of Fading Awareness, carers often developed routines and differing tactics in a constant endeavour to maximise the positive aspects of care. As has been noted in the literature, the longer caring continues the less stressful it may become (Motenko, 1989), and the more competent carers feel in their role the less likely they are to be stressed or burdened (Archbold *et al.*, 1992; Harvath *et al.*, 1994).

It is at this point that many carers have their first contact with formal services and it is very important that due account is taken of the carers' perspective. Yet services often fail to do this and may inhibit or even obstruct carers from reaching their goals. This is not an isolated finding as many other studies have demonstrated how services can ride roughshod over carers' carefully planned routines (Lewis and Meredith, 1988; Braithwaite, 1990; Clarke, 1999). It is here that the balance between what Harvath *et al.* (1994) term 'local knowledge' and 'cosmopolitan knowledge' is important. These authors argue that carers have local knowledge, that is expertise in their particular circumstances, especially the way that the person they are caring for responds to their illness. It has been suggested that carers have three primary types of what might be termed local knowledge, i.e. knowledge of the cared-for persons illness or disability, knowledge of the cared-for persons normal behaviour and biographical knowledge of past and present interests, likes, hopes and aspirations (Nolan and Grant, 1992). Cosmopolitan knowledge on the other hand is more global and generic. It is not concerned with the 'specifics' of a situation but the generalities. Harvath *et al.* (1994) suggest that it is the skilful blending of these differing types of knowledge that is likely to result in the most profitable interactions between carers and service providers.

However, despite the suggestion that service providers can assist carers by bringing to bear a wide range of knowledge and theoretical perspectives and applying them with judgement and skill (Hughes, 1993), others have argued that one of the ways in which professionals assert their power is via controlling access to services (Bond, 1992; Ellis, 1993). Nikkonen (1994) in an analysis of expert power suggests that an 'expert's position of authority' is based on the belief that the knowledge they have is not available

to 'all and sundry'. This has led some to conclude that professionals can be overly paternalistic and seek to keep their expertise to themselves (Triantifillou and Meshenesco, 1994), and in order to counteract this, these authors argue that trust between professional and family carers is essential. However, they recognise that in order to facilitate trust professional carers need additional training and experience in working with family carers. Training alone however is likely to be insufficient unless it is accompanied by a cognitive shift so that professionals are more willing to relinquish their authority and both share their knowledge with carers and learn from them (Schulz *et al.*, 1993). Fundamentally, this means adopting the role of facilitator and enabler rather than doer or provider.

d) Reaching the End

Describing the results of a number of studies looking at the manner in which older people entered nursing and residential care, Nolan *et al.* (1996) note the invidious position in which many carers are placed, particularly when admission follows a period of hospitalisation. Due to the 'taboo' nature of residential care most carers have not discussed wishes and preferences with the older person in anticipation of a possible admission, nor do they have any clear criteria of their own on which to base a judgement. Moreover, due to the perceived exigency of discharge in the eyes of many professionals, particularly doctors, carers feel additional pressure to make decisions hurriedly.

With few exceptions carers received minimal help during this difficult period and were generally considered that they were left to 'sink or swim'; an issue reflected in the length of time these interviews took during phase 1 of the study (see: Appendix 4). A range of emotional reactions were described including guilt, anger, relief and helplessness. Although the long-term effects of having to make this decision cannot be judged, on the basis of the work conducted by Nolan *et al.* (1996) the literature suggests that many carers are left with legacy of guilt and continued stress (see also: Zarit and Whitlach, 1992; Dellasega and Mastrian, 1995; Ducharme, Lévesque and Cossette, 1997). The present study endorses the above conclusions with carers often describing guilt that had persisted unabated with the passage of time.

On this basis there are obvious deficits in the way that people with dementia and their carers are assisted to make decisions about entry to residential or nursing home care. Making the decision however is only the first step, and there are equally important choices to be made subsequently, especially concerning the type of home to be selected. Finding a home therefore poses another dilemma for both carer and cared-for person. The concept of choice would suggest that in ideal circumstances a home could be selected from a range of options according to a list of preferred criteria. In reality such a selection process is rarely achieved. Firstly, carers do not usually have criteria upon which to make a selection, as little prior thought has been given to the prospect of entering a nursing home. Second, because entry to care often occurs at a time of crisis there is relatively little time to engage in a thorough search. Third, even if a home is selected there is no guarantee that a place is available.

Adequate and sensitive professional input at this time can however ease the situation considerably and a number of instances of 'best practice' were observed in the above scenarios (Nolan *et al.*, 1996). It has been suggested that discussing the possibility of admission to care should be raised before crises occur (Hunter, Brace and Buckley, 1993; Nolan *et al.*, 1994), and Beach (1993) argues that it ought to be raised during the early stages of caring. However, if difficult decisions have to be made at a time of crisis and under the additional pressure of time constraints, then people with dementia and their carers need greater assistance. Nolan *et al.* (1996) describe a typology of admissions ranging from the positive choice through the rationalised alternative and discredited option to the *fait accompli*. They argue that the positive choice represents the ideal situation, but that the *fait accompli* is becoming increasingly prevalent. Four sets of processes interact to produce a positive choice, these being: anticipation (the degree of prior thought that has been given to the move); participation (the degree of active involvement achieved by older people and their carers); information (how much advice has been offered); and exploration (of alternatives to admission, of feelings about admission and of a range of possible homes). The literature, and findings from this study, would suggest that such considerations rarely apply.

Over and above this carers also need support to deal with the conflicting emotions that many still feel. Without this it is difficult to move on to A New Beginning, which requires that carers have a balanced perception of what they have achieved during

caring, recognise the value of their efforts over several years and come to the realisation that the choice to place the cared-for person in alternative care was the right and the best one. Furthermore, as described by many informants in the present study, entry to care does not mark the end of caring *per se*, but rather may signal the start of a new and still potentially stressful form of involvement. There was clear evidence from the interview data that a number of carers wanted to 'maintain involvement' after placement by undertaking and still providing forms of support and care. As Aneshensel *et al.* (1995) point out, a delicate balance needs to be struck so that carers do not feel pressurised to continue to provide care, but alternatively are made to feel welcome if this is their wish. This is an area in which there is a need for further study.

e) A New Beginning

McLoughlin and Ritchie (1994) argue that most carers are ill-prepared for a life after caring and that this is exacerbated for those who have been caring for the longest period. Certainly the life of carers following the end of formal caregiving is an under-researched area of dementia care. Some carers in this study wanted 'to give something back' to 'dementia' by becoming, or remaining, involved in support groups and/or local voluntary organisations, such as the Alzheimer's Disease Society. However, this was not the case for all carers, with many having concerns about the possible 'genetic inheritance' of Alzheimer's disease (Williams, Keady and Nolan, 1995), and/or fear for the future of their children. Carers also expressed a fear that something similar 'could happen to them', and they were unsure what they would do if they 'noticed' (in themselves) the early signs of dementia. Moreover, the legacy of caring meant that carers also had finely-tuned skills in problem-solving and day-to-day care of people with dementia, skills that became 'lost' when services were withdrawn. Much remains to be explored about the life and legacy of ex-carers, and the final stage of the integrated scheme, A New Beginning, provides an area ripe for additional empirical study.

The foregoing has provided a brief consideration of the way in which the grounded theory produced from this study has added to knowledge in the field of dementia care, as well as giving an indication of the areas in which there is scope for further research. Some of these points are elaborated upon below when policy and practice implications are addressed. Before moving on however, the potential for the theory to move from a substantive to a formal grounded theory is considered.

7.4 Moving the Grounded Theory from a Substantive to Formal Level: Some Pointers for Development

As rehearsed in chapter 3 (pp.81-82), a substantive grounded theory can move to a formal level by testing its findings in another, related, area of interest. Glaser and Strauss (1967) gave examples of this movement in their *Discovery book* relating to stigma, status congruency and social mobility, although they recognised that such a development is rarely approached as:

Formal theory can be considered too abstract {and} divorced from people and everyday life to seem real. (p.93)

However, this does not mean to say that it should not be attempted. In the dementia field, a recent example of this movement was provided by Hutchinson, Leger-Krall and Wilson (1997) when the authors applied Glaser and Strauss' (1965) typology of 'awareness contexts' (a substantive theory generated from the experience of death and dying in hospital) to people living with probable Alzheimer's disease. By conducting the study these authors found that 'awareness contexts' were a useful framework for understanding this transitional experience, and suggested that couples who developed an 'open awareness context' of the experience were able to view their relationship 'as becoming stronger' (Hutchinson, Leger-Krall and Wilson, 1997 p.1406). This finding has an obvious overlap to the conditions necessary to 'work together' reported in the present study, and the conceptual and abstracting properties of this process are ripe for further development.

Several more possibilities exist to turn elements of this study into formal grounded theory. The first, and perhaps most obvious, is to explore the properties of 'maintaining involvement' in other areas of chronic illness. This could be continued in the field of dementia care more generally, such as 'discovering' how professional workers 'maintain involvement' in the differing phases of dementia. Alternatively, 'maintaining involvement' could be applied to other areas of interest, such as in the field of learning disability, where its properties could be used to explore the dynamics of care and meaning attached to such inter-dependent relationships.

A further area that could be used to generate formal grounded theory from this study would be the application of the integrated scheme (Recognising the Need - A New

Beginning), together with its supporting basic social processes of Working Apart; Working Together; and Working Alone, to other caregiving/illness awareness contexts. One parallel area highlighted earlier in the thesis is the (subjective) awareness attached to developing Parkinson's disease, and the range of dynamics and experiences that could be encountered as the condition is acknowledged (for the person and then for others), diagnosed and 'worked through'. Basing a future project on the substantive findings from this study, and then layering them onto a 'new' area for conceptual development, would help to raise the ensuing grounded theory to a formal level if the integrated scheme and its supporting basic social processes were found to have utility.

The chapter will now consider some of the policy and practice issues that have arisen from this study.

7.5 Policy and Practice Issues

Attention is now turned to the potential for the study to inform policy and practice in dementia care. The section commences with a discussion on the policy context relating to the person with dementia, before moving on to explore a range of implications of the study for carers.

a) The Person with Dementia

From the time of commencing to completing this study, the momentum to move the person with dementia from the margins to the mainstream of social science research and practice provision increased significantly. This movement has highlighted the need to consider how dementia is constructed and perceived by others, both at an individual and societal level (see: Sabat and Harré, 1992; Cotrell and Schulz, 1993; Goldsmith, 1996; Bender and Cheston, 1997; Downs, 1997; Gwyther, 1997; Harding and Palfrey, 1997; Kitwood, 1997; Bender, 1998; Dabbs, 1999; Miesen, 1999).

Developments also need to be seen in the context of emerging drug therapies, such as Aricept® and Exelon® which, for the first time, are available for people diagnosed early in their dementia (for reviews and discussion see: Alzheimer's Disease Society, 1997; Norman, 1998; Packer, 1998). However, the impact of the current generation of drugs is uncertain with deterioration being slowed, rather than the process being reversed

(Hopker, 1999). As Birks and Meltzer (1999) report, whatever the *de facto* effects, they cannot be assumed to lead to better quality of life as greater cognitive awareness might, for instance, be distressing for people with dementia and their carers who have to 'struggle' once again with a heightened awareness of their situation. This argument was rehearsed in a recent letter sent to the *ADS Newsletter* by a carer, Mrs. Shirley Poustie, who was relating her experience to her husband's recent prescription of Exelon®:

Harry's {referring to her husband} mental agony and frustration manifested itself physically, often quite violently. He was restless again, trying to get to some unknown destination, feeling trapped if he could not get out and often lost if he did. (Poustie, 1999 p.8)

In this case Mrs. Poustie is simply asking whether it is 'kind' to prolong the 'agonising' earlier stages of dementia, particularly at the point where 'awareness' was heightened.

In the integrated model presented in the thesis, timing and the pre/post diagnostic relationship are crucial matters. If the drug therapy is introduced early, before the person enters the (heuristic) critical juncture of Fading Awareness, then it is likely that its effects would be more positive (presuming the drug therapy actually worked), potentially increasing the time available to Work Together (explicitly). In contrast, if it is prescribed later in the process, the person with dementia might move back to the (heuristic) critical juncture of Fading Awareness, with the carer and person with dementia having to re-live this experience. This prospect raises moral and ethical questions particularly when viewed through the rubric of quality of life. On the one hand, it could be seen as a denial of human rights to deprive a person with dementia access to treatment when there is at least the possibility of an improvement in cognitive performance. On the other, the prospect of treatment could raise false expectations and, as the previous example illustrated, diminish the relationship with the carer. Clearly, this is an issue that requires further empirical research and ethical debate as the new millennium approaches.

Moving beyond drug therapies, one of the few reports that directly considered the needs of people with dementia was that of the Social Services Inspectorate and Department of Health who visited five local authorities in England to consider the assessment of older people with dementia living in the community (Department of Health, 1996). This

influential report suggested that in each of the areas they visited, the interface between GPs, primary health care teams and other agencies, such as social services and secondary health services, was crucial to fostering assessment and care planning, with the 'focal point' of assessment being the GP. However, the report reaffirmed that GPs did not necessarily possess all the skills or interest to perform this task; a point reiterated in this thesis and other studies (see: O'Connor *et al.*, 1988; Fortinsky, Leighton and Wasson, 1995; Wright and Lindesay, 1995; Downs, 1996; Iliffe *et al.*, 1999). However, the joint report was careful not to lay all the responsibility at the feet of GPs, suggesting that all professionals had not developed their role sufficiently and that the key to effective joint working was the 'ability to show GPs that social work/community care had something to offer patients with dementia' (p.9). As the report suggested, GPs may be reluctant to refer people with (suspected or diagnosed) dementia to social services when their previous experience is of delays in assessment and little feedback on the outcome of the referral.

The above report (Department of Health, 1996) also included a discussion on the 'vital' need for early identification of dementia. However, in the areas visited, this was rarely the case as older people with dementia were not identified in the community until their problems became severe, thus limiting the range of services and support that could be offered. The report suggested that the annual over 75s health check was a 'good tool' for recognising (probable) dementia at an early stage, but few authorities had progressed this idea into a formal assessment procedure, and fewer still had integrated a mental health/memory 'screen' as part of the assessment process.

