



McGhee, Hugh Gerard (2005) The carer/key-worker enhanced relationship cycle: a theory of the reciprocal process. PhD thesis

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**THE CARER/KEY-WORKER ENHANCED RELATIONSHIP CYCLE: A
THEORY OF THE RECIPROCAL PROCESS**

BY

HUGH GERARD McGHEE

Submitted for the Degree of PhD, Section of Public Health and Health Policy,
Division of Community Based Sciences, University of Glasgow, May 2005.

Acknowledgements

I would like to take this opportunity to express my thanks to all those helped me towards the completion of this thesis

Dr. Jacqueline Atkinson:

For her guidance, support and supervision.

My wife Carol:

For her support, understanding and continuous encouragement throughout the period of this study.

My children Steven and Katy:

For their understanding and tolerance.

All carers and key-workers who took part in my study:

For their time and enthusiasm.

My colleagues within Bell College, Hamilton; particularly Miss Denise Gray, Mrs. Margaret Brown and those within the mental health teaching team:

For all their practical advice, support and feedback.

The Post Graduate Certificate/MSc in Specialist Nursing Practice students, Bell College, Hamilton,

Mrs. Jayne Donaldson,

Dr. Glenn Marland:

For their help in undertaking the verification exercise.

Mrs. Anne Kay,

Mr. Michael Brennan:

For their efforts in proof reading this thesis.

Mrs. Jean Shields:

For her assistance in audio typing all interviews

Bell College, Hamilton:

For part-funding this study.

Mrs. Heather Simpson, Head of Department, Bell College, School of Health Studies:

For her support.

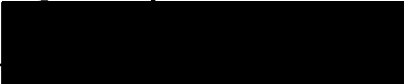
My close friends Amanda and Colin; Diane and John; Helen and Alister:

For their ongoing encouragement.

Declaration

I, Hugh Gerard McGhee, confirm that I as the named author conducted the research study detailed in this thesis. No portion of this work has been submitted in support of an application for another degree or qualification of this or any other university or institute.

Signature

A black rectangular box redacting the signature.

Date

13/1/06

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Abstract

The increasingly important role of the family in providing home care for a relative diagnosed with dementia has become a recognised feature of contemporary health care. Few studies exist, however, that have examined the relationship these carers develop with the professional assigned to help them undertake care-giving. The relationship held with a key-worker may significantly influence their ability and motivation to undertake the tasks and lifestyle changes necessary for this role.

This study's aim was to examine this relationship in detail and generate a theoretical explanation allowing a clearer understanding of the influential factors associated with creation and enhancement of this relationship. Grounded theory was considered the methodology best suited to this aim. Its principal advantage is that it allows the researcher to generate rather than simply test theory and it also provides the necessary degree of flexibility essential for such an exploratory study.

In order to meet ethical approval requirements a purposive, rather than theoretical, sampling approach was used for the selection of carers. Approach into the carer sample was through the consultant psychiatrist who forwarded research packs to potential participants via the person with dementia. Eighteen carers met the entry requirements and were subsequently included within the study; along with their chosen key-workers who numbered eleven in total. The key-worker group were all front line workers from either a health or social care background. Nine of this key-worker group were qualified and registered

workers while the remaining two were unqualified care workers working under the direct supervision of a registered social or health care professional.

The carer/key-worker pairs were interviewed in tandem and all interviews recorded. These were then analysed using the constant comparative method, a process helped by the use of NUD*IST computer software. The analysis progressed from initial data categories through to the final core category that provided an explanation of all subordinate data. This core category became the title for the theoretical framework that eventually emerged. Subsequently, a theoretical explanation of the relationship's development was generated along with how it impacted upon the care-giving environment.

The theory began with the major category 'The Enhanced Relationship Drivers', which highlighted that while characteristics associated with this relationship were often obscure, there were significant qualities and actions that clearly enhanced the relationship. Once these were engaged both parties moved towards the closer 'therapeutic alliance' contained within the second major category area, 'Models of Action'. Here shared qualities and attributes were more successfully directed towards the care of the person with dementia. A direct outcome of this alliance was a potentially closer and more productive working relationship for both the carer and key-worker. This could result in the creation of an improved therapeutic milieu, minimising the more negative interpretations associated with care-giving. These more negative perceptions of care-giving were highlighted within the third major category 'Impact upon the World of Caring'. However,

when the enhancing influences of the preceding major categories were enacted, a more 'Rewarding Care Experience' was possible.

External mediators could impinge upon the relationship, either impeding or enhancing its development. These included factors such as the management style of the key-worker's employing authority, the availability of alternative support networks for the carer, as well as the educational/life experience of both members of this dyad. The derived theory has been diagrammatically represented to provide a clear demonstration of all theoretical links between codes and categories, facilitating a better understanding of the developed theory.

The study provided a clear insight into the interpersonal processes associated with the carer/key-worker relationship and how this relationship may more effectively be initiated, managed and strengthened. This theory has important implications for future research into similar psychosocial aspects of care-giving. These findings have ramifications for carer training as well as education and training courses preparing professionals to work more effectively with carers. It has implications for health and social care managers in terms of their level of awareness of the importance of this relationship and the need for investment in it. It is important that this theory is exposed to more rigorous empirical study allowing for a more confident prediction that its propositions will produce the direct benefits for this relationship that this theory suggests.

CHAPTER ONE

INTRODUCTION TO THE STUDY

Dementia is a condition that is just as devastating to those who care for the person with the diagnosis as it is for those with the illness itself. Carers have to watch as their loved one's condition deteriorates, often expressing feelings of helplessness and guilt over their inability to help in this decline (Chapman 1997). The dementia carer's 'care giving' environment has been acknowledged as a complex multi-factorial area (Clarke 1999a). Historically there has been a significant level of scientific study into the burden associated with caring for a person with dementia, and ways in which the carer's role could be made less arduous (Rabins et al 1982; Macerra et al 1983; Argyle et al 1985; Chenoweth & Spencer 1986; Brodaty & Gresham 1989; Stephens et al 1991; Jones & Peters 1992; Tissier 1993a).

My interest in this research topic was first triggered during my early career as a Community Psychiatric Nurse (CPN), in the early 1980's, through to my joining Lanarkshire College of Nursing and Midwifery as a Mental Health lecturer in 1989. During these years I became increasingly concerned for the circumstance and welfare of these carers. As I visited them, and their dependants, I suspected that my involvement with them was potentially significant in helping them cope with their changing lives. If I could understand how to strengthen my relationship with these carers could I consequently increase my ability to help and influence them in their management of the dependant?