Reinforcing the above the findings, the current study suggests that people with dementia and their carers require early identification and intervention if their transition through dementia is to be as smooth as possible. For instance, following an early diagnosis and an agreement to Work Together, the carer and person with the early experience of dementia may wish to seek outside support to explore strategies for memory enhancement. However this is rarely available. Whilst such interventions are presently in their infancy, as Moniz-Cook *et al.* (1998) reported in their pilot study, psychosocial support appears crucial in helping to improve the well-being and adjustment processes for both the person with the early experience of dementia and their carer. The present study, by beginning to elaborate upon differing caring trajectories and the conditions

necessary to ensure that people 'work together', has the potential to inform practice in this area, but further empirical development is required.

While the last decade has witnessed a move towards sharing an early diagnosis (Alzheimer's Disease Society, 1995b,c; Pitt, 1997; Heal and Husband, 1998; Husband, 1999), little thought has so far been given to developing appropriate professional support (Moniz-Cook *et al.*, 1998) and to how to handle the disclosure of the diagnosis to the person with dementia (Rice and Warner, 1994; Gilliard and Gwilliam, 1996). Indeed, given the practice of not telling the person with the dementia about their condition, as seen in the phase 2 interviews, it is not surprising that those involved were often bewildered about the meaning and purpose of the 'assessment process' and the battery of cognitive tests that they completed. From the interview data, the assessment process only tended to lead to a poor early experience of professional interventions. Unfortunately, such experiences do not appear to be an isolated phenomenon, as the anxiety and misunderstandings over 'being assessed for dementia' were later shared in a larger, and separate, survey of people with the early experience of dementia (n=62) (Keady *et al.*, 1999a,b).

To improve the above situation two aspects of assessment might usefully be developed. Firstly, assessment could be improved by a greater awareness of the person's unique biography. The Gloucester project (Johnson *et al.*, 1989) described the input of services to older adults using such a framework and it found that the approach worked well. Second, biographical approaches to assessment suggest that the role of psychometric tests is more limited than is currently the case. Rather, what might be more helpful, is a model which places the person with (undiagnosed) dementia in a position of greater control so that their anxieties are lessened and a fuller picture of their circumstances emerges. Although formal testing still has a role, especially if there is a need to investigate sub-areas of cognitive performance, the person with (undiagnosed) dementia must be seen to appreciate its purpose, as one interviewee from phase 2 of the study revealed:

I wanted to have more say and information on what was happening to me. I never knew what was going on most of the time. I felt a little used to tell you the truth.

(interview: 67)

The potential for confusion and mis-communications in 'traditional' psychometric assessment must be avoided; rather, the assessor's first and most important task is to establish a common ground for a co-operative venture (see also: Bender, Levens and Goodson, 1995). This would mean that assessment would need to be completed more slowly, as trust and communication must be established, common goals discussed and a co-operative partnership negotiated. Informed by the results of the present study, Table 6 on the next page compares and contrasts a 'traditional' assessment with the 'person-respectful' model outlined above.

Whilst this approach will be more time-consuming, it may, by preventing or minimising alienation, require less time in the treatment phase, and thus be a more efficient and effective way of helping people tackle emotional problems. This of course requires additional empirical research.

Another way of improving the assessment practice is in the provision of information to the person with the early experience of dementia, and their carers. The Alzheimer's Disease Society responded to this challenge by compiling an information sheet 'What if I have dementia?' (Alzheimer's Disease Society, 1996a), and a more comprehensive booklet entitled 'I'm Told I Have Dementia' (Alzheimer's Disease Society, 1996b), although this latter booklet contained an unfortunate reference to 'brain donation' within its general advice on coping with memory difficulties. However, the provision of information remains an important first step, and much needs to be done to make information meaningful and useful to the lives of people with the early experience of dementia and their carers (see also: Moniz-Cook *et al.*, 1998). The author first identified this issue early in phase 2 of the study, and made tentative notes in his theoretical memo book to this effect. Following the author's presentation of the study to the memory clinic in May, 1995, this particular 'finding', together with the processes emerging from phase 2 of the study, were taken forward by Social Worker A at the memory clinic with the support of Professor A.

Table 6: Comparison of 'routine memory assessment' and 'person-respectful assessment'

	ROUTINE MEMORY ASSESSMENT	PERSON-RESPECTFUL ASSESSMENT
1.	Others, e.g. relatives, G.P., define problem/difficulty.	Person decides they have a problem.
2.	Others initiate actions, such as referral.	Person, through discussion with a professional, initiates action.
3.	Assumption by assessor that major problems already known.	Therapist seeks view of person and asks to elaborate on any difficulties.
4.	Since no opportunity to negotiate definition of situation, levels of anxiety and fear high.	Therapist strives to build-up a relationship of trust and low anxiety, in which person feels safe to explore problems.
5.	Fixed amount of time allocated to the process.	As much time as is needed/useful.
6.	A battery of tests is given.	Formal assessments only undertaken if agreed by person <u>and</u> in the context of problem solving.
7.	Same test battery given, with little variability, to all patients.	Tests only given if relate to expediting understanding of person-defined problem(s).
8.	A process of licence to act due to greater authority/power on part of assessor.	A cycle of informed consent.*
9.	Feedback often given to others (or aimed at others, even if patient present).	Feedback only to person in confidential relationship. Further communications to others the responsibility and choice of the person.
10.	Others decide appropriate action.	Therapy continues.
11.	Patient feels frightened, confused and powerless.	Person feels in control of situation and feels valued.

Source: Keady and Bender (1998 p.141)

* Prior "informed consent" would not be useful as what will happen is a function of negotiation between patient and therapist. Also, the similarity with surgical operations could make such a procedure counter productive.

The aims of this additional study (where the author had a liaison role) was to produce a more comprehensive overview of coping styles and information needs, together with a review of the strategy of diagnostic disclosure at the clinic. Social Worker A's study, completed over a nine month period, involved interviewing 9 people with the early experience of dementia. The transitional processes and stages reported here were seen to have utility, in terms of generating information needs and service requirements from people with the early experience of dementia. Three main points areas emerged from this and the second study, and these are rehearsed below (see also: Keady and Gilliard, 1999, pp.227-256).

i) Developing a Range of Information Needs

If service providers are going to offer people with cognitive loss for an early assessment and diagnosis, and if that diagnosis is then to be shared, an understanding of an individual's experiences and information needs is crucial. But what information do people with the onset of dementia actually want? From both studies this was often very difficult for people with dementia to articulate. One person with dementia was very clear that what he wanted was access to a central reference point as he felt he had been passed from 'pillar to post' during the time of his assessment and diagnosis. Other information needs emerging from people with the early experience of dementia were:

- Technical information about what was happening to their brain so that they could try to make some sense out of the maze in which they were living;
- Help to overcome feelings of anxiety during the diagnostic process. In particular information on what to expect from the assessment procedure; the purpose of the memory and screening tests; how long each test would last and the role of professional staff involved in the assessment procedure;
- Reassurance about the cause of dementia, especially that it was not their fault;
- Practical information about services and benefits to which they were entitled;
- Advice about coping within the caring relationship. People with dementia expressed a great deal of concern about the burden they posed for their carer; and
- Accessible information in various forms, such as via audio cassette, video cassette or large-print writing, which would allow for repeated access.

This initial attempt to generate information needs from the perspective of people with the early experience of dementia needs to be further developed so as to evaluate the impact of information-giving on people's lives (see also: Keady *et al.*, 1999b). However, what was heard loudest and most clearly in each study was what people with dementia did not want. In particular they did not want a lot of detailed information about the future. As one interviewee stated:

I don't know anything about it. I don't want to know. I just take things day by day. The only thing I know about it is eventually I won't be able to do the things I could do before and I shall be in a chair or something. But I don't want to know.

(interview: 66)

It seems that people with the early experience of dementia cope largely by taking things one day at a time. However, whilst this may be an effective coping strategy on a day-by-day basis, it could be difficult to sustain if the person avoids any attention to their future, and perhaps there is a place for accommodating such views through a living will (see also: Erin and Harris, 1994). For practitioners, therefore, a delicate balance will need to be struck between constructing practical support, information-giving and approaches to partnership around a philosophy that centres around day-to-day living, whilst still keeping an eye on the future. Brokering a path through such sensitive issues is the challenge for practitioners involved with people with dementia and their carers at this point in their lives.

ii) **Creating Separate and Distinct Services**

During the interviews there was, at times, a degree of hostility expressed towards the carer. The reason for this anger was distress that their carer was receiving group support to which they were not invited, although they were aware that they were being discussed. Some people with the early experience of dementia also stated that they would like the opportunity to discuss and share their feelings with others living through similar experiences, whilst others wanted the opportunity to learn how to improve their memory. In the present sample no professional staff from either health or social service authorities visited the person with dementia at home. The lack of involvement from outside agencies meant that people with dementia had no-one else to turn to. This created a tension as at times people with dementia wanted to keep additional losses from their carers, such as suddenly being confronted by additional lapses of memory, but,

paradoxically, they also wanted to share this development with someone who would understand. It would appear, therefore, that there is a need for people with the early experience of dementia to have access to an independent confidante outside the family relationship where, if they so choose, the person can discuss their fears and patterns of coping (see also: Froggatt, 1988; Keady and Nolan, 1995a; Keady, 1997). A step towards this partnership has begun in the formation of support groups specifically designed for people with the early experience of dementia, but as discussed earlier the development and availability of these groups still remains an exception rather than a rule (Reilly, 1995; Dabbs, 1999).

iii) Involvement in Professional Training

As the author highlighted previously, the early identification of dementia is crucial to empowering the person with dementia, but access to specialist services and centres, such as a memory clinic, is dependent largely upon geographical accident. Yet none of the informants in either the author's, or Social Worker A's study, associated their initial noticed 'signs' with dementia. This suggests a need to increase public awareness via local health promotion/education campaigns (see for instance successful studies by: Commissaris *et al.*, 1994; Commissaris, 1997). It is also crucial that the training of professional staff in dementia care practice generally, and the early experience of dementia specifically, is improved and that joint training programmes are initiated (Nolan and Keady, 1996a,b).

Moving beyond the information needs of people with the early experience of dementia, it is important to consider the issue of suicidal ideation and dementia, an area that has received relatively little policy and practice attention. However, where literature does exist (see: Alfonso and Cohen, 1994; Rohde, Peskind and Raskind, 1995) it is noticeable that successful attempts are associated with: an early diagnosis of dementia; a communication of the diagnosis and its prognosis to the person concerned; and the relative failure of drugs to improve cognitive performance. Although there is at present no empirical support, it is possible that a key 'danger point' for potential suicide may occur in the strategy of Closing Down. Hypothetically, it is at this point where some people with (undiagnosed) dementia may be unable to: rationalise their feelings and experiences of loss; draw on other compensatory coping strategies; rationalise their meaning; and 'construct a new me' from within a shifting reality. This may lead the

person to experience feelings of helplessness and hopelessness. From here it is only a short cognitive step to develop suicidal ideation (see: Williams and Pollock, 1993). Indeed, it is likely that it will be at this point that intervention and information may be most usefully targeted.

However, if a more therapeutic approach to intervention in the early experience of dementia is to be developed, there is a need for appropriate practice development, as little in the way of facilitative models currently exist (Whitehouse *et al.*, 1997). To begin to redress this balance, the findings of this study have been used to generate a new exploratory index for developing partnerships between practitioners, people with the early experience of dementia and, where appropriate, their carers. Based on the stages Keeping it Hidden and Sharing the Load (as originally formulated), and their supporting strategies, the author developed a forty-two item 'Index of Managing Memory Loss' (IMMEL) (Keady and Nolan, 1995b,c; and see: Appendix 8).

Whilst considering the use of IMMEL in a practice context, a number of caveats were suggested before its use was recommended (Keady and Nolan, 1995b p.313), and these are restated below:

- Memory use should be formally diagnosed before using IMMEL and the individual concerned should be willing to talk about its effects on their life. The individual's understanding of their condition must be clarified;
- The practitioner should establish a therapeutic and meaningful relationship with the person and his/her carer before IMMEL is introduced;
- Consent to complete IMMEL must be first obtained from the person with dementia and, where appropriate, their carer;
- Sufficient time to administer IMMEL should be made available and jointly completed by the person with dementia, their carer (if appropriate) and the carer. IMMEL should not be left solely with the person with dementia to complete on their own; and
- The role of the carer in the relationship must be established before the use of IMMEL.

In a second supporting article, Keady and Nolan (1995c) suggested that IMMEL challenged the prevailing attitude that people with dementia were simply passive recipients of their dementia whose voice could afford to be overlooked. Following its publication, IMMEL stimulated interest among numerous practitioners and clinicians, suggesting the need for further empirical testing and development of the index.

A further policy and practice development that emerged from the study was the publication of the Framework for Action in Dementia (FADE) (Keady and Nolan, 1995d). Drawing from the personal experiences of people interviewed in phase 2 of the study, the intention of the framework was to stimulate action and debate within the caring professions, particularly nursing. FADE further promoted an empowerment approach to people with the early experience of dementia, to help them to retain an element of control over their lives, as illustrated in Table 7:

Table 7: Framework for Action on Dementia (FADE)

Whilst fully acknowledging the need of family carers, individuals in the mild stage of dementia have a right to:

1. Be treated with dignity and respect at all times
2. Determine their environment of care
3. Remain in an environment of their choice
4. Have an enduring voice in assessment and care arrangements
5. Have an awareness of the diagnosis
6. Be given individually tailored information about prognosis and service entitlement
7. Have access, if required, to an independent confidante
8. Participate actively in decision-making
9. Have services tailored to their needs
10. Be given continuing, skilled and sensitive support

Source: Keady and Nolan (1995d p.1337)

FADE also challenged nurse educationalists to focus attention on the early experience of dementia, particularly in the development of the nursing role in memory clinics where (at the time) there was a complete absence of literature. Since this time the Royal College of Nursing have developed a training initiative and position statement on nurses working within memory clinics (Dewing and Pritchard, 1999), which drew heavily on some of the published findings from this study, particularly FADE and IMMEL. Encouragingly, other 'empowering' frameworks have also emerged, most notably the recent attempt by Alzheimer Europe (1999) to compile a seven item *Declaration of the needs and rights of people with dementia and their carers*. This *Declaration* is the first step in developing a common Charter for Alzheimer Europe and called for:

- Accurate and timely diagnosis;
- Information and understanding;
- Health and social care;
- A right to be involved in decisions about their own lives, to protection under the law and to the best available health and social care in the country where they live.

(Alzheimer Europe, 1999 p.7)

The *Declaration* noted that carers and family members are essential to the support of people with dementia, and that they have a right to be consulted and involved in the provision of care and development of services.

The implications of the present study for policy and practice with carers is outlined below.

b) Carers

As highlighted in chapter 2, it has been recognised for some time that an inadequate understanding of the progressive nature of dementia causes carers tremendous anxiety and stress (Barnes *et al.*, 1981). Zarit, Orr and Zarit (1985), in their important text on psychosocial approaches to dementia practice, suggested that practitioners should base their interventions with carers on a staged information-giving model which, they argued, would ameliorate the constant build-up of stress and anxiety in the carer. This approach utilised a straightforward problem-solving cycle, and the emphasis was placed upon the

consistent supply of local and national information on available support, augmented by practical, research-based advice on coping with emotional and challenging behaviour.

From the present study it was clear that many carers have their first prolonged contact with formal services during the transitional period following diagnosis (represented in the integrated scheme by the stages Taking it On and Working Through It), and it is very important that due account of the carers' perspective is taken at this stage. Yet analysis of the data from this study suggested that such support is rarely given, and that typically carers experience one or more of four experiences as follows:

- i) Banging my head against a brick wall;
- ii) Who's that knocking at my door?;
- iii) Caring in a vacuum; and
- iv) Be there when I need you.

(Keady and Nolan, 1995e)

Supported by the data, each of these experiences is explored in further detail below.

i) Banging my head against a brick wall

At the beginning of the active stage of caregiving, what carers wanted was: written and verbal information on the availability of support; an explanation of the diagnosis; and an introduction to practical coping skills. During the immediate post-diagnostic phase what was apparent from the data, was that information became a central plank to the process of adaptation and helped lay the foundation for future successful caring. The following two quotations help illustrate this point further:

Information about dementia helps me manage his different moods and know that it is not his fault. I now know how to respond and what to do. In the beginning I used to lose my temper all the time, which did neither of us any good.

(interview code: 24)

Information is so important as you have a guide of what to expect and ways of dealing with it.

(interview code: 29)

This personalised practical approach to the provision of information was, at the early contact stage of Taking it On, considered by carers to be crucial. Unfortunately, more often than not, a co-ordinated response was not forthcoming, which left carers confused and uncertain.

ii) Who's that knocking at my door?

Once a diagnosis had been made and services initiated to support the carer during the processes of Working Together or Working Alone (depending upon the timing and context surrounding the diagnosis), carers frequently reported feelings of uncertainty as to the role, and title, of those professionals providing help. During phase 1 of the study, one carer laughingly recalled that once her mother's diagnosis of dementia had been made, she was visited a few days later by the district nurse, occupational therapist and community psychiatric nurse all of whom turned up at the same time in their separate cars, to assess the level of help she needed. As the carer explained, she was still trying to 'come to terms' with the implications of the diagnosis, and the last thing she wanted was three strangers in her house, however well intentioned their visit.

The working/professional roles of community practitioners were also of great concern. Generally, carers understood the role of the GP, but the roles and titles of other practitioners were not as clear cut. For example, when the provision of the services of a 'community psychiatric nurse for the elderly mentally ill' was first mentioned to six carers in the study (interview codes: 13, 18, 23, 28, 35 and 38), their initial response can be summarised as 'acceptance with reservations'. For these carers, the title 'community psychiatric nurse for the elderly mentally ill' conjured up images of 'white coats', institutional care and, perhaps most worryingly of all, separation from the person they cared about. Indeed, the title was considered offensive to the extent that they nearly refused to accept the service. Several carers were also uncertain of the differences in roles between the district nurse and the health visitor for the elderly. As one adult child carer explained:

I want to know what you do. I don't understand your fancy titles. The best help I ever have is from the district nurse because she gives my father a bath and that really helps me cope as I know that he has been properly washed at least once a week.

(interview code: 30)

The clear implication here is that service providers need to explicate their roles, both to each other and to those in receipt of their services, if optimum benefit is to be obtained.

iii) Caring in a vacuum: the need for on-going information and relevant services

The importance of information at an early stage of caregiving has been already highlighted, but the need for on-going information in the active stage was a consistent plea made by carers. It was also an area in which community practitioners were seen as playing a potentially leading role. However, carers have varying needs for information, ranging from:

- Everything and anything on dementia as soon as possible (interview code: 22); to
- Just a little at first, I'm not sure how much I want to know (interview code: 16).

The diverse nature of information needs during this time reflects carers' individual personalities and coping styles. However, what became clear during the study was that community practitioners did not have a systematic method of responding to requests for information, and most carers relied on the Alzheimer's Dementia Society or other voluntary services, to fulfil this function.

Eight carers in the study, who did not receive the advice they needed from the primary health care team, actively sought information and went to the nearest library to find out about dementia from medical texts (interview codes: 5, 8, 14, 15, 19, 26, 32 and 37). A further four went to the Citizens Advice Bureau to find out about the support they were entitled to (interview codes: 6, 12, 21 and 33). When discussing the provision of information on dementia in health centres or clinics, most experienced carers in the study were aware only of the 'availability of leaflets' as a potential source of information, and only four had consistently received information from community practitioners (interview codes: 18, 23, 31 and 38) and in these interviews it was noticeable that the carer had received consistent support from one identified professional. Adequate information appears central to carers and people with dementia if empowerment is to lie at the heart of an effective stress-reduction model (see: Zarit, Orr and Zarit, 1985). Such information is particularly necessary in the active stage of caregiving described in Working Through It and beyond. However, from the interviews

conducted in this study, it would appear that carers' needs in this respect are not being met.

It was also apparent that whilst most carers valued information throughout the caregiving period, the nature and flow of this information varied. In the early stages of Working Through It, carers were largely recipients of information, at times eager to absorb all they could. Later, as they became more experienced, many carers had a strong desire not only to receive information, but also to give it. Whilst new information helped carers to adapt to their situation, information had also become a form of exchange; a means of enabling carers to experience a sense of expertise and mastery. For example, of those carers who attended a local support group, all commented that this was a valuable way of hearing what others had to say and of exchanging advice and support (interview codes: 8, 13, 18, 20, 22, 26 and 36), particularly at times of bereavement (interviews: 51, 52, 53, 54, 55, 56, 57 and 58). Indeed, as highlighted earlier, one carer commented that he was the 'local exchange bureau' and was constantly receiving calls from other carers asking him what to do in certain situations (interview code: 36).

The desire to exchange and explore information needs with others was viewed in a very positive light. Indeed, the chance to demonstrate expertise in managing dementia was seen as particularly useful, and many carers valued the opportunity to do so, especially with professional care workers. The contribution that carers can make in this regard should be valued and built upon by community practitioners, so that carers become partners in the true sense of the word. This allows carers to experience a sense of ownership and involvement, which helps both to validate and legitimise their role.

iv) Be there when I need you: the need for continuing support for the carer

As the transition through the experience of dementia continues, carers in this study placed great emphasis on receiving continuing support from members of the primary health care team. Often, however, either the carer was not seen as the 'client', or the services delivered were instrumental in nature and designed to maintain the carer in their role. This finding is consistent with national studies (Twigg and Atkin, 1994). Carers wished to be treated as full and equal partners and expected service providers to see them in this light. Indeed, this explicit focus on developing partnerships was more

recently expressed by the UK Government in their *National Strategy* for carers (Department of Health, 1999b) as follows:

Service providers must see carers as partners in the provision of help to the person needing care, and must involve them as partners. Carers need the help of the statutory services – working together – to provide the best possible care. (p.45)

The study suggests that the notion of partnership can be reflected in the ‘carers as experts model’ (Nolan, Grant and Keady, 1996), underpinned by the A-E problem-solving framework.

During the active stage of Working Through It, carers felt, as noted above, that it was important to have a key individual to whom they could relate, rather than having to rely on a range of people. Once contact with services had been made, most carers wished to be allocated a key worker with whom they could develop a continuing and trusting relationship (interview codes: 9, 13, 18, 23, 35 and 38). However, the present arrangements for care management and the separation of assessment from the delivery of services (Department of Health, 1990) does little, if anything, to foster such an arrangement.

Elsewhere the tenets of an informed choice has been described in the following way:

- Sufficient information on the illness/disease, its progress and treatment, to be able to form a realistic picture of the likely future, even if this is only to know that it is uncertain;
- On the basis of this information, carers will have a better idea of what is likely to happen. They should also be informed of what they can expect to receive in the way of support and services;
- There should be a full exploration of what it is reasonable to achieve in terms of caring. Discussion of the fact that there may well be times of emotional turmoil, anger and frustration and that these are normal reactions is useful. Furthermore, achievable standards for caring should be considered. Many carers set their own standards too high, leading to potential disappointment and failure; and

- The limits and burdens of care should be discussed, as should carers' rights to some time to themselves. Even at this early stage, it is appropriate to discuss situations in which alternatives to home care might be considered and what the alternatives are. Once again, setting realistic limits can do much to ease future decision-making.

(adapted from Nolan *et al.* 1994 p.32)

In the author's opinion, the stage of Taking it On should be seen as a priority in terms of professional intervention and support. It was recognised some time ago that the 'beginning' stage of care is a fertile period for instituting help (Bell and Gibbons, 1989) and recently a number of authors have reaffirmed this contention (Motenko, 1989; Braithwaite, 1990; Given and Given, 1991; Archbold *et al.*, 1992; Beach 1993; Langer 1993).

A key concept here is that of 'preparedness' (Archbold *et al.*, 1992) which is the extent to which carers feel able and competent to take on their role. High levels of preparedness, in terms of having the necessary knowledge, skills and emotional support are associated with lower levels of depression (Archbold *et al.*, 1992; Harvath *et al.*, 1994). Conversely, in circumstances where carers feel ill-prepared for their role, considering they have much to learn and are faced with an unpredictable situation, then levels of burden are higher (Braithwaite, 1990). Langer (1993) suggests that the critical question becomes 'how can carers navigate the passage of time with a reasonable sense of competence?' Certainly most carers do not initially have such a sense of competence and usually acquire their skills by a process of trial and error (Wilson, 1989a,b; Stewart *et al.*, 1993; Lea 1994; Harvath *et al.*, 1994) – this has also been described as 'flailing about' (Stewart *et al.*, 1993). Taraborrelli (1993) argues that most carers 'take it on' in a state of 'initial innocence' in which they have very little information and advice, and are generally ignorant of both the extent and the nature of the care they will be expected to deliver. This is by no means uncommon (Lewis and Meredith, 1988; Bell and Gibbons, 1989; Nolan and Grant 1992). Moreover, there appears to be little professional input at this time, and the limited support that is offered is largely confined to the physical aspects of care (Stewart *et al.*, 1993; Nankervis *et al.*, 1997). Those studies which have focused on the transitions to care suggest that 'new' carers who have previous experience, either of caring or of having worked in a 'caring' profession, are more likely to adapt quickly and successfully (Stewart *et al.*, 1993; Taraborrelli, 1993).

The remainder operate in the trial and error mode, although eventually many do become 'experts'.

Finally, at the other end of the caregiving spectrum, in recent months the proposals made by the Royal Commission Long-Term Care for the Elderly were made public in a report entitled *With Respect to Old Age* (Department of Health, 1999a). This report proposed to make all nursing and personal care, which included administering medication and help with washing and dressing, free to all those assessed as needing it, with the establishment of a National Care Commission to oversee the system. Whilst the report did not carry the unanimous support of all its members, it nevertheless challenged the current inequitable *status quo* whereby nursing care in hospital and most community care settings is free, but the moment a person enters a 'nursing home' it is charged for; an inequality compounded over the last decade by the steady, and quite dramatic, withdrawal of NHS provision of long-term beds for people with dementia (Alzheimer's Disease Society, 1997). As people with dementia make-up a significant percentage of residents in nursing home care (Alzheimer's Disease Society, 1997), the easing of the financial 'penalty' attached to admission would do much to assist carers at this difficult time, and perhaps, for practitioners, people with dementia and carers alike, help the decision-making processes identified in the stage of Reaching the End (see: Figure 8 p.157). However, whilst organisations representing older people (including the Alzheimer's Disease Society and Alzheimer Scotland – Action on Dementia) broadly welcomed the report and endorsed its proposals, the UK government has, so far, stopped short of accepting them. In part, this reluctance to implement the main parts of the proposals are associated with the projected rise of costs associated with such an initiative; indeed, commenting on the report, Frean (1999) suggests that if the proposals were implemented, the costs to the state would increase from the present £8.2 billion to £33 billion by 2050. It seems a shame that, once again, costs and a fear of ageing take precedent over the support and decision-making of ordinary people facing extraordinary circumstances. Rather than the 'chaos and faeces' of the past, perhaps it is this analogy that provides a more apt description of the experience of dementia.