My interest in this topic has remained with me as I changed career and, as a college mental health lecturer, I gained further exposure to wider theoretical

literature surrounding dementia and its management. This general exposure reinforced my impression that this was a relatively unclear and unexplored aspect of dementia care.

My study has centred upon this group of carers and endeavoured to increase understanding into this 'complex multi-factorial' area through investigating the relationship that both existed and developed between the dementia carer and the dedicated professional whom they considered to be their key-worker.

THE NATURE OF DEMENTIA

Within this thesis it is necessary to provide an understanding of dementia in order to put the carer's role in context. The word dementia derives from the Latin term 'demens' which means to be 'without a mind' (McKeith & Fairbairn 2001; Burns 2002). Dementia is the most common serious mental disorder to affect older people and is a condition that principally leads to a decline in memory and thinking resulting in a progressive inability for the individual to recall, think and/or reason (Phair 1996a; McKeith & Fairbairn 2001). Dementia is characterised by a decline from a previous existing level in functional and cognitive abilities and is associated with symptoms of abnormal behaviour, depression and psychotic experiences (Donaldson et al 1997). The term is used either as a collective term or to describe a group of different diseases, all of which create similar symptoms. As a collective term its use suggests a single clinical entity, whereas the second interpretation involves the term being used for one of a variety of conditions that includes Alzheimer's disease; vascular dementia; diffuse Lewy body disease and sub-cortical dementia (Adams 1997).

According to Burns (2002) the diagnostic criteria most commonly used to identify this group of disorders is either the World Health Organisation's 'International Classification of Disease' directory (ICD 10) (WHO 1993), or the United State's 'Diagnostic and Statistical Manual of Mental Disorders' (DSM IV) (American Psychiatric Association 1994).

The first of these conditions, Alzheimer's disease, accounts for the largest group diagnosed with dementia, accounting for 50% - 60% of all cases (Phair 1996b; McKeith & Fairbairn 2001). It causes changes within brain tissue, identifiable on post mortem. These changes, termed 'plaques and tangles', affect the temporal and parietal lobes of the brain (Phair 1996b; Adams 1997; McKeith & Fairbairn 2001). This creates a variety of problems for the affected individual that, in addition to its most striking feature of memory impairment, include some of the following symptoms:

- aphasia (dysphasia) - difficulties in speech
- apraxia (dyspraxia) - difficulties in carrying out motor tasks
- agnosia - inability to correctly process sensory inputs, for example, the inability to recognise familiar objects etc.

Delusions and hallucinations, as well as behavioural problems such as apathy, over activity, aggression and sexual disinhibition, can also feature (Adams 1997; Thomas & O'Brian 2002).

The second most common form of dementia is referred to as Dementia with Lewy bodies (DLB) and accounts for between 20% and 30% of all dementia

cases (McKeith & Fairbairn 2001). The Lewy bodies are pink staining structures identified within the cytoplasm of neurones (Phair 1996b). These protein deposits were first described in people with Parkinson's disease although only some DLB patients share the physical characteristics of Parkinson's disease (Adams 1997). The symptoms associated with DLB are similar to Alzheimer's disease where the individual experiences hallucinations and delusions, but with DLB the person's mental abilities fluctuate from day to day or even hour to hour, a feature that is core to DLB (Fares 1997; McShane 2002).

A further form of dementia is referred to as 'vascular' and formally known as arteriosclerotic dementia, arising from its cerebral arterial pathology. This condition accounts for 20% of all those diagnosed with dementia within Western Europe (Phair 1996b; Adams 1997). The diagnosis of vascular dementia has become increasingly uncertain over recent years as concepts relating to this type of dementia are continually changing (McKeith & Fairbairn 2001; Stewart 2002). Vascular dementia arises out of the individual experiencing multiple small cerebral blood clots causing a lack of oxygen to those particular areas of the brain resulting in the death of associated brain cells (Phair 1996b). The features associated with this type of dementia depend on which area of the brain is affected and can occur suddenly and dramatically (Fares 1997; Adams 1997; McKeith & Fairbairn 2001). According to Adams (1997) in addition to aphasia and apraxia, discussed earlier under the symptoms of Alzheimer's disease, resultant damage to the brain will also lead to following features:

agraphia

- loss of ability to express through writing

- acalculia - loss of ability to do simple arithmetic
- visuospatial deficits - inability to correctly read visually guided targets.

Other less common forms of dementia include subcortical types in which memory impairment results in damage to the subcortex rather than the cortex area of the brain. This group includes such illnesses as Huntington's disease, Wilson's disease and Parkinson's disease (McKeith & Fairbairn 2001).

RATIONALE FOR THE STUDY

Care provision for those diagnosed with dementia has increasingly seen an emphasis on supporting carers most heavily involved in coping with the day-to-day management of this group (Department of Health 1994). However, from my own professional experience, an area of dementia care not so evident within the literature is the relationship between the professional care provider (key-worker) and the carer involved with a person diagnosed with dementia. Twigg (1989) examined the relationship between social service providers and how they conceptualised the relationship with the carer. She explained the relationship by placing the carer into one of three categories, either as a resource, a co-worker or as a co-client. The category of 'superceded carer' was introduced within a latter publication (Twigg & Aitken, 1994). These categories were considered by Nolan et al (1996a) to be inappropriate and they suggested a further category, that of 'carers as experts'. They concluded that this 'carer as expert' perspective involved professionals acting to increase carer competency by supporting their role throughout their caring career.

The above theoretical explanations appeared to be largely based on a top down or anecdotal interpretation of this relationship, and largely avoided conceptualisation of the relationship from the perspective of the carer. This would be necessary in addressing the development of a coherent theoretical explanation of the relationship between a key-worker and carer.

Looking at the meanings that underpin caring, Clarke (1999b) provided some insight into the care relationships surrounding the individual with dementia. Here she identified a 'process of interaction' that explained the communication between the carer, the dependant and the key-worker, highlighting tensions that existed between each of these parties. While this study provided a valuable understanding of this complex process, it did not explore the inherent factors associated with the dynamics of the Carer/Key-Worker relationship. In addition, it did not identify how the carer could modify and influence key-worker involvement, a phenomenon first described by Hasselkus (1988). Within her ethnographic study designed to discover meaning within family caring, Hasselkus found that the carer, in order to make sense of managing their dependant, modified the instructions of the involved professionals. Hasselkus (1988) stated that:

'Effective collaboration between family and professionals depends not so much on shared tasks and functions as on shared perspectives and understandings of the invisible work of care giving' (p.690).