In order to advance practice along the aforementioned lines, it is essential that greater attention is turned to the education and training of practitioners working with people with dementia and their carers. Recent studies in this area continue to demonstrate that

the education and preparation for all professional groups is inadequate, with little attention paid to developing assessment and intervention skills (Nolan and Keady, 1996a,b). This is a trend that must be reversed. For meaningful progress to ensue, it is essential that professionals begin to understand and respond to the experience of dementia as it is seen by those who live with its enduring impact and legacy (see also: Sällström, 1994). Arguably, it is here that the findings of the study have their greatest relevance as it presents a re-orientation of values and conceptualisation of the experience of dementia that can assist in the education and preparation for practice. For instance, providing training that outlines the steps necessary to 'work together' (pp. 230-231) would help clarify primary health care team responsibilities and roles for the early identification of dementia within a framework that is sensitive to inter-personal dynamics. It is little wonder that few older (or younger) people present at GP surgeries for memory assessment if their anxieties and fears are not acknowledged (Department of Health, 1996; Keady and Bender, 1998; Pritchard and Dewing, 1999), or they are 'screened' by professional groups who have little understanding of the meaning and complex nature of this task (Ford *et al.*, 1997; Nolan, Murray and Dallender, 1999; Secker, Pidd and Paraham, 1999). Incorporating the findings of this study within a broader educational programme may help to address some of the earlier concerns of Hasselkus (1988) and begin to build genuine partnerships between carers, people with dementia and professionals that stem, first and foremost, from its lived experience.

7.6 Grounded Theory: Methodological Considerations

The author hopes that the work contained in this thesis demonstrates the value and power of grounded theory, not only in the development of substantive theory, but in embellishing the theory with the necessary 'fit and grab' in order to inform policy and practice. This would seem to commend grounded theory to other researchers in the health and social care field. Indeed, grounded theory has been widely used, but in contrast to the Glaserian model adopted in the present study, most researchers have opted for the model by Strauss and Corbin (1990) (for a discussion see: Melia, 1996). It is important at this point briefly to reflect on why this might be the case in order to help other researchers make more informed choices. Certainly, the theoretical axial coding suggested by Strauss and Corbin (1990) provides a degree of structure and a greater sense of direction to data analysis. However, this is potentially at the expense of 'forcing' categories. Unfortunately, the

often complex way in which Glaser (1978; 1992) advanced many of his ideas, and the lack of guidance in key areas (see: chapter 3), means that the Glaserian model may be inaccessible conceptually to the 'beginning' researcher. Moreover, the time-consuming nature of the approach, particularly the constant comparative method, may make it unrealistic in the fast-changing world of present day social research. Certainly, few researchers would be able to spend the years on data collection and analysis that were required in the present study, albeit on a part-time basis. This section will therefore begin with some methodological reflections on working within a grounded theory approach.

a) Working Within a Grounded Theory Approach: Some Personal Reflections

In operationalising a qualitative research design, grounded theory remains a popular choice in diverse areas of health and social care research (see for example studies by: Cowley, 1991; Henwood, 1993; Hilton, 1993; Wilde *et al.*, 1993; Riessman, 1994; Stern and Kerry, 1996; Bererö, Eriksson and Ek, 1997; Byrne and Heyman, 1997; Arden, 1999). Moreover, the continued contribution of grounded theory to the general advancement of qualitative research has been noted by several commentators (see: Bowers, 1988b; Charmaz, 1990; Guba and Lincoln, 1994; Richardson, 1996), with the element of theory verification inherent in the constant comparative method serving to convince more quantitatively driven professions, notably psychology, of its benefits in exploring human behaviour (for a discussion and case illustration see: Pidgeon and Henwood, 1996).

However, after studying grounded theory for a number of years and working through a modified Glaserian approach, the author would raise two main concerns about its overall accessibility for existing/future research usage, namely:

- i) The schism between the co-founders of the grounded theory methodology that continues to divide and dilute the approach; and
- ii) The unnecessarily complex and, at times, ambiguous language used to communicate some of its basic concepts.

Developing point (i) first, the schism in the grounded theory approach that was evident when the author first began this study, continues to the present. Fundamentally, this schism rests upon two opposing viewpoints. On the one hand, Glaser (1978) asserts that

the temporal development of 'theory as process' is central to the emergence of grounded theory, being driven by: constant comparative analysis of the data; the depth of the analysts' theoretical sensitivity to the phenomenon under study; and the continual use of theoretical memos to document, shape and test conceptual thinking. Moreover, Glaser (1978) requires the analyst to be creative in their approach to analysis and to 'trust' in the notion of emergence of theory from data. On the other hand, Strauss and Corbin (1990) contend that a more transparent and formulaic analytical process is necessary in order to generate grounded theory, and that this is best achieved through the application of a pre-set 'conditional matrix'. Only by following a pre-set 'conditional matrix', Strauss and Corbin argue, can rigour and transparency be integrated into the grounded theory research process, and confidence be placed in the findings (in this thesis, for a more detailed appraisal of the existing divide in grounded theory, see: chapter 3 pp.85-89).

With both approaches retaining the name 'grounded theory', this polarisation of the methodology has led to more than a little confusion for potential users over which approach to adopt, and uncertainty if findings actually comprise 'a grounded theory'; a point echoed by leading grounded theorists from both the UK (see: Melia, 1996) and the USA (see: Charmaz, 1990; 1995). However, if author-based citations of peer reviewed 'grounded theory' studies are used as a measure of its utility to the wider academic/practice community, then there is little doubt that the approach advocated by Strauss and Corbin (1990) dominates. For instance, even a cursory glance through the 'methodology' sections of the previously cited grounded theory papers, reveals little mention of Glaser's contribution over and above his role as a co-author of the *Discovery book* (Glaser and Strauss, 1967). Certainly, in these published accounts, there is little attempt to discuss the emergence of: theoretical sensitivity; memo writing; basic social processes; linking schemes; and so on, or to test the properties of 'formal grounded theory' as indicated in the original methodology (Glaser and Strauss, 1967). It was probably this lack of recognition that led Glaser, early in 1999, to establish, and direct, 'The Grounded Theory Institute' at the University of California to promote and disseminate his beliefs on the future direction of grounded theory. However, for the methodology itself, this initiative hardly promulgates a unified vision for the future. Moreover, if a Glaserian model is to be followed, then many of its canons require much clearer exposition.

Moving on to the second point (ii), throughout *Theoretical Sensitivity* Glaser (1978) introduced a new conceptual language to explain his revision to the general method of grounded theory, but, at times, left the reader struggling to interpret their meaning. For instance, whilst the difference between a 'linking scheme' (the emergence of 'maintaining involvement') and an 'integrated scheme' (Recognising the Need to A New Beginning in the carer's model) is now reasonably clear, whilst initially struggling through the supporting text such subtle differences in meaning were often hard to appreciate, particularly when they were presented without supporting examples or, worse, as a *fait accompli*, as in the original presentation of 'theoretical saturation' (see: Glaser and Strauss, 1967 pp.61-62). Moreover, Glaser's emphasis on academic style over practical illustration, does little to convince the reader of the accessibility of the approach.

In this study, developing a 'working knowledge' of Glaser's thoughts to generating grounded theory was best achieved by continually applying the meaning of the approach to the data under study, and using theoretical memos to help clarify conceptual thinking. Arguably, it was also the author's motivation to understand further the language of grounded theory that enabled him, under supervision, to tease out meanings and links in the data; in turn, this could be seen to produce a 'creativity' in data analysis that Glaser requires from students of (his) methodology. As the author found to his cost, however, this is a time-consuming process and Glaser's basic 'trust' in the analyst can, at times, be disconcerting and create a feeling of anxiety, particularly when links in the data become hard to find and/or there is an uncertainty if the properties of an emerging process actually comprise a stage, phase, dimension, strategy, tactic, and so on.

In the author's opinion, this has created a vacuum of uncertainty in the foundations of grounded theory, and allowed respected champions of qualitative research, such as Morse (1994), to advocate a homogeneous analytical approach that simply overlooks the finer points of the methodology. In advancing her argument, Morse (1994) does not believe that findings simply 'emerge' from the data and argues strenuously that there are four cognitive, and sequential, processes integral to all qualitative methodologies, these being: comprehending; synthesising; theorizing; and recontextualizing. For instance, in the first process of 'comprehending', Morse (1994) contends that researchers use 'all means at their disposal', including existing literature, to find out as much as possible

about the subject area before entering the field. Whilst the author has a broad level of agreement with this assertion, and indeed used it himself as part of his own modification to the grounded theory approach (see: chapter 3 pp.91-92), it is antithetic to the methodology if it is promoted without reference to developing theoretical sensitivity; a point Morse (1994) fails to consider. Indeed, in developing the properties of 'comprehending' further, Morse (1994) goes as far as suggesting that:

... if the researcher has a previously established work role in the setting, then qualitative work is handicapped. (p.27)

Quite why qualitative research should be 'handicapped' in this way is not made explicit, but Morse's revision to grounded theory clearly inhibits a prior clinical knowledge of the subject area by the interviewer/researcher before entering the field, a dimension that could be considered essential if theoretical sensitivity is to emerge. This will be returned to again shortly.

The difficulties in understanding some of Glaser's writings has, in the author's opinion, resulted in a truncated view of grounded theory which dilutes the methodology. Therefore, studies purport to follow a 'grounded theory approach' (see for instance: Wilde *et al.*, 1993; Hart, 1998) but are, in reality, only pale imitations of Glaser and Strauss' original thinking; Bryman and Burgess (1995) previously summarised such studies as having a 'general disposition towards grounded theory' (p.221). This is an unfortunate outcome as, in the author's experience, the conceptual power of grounded theory rests upon its process of temporality and ability to integrate theory verification and theory generation within the constant comparative method; this can only be achieved successfully if it is supported through the theoretical sensitivity of the analyst, and underpinned by the philosophy of symbolic interactionism to help guide a theoretical understanding of the 'generalised other'. Perhaps what is needed is a more accessible and instructive text that helps promote and guide such an approach.

Whilst the author has, so far in his reflections, perhaps been rather critical of the grounded theory methodology, it is only proper to temper this impression. Without the contribution of Glaser to the methodology, the author firmly believes that he would have been unable to produce the theory as presented in this thesis (whatever its merits), as it was Glaser who encouraged the development of theory as process, placed trust in the

sensitivity and 'skills' of the analyst (however burdensome this may, at times, have felt), and couched the temporal processes in the language of: stages; phases; basic social processes; critical junctures, and so on. Without this contribution, and Glaser's faith in the relative merits of 'thinking about data', the author may well have overlooked the development of the dynamic decision-making processes and critical junctures that, for people with dementia and carers (both individually and jointly), appear to underpin their transition and adjustment over time.

Specifically, after working through a modified version of the methodology, the author would also highlight the importance of developing and keeping theoretical memos as part of generating a substantive grounded theory. Glaser (1978) had previously described this process as 'the core stage in the process of generating theory' (p.83) and, as the author embarked upon data collection and constant comparative analysis, he quickly learnt to appreciate the value of this advice. Shortly after completing the first interview in the study, the author challenged Glaser's (1978) notion that theoretical memos (and *de facto* the theoretical memo book in which they are stored) are only for 'the theorizing write-up of ideas about codes' (p.83), and started to keep a more detailed longitudinal record of the research process. The author first approached this record by assimilating the following markers into his theoretical memo book:

- Documenting detailed, and dated, methodological notes and reflections after each research encounter;
- Documenting the process of conceptual development and linkage (however tenuous), using the theoretical memo book to record, and sketch, thinking in such areas;
- Using the theoretical memo book as a guide to receiving research supervision; and
- Transferring key passages from interview transcripts to dated pages in the theoretical memo book(s) in order to trace, and empirically support, the development and properties of emerging processes.

By adopting this approach throughout the study, the author found that his theoretical memo book(s) acted as the primary source of theory development, particularly in the conceptual development of processes and the clarification of inter-relationships in the data; a process documented throughout chapters 4, 5 and 6. Accordingly, and in

agreement with Glaser (1978) and other commentators (see: Bowers, 1988b; Charmaz, 1990; 1995; Melia, 1996; Pidgeon and Henwood, 1996), the author would contend that developing a systematic method of memo recording to support the constant comparative approach is a cornerstone of a (Glaserian) grounded theory as it keeps the researcher/analyst 'in touch' with the data under study, and with the experiences of those who comprise a 'theoretical sample'. The author found the ability to 'keep in touch' with participants essential whilst undertaking interviews, particularly those of a sensitive nature, as the expression of genuine interest provided a firm foundation for the ensuing interaction.

Having briefly considered some of the methodological issues emerging from the study, attention is now turned to another area of interest, the potential conundrum that can arise when interviewing about sensitive topics and the lessons that a practitioner-researcher may face.

7.7 Dilemmas in Data Collection

As the author discovered during the three phases of this study, interviewing as a method of data collection raises several important points. For instance, the author found that generally carers and people with dementia were grateful for the opportunity to 'tell their story', and that this facilitated a process of 'unburdening'. This does not seem to have been addressed previously in the grounded theory texts. Whilst conducting this study, therefore, and in common with other qualitative studies involving sensitive areas, for example exploring communication patterns when coping with early stage breast cancer (see: Hilton, 1993), the interview itself was found to have a therapeutic element. As Ramos (1989) has argued, this not only 'complicates' the research process, but also extends the responsibilities of the researcher to potentially providing comfort, advice and support; a point more recently echoed by Reed and Proctor (1995).

For carers, this process of 'unburdening' was particularly helpful and may have been facilitated by prior knowledge of the author's nursing background; this was however a 'double-edged' sword, and at times made it difficult, if not unacceptable, to remain simply as 'the interviewer'. Therefore, at times, the author felt it was appropriate to take a more therapeutic stance, such as when carers:

- Expressed ‘guilt’ about admitting the cared-for person with dementia into a residential or nursing home care, having subsequently received little or no follow-up support from community staff;
- Reported an absence of satisfaction in the caregiving relationship, and feelings of being ‘trapped’ in the role;
- Expressed a fear of the ‘future’ and the potential for genetic transmission of Alzheimer’s disease to their children - this was particularly (but not exclusively) evident for younger carers of younger people with dementia; and/or
- Shared ‘secret knowledge’.

As an illustration of this latter case, during an interview with a (younger) carer about his emotional relationship with his wife (interview: 7), the carer unexpectedly broke down in tears and informed the author that, for the last two years, he had ‘spent her money {referring to his wife’s attendance allowance} paying for sex’. From the nature of this disclosure, it was evident that this was the first time the carer had revealed this behaviour to anyone else, and his emotions were expressed through a combination of shame, guilt and fear. As the interview developed and the carer felt more relaxed in discussing this part of his life, it emerged that he ‘paid for sex’ as he did not want to take advantage of his wife’s inability to consent to sexual intercourse. This situation, the carer believed, was ‘intolerable’ on three accounts. Firstly, he still experienced the physical needs of, in the carer’s words, ‘any ordinary man his age’. Second, he believed he had been ‘unfaithful’ to his wife and broken their marital vows; after the disclosure the carer was at pains to point out that ‘he had never done anything like this before’ and had waited three years after the diagnosis until taking this course of action. Third, he felt his ‘guilt’ was compounded by the need to be seen (and want to be seen) as a ‘loving and caring husband’, an image he particularly wanted to nurture and sustain in front of their children and local community. As it emerged in the interview, the carer believed that if his ‘secret’ activity was discovered then this carefully nurtured image would be ‘shattered’, a process that could only result in further emotional pain and upset.

For the author, managing the cathartic nature of this disclosure, whilst remaining non-judgmental and supportive, was essential. The author has little doubt that his clinical experience both helped him to cope with this disclosure, and helped the carer to reflect on his actions. Following the interview and a period of reflection, the carer felt it important that the potential for his story to 'help others' was explored. Therefore, with his permission, the author was able to include his experiences in exploring issues facing carers of younger people with dementia (see: Keady and Nolan, 1997; 1999). Subsequently, the author has received many letters of support and understanding for this specific contribution, with each item of correspondence then forwarded to the carer concerned. Indeed, as this action intimates, communication with the carer is still ongoing, and even though his wife has now died, the carer believes he has contributed 'something' to the on-going debate about the lives and circumstances of family carers.

To take another example, on one occasion during an interview the author provided practical advice to a carer on how to claim statutory benefits in order to support her domestic caregiving situation (interview: 35). This advice was provided when the carer was speaking tearfully about her lack of financial resources, with worry over paying the gas bill having stopped her 'putting on the fire at night' when her husband was 'up and around with next to nothing on'. As this interview progressed, it emerged that the carer had not been informed by statutory service providers about her husband's entitlement to attendance allowance, and the carer had lived in ignorance of this for some time. On hearing this, the author felt uncomfortable about not sharing this basic information with the carer as provision of the financial entitlement for 'day and night' attendance allowance - for which the person with dementia clearly qualified - would have helped to improve their quality of life. On the other hand, by taking such direct action, the author failed to meet the 'objective' criteria that some would claim is the benchmark of good empirical data collection (Bulmer, 1984b; Denzin, 1989; Morse, 1994), and could be accused of drifting too far away from a 'conversation with a purpose' as some have called a grounded theory interview (Chenitz, 1986).

Perhaps when researchers are also health (or social care) practitioners in the area under study, there are no easy solutions to be found and a trade-off will have to be made between, on the one hand, the depth of understanding of the subject area that could aid theoretical sensitivity and data analysis, and on the other, the possibility for 'role

blurring' to occur (see also: Buckeldee, 1990). For nurse researchers, such an ethical dilemma was not addressed in recent guidance (Royal College of Nursing, 1998), with this guidance suggesting that the benefit of the research process to participants was 'most likely to become apparent only some time after the completion and publication of the work' (p.7). However, this statement clearly overlooks the possibilities for research interviews to be cathartic and therapeutic in nature.

Based on the author's experience from conducting this study, intervening within the context of a qualitative interview can be justified in certain cases. This needs recognition and further debate in the methodological literature. It is perhaps important to acknowledge that the flow of information in a research interview is not a one way process from subject to researcher, but a partnership. Support for this opinion can be found in the work of Coyle and Wright (1996) who suggested that interviewers in sensitive areas also practice counselling skills in order to help people cope with the potential stress of the interview process:

... it verges on the unethical for a researcher to address sensitive issues with respondents, restimulate painful experiences, record them and then simply depart from the interview situation. (pp.432-433)

In a similar vein, whilst interviewing people with the early experience of dementia, it was also the author's experience that his (past) clinical role and knowledge made it easier to elicit information from participants; a perspective noted by other commentators who have previously, contemporaneously and subsequently conducted similar interviews (see for example: Froggatt, 1988; Cromwell, 1994; Wuest, Ericson and Stern, 1994; Gillies, 1995; Rohde, Peskind and Raskind, 1995; Goldsmith, 1996; Bender and Cheston, 1997; Reid, 1998; Husband, 1999). During these phase 2 interviews there was an implicit expectation of the researcher to become involved and to respond in a humanistic manner to what the interviewee was saying, and to place an emphasis on developing trust from the earliest possible moment in the research encounter. Paradoxically, it was also necessary to 'play down' the significance of the research interview whilst still ensuring informed consent to participate; the author found that this was best achieved through the (safe) self-disclosure of personal details, and showing genuine interest in the person, their surroundings and the person they were living with. Furthermore, having clinical knowledge and sensitivity about the impact of dementia on

levels of cognitive functioning and language expression, also helped the author during the interview process to decide when it was best to terminate such interviews, for instance through the person's repetition of subject matter and/or subtle non-verbal signs of distress. Indeed, and in agreement with Froggatt (1988), the author would contend that holding such knowledge is an essential pre-requisite for conducting interviews with people with the early experience of dementia.

Understanding further the research protocol and ethical boundaries for involving people with the early experience of dementia in research activity could constitute a proactive way forward for the study and, indeed, recent findings from a pan-European project would appear to underscore this direction (Høeg, Nielsen and Samuelsson, 1999). On a more practical level, the author hopes that the study findings could be tested and refined further, within both the dementia-specific setting and also the broader context of family care (for an illustration of this latter aspiration see: Nolan, Grant and Keady, 1996). For people with dementia, one particular avenue that is ripe for further empirical study and development is the basic social process of Working Alone and its application to people who live alone with dementia. As highlighted earlier in the text, this is one area where much remains to be achieved and understood. In a similar vein, conducting a longitudinal study that tests out and develops the stages and critical junctures presented in the thesis with a small sample of people with dementia and their carers could be an exciting, and potentially enriching, way forward.

Having considered the development and applicability of the presented grounded theory, the author will now discuss the study limitations.

7.8 Study Limitations

Glaser (1978) acknowledged that 'theory will always contain gaps' (p.10), and that it is the existence of gaps in knowledge that leads to further empirical study and a more critical appraisal of existing theory. While the author considers that the theory as presented is robust, it has raised numerous areas for further research and these have been alluded to throughout this final chapter. Two specific limitations of the study however deserve specific attention, these are:

- a) Family caregivers comprising the study sample; and the
- b) Methodological weakness of relying on cross-sectional interviews.

a) Family Caregiving Comprising the Study Sample

By focusing on the experiences of people with dementia who were supported through a family network, the study failed, more generally, to account for two salient experiences. Firstly, the social networks and support of friends and neighbours, whose contribution to the support of people with dementia living in the community has been recognised for some time (see for example: Levin, Sinclair and Gorbach, 1989; Wenger, 1994). Second, the study did not gather data on the experience of people with dementia who live on their own.

Starting with the first point, the original purpose of the study was to continue the existing work on family carers at the University of Wales, Bangor (see for instance: Nolan, Grant and Ellis, 1990; Nolan and Grant, 1992), and to supplement this with the specific experiences of family carers of people with dementia, a perspective that was to be assimilated into later publications which had a direct relevance to practice (see in particular: Nolan, Keady and Grant, 1995; Nolan, Grant and Keady, 1996; 1998). This study was therefore a product of the area in which it was conceived. However, it is important to recognise the role of other support networks in dementia, and the relevance of the theory presented in the study requires further testing and refinement in this area.

On the second point, the experience of living alone with dementia is seriously under-researched, and this probably stems from the practical and ethical difficulties involved in designing a study that secures early participation and informed consent to take part. From informal discussion with clinical staff at the memory clinic during the time of phase 2 data collection, it was reported as being 'extremely unusual' for a person to present at the clinic on their own. From the findings reported in this study, the clinic staffs' observations probably reflect the lack of Working Together and 'opening up' that were seen to form the start of a (joint) decision-making process integral to seeking early medical help on the cause of the 'unusual' experiences. For people with (undiagnosed) dementia living on their own, it is probably much easier to deny and/or cope with the onset of memory loss or forgetfulness in the absence of challenge from another.

However, for people living on their own with (undiagnosed) dementia, recognising these signs as part of an illness experience, and then deciding to do something positive about it, raise major policy and service issues (Department of Health, 1997). The Alzheimer's Disease Society, in one of the few surveys on the area, suggested that in the UK there are 154, 000 people living on their own with dementia, with half this total being aged 85 years or over and exposed to increased risks, such as: undetected self-neglect; financial exploitation; and falls (Alzheimer's Disease Society, 1994). Clearly further work is needed in this area.

b) Methodological Weakness of Relying on Cross-Sectional Interviews

Inevitably, any study has to operate under financial and temporal constraints and these impose limitations on the data that can be collected. By and large interviews in the present study were 'one-off' events and this affected the opportunity to 'check-out' informants' interpretations of the data collected, although this was possible in some cases (interviews: 7, 39, 41 and 60). Whilst the constant comparative method and theoretical sampling in grounded theory compensates for this to a degree, the limitations of a 'one-off' interview have to be acknowledged.

Perhaps more importantly in seeking to explore a temporal process, the limitations of cross-sectional interviews must be confronted. As Nolan, Grant and Keady (1996) point out in their review of the literature, the majority of studies in family caregiving have been cross-sectional and they advocate the need for more longitudinal work. Although this represents the ideal, the challenges, both financial and operational, of repeated interviewing over a period of several years, are quite apparent. One way forward in testing the presented theory might be to collect data over a longer period to try and capture some of the key transition points and relevant dynamics. However, it is only when funding bodies recognise the importance of a longitudinal perspective, is progress in the area likely to occur.

7.9 Conclusion

A few years ago, and highlighting the lack of any dementia-specific recommendations in the mental health review (Department of Health, 1994), the author suggested that a review of dementia care nursing in the UK was necessary to both consolidate areas of

practice and to clarify the future direction of the profession (Keady, 1996). After undertaking this study and keeping abreast of the literature (as far as possible given the plethora of available journals) and practice initiatives, little has changed to alter the substance of this observation. Indeed, reflecting on the research process and findings that underpinned this study, it is noticeable how much emphasis the author first placed on the need for this study to develop and re-orientate 'practice'. For the author, at the outset of the research process, to be an effective practitioner it seemed important to complement and build upon the carer's level of understanding, and to do this required a new way of looking at the experience of dementia.

The development of the theory presented in this study, and its policy and practice implications, attempt to reflect this vision. At times brokering a path through the research process has been complex, and the author is under no illusion that many challenges lie ahead in operationalising some of the concepts presented here. However, if this re-orientation of the experience of dementia is seen as being meaningful, and the findings used to influence practice, then the exercise will have been worth the effort.

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APPENDIX 1

**SEMI-STRUCTURED INTERVIEW GUIDE
FOR CARER INTERVIEW**

Interview Guide for Carer Interview

Open, qualitative section

1 Introduction

- self
- background
- experience
- study aims
- confidentiality of replies

2 Caregiver Personal Account

General discussion about caregiving history to allow carer to describe their situation in their own words. Topics would include:

- Entry to caring role
- Experiences of caring
- General perceptions of:
 - i difficulties experienced
 - ii satisfactions experienced
 - iii coping strategies used

a) *Caregiver* - Coping strategies

- Onset
- During
 - mild
 - moderate
 - severe

b) *Family* - Coping strategies

- Onset
- During
 - mild
 - moderate
 - severe

Perceptions of whether difficulties and coping are more or less difficult over time.
Range of help received (and satisfaction with) from:

- Family
- Other informal
- Statutory/Voluntary/Private

Perceptions of any particular expertise gained as a carer.

COMPLETE STRUCTURED QUESTIONNAIRE

Structured Questionnaire for Caregiving History, Difficulties, Satisfactions and Coping

SECTION ONE

About the person you care for and your current situation:

1.1 What is their age? _____ Years _____ Months

1.2 Are they male female

2 How long have you been caring for him/her: _____ Years _____ Months

3.1 Is the person you care for your:

- Father Mother Husband Wife
 Son Daughter Son in Law Daughter in Law
 Brother Sister Other Female Relative
 Other Male Relative Female friend/neighbour
 Male friend/neighbour

3.2 If spouse, how long married: _____ Years _____ Months

4.1.1 Do you live in the same household? Yes No

4.2 If YES please indicate below the age and relationship to you of all other individuals sharing your house:

Relationship to you	Age
_____	_____
_____	_____
_____	_____
_____	_____

4.3 If NO how far away do you live from the person you care for:

- Under half a mile Under a mile
Between 1-5 miles Over 5 miles
-

5 How often do you provide care and/or supervision?

- Constantly night and day Constantly by day
Constantly by night Frequently during the day
Daily Less than daily, more than weekly
Weekly or less often
-

6.1 In addition to your caregiving role, are you in paid employment?

Yes No

6.2 *If YES is this:* Full time Part time

6.3 *If NO is this because:*

You have never been employed

You retired from work and later became a carer

You gave up work to look after the person you care for

Other reason (*please specify*) _____

7. Code responses to the questions below in the following way:

Help: (*includes direct assistance and/or supervision*)

	<i>Score</i>
Help needed throughout/unable to perform	3
Help with part of activity/can perform part of activity	2
Can complete independently	1
Frequency: Frequently (<i>at least daily</i>)	5
Regularly (<i>3-6 times a week</i>)	4
Occasionally (<i>once or twice a week</i>)	3
Rarely (<i>less than weekly</i>)	2
Never	1
Stressful: Very	3
Moderately	2
Not	1
Coping How do you personally deal with it (<i>list open response</i>)?	