Bowers (1987), in his Grounded Theory study, attempted to identify what families considered good quality care within the institution. Care was found to be dependent upon family involvement, and that the professional required to be taught by the carer on how to provide adequate care for their dependant.

It was clear that an understanding of such ‘perspectives and understandings’ would only be achieved through in-depth study of the relationship that existed between carer and key-worker. Zarit & Leitsch (2001), following their review of the carer literature, pointed out that when a health care professional’s activities were directed towards either a dependant, or their carer, both experienced a significant change. Such comment, therefore, suggests the need to explain this relationship more explicitly. Creating a more positive relationship around the carer is a necessary achievement as it has the potential to improve their health, well being and longevity, whereas negative relationships hold exactly the opposite outcome (Flannery 2002).

It is important to be clear how the term ‘carer’ was used within my study. These are individuals who are unpaid, with no fixed hours, no terms and conditions of employment and often with few, if any, rights. They spend a significant period of their lives looking after the health and personal needs of a relative, friend or neighbour, who may or may not reside with that individual (Cayton 2002). The Carers Recognition and Services Act (1995) defines the carer as someone who provides a significant amount of regular care to another person (Department of Health 1995). My study distinguished this particular carer from other care workers employed by, or associated with, a care-giving organisation. The term

key-worker described the care-worker that the carer deemed to be the most significant in helping them in their care-giving role. Within my thesis such titles as informal or lay carer were not used, unless specified as such within particular literature, as these terms failed to accurately reflect the importance of, and demands associated with, this role (Cayton 2002).

An important consideration within my study was recognising that the carer had a clearly distinct circumstance from other care-workers, as to care for someone close to you is not simply a job of work but rather a way of life (Allan 2004). This 'way of life' may involve the person with dementia surviving between two and twenty years, with an average life expectancy of ten years (McKeith & Fairbairn 2001). Within Scotland there is an estimated 57,000 people over the age of 65 living with dementia (NHS Health Scotland 2003). These figures are predicted to grow substantially in the years to come, a fact made more significant by a corresponding estimated increase in the numbers of people within high-risk groups. These high risk groups range from those with specific problems, such as learning difficulties and dependency problems, to those within the general population who are increasingly living longer (NHS Health Scotland 2003).

THESIS LAYOUT

This thesis contains ten chapters and differs from the conventional layout of a doctoral thesis in several regards. Chapter two presents the study's research aim and associated research questions. In chapter three the rationale for selection of the research methodology is provided along with the perspectives and approaches adopted. Two of the most significant decisions debated within this chapter were

writing the thesis in the first person and not to consult, review and critique the related literature prior to commencing the fieldwork. In keeping with this study's adopted methodology the data collection, analysis and the review/critique of the literature occurred simultaneously and so a specific literature chapter does not appear before the results chapters. Clear methodological reasons are provided within chapter three to support these decisions.

Chapter four identifies some of the problems that presented from the pilot study and during the design process, in particular, the difficulties in accessing the participant group and the complications that arose from the requirements of the Lanarkshire Local Research and Ethics Committee (LREC). These problems had a significant impact on the design of this study and so are commented upon alongside the discussion of the study design.

As indicated, the use of the literature was restricted until reporting on the results. Only literature that I had already been exposed to during my career was considered prior to fieldwork and briefly discussed within chapter one. All other literature was accessed (theoretically sampled) only when clear data categories had emerged. The literature was searched for using the emergent data and therefore only appeared within the chapters reporting on these concepts (Chapters five–eight). Chapter four goes on to explain fully how this literature was analysed, coded and linked to the emergent codes and categories using the computer software programme NUD*IST.

Chapters five to eight report on the results from the study. Each of the four chapter titles corresponds to the four major categories that emerged from the study's data. Each chapter begins with an explanation of its content followed by a table displaying the data categories and their links to higher order substantive codes and the major category. Raw data quotations are used extensively throughout these chapters to allow the reader to form his/her own judgements on how well the theoretical framework is grounded in the emerging data. All of the studies consulted within this study were critiqued and analysed in a similar way to the data itself. However it was not practical to always include critiques on all of the studies appearing within these chapters and so only those with significant strengths or weaknesses were highlighted. Once higher order concepts emerged these were examined for relationships with other concepts in an effort to begin the development of a theoretical perspective using the process termed 'theoretical coding'.

Chapter nine picks up on these emergent codes and categories and explains the relationships and patterns between these higher order concepts. The developing theoretical framework is outlined in a step-by-step build up process moving from the first major category through to the fourth.

The final chapter examines the effects the Lanarkshire Research Ethics Committee (LREC) requirements had on the study following its completion, in particular, the issues of access to participants and their level of response. The participant contribution rate is reported and some conclusions are drawn from this experience. Also considered here are the problems associated with the saturation of the codes and categories following completion of the study.

Finally, the implications from the developed theory are discussed alongside its overall applicability to the care-giving environment and its future influences on practice and education.

In summary, given the apparent lack of research into, and ambiguity over, the relationship between the carer and professional key-worker, this study proposes to explore this vitally important area of contemporary practice. It is clear that an understanding of such 'perspectives and understandings' will only be achieved through in-depth study of the relationship that exists between carer and key-worker. Zarit & Leitsch's (2001) earlier comments, highlighting how the health care professionals exert change within both the carer and dependant through their intervention, highlight the need to develop a theoretical framework that adequately explains this relationship more explicitly. My study consequently focussed on the professional key-worker's developing relationship with the carer, this being potentially one of the most important relationships that could exert an influence on both the quality and level of support received by the carer, as well as quality of care provided to the dependant. This consideration gives additional impetus to the need to gain a clearer insight into this relationship. Gaining clarification could greatly enhance existing educational programmes by narrowing the potential gap between theory and practice, a criticism often levelled at contemporary health care education and training (Burnard 1989).

CHAPTER TWO THE RESEARCH AIM AND RESEARCH QUESTIONS

RESEARCH AIM

The aim of this study was to create a theoretical explanation of the development of the relationship between key-workers and carers involved in the care management of an individual diagnosed with dementia and living at home.

THE RESEARCH QUESTIONS

The research questions relate closely to the methodology adopted and the research questions within any qualitative study significantly differ from the hypothesis, or null hypothesis, generated at the beginning of any quantitative study (Smith & Biley 1997). In particular the questions within a qualitative design have to be open ended and flexible to allow the theory to develop, while being broad enough to allow investigation of all facets of the phenomenon being studied (Smith & Biley 1997). Such questions minimise the risk of the researcher ‘floundering’ during the interview process by providing a focus for the interviewer. The questions asked within this particular study were:

- What are the essential processes, associated with the support provided by the key-worker, which enhance or detract from the carer’s ability to effectively manage their care responsibilities?
- What are the key-worker attributes identified by the carer as being conducive to an effective working partnership?