8 How much help does the person you care for need with:

Task	Help	Frequency	Stressful
Washing			
Dressing			
Feeding			
Toileting			
Walking			
Bathing			
Household Tasks			

9 Does the person you care for ever have problems with their continence?
(Do they ever wet or soil themselves)?

	Frequency	Stressful	Coping
Wet during day			
Wet during night			
Soil during day			
Soil during night			

10 Does the person you care for:

	Frequency	Stressful	Coping
Have a tendency to wander in their home environment			
Have a tendency to wander out of their home environment			
Behave in a way which could be considered as a danger to themselves			
Have difficulty remembering the time of day			
Have difficulty remembering where she/he is			
Behave in an embarrassing way			
Behave in a way which you find upsetting			
Become uncooperative with your requests			
Have difficulty holding a normal conversation			

11. *I will now read you some statements that other carers have made about the sorts of difficulties they face. For each statement could you please tell me three things:*

11.1 If this applies to your situation

- A. All of the time 3
- B. Some of the time 2
- C. Never/does not apply 1

11.2 How stressful you find it:

- A. Very 3
- B. Moderately 2
- C. Not stressful 1

11.3 How you normally deal with that difficulty

Statement			
<i>Caring can be difficult because</i>	Frequency	Stressful	Coping
I don't have enough private time for myself			
I sometimes feel helpless/not in control of the situation			
I can't devote enough time to other family members			
It causes financial difficulties			
The person I care for sometimes manipulates me			
The person I care for is immobile/has problems getting about			
Professional workers don't seem to appreciate the problems carers face			
It restricts your social life/outside interests			
It can put a strain on family relationships			
It is physically tiring			
The person I care for can demand too much of me			

Statement			
<i>Caring can be difficult because</i>	Frequency	Stressful	Coping
I no longer have a meaningful relationship with the person I care for			
The person I care for needs a lot of help with personal care			
The person I care for doesn't always help as much as they could			
My sleep is affected			
Relatives don't keep in touch as often as I'd like			
I feel angry about the situation			
I can't see friends as often as I'd like			
My emotional well-being suffers			
I can't have a break or take a holiday			
My standard of living has fallen			
The person I care for doesn't always appreciate what I do			
The person I care for is incontinent			
The behaviour of the person I care for is a problem			
There is no satisfaction to be gained from caring			
I don't get enough help from the health and social services			
Some family members don't help as much as they could			
I can't relax because of worry about caring			
I feel guilty about the situation			

Probe to see if any areas left out

12 *Now a few questions about YOUR health:*

12.1 How would you describe your present physical health?

Excellent Very Good Good
 Fair Poor Very Poor

13 How would you describe our present emotional well being?

Excellent Very Good Good
 Fair Poor Very Poor

	<i>Yes</i>	<i>No</i>
Do you often have backache	1	2
Do you feel tired most of the time	1	2
Do you often feel miserable or depressed	1	2
Do you often have bad headaches	1	2
Do you often get worried about things	1	2
Do you usually have great difficulty in falling asleep or staying asleep	1	2
Do you wear yourself out worrying about your health	1	2
Do you often get into a violent rage	1	2
Do people often annoy and irritate you	1	2
Do you at times have a twitching of the face, head or shoulders	1	2
Do you often suddenly become scared for no good reason	1	2
Are you scared to be alone when there are no friends with you	1	2
Are you easily upset or irritated	1	2
Are you frightened of going out alone or of meeting people	1	2
Are you constantly keyed up or jittery	1	2
Do you suffer from indigestion	1	2
Do you often suffer from an upset stomach	1	2
Are you frightened of going out alone or of meeting people	1	2
Are you constantly keyed up or jittery	1	2
Do you suffer from indigestion	1	2
Is your appetite poor	1	2
Does every little thing get on your nerves and wear you out	1	2
Does your heart often race like mad	1	2
Do you often have bad pains in your eyes	1	2
Are you troubled with rheumatism or fibrositis	1	2
Have you ever had a nervous breakdown	1	2

14 Whilst caring is often difficult some carers also find it provides them with some moments of satisfaction and achievement. Here are some statements which carers have made about those aspects of caring that they find satisfying. For each statement I read will you please tell me how it applies to you.

Caring can be satisfying because	Does not apply	This applies and provides:		
		No real satisfaction	Quite a lot	A great deal
Caring has allowed me to develop new skills and abilities				
_____ is appreciative of what I do				
Caring has brought me closer to _____				
It's good to see small improvements in _____'s condition				
I am able to help _____ reach their full potential				
I am able to repay the past kindness of _____				
Caring provides a challenge				
Despite all their problems, _____ does not grumble or moan				
It is nice to see _____ clean, comfortable and well turned out				
Caring has enabled me to fulfil my sense of duty				
I am the sort of person who enjoys helping people				

Caring can be satisfying because	Does not apply	This applies and provides:		
		No real satisfaction	Quite a lot	A great deal
I get pleasure from seeing _____ happy				
Knowing _____ the way I do means I can give better care than anyone else				
It helps to stop me from feeling guilty				
Caring helps me feel a good person				
It's nice to feel appreciated by those family and friends I value				
Caring has strengthened close family ties and relationships				
It's good to help _____ overcome difficulties and problems				
It's nice when something I do gives _____ pleasure				
I am able to keep _____ out of an institution				
I feel that if the situation were reversed _____ would do the same for me				
I am able to ensure that _____ is well fed and their needs tended to				
Caring has given me the chance to widen my interests and contacts				
Maintaining the dignity of _____ is important to me				

Caring can be satisfying because	Does not apply	This applies and provides:		
		No real satisfaction	Quite a lot	A great deal
I am able to test myself and overcome difficulties				
Caring is one way of showing my faith				
Caring has provided a purpose in life that I didn't have before				
At the end of the day I know I will have done the best I could				
Caring is one way of expressing my love for _____				
Caring makes me feel needed and wanted				

Probe to see if any areas left out.

15 How would you describe your PAST relationship with the person you care for?

Excellent Very Good Good
 Fair Poor Very Poor

16 Compared with your past relationship would you say that your present relationship has:

Generally Improved Stayed about the same
 Getting Worse

17 How do you see the caregiving situation developing in the future?

Improving Staying about the same
Getting Worse

18 What is your age? _____ Years _____ Months

19 *Are you* *Male* *Female*

Space for Post Interview Reflections

APPENDIX 2
SUBJECT RECRUITMENT FORMS (PHASE 1)

Specimen letter to be used to recruit carers to the study. Fictitious details have been added to illustrate the form the letter will take.

HEALTH STUDIES RESEARCH DIVISION
University College of North Wales
Upper School
St. David's Hospital
St. David's Drive
BANGOR. LL57 4SL

1st October 1992

Tel: 0248 370036 Ext. 312

Dear Mrs Jones

My name is John Keady and I am currently working in the Research Division of the Faculty of Health Studies, University of Wales, Bangor. I am writing to you to ask if you would consider taking part in a project that I am undertaking.

As you may be aware, work on the experiences of informal carers has been an important area of study at the University of Wales, Bangor for a number of years now. The main focus of my own study is on the experience of family members caring for a relative who has dementia. I am particularly interested in the sort of day-to-day challenges that carers face. It is my hope, as a result of the study, to improve our understanding of carers' needs.

I have obtained your name and address from, and with the express permission of, Consultant A whom you know as the Consultant Psychiatrist at the Ysbyty Gwynedd in Bangor. I understand from Consultant A that you are caring for your husband who has dementia and I was wondering if you would kindly allow me to talk to you about this? Our conversation would of course be completely confidential and would not take up too much of your time.

If it is convenient, I would like to call and see you at home on Monday, October 5th at 10.00 am. However, should the appointment time be inconvenient, or you would prefer not to be interviewed for the study, please contact me at the above address, either by telephone or by dropping me a line.

Thanking you in anticipation and I look forward to seeing you soon.

Yours sincerely

John Keady
Principal Researcher

Specimen letter to be used to inform GP of subject recruitment. Letter to be sent once agreement to participate has been confirmed and interview details established.

HEALTH STUDIES RESEARCH DIVISION
University College of North Wales
Upper School
St. David's Hospital
St. David's Drive
BANGOR. LL57 4SL

1st October 1992

Tel: 0248 370036 Ext. 312

Dear Dr.

re: Advanced Notification Of One Of Your Patients Being Interviewed As Part Of A Research Study

VISIT TO: Mr. John Williams
ADDRESS: 17 Seaview Court
Holyhead
D.O.B: 17.01.1920
DATE OF VISIT: 21st. October 1992

I am a community psychiatric nurse (EMI) currently on a 3 month secondment to the Research Division at the Faculty. My name is John Keady and I am currently working in the Research Division of the Health Studies Research Division, University of Wales, Bangor. I have recently enrolled with the University for a MPhil degree, and the main focus of the research, and hence the need to interview the above person, is to gain the dementia carer's subjective account of their coping patterns, stressors, support and levels of satisfaction they experience within their caregiving role.

The aims of the research study have been granted ethical approval by Gwynedd Health Authority Research Ethics Committee and Consultant A/Consultant B, Consultant Psychiatrist at Ysbyty Gwynedd, who provided your patients name and address, is also supporting the research study.

If, prior to my visit, you have any questions over the research protocol please do not hesitate to contact me at the above address.

Yours sincerely

John Keady
Community Psychiatric Nurse (EMI)
Principal Researcher

CONSENT TO INTERVIEW

NAME:	
ADDRESS:	
TELEPHONE NUMBER:	
SIGNED:	
DATE:	

NOTE

Please now return this form to Consultant A / Consultant B in the pre-paid envelope provided.

Thank you.

Welsh translation of 'Consent to Interview' form

CANIATAD I GYFWELD	
ENW:	
CYFEIRIAD:	
RHIF FFON:	
ARWYDDWYD:	
DYDDIAD:	

NODER

A fydddech cystal nawr â dychwelyd y ffurflen hon I Consultant A / D. B. yn yr barod a ddarparwyd.

Diolch yn fawr

APPENDIX 3
SUBJECT RECRUITMENT FORMS (PHASE 1):
ADDITIONS FOLLOWING ETHICAL COMMITTEE COMMENTS

Amendments to study design following Ethical Committee Comments: Approach 1

Specimen Letter: Approach by Consultant A or Consultant B to recruit into the study

Consultant A/Consultant B
Day Hospital
Ysbyty Gwynedd
Bangor
Gwynedd

Tel 01248 370007

Dear

Following our recent conversation I was very pleased to hear that you have agreed to be interviewed by Mr. John Keady as part of a research project concerned with coping. As I explained, the aims of the research are being supported by myself and the Faculty of Health Studies, University of Wales, Bangor as it is very important that we appreciate in greater depth how you, and carers like yourself, cope with the demands of caring.

However, prior to Mr. Keady calling to see you at home, I would be very grateful if you could arrange for the attached "Consent to Interview" form to be completed and returned to me at Ysbyty Gwynedd. A stamped addressed envelope is enclosed for this purpose. Only when I have received the signed consent form will I contact Mr. Keady and make him aware of your agreement to participate in the research study. Mr. Keady will then contact you at home to arrange a mutually convenient appointment time and discuss the research in more detail. The interview will be totally confidential and anonymity will be assured.

I do hope that this letter, and the research aims, continue to meet with your approval, and I look forward to receiving your reply in due course.

With best wishes

Yours sincerely

Consultant A / Consultant B
Consultant Psychiatrist

Enc.

Welsh translation

Amendments to study design following Ethical Committee Comments: Approach 1

Ysbyty Dydd Menai

Ysbyty Gwynedd

BANGOR

Gwynedd

Annwyl

Yn dilyn ein sgwrs ddiweddar roeddwn yn falch iawn o glywed eich bod wedi cytuno I gael eich cyfweld gan Mr John Keady fel rhan o brosiect ymchwil yn ymwneud ag ywdopi. Fel yr esboniais, mae bwriadau yr ymchwil yn cael eu cefnogi gennyf I a'r Gyfadran Astudiaethau Iechyd, Prifysgol Cymru, Bangor, ac mae'n bwysig iawn ein bod yn gwerthfawrogi mewn mwy o ddyfnder sut ydych chi, a gofalwyr fel eich hun, yn ymdopi â gofynion gofalu.

Fodd bynnag, cyn I Mr. Keady alw i'ch gweld adref, byddwn yn ddiolchgar iawn petaech yn medru trefnu bod y ffurflen "Caniatad I Gyfweld" yn cael ei chwblhau a'i dychwelyd I mi yn Ysbyty Gwynedd. Dim ond pan fyddaf wedi derbyn y ffurflen ganiatad wedi ei harwyddo y byddaf yn cysylltu â Mr. Keady a'i wneud yn ymwybodol o'ch cytundeb I pymeryd rhan yn yr astudiaeth ymchwil. Bydd Mr. Keady wedyn yn cysylltu â chi gartref I drefnu amser apwyntiad cyfleus I bawb a thrafod yr ymchwil mewn rhagor o fanylder. Bydd y cyfweiliad yn hollol gyfrinachol ac sicrheir fod y cyfan yn aros y ddi-enw.

Rwyf yn gobeithio fod y llythyr hwn, a bwriadau'r ymchwil, yn parhau I ennill eich cymeradwyaeth, ac edrychaf ymlaen I dderbyn eich ateb yn y man.

Gyda dymuniadau gorau

Consultant A / Consultant B

Seiciatrydd Ymgynghorol

Amg

Amendments following Ethical Committee Comments: Approach 2

Specimen Letter: Approach by Consultant A or Consultant B to recruit into the study

Consultant A/Consultant B
Day Hospital
Ysbyty Gwynedd
Bangor
Gwynedd

Tel 0248 370007

Dear

Request for your participation in a Gwynedd research Study

As you are aware, I have been involved in the care of your since the possibility of dementia was first raised.

I am now approaching you to enquire if you would be willing to be interviewed as part of a research study on COPING which is being supported by myself and the Faculty of Health Studies, University of Wales, Bangor. I am supporting the research study as I believe that it is very important that as health professionals we gain a broader understanding on how you, and carers like yourself, cope with the demands of caring. Only by fully exploring these issues with carers will we be able to improve the personal services and support that we can offer.

The person undertaking the main research for the study is Mr. John Keady who is currently on secondment to the Faculty of Health studies from his regular employment as a community psychiatric nurse.

If you agree to provisionally participate in the research study, I would be very grateful if you could arrange for the enclosed "Consent to Interview" form to be completed and returned to me at Ysbyty Gwynedd. A pre-paid envelope is enclosed for this purpose. Only when I have personally received the signed consent form will I contact Mr. Keady and inform him of your agreement to participate in the research study. Mr. Keady will then contact you at home to arrange a convenient appointment, and I am assured that the interview will not take up too much of your time. Mr. Keady would like to tape record the interview for the purpose of recalling the details; a consent form for this purpose is also enclosed for your kind attention and return. Each interview will be held in confidence and anonymity will be assured.

I do hope that the research aims meet with your support and, if so, I look forward to receiving your reply in due course.

With best wishes

Yours sincerely

Consultant A / Consultant B
Consultant Psychiatrist

Enc.

Welsh translation

Amendments to study design following Ethical Committee Comments: Approach 2

Ysbyty Dydd Menai

Ysbyty Gwynedd

BANGOR

Gwynedd

Annwyl

Cais I chi gymeryd rhan mewn Astudiaeth Ymchwil Gwynedd

Fel y gwyddoch, rwyf wedi bod ynglyn â gofal eich ers i'r posibilrwydd o orddryswch gael ei godi gyntaf.

Rwyf nawr am ofyn I chi a fydddech yn fodlon I gael eich cyfweld fel rhan o astudiaeth ymchwil ar YMDOPI sy'n cael ei gefnogi gennyf I a'r Gyfadran Astudiaethau Iechyd, Prifysgol Cymru, credu ei bod yn bwysig iawn I ni fel pobl broffesiynol ym myd iechyd I gael dealltwriaeth ehangach ar sut ydych chi, a gofalwyr tebyg I chi'ch hunan, yn ymdopi â gofynion gofalu. Dim ond trwy archwilio y materion hyn yn llawn gyda gofalwyr y gallwn wella y gwasanaethau personel a'r gefogaeth y medrwn ei gynnig.

Y person sydd ywgymryd â'r prif ymchwil ar gyfer yr astudiaeth yw Mr. John Keady sydd ar hyn o bryd ar secondiad i'r Gyfadran Astudiaethau Iechyd o'i waith rheolaidd fel nyrs seciatrig cymunedol.

Os y cytunwch I gymeryd rhan yn amodol yn yr astudiaeth ymchwil, byddwn yn ddiolchgar petaech yn medru trefnu fod y ffurflen "Caniatad I Gyfweld" yn cael ei chwblhau a'i dychwelyd I mi yn Ysbyty Gwynedd. Amgaeir amlen baron ar gyfer y pwrpas hwn. Dim ond pan fyddaf wedi derbyn y ffurflen Ganiatad wedi ei harwyddo y byddaf yn cysylltu â Mr. Keady a'i wneud yn ymwybodol o'ch cytundeb I gymeryd rhan yn yr astudiaeth ymchwil. Bydd Mr. Keady yna yn cysylltu â chi adref I drefnu apwyntiad cyfleus, ac rwyf yn siwr na fydd y cyfweliad ymchwil yn cymeryd gormod o'ch amser. Cynhelir pob cyfweliad yn gyfrinachol a sicrheir na ddatgelir eich enw.

Rwyf yn gobeithio eich bod yn cafnogi amcanion yr ymchwil, ac os felly, edrychaf ymlaen I dderbyn eich ateb cyn hir.

Gyda dymuniadau gorau

Gyda dymuniadau gorau

Consultant A / Consultant B
Seiciatrydd Ymgynghorol

Amg

Consent to Tape Record Research Interview

To be completed by Carer and Main Researcher prior to commencement of Research Interview.

CONSENT TO TAPE RECORD RESEARCH INTERVIEW

I Agree for this research interview to be tape-recorded and used for the purposes that have been explained to me.

NAME (Carer):

Signature:

Date:

I confirm that this tape recording and tape will be destroyed after a period of 2 years following the research interview.

NAME (Researcher):

Signature:

Date:

I'w gwblhau gan y Gofalwr a'r Prif Ymchwilydd cyn dechrau y Cyfweiliad Ymchwil.

CANIATAD I RICORDIO CYFWELIAD YMCHWIL AR DAP

Cytunaf i'r cyfweiliad ymchwil hwn I gael ei ricordio ar dap ac i gael ei ddefnyddio i'r dibenion a esboniwyd i mi.

ENW (Gofalwr):

Llofnod:

Dyddiad:

Cadarnhaf y bydd y ricordiad a't tap hwn yn cael eu distrywio ar ol cyfnod o 2 flynedd yn dilyn y cyfweiliad ymchwil.

ENW (Ymchwilydd):

Llofnol::

Dyddiad::

APPENDIX 4

**COMPLETE INTERVIEW SCHEDULE:
PHASES 1, 2 & 3**

Interview Schedule										
Interview	Person Interviewed	Age	Gender	Relationship to PWD	Place of interview	Date of interview	Length of interview	Transcription undertaken	Caring History	Special Circumstances
Phase 1										
1	Carer	82	Female	Wife	Carer's home	22.10.92	1.5 hours	22.10.92	12 years	
2	Carer	76	Female	Wife	Carer's home	24.10.92	2 hours	24.10.92	10.5 years	
3	Carer	78	Male	Husband	Carer's home	25.10.92	2.5 hours	26.10.92	8 years	
4	Carer	57	Female	Daughter	Carer's home	29.10.92	2 hours	30.10.92	11.5 years	
5	Carer	76	Female	Wife	Carer's home	4.11.92	1.75 hours	4.11.92	9 years	
6	Carer	46	Female	Daughter	Carer's home	7.11.92	2.25 hours	7.11.92	8 years	
7	Carer	54	Male	Husband	Carer's home	16.11.92	3 hours	16.11.92	5 years	Contact maintained
8	Carer	52	Male	Son	Carer's home	17.11.92	1 hour	17.11.92	3 years	
9	Carer	82	Male	Husband	Carer's home	18.11.92	2.25 hours	18.11.92	9 years	
10	Carer	86	Female	Wife	Carer's home	19.11.92	2 hours	19.11.92	18 years	
11	Carer	82	Male	Husband	Carer's home	20.11.92	1.5 hours	20.11.92	4.5 years	
12	Carer	58	Female	Wife	Carer's home	21.11.92	2 hours	21.11.92	6 months	
13	Carer	56	Male	Son	Carer's home	22.11.92	1.5 hours	22.11.92	4 years	
14	Carer	78	Female	Wife	Carer's home	23.11.92	2.5 hours	23.11.92	7 years	

15	Carer	81	Male	Husband	Carer's home	24.11.92	1.75 hours	24.11.92	3 years	
16	Carer	51	Female	Daughter	Carer's home	25.11.92	2 hours	25.11.92	2 years	
17	Carer	46	Female	Daughter	Carer's home	26.11.92	1.5 hours	26.11.92	3 years	
18	Carer	75	Female	Wife	Carer's home	27.11.92	2 hours	27.11.92	6 years	
19	Carer	77	Female	Wife	Carer's home	28.11.92	2.75 hours	28.11.92	7.5 years	
20	Carer	84	Male	Husband	Carer's home	29.11.92	2 hours	29.11.92	5 years	
21	Carer	45	Female	Daughter	Carer's home	30.11.92	2.5 hours	30.11.92	4 years	
22	Carer	48	Female	Daughter	Carer's home	6.12.92	1 hour	6.12.92	5 years	
23	Carer	42	Female	Daughter	Carer's home	7.12.92	2 hours	8.12.92	2 years	
24	Carer	76	Female	Wife	Carer's home	8.12.92	1.5 hours	8.12.92	6 years	
25	Carer	78	Male	Husband	Carer's home	9.12.92	2.5 hours	9.12.92	9 years	
26	Carer	56	Male	Son	Carer's home	10.12.92	1.75 hours	10.12.92	4 years	
27	Carer	76	Female	Wife	Carer's home	11.12.92	4 hours	12.12.92	7 years	Person with Dementia in care
28	Carer	28	Female	Daughter	Neutral venue	13.12.92	1 hour	Notes taken during interview	3 years	
29	Carer	42	Male	Son	Carer's home	15.12.92	1.5 hours	15.12.92	4 years	
30	Carer	56	Female	Daughter	Carer's home	16.12.92	2 hours	17.12.92	6 years	
31	Carer	82	Female	Wife	Carer's home	18.12.92	3.5 hours	18.12.92	7 years	Person with Dementia in care
32	Carer	48	Female	Daughter	Neutral venue	7.1.93	1 hour	7.1.93	4 years	

33	Carer	53	Male	Son	Carer's home	15.1.93	2.5 hours	15.1.93	3 years	
34	Carer	79	Male	Husband	Carer's home	24.1.93	2 hours	25.1.93	8 years	
35	Carer	76	Female	Wife	Carer's home	27.1.93	3 hours	28.1.93	6 years	
36	Carer	82	Male	Husband	Carer's home	4.2.93	1.5 hours	4.2.93	10 years	
37	Carer	79	Male	Husband	Carer's home	17.2.93	3.5 hours	18.2.93	9 years	Person with Dementia in residential care
38	Carer	48	Male	Son	Carer's home	26.2.93	3 hours	27.2.93	7 years	Person with Dementia in residential care
39	Carer	56	Female	Wife	Carer's home	28.2.93	2.75 hours	28.2.93	7 years	
40	Carer	72	Female	Wife	Carer's home	4.3.93	1 hour	4.3.93	2 years	Person with Dementia in interview
41	Carer	66	Female	Wife	Carer's home	7.3.93	2.25 hours	8.3.93	7 years	Carer bereaved
42	Carer	56	Male	Son	Carer's home	6.4.93	3 hours	6.4.93	6 years	Person with Dementia in care
43	Carer	74	Female	Wife	Carer's home	9.4.93	1.5 hours	9.4.93	1.5 years	Person with Dementia in interview
44	Carer	80	Male	Husband	Carer's home	17.6.93	2.5 hours	17.6.93	11 years	Person with Dementia in care
45	Carer	70	Male	Husband	Carer's home	14.9.93	1 hour	14.9.93	2 years	Person with Dementia also present
46	Carer	79	Female	Wife	Carer's home	21.10.93	2.5 hours	21.10.93	8 years	

47	Carer	58	Female	Wife	Carer's home	3.11.93	3.5 hours	3.11.93	9 years	Person with Dementia in residential care
48	Carer	76	Male	Son	Carer's home	15.11.93	1.5 hours	15.11.93	2 years	Person with Dementia in interview
49	Carer	73	Male	Husband	Carer's home	28.11.93	2.5 hours	28.11.93	8 years	Person with Dementia in residential care
50	Carer	80	Male	Husband	Carer's home	5.12.93	3 hours	6.12.93	7 years	Person with Dementia in residential care
51	Carer	69	Male	Husband	Carer's home	8.1.94	2 hours	8.1.94	7 years	Carer bereaved
52	Carer	49	Female	Daughter	Carer's home	27.1.94	2.5 hours	27.1.94	9 years	Carer bereaved
53	Carer	77	Female	Wife	Carer's home	16.2.94	2 hours	16.2.94	10 years	Carer bereaved
54	Carer	87	Male	Husband	Carer's home	27.2.94	1.5 hours	27.2.94	4 years	Carer bereaved
55	Carer	56	Male	Son	Carer's home	3.3.94	2.5	3.3.94	7 years	Carer bereaved
56	Carer	84	Female	Wife	Carer's home	26.3.94	2 hours	26.3.94	9 years	Carer bereaved
57	Carer	81	Female	Wife	Carer's home	16.4.94	2.5 hours	16.4.94	8 years	Carer bereaved
58	Carer	79	Male	Husband	Carer's home	24.5.94	1 hour	24.5.94	7 years	Carer bereaved

Phase 2

Interview	Person Interviewed	Age	Gender	Relationship	Place of interview	Date of interview	Length of interview	Transcription undertaken	Diagnosis made	Special Circumstances
59	Person with Dementia	74	Male	Husband/wife	Person's home	22.8.94	10 mins. alone	22.8.94	8 months ago Alzheimer's disease	
	Carer	N/A	Female	Husband/wife	Person's home	22.8.94	10 mins. joint	22.8.94		
60	Carer	N/A	Female	Husband/wife	Person's home	22.8.94	10 mins. alone	22.8.94		
	Person with Dementia	72	Female	Wife/Husband	Person's home	23.8.94	45 mins alone	23.8.94	6 months ago Alzheimer's disease	Visited twice
Carer	N/A	Male	Wife/Husband	Person's home	23.8.94	20 mins. joint	23.8.94			
61	Person with Dementia	78	Female	Wife/Husband	Person's home	24.2.95	30 mins joint	24.2.95	1 year ago	2 nd visit
	Carer									
62	Person with Dementia	71	Male	Husband/wife	Person's home	24.8.94	45 mins. joint	24.8.94	6 months ago Alzheimer's disease	
	Carer	72	Female	Husband/wife	Person's home	24.8.94		24.8.94		
63	Person with Dementia	82	Female	Mother/daughter	Person's home	25.8.94	45 mins. joint	26.8.94	1 year ago Alzheimer's disease	
	Carer	56	Female	Mother/daughter	Person's home	25.8.94		26.8.94		
64	Person with Dementia	73	Female	Husband/wife	Person's home	14.11.94	5 mins.	14.11.94	6 months ago Frontal lobe dementia	Person with dementia in denial - interview did not proceed
	Carer	75	Male	Husband/wife	Person's home	14.11.94	15 mins.	14.11.94		

65	Person with Dementia	70	Female	Husband/wife	Person's home	15.11.94	45 mins. joint	15.11.94	6 months ago Alzheimer's disease
	Carer	72	Male	Husband/wife	Person's home	15.11.94		15.11.94	
66	Person with Dementia	70	Female	Wife/Husband	Person's home	16.11.94	45 mins. joint	16.11.94	1 year ago Alzheimer's disease
	Carer	N/A	Male	Wife/Husband	Person's home	16.11.94		16.11.94	
67	Person with Dementia	76	Female	Husband/wife	Person's home	17.11.94	45 mins. joint	17.11.94	6 months ago Alzheimer's disease
	Carer	78	Male	Husband/wife	Person's home	17.11.94		17.11.94	
68	Person with Dementia	74	Male	Husband/wife	Person's home	6.1.95	45 mins. Joint	6.1.95	6 months ago Alzheimer's disease
	Carer	N/A	Female	Husband/wife	Person's home	6.1.95		6.1.95	

Phase 3

69	Carer	69	Female	Wife	Carer's home	26.6.95	2 hours	27.6.95	1.5 years
70	Carer	78	Male	Husband	Carer's home	28.8.95	1.5 hours	29.8.95	8 years
71	Carer	52	Male	Son	Carer's home	15.11.95	2.5 hours	16.11.95	6 years
72	Carer	77	Male	Husband	Carer's home	17.1.96	2 hours	18.1.96	7 years
73	Carer	81	Female	Wife	Carer's home	28.3.96	3 hours	29.3.96	4 years
74	Carer	70	Male	Husband	Carer's home	27.7.96	2 hours	28.7.96	10 years

APPENDIX 5

SUBJECT RECRUITMENT FORMS (PHASE 2)

HEALTH STUDIES RESEARCH DIVISION
Upper School
St David's Hospital
BANGOR
Gwynedd. LL57 4SL

Our Ref.: JHD/IV.ltr

Tel: 0248 370896
Fax: 0248 351859

Date as received

Dear Sir/Madam

**re Permission to be Interviewed as Part of a Research Study into Managing
Memory Loss**

My name is John Keady and I am currently working with Professor A and Social Worker A at the Clinical Research Centre. The purpose of my secondment to the Clinical Research Centre is to undertake a series of interviews with people who have an early stage memory impairment. This is where I would most appreciate your help.