- What are the carer attributes identified by the key- worker as being conducive to an effective working partnership?
- What are the boundaries of care responsibility associated with the carer as perceived from both the carer's and the key- worker's perspective?
- What factors, directly or indirectly, influence the perceptions of such boundaries?

CHAPTER THREE METHODOLOGY I: JUSTIFICATION OF

METHOD AND DESIGN

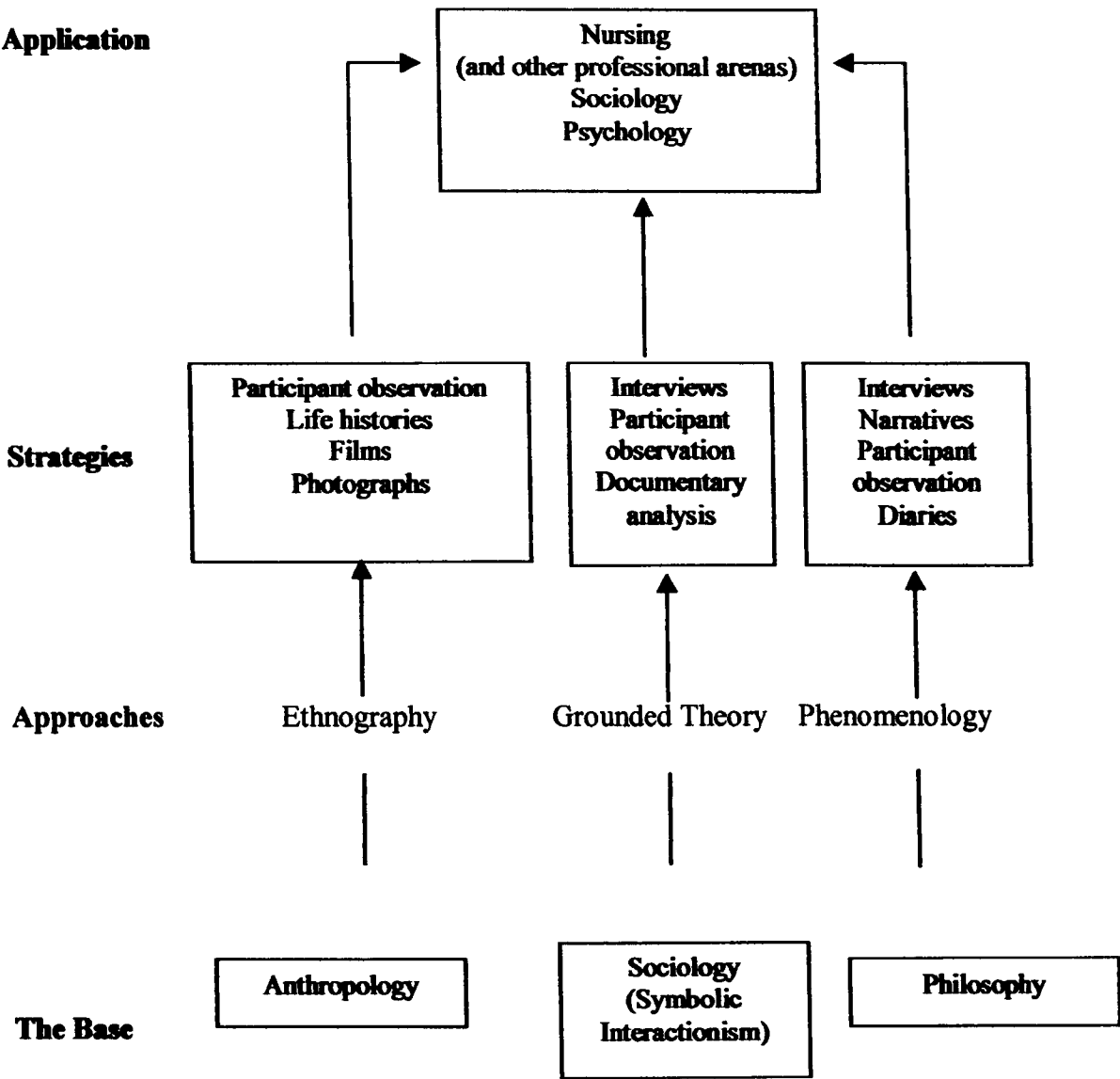
APPROACHES TO QUALITATIVE RESEARCH

The specific methodology adopted within this study is that of Grounded Theory. In order to justify this choice, it is important to explore and analyse other qualitative methodologies. Lipson (1991) and Lowenberg (1993) both identified the three principal methodological approaches to qualitative health research as Phenomenology, Ethnography and Grounded Theory. Although these methods share certain properties, in that they aim to discover meaning by focusing on subjectivity and eliminating the distance between the researcher and the participant, they have differing 'epistemological' assumptions (Holloway & Wheeler 1996; Harper & Hartman 1997). Figure 1 gives a clear diagrammatic representation of these three major approaches from their theoretical origins to their application.

PHENOMENOLOGY

The German philosopher Husserl first conceived Phenomenology as a research approach at the beginning of the 20th century to investigate consciousness as experienced by the participant (Baker et al 1992). Polit & Hungler (1999) defined phenomenology as 'A qualitative research tradition, with roots in philosophy and psychology that focus on the lived experience of humans.'(p.710). According to Burns & Grove (1999) Phenomenology could be considered both a philosophy and a method with which to conduct qualitative research.

Figure 1. Three interpretative approaches (Holloway & Wheeler 1996 p2)



As a research method its principle purpose is to describe experiences as they are lived. The philosophical base of Phenomenology expounds that only those who have actually experienced phenomena are capable of communicating them to the wider world (Parahoo 1997). It is a methodology closely linked to the qualitative research tradition of hermeneutics which concentrates upon the lived experiences

of humans to better understand social, cultural, political or historical contexts in which the experiences occur (Polit & Hungler 1999). Clair & Hamilton (2003) considered the goal of hermeneutics to be 'the study of understanding', but went on to emphasise that this was particularly focused on the 'understanding of texts'. Within the hermeneutic perspective there is an emphasis on language rather than the importance of context (Lowenberg 1993).