I am particularly interested in exploring with you and your partner (if any) your experiences of coping with memory loss and your opinion on the provision of specialist services. If you would like to take part in the study, please complete the attached form and return it to me in the enclosed envelope. This study will start during the month of August and I will send you an appointment to meet me at the memory clinic, or if you would prefer, at your home.

Our conversation would last no more than 45 minutes with anonymity and confidentiality personally guaranteed.

Thank you for considering this letter.

Yours sincerely

John Keady
Research Officer

Enclosure

INVITATION TO TAKE PART IN THE MANAGING MEMORY LOSS STUDY

Name of Patient:				
Address:				
Tel No:				
I would like to take part in the study of Managing Memory Loss			YES/NO*	
* Delete where not applicable				
If YES, please indicate (tick) which times are convenient for interview:				
		Tick Here		Tick Here
Monday	Morning		Afternoon	
Tuesday	Morning		Afternoon	
Wednesday	Morning		Afternoon	
Thursday	Morning		Afternoon	
Friday	Morning		Afternoon	
I would like to take part in the study but find it difficult to travel to the Memory Clinic because:				
Signed:				
Date:				
Using the pre-paid envelope provided please now return the signed forms.				

Thank You

INVITATION TO TAKE PART IN THE MANAGING MEMORY LOSS STUDY

Name of Partner:	
Address:	

Tel No:	
---------	--

I would like to take part in the study of Managing Memory Loss	YES/NO*
--	---------

* Delete where not applicable

If YES, please indicate (tick) which times are convenient for interview:

		Tick Here		Tick Here
Monday	Morning		Afternoon	
Tuesday	Morning		Afternoon	
Wednesday	Morning		Afternoon	
Thursday	Morning		Afternoon	
Friday	Morning		Afternoon	

I would like to take part in the study but find it difficult to travel to the Memory Clinic because:

Signed:	
---------	--

Date:	
-------	--

Using the pre-paid envelope provided please now return the signed forms.

Thank You

CONSENT TO INTERVIEW (PATIENT)

Name:	
Address:	
Telephone Number:	
Signed:	
Date:	

CONSENT TO INTERVIEW (PARTNER)

Name:	
Address:	
Telephone Number:	
Signed:	
Date:	

CONSENT TO TAPE RECORD INTERVIEW (PATIENT)

Name:

Address:

Telephone Number:

Signed:

Date:

CONSENT TO TAPE RECORD INTERVIEW (PARTNER)

Name:

Address:

Telephone Number:

Signed:

Date:

APPENDIX 6

**SUBJECT RECRUITMENT FORMS (PHASE 2):
ADDITIONS FOLLOWING ETHICAL COMMITTEE COMMENTS**

HEALTH STUDIES RESEARCH DIVISION
Upper School
St David's Hospital
BANGOR
Gwynedd. LL57 4SL

Our Ref.: JHD/IV.ltr

Tel: 0248 370896
Fax: 0248 351859

Date as received

Dear Sir/Madam

**Re: Permission to be Interviewed as Part of a Research Study into Managing
Memory Loss**

My name is John Keady and I am currently working with Professor A and Social Worker A at the Clinical Research Centre. The purpose of my secondment to the Clinical Research Centre is to undertake a series of interviews with people who have an early stage memory impairment. This is where I would most appreciate your help.

I am particularly interested in exploring with you and your partner (if any) your experiences of coping with memory loss and your opinion on the provision of specialist services. If you would like to take part in the study, please complete the attached form and return it to me in the enclosed envelope. This study will start during the month of August and I will send you an appointment to meet me at the memory clinic, or if you would prefer, at your home.

Our conversation would last no more than 45 minutes with anonymity and confidentiality assured.

Finally, if you or your partner decide not to participate in the research study, you will, in no way, be excluded from any further service provided by the Clinical Research Centre.

Thank you for considering this letter.

Yours sincerely

John Keady
Research Officer

Enclosure

APPENDIX 7

**PUBLICATIONS, CONFERENCE AND WORKSHOP PRESENTATIONS
(SELECTED) RESULTING FROM THE STUDY**

PUBLICATIONS, CONFERENCE AND WORKSHOP PRESENTATIONS (SELECTED) RESULTING FROM THE STUDY

PUBLICATIONS

BOOK

Nolan, M., Grant, G. and Keady, J. (1996). *Understanding Family Care: A Multidimensional Model of Caring and Coping*. Milton Keynes, Bucks: Open University Press. See Chapter 5: Family Caregiving: A Temporal Perspective. Pp. 107-132.

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- Keady, J. and Nolan, M. (1994). Working with Dementia Sufferers and their Carers in the Community : Exploring the Nursing Role. *International Nursing Conference*, University of Ulster, Coleraine, N Ireland, 30th August, 1994. Main presenter: Professor M. Nolan.
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- Keady, J. and Nolan, M. (1993). Understanding the Experience of Dementia Caregivers: Developing a Transactional Model of Care as a Basis for Interventions and Service Delivery. *British Society of Gerontology Annual Conference*, Norwich, 19th September, 1993.

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- Keady, J. and Nolan, M. (1993). Coping with Dementia: Towards a Comprehensive Assessment of the Needs of Informal Carers. *International Conference on Mental Illness in Old Age*, Institute of Human Ageing, University of Liverpool, 25th June, 1993.
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OTHER CONFERENCE PRESENTATIONS (SELECTED)

- Keady, J. (1999). Issues surrounding carer involvement in continuing care homes. Consensus Conference: The involvement of families of people with dementia in long-term care facilities. *University College London*. London, 20th April, 1999
- Keady, J. (1998). Coping with dementia. Address to a local Conference organised by Parkside Health, Community Mental Health Unit (Old Age Psychiatry), *St. Charles' Hospital*. London, 11th July, 1997.
- Keady, J. (1997). The IMMEL Assessment System. Workshop Session. Dementia in the Family. *UMIST Conference Centre*. Manchester, 19th June, 1997.
- Keady, J. (1995). Experiencing Dementia. *Blackberry Hill Hospital*. Bristol, 25th May, 1995.
- Keady, J. (1995). Coping with Caring. *Carers Outreach (Gwynedd) Annual Conference*. Llanberis, 25th April, 1995.
- Keady, J. (1995). Understanding the Early Experience of Dementia: implications for service providers. *International Network for Studies Concerning Older People: 2nd International Network Conference*. University of Wales, Bangor. Bangor, 10th April, 1995.
- Keady, J. and Nolan, M. (1993). Carers Research. *Alzheimer's Disease Society (Wales) Annual Conference*. Mold, 9th July, 1993.
- Keady, J. and Nolan, M. (1993). Carers Research. *Alzheimer's Disease Society (Wales) Annual Conference*. Swansea, 7th July, 1993.
- Keady, J. (1993). The Six Stages of Care. *Crossroads Care Annual Conference*. Anglesey, 16th April, 1993.

WORKSHOP PRESENTATIONS (SELECTED)

- Keady, J. (1999). Working with Families in Caring. Workshop Session. *The Role of Nursing in the Independent Sector in the 21st Century: Welsh National Board for Nursing, Midwifery and Health Visiting and British Association for Services to the*

Elderly - joint Conference. North Wales Conference Centre, Llandudno. Llandudno, 14th May, 1999.

Keady, J. (1999). Working with Families in Caring. Workshop Session. *The Role of Nursing in the Independent Sector in the 21st Century: Welsh National Board for Nursing, Midwifery and Health Visiting and British Association for Services to the Elderly - joint Conference.* County Hall, Cardiff. Cardiff, 21st May, 1999.

BRITISH ASSOCIATION FOR SERVICES TO THE ELDERLY (BASE) WORKSHOPS (SELECTED)

September 1999

Two one day workshops on 'Working with Carers'. Rhondda Cynon Taf Social Services. Pontypridd.

October 1996

One day workshop on 'Interventions for Early Stage Dementia'. Shropshire Mental Health Service. Shrewsbury.

October 1995

Two separate study days on 'Caring Counts'. South Glamorgan Social Services Initiative. Swansea.

March/April 1995

Six separate BASE study days on the 'Approaches to the Understanding of Chronic Illness and Family Carers'. Mid Glamorgan Social Services. Llandysul.

April 1994

On day workshop on 'Carer Stress.' Wolverhampton Social Services. Woverhampton.

November 1993

On day workshop to interagency staff and carers on 'Assessment and Intervention Skills for Dementia Practitioners'. Swansea.

APPENDIX 8

INDEX OF MEMORY LOSS (IMMEL)

Index of Managing Memory Loss (IMMEL)

A Practitioner's Guide to Completion

John Keady and Mike Nolan

Introduction

IMMEL: An Index to Assess Coping Behaviour in Early Memory Loss

People with the signs of memory loss often have a variety of ways of dealing with the challenges they face. IMMEL has been designed specifically to assist practitioners to identify the range of coping behaviours that individuals with early memory loss may use. The statements on IMMEL were generated from a series of interview with such individuals, thereby providing a comprehensive, but not exhaustive list. Practitioners using IMMEL will still need to explore other individual methods of coping and space has been left on IMMEL for this purpose.

IMMEL: A User Guide

Once an diagnosis of early memory loss has been established and a relationship with the person established, IMMEL can be used **jointly** to identify coping behaviours. We consider it important that the assessment using IMMEL is undertaken as a joint venture based on a relationship of trust. This is crucial as IMMEL covers some personal and potentially challenging issues. However, IMMEL is useful to explore the range and perceived effectiveness of current coping behaviours. This information can then be used as a basis for planning future care initiatives.

IMMEL consists of a series of statements about potential ways to deal with the signs of memory loss. Once the statement has been read and understood, there is a series of options available for the response. We would suggest that you complete the documentation and clarify each answer with the individual. Upon completion, responses can then be reviewed and any additional coping behaviours recorded in the space available at the end of IMMEL.

We trust that you find this a useful addition to your practice and we would be interested in receiving any comments.

John Keady
Lecturer in Nursing

Mike Nolan
Professor of Gerontological Nursing

Index of Managing Memory Loss (IMMEL)

One Way to Deal with the Signs of My Memory Loss is by:	I Use This and Find It:			I Don't Use This
	Very Helpful	Quite Helpful	Not Really Helpful	
Being open and honest about my memory loss with people that I meet				
Accepting my memory loss and finding ways to overcome it				
Establishing a regular routine and sticking to it				
Talking over my memory loss with someone I trust				
Keeping my fears and feelings secret				
Believing that there are always others worse off than me				
Using lists and other memory aids to help me remember				
Writing a personal diary about my feelings				
Regularly practising relaxation techniques and such like				
Relying on others to fill in the gaps when I am unable to remember				
Not taking part in conversations				
Believing that my memory loss is a normal part of getting older				
Staying in familiar surroundings				

One Way to Deal with the Signs of My Memory Loss is by:	I Use This and Find It:			I Don't Use This
	Very Helpful	Quite Helpful	Not Really Helpful	
Avoiding the company of friends and close acquaintances				
Finding out from professionals and other agencies as much information as possible about the causes of my memory loss				
Constantly repeating things to myself to help me remember				
Learning to laugh about my memory loss				
Engaging in challenging activities such as puzzles, crosswords and the like				
Staying out of the house for as long as possible by going for walks and so on				
Actively seeking professional help and guidance in dealing with my memory loss				
Recognising that there are times during the day when my memory is better and doing as much as possible during these periods				
Not dwelling on the problems that I face				
Being thankful for the close support of family and others around me				
Having a good cry when no-one is around				
Keeping any further memory loss to myself for as long as possible				
Ignoring my memory loss and hoping that it will eventually go away				
Accepting that my memory loss is not my fault				

One Way to Deal with the Signs of My Memory Loss is by:	I Use This and Find It:			I Don't Use This
	Very Helpful	Quite Helpful	Not Really Helpful	
Taking life one day at a time				
Discussing things with people in a similar situation to me				
Keeping as active as possible around the home				
Trying to avoid new situations as far as possible				
Having a set answer ready in case I can't answer questions				
Fighting the memory loss and trying not to let it get the better of me				
Planning out my day well in advance				
Remembering all the good times I have had				
Joining local memory clubs and such like				
Relying on myself to find answers to the problems I face				
Relying on others to perform the domestic chores in and around the home				
Thinking things through slowly and carefully before responding				
Making up stories to fill in the gaps in my memory				
Relying on the support of the person closest to me				
Trying to keep calm and relaxed at all times				

1) **Other Ways of Coping which are Used**

2) **Jointly Identified Areas for Attention and Development**