Hardey (1994) articulated how the Phenomenological methodology allowed health researchers to distance themselves from the domination of the natural science methodology and the biomedical model. He pointed out, however, the complexity of the philosophical basis to this research approach, and that there was no 'standard' or 'well-defined' way of undertaking this type of study within the healthcare environment. Holloway (1997) reiterated that Phenomenology was not a research method in itself and argued that some researchers using this approach were not willing to specify the techniques adopted. Clair & Hamilton (2003) concurred that the philosophical underpinnings to Phenomenology were complex and difficult to fully understand. These authors claimed that the application of the phenomenological research method itself was even more difficult to achieve, and further suggested that for some academics there was indeed no such method.

Field & Morse (1985) indicated that in choosing the Phenomenological approach, the researcher required to ask more experiential questions and, therefore, this is a method particularly geared to explore this more 'lived experience' type question. It is not a design that allows the generation of a

theoretical explanation of the phenomena under study (Hardey 1994). Indeed this methodology strives to 'interpret and understand' rather than to 'explain' through the generation of any theoretical perspective (Brykczynska 1998). This is an important distinction in terms of my own study's requirement to generate a theoretical perspective that explains the Carer/Key-Worker relationship and therefore its use within this study is not particularly appropriate.

ETHNOGRAPHY

One of the key strengths of ethnographic research is that the researcher, as best as is possible, becomes immersed in the culture being studied, and thus experiences the world from the participant perspective (Stevens et al 1993). They go into the real situation and endeavour to fully understand it in its entirety. The terms used within the results of such a study must have meaning to the cultural group involved (Hilton 1987). In this study it was not possible to access the participant groups in the manner demanded by ethnographic research, nor was it possible to develop the necessary depth of relationship within the time scale available. This was the significant factor making this methodological approach unsuitable for my study.

THE GROUNDED THEORY METHOD

While Ethnography may be unsuitable for use within my study, like other forms of qualitative methodologies, it carries many similarities to the next methodology to be discussed, that of Grounded Theory. Indeed, some authors believe that Grounded Theory is a form of 'ethnographic data analysis' rather than a separate qualitative methodology (Field & Morse 1985). However, others view Grounded

Theory as a departure from both Phenomenology and traditional Ethnography.

Citing Schatzman & Strauss (1973), Thorn (1991) stated that:

‘While interviews and participant observation remain the major data collection methods, their purpose in Grounded Theory research is to discover the underlying social forces shaping human action. This aim is radically different from Ethnography’s quest to determine why the actor thinks it is doing what it is doing or Phenomenology’s project of discovering how the actor articulates the experience of whatever it is experiencing.’(p.186).

Glaser & Strauss, two American sociologists, collaborated to design a methodology that reflected their different research backgrounds. Glaser came from a predominantly quantitative background, while Strauss was principally involved within the qualitative paradigm. In developing Grounded Theory, they demonstrated the need to focus closely on data, remain out in the field, and generate theory that reflects, and respects, the participant’s own perspective within the area of study (Glaser 1992).

Within the Grounded Theory approach the researcher should, ideally, keep one foot in the world of the participants and the other foot outside their experiences (Chenitz & Swanson 1986). Once a group has been identified, the researcher requires ‘interpersonal interaction’ that involves becoming part of the participant’s world and must develop a good sense of self-awareness. Only by examining his or her own level of self-awareness can the researcher begin to search for and more fully understand another individual’s world. It is this level

of understanding that is so crucial to field research, with the important realisation that the grounded theorist does not adversely influence the data with his/her own problems or perspectives (Glaser 1992; Hutchison 1993). The issue of 'forcing' the data in this way has become one of the fundamental differences between Glaser & Strauss's more recent interpretations on the use of Grounded Theory and is further discussed later within this chapter.

In his book entitled 'Basics of Grounded Theory Analysis' Glaser (1992) demonstrated Grounded Theory's relevance to a wide range of professional areas including public health, social work, political science, educational sociology and health. It can be utilised as a methodology for either research teams or adopted by the solo researcher (Field & Morse 1985). The Grounded Theory methodology involves alternating inductive and deductive reasoning, thereby allowing the required degree of flexibility necessary for an exploratory study (Simms 1981; Corbin 1986). This enables the researcher to be creative and to utilise their discretion, provided that this does not undermine the essential qualities of 'application and rigor' that are so important to the success of the analysis (Stevens et al 1993 p.48).

The principal benefit in using the Grounded Theory methodology is its ability to generate rather than to test theory. This offers a real advantage in allowing in-depth examination of complex situations that make up the reality of the contemporary health care environment. Given the apparent limited research around the Carer/Key-Worker relationship, the case for theory generation is much stronger than theory verification (Hardiman 1993). Glaser & Strauss

(1966) considered that Grounded Theory has particular applicability in preliminary, exploratory and descriptive studies. Hardiman (1993) strongly supported its use when examining complex organisational problems such as those of health care, education and practice. Interpreting data grounded in reality provides a powerful means to understand the real world (Strauss & Corbin 1990). The Grounded Theory methodology is appropriate when either little is known about a topic or a new or fresher perspective on the subject area is particularly desirable (Parahoo 1997). These comments adequately support the appropriateness of a Grounded Theory approach within this study.

Strauss & Corbin (1990) identified four basic purposes associated with the analytic procedures of Grounded Theory:

- To generate rather than only test theory.
- To give the research process enough rigour to ensure the theory is 'good' science.
- To allow the analyst to break through any biases and assumptions brought to or developed during the research process.
- To ensure that the grounding, building of density, and development of sensitivity and integration leads to the generation of a tightly woven explanatory theory that closely approximates upon the reality it represents.

Grounded theorists assume that people, no matter how disordered their environment may appear to outsiders, order and make sense of the world in which they exist. They base their research on the further assumption that 'each group shared a specific social psychological problem that is not necessarily

articulated and which is resolved by means of social psychological processes’ (Hutchinson 1993 p.185).

Theoretical Framework Underpinning Grounded Theory

The theoretical frameworks underpinning Grounded Theory within my study were those of Symbolic Interactionism and Reflexivity. Chenitz & Swanson (1986) suggested that both Phenomenology and Symbolic Interactionism involved internal aspects of human behaviour and how human beings respond in terms of their belief system, and that the Grounded Theory approach was a method that had its roots in the ‘Symbolic Interactionist’ school of sociology. Blumer (1969) stated that there were three premises on which Symbolic Interactionism was based:

- Human beings acted towards things on the basis of the meaning they had to them.
- Such meanings were derived from, or arose out of, interactions with one’s fellow human beings.
- Such meanings were dealt with, and modified, through an interpretative process by the individual as they dealt with the things they encountered.

Symbolic Interactionism puts forward the position that we all act and interact utilising symbols that have meaning and value to those involved. For example using words for an object rather than using the object itself, or the use of ‘body language’ communicating information without the use of words (Stern et al 1982). ‘It is a dynamic process in which roles change and adjust over time’ (Seaman 1987 p.91). Symbolic Interactionism provides an explanation of the

process of how meaning is arrived at by people in their everyday interactions with others (Stevens et al 1993). The Symbolic Interactionist views the individual as being active and creative. They consider that they 'create actions and revise them' (Holloway & Wheeler 1996 p.99). On the basis of this the individual interprets the behaviour of others and adopts appropriate roles accordingly, sharing particular reactions to situations with their social group. Hence the social group interprets language and gestures within their community, and responds accordingly to these interpretations (Holloway & Wheeler 1996).

The interpretations made by group members can only be understood within the context of the group and, as Grounded Theory places emphasis on the importance of context, it is well placed to provide an explanation of such interactive processes (Holloway & Wheeler 1996). Individuals and their behaviours cannot be fully understood outside of their social context and so Grounded Theory is principally aimed at understanding how a group of people define, through social interaction, the reality of their world (Stern et al 1982). Its use within this study appears particularly appropriate given that Grounded Theory is said to explain a particular social circumstance by highlighting the 'core and subsidiary categories operating in it' (Baker et al 1992 p.1357). Within my study, in order to develop a recognisable theoretical explanation, I had to generate such categories.

Replicability is greatly valued within quantitative research, a requirement that is demonstrated through the reliability and validity of the methods used (Webb 1992). Within qualitative research these concepts cannot be defined and

evaluated in the same way due to the adopted methods being so different (Webb 1992). Polit & Hungler (1999) defined construct validity as 'The degree to which an instrument measures the construct under investigation.'(p.698).

Webb (1994) considered the issue of 'face validity', a concept later defined by Polit & Hungler (1999) as: 'The extent to which a measuring instrument looks as though it is measuring what it purports to measure.'(p.702). This form of validity, also referred to as 'content validity', tends to be discussed in terms of the design of the questionnaire within the literature (Parahoo 1997). Webb (1994) considered face validity to be effectively measured by 'member checks', or, as Parahoo (1997) suggested, by going back to the research participants and gaining their impressions of the analysis, and refining on the basis of these views. This returning of the findings to the research participants, however, can be problematic as the participants and the researcher will, to a greater or lesser extent, have varying perspectives or agendas. This can, as the coding moves from a substantive to a more generalised and theoretical level, lead to the participants finding codes and categories less recognisable and meaningful to them (Horsburgh 2003).

Morse (1998) pointed out that, as the theory develops from the synthesis of a number of interviews, it is not advisable to attempt to validate the findings as a whole by involving individual participants. It is inappropriate to return the results to the participants for comment in order to gain face, or participant validity but, within certain interview settings the researcher can, through the interactive process of the interview, determine participant validation and clarify

the individual's perceptions (Horsburgh 2003). Indeed, through the process of interview and emerging concepts being checked and clarified within subsequent interviews, a significant level of participant validity can be achieved (Melia 1982). Therefore, by constantly comparing and contrasting data within the Grounded Theory methodology, an inherent check on validity is already being addressed (Glaser 1992; Hutchinson 1993).

Chenitz & Swanson (1986) considered that the credibility of theory is important and must 'fit' the phenomena being studied, have 'grab and work' when applied. 'Fit' refers to the categories being generated and must be indicated by, and readily applied to, the data. 'Grab' suggests that the theory is relevant to the social or practice world of the person in that world, and 'Work' refers to the 'usefulness of the theory to explain, interpret, and predict phenomena under study' (Chenitz & Swanson 1986 p.13). 'The theoretical constructs are grounded in substantive or categorical codes, precluding the possibility of unfounded abstract theorising' (Hutchinson 1993 p.197).

A lack of reliability and replicability has been a major source of criticism of the Grounded Theory method (Chenitz & Swanson 1986). However, as Hutchinson (1993) pointed out, this question of replicability is not particularly relevant to Grounded Theory as theory generation is to offer a new perspective on a given situation and provide useful ways of looking at a certain world (Hutchinson 1993). However, one of the ways in which validity can be addressed within a Grounded Theory study is through the process of Reflexivity. Through the use of field notes existing biases and prior knowledge can be acknowledged, and any

thoughts and feelings recorded and reflected upon (Webb 1994; Holloway & Wheeler 1996). Here the researcher systematically provides reports on the rationale for decisions made during the whole research process, and how she or he has influenced either the process or the content of the research (Koch 1994).

Reflexivity has not been well explained within the literature and is considered to be a rather 'nebulous' term where, even when being discussed within qualitative methodological texts, its description has not been given with any clear precision. (Aitkinson & Coffey 2002; Carolan 2003). This ambiguity aside, the relevance and importance of Reflexivity within the qualitative paradigm has been clearly acknowledged (Abbott & Sapsford 1998).

Horsburgh (2003) commented that qualitative research cannot operate under the belief that the researcher is able to detach him or herself totally from the study undertaken, even if this is desirable. The researcher is a part of, rather than separate from, the data being collected and any theory arising out of a qualitative study must include an essence of the researcher (Lipson 1991; Johnston 1995; Ersser 1996). The traditional positivist approach has resulted in the researcher writing themselves out of the text, believing that to do otherwise would result in them somehow contaminating the emerging data (Northway 2000). It is essential to realise that in qualitative approaches the assumption is that the researcher being separate or neutral from the data is an erroneous one (Henwood & Pidgeon 1993; Porter 1993; Mason 1996; Hand 2003).

To write in the third person has traditionally been a more acceptable way of documenting academic work (Northledge 1990; Goodall 1995). Early studies were generally experimental and tightly controlled, occurring under laboratory conditions where objectivity was the ideal (Holloway & Wheeler 1996). This objectivity, required within quantitative research, related to the existence of an independent researcher where bias had to be excluded in order to provide the truth (Munhall & Oiler Boyd 1993). It was for this reason that the voice of the researcher, as they provided documentary evidence of their research process, was written in the passive form or the third person (Webb 1992).

As previously argued Reflexivity is a way of offsetting the risk of bias within the more interpretative social paradigm of the qualitative study. The use of Reflexivity, where the researcher indicates their 'personal involvement' within the study, is demonstrated through the use of the first person (Norton 1999; Horsburgh 2003). Writing in the first person is considered essential for qualitative research and by not doing so the writer is not in keeping with the epistemology of the interpretative approach. This can result in the social elements becoming more obscured which can prevent the reader from fully evaluating the quality of the study (Webb 1992). I acknowledge that there are differing opinions with regard to this matter within the academic community. However, it is for the reasons outlined above that my study and its resultant findings have been written and presented in the style of the first person.

Reflexivity allows recognition of this fact and seeks to make the reciprocal relationship, between the researcher and the research process, transparent and

open (Lamb & Huttlinger 1989; Koch & Harrington 1998; Horsburgh 2003). Hutchison (1993) linked Reflexivity to Grounded Theory by claiming that, as Grounded Theory research requires an interpersonal dialogue, the researcher is inevitably part of the observations taking place. Indeed, Turner (1981) strongly argued that the positive aspect of Reflexivity within the Grounded Theory approach is that, coupled with the creativity of the researcher, it leads the researcher into the creative core of the research process. By enhancing the application of intellectual and imaginative processes to the analysis, Reflexivity greatly assists in the demanding process of interpreting research data.

Reflexivity allows 'taken for granted' value systems and personal beliefs to be recognised with the researcher becoming sensitive to the effects their actions have on the experience under investigation, especially on the meaning and context of the data uncovered (Gray 1997; Pellatt 2003). Koch & Harrington (1998) believed Reflexivity to be a 'counter practice' to the risk of 'self indulgence and narcissism' (p.888), and that its application leads to research that is both 'believable and plausible' (p.883). Parahoo (1997 p.292) also stated that the researcher must continually reflect upon their 'own values, preconceptions, behaviour or presence' continuously during the ongoing study. Koch (1994) stated that while the reader of a research study may not hold the same interpretation as the researcher, they should still be able to clearly see the rationale behind the approaches adopted within the study. This is achieved by using what she terms the decision or 'audit' trail. In this, the researcher makes clear the thinking involved in any theoretical, methodological and/or analytical decisions.

Developing Codes and Categories

The utilisation of the Grounded Theory approach involves a 'constant comparative' method which is an ongoing tightly interwoven process of data collection and analysis. This 'constant comparative method of analysis' is used to achieve the goals of 'conceptualising' and 'categorising' data using open coding (Strauss & Corbin 1990; Glaser 1992). Comparisons are continually made between sections of data, in my case interview transcripts, for similarities and differences between the participants interviewed. The interview transcripts under study are firstly examined using what Strauss & Corbin (1990 p72) termed 'line by line analysis' whereby words, or phrases, verbalised by the participants are identified. These are then compared, clustered and given an initial label from which higher order categories and codes are formed. This process facilitates the development of theoretical constructs from the data by clarifying the properties of the emerging categories and codes, enabling relationships between these to be identified which helps to explain the phenomena under study.

Strauss's method of discovering categories drew particular criticism from Glaser (1992). His concern was that Strauss's strategy within the open coding stage of labelling each incident carried with it a risk of generating hundreds of conceptual labels which leads to the researcher not knowing which are relevant or not. This, he considered, is labour intensive, tedious, yields no analysis and is entirely unnecessary. Fleming (1998) addressed this concern in her study aimed at developing a model for midwifery practice using Grounded Theory, a study

broadly parallel to my own. She made it clear that the early writing of Glaser & Strauss (1966) led to every line and, even every word in some instances, being coded. She concludes that this is ‘... too reductionist and less representative of the positions of the midwives and clients who participated in this research’ (p.138).

Glaser (1992) considered that there were really only two types of coding within Grounded Theory, substantive and theoretical. The former arises when ‘conceptual meaning’ is given to the patterns within the incidents found in the field. Theoretical codes are then formed when conceptual models, or relationships, are established between these codes. Strauss & Corbin (1990) suggested that incidents are labelled and given a conceptual name representing the phenomena, Glaser, on the other hand, stated that all that is required is that incidents and or categories are compared, and the patterns among them conceptualised (Hickey 1997).

Glaser (1992) also criticised Strauss & Corbin’s (1990) procedures on how to reconstruct data following open coding. These procedures, referred to as axial coding, were considered by Glaser (1992) to be unnecessary. He considered that Strauss & Corbin (1990) had written:

‘... a dangerous chapter as, for the grounded theorist... its exhortations will produce a combination of imposed and generated conceptual connections between categories and properties, so the reader will never be able to evaluate the Grounded Theory.’ (p.62)

This argument reflected the 'emerging' versus 'forcing' debate that now divides these former associates, and has both confused and influenced my decisions in applying the Grounded Theory method. I found myself in agreement with Fleming's premise, more in keeping with Glaser's (1992) later text, that it is permissible for data to be considered more within its context rather than risking over conceptualising the data by labelling every word and/or line. I also agreed with Glaser's (1992) approach towards higher order conceptualisation using theoretical coding in which relationships linking codes and categories are identified. These approaches were therefore adopted within this study and directed the coding and conceptualisation procedures throughout the analytical process of my study.

Strauss and Glaser both agreed that memo writing was an important process within Grounded Theory. Strauss & Corbin (1990) considered memos to be the written forms of the researcher's abstract thinking about the emerging data, and Glaser (1992) described memos as 'the theorising write-up of ideas as they emerge' (p.108). According to Hutchinson (1993) to generate a good quality theory 'the descriptions of empirical events must be elevated to a theoretical level. Memoing is a vital part of that process' (p.201). Memos evolve and conceptually grow in complexity, density, clarity, and accuracy as a study progresses, and these notes are important components of the analysis throughout the study helping the researcher to 'gain analytical distance from materials' (Strauss & Corbin 1990 p.199). In writing the memos, the relationship that one code has to another is questioned, or if one incident is the cause or consequence

of another? What conditions influence the codes? According to Hutchinson (1993) it is through this process of continual questioning that a theory eventually evolves.

As indicated, the formation of data categories is a development that derives from the initial codes given to the raw data (in-vivo codes) on initial readings of the transcriptions. This is a process that is considerably helped by the use of both written and recorded memos (Strauss & Corbin 1990; Hutchinson 1993). Following each interview the researcher records his/her initial views and impressions of the interview, identifying strengths and weaknesses within the interview process. This allows for the identification of problem areas that can then be addressed within subsequent interviews. These memos also allow the researcher to identify initial emerging themes from the interviews that can be further explored within follow-up interviews, an aspect of the research process that is very much in keeping with the Grounded Theory approach (Hutchinson 1993). Such interview field notes were recorded following each of the interviews associated with my study.

In order to extract theory out of the data, a Grounded Theory researcher has to develop the ability to 'see' with some analytic depth what is in front of them. This is referred to as 'theoretical sensitivity' (Strauss & Corbin 1990; Glaser 1992). In the early stages of the study the researcher requires ways of opening up their thinking about the phenomena under study. Theoretical sensitivity involves the researcher retaining insight and an ability to understand and give meaning to the data, and an ability to separate what is meaningful from that

which is not (Strauss & Corbin 1990). Glaser (1992) pointed out that this aspect of theoretical sensitivity involves the researcher asking these formal questions of the study area:

- What is the main concern or problem for the people in the substantive area, and what accounts for most variation in processing the problem?
- What category or what property did this incident indicate?

Cutcliffe (2000) considered that the fundamental difference between the Glaser and the Strauss perspective centres principally on the issue of ‘forcing and emerging’. He cited Stern (1994) who explains these differences in terms of the questions each ask of the data. Strauss asks ‘what if?’ where as Glaser asks ‘what do we have here?’ Glaser believed that Strauss had deviated so far from the original method that his methodology should be given a different name (Cutcliffe 2000).

Their disagreement potentially leads to budding grounded theorists experiencing a degree of anxiety as they contemplate which question to ask of the data, and what if they ask both questions, are they using a differing version of the method (Cutcliffe 2000)? Cutcliffe considered that focusing on this dilemma does not help the researcher and results in disability and restriction, leading to the researcher becoming more concerned with ‘process questions rather than creative, interpretative questions’ (p.1483). The researcher can instead consider combining the questions, a combination of ‘What if?, and ‘What do we have here?’, and ‘What categories, concepts or labels do we need to account for the

phenomena?'. These questions, according to Cutcliffe (2000), can lead to a much richer and deeper understanding of the data. I am in broad agreement with these views and asked the variety of questions, suggested here, of all incoming data within my study.

I was also mindful of the approach, highlighted earlier within this chapter, used by Melia (1982) while interviewing student nurses. Any ideas raised during one interview are followed up and further explored within the subsequent interviews. Therefore as the interview process progresses, interview questions evolve and grow. While analysing transcripts the importance of simple and focused questioning of the data, and the researcher maintaining an intellectual objectivity in order to avoid forcing the data with his/her own problems, were paramount considerations within my study.

I shared Cutcliffe's (2000) opinion that the most important consideration, when examining the disagreement between Glaser and Strauss, is that the researcher has to be open and honest in how he or she carries out the research. This, along with the checking out of emergent concepts within subsequent interviews, as suggested by Melia (1982), greatly influenced my own approach and direction within this study.

Analysing the Data

The computer has become an important tool for the qualitative researcher and involves both conceptual and mechanical aspects that are inherent within qualitative research. The conceptual aspect of the research process involves

gathering, grouping and labeling data followed by analysis to extract understanding and meaning from that data; the mechanical aspect involves storage, organization and retrieval of data (Knafl & Webster 1988; Russel & Gregory 1993).

Historically, qualitative researchers have been less inclined to adopt computer assisted data analysis than their quantitative counterparts, a surprising fact given the vast amounts of data that is generated by qualitative methods that then requires to be kept track of (Baker 1988; Pateman 1998). Qualitative software packages have however also been accused of having a 'corrupting influence' when compared to more traditional manual forms of analysis (Morrison & Moir 1998; Glaser 2001). The use of such computer programmes can also be problematic in that they may distance the researcher from the data and so reduce essential theoretical sensitivity (Becker 1993; Glaser 2001). However, Pateman (1998) indicated that this distance created between the researcher and the whole data set may allow the researcher to concentrate more on each transcript. Tait (1999) described the essential qualities of a suitable computer software package as:

- to store and organise text files along with any coding categories and results;
- to allow for the searching, retrieval and interpretation of data;
- to facilitate the management of multiple documents in separate windows allowing for cutting and pasting;
- to facilitate the construction of theoretical frameworks and concepts.

Computer software packages aid the organisation and management of data, but still require the researcher to actively and thoughtfully engage with the data in order to produce an effective analysis (Tesch 1991; Morrison & Moir 1998).

A tendency to over-code the data is another acknowledged problem that could occur in both manual and computer data management systems, and was described by Pateman (1998) as a 'coding fetishism'. This problem can be increased when using computer based packages where the physical evidence of data is less obvious. As the interviews progress this tendency can become somewhat easier, with the researcher becoming more sensitive to the data and so coding more appropriately (Richards 1997). There are a variety of computer packages available for use by the qualitative researcher. Russel & Gregory (1993) identified NUD*IST (Non-numerical Unstructured Data) as being particularly applicable to a study that was engaged in theory building, as was the case in my particular study.

Developing the Theory

It is important when reporting on the results to include actual quotes from the data to enhance the 'explanatory power' of the report. 'Segments of data usually 'hook' the reader and allow him to make independent judgements about how well the theoretical scheme is grounded in the data' (Antle May 1986 p.150). It is for this reason that the four chapters containing the results and analysis of these results from my study have made extensive use of verbatim data quoted from the participants, along with any relevant theoretically sampled literature.

The theory comes together around a core category, or variable, and there are six characteristics associated with the core category (Hutchinson 1993):

- it recurs frequently in the data;
- it links the various data together;
- due to its centrality, it explains much of the variation of the data;
- it has implications for more general or formal theory;
- as it becomes more detailed, the theory moves forward;
- it allows the maximum variation in analysis.

Core categories become the basis for the generation of theory. The integration and density of the theory is dependent upon the discovery, or identification, of a core category (Munhall & Oiler 1986). Such theories are not proven, only proposed, as they are based upon an integrated set of hypotheses and not actual scientific findings (Fleming 1992).

The relevance of the material being collected, the saturation of the categories, the emergence of new categories and the speed of coding all vary as the research process progresses. 'Lower level categories emerge rather quickly during the early phases of data collection. Higher level overriding and integrating conceptualisations - and the properties that elaborate them - tend to come later during the joint collection, coding and analysis of data' (Glaser 1978 p.36).

The Use of the Literature within a Grounded Theory Study

Some researchers believe that the initial review of the literature has some importance as it enables the reader to see the area from the researcher's perspective as the project begins and provides justification for launching the Grounded Theory study (Antle May 1986). The researcher must then move to a second review of the literature that links existent research and theory with the concepts, constructs, and properties of the new theory (Hutchinson 1993). As in other aspects of the Grounded Theory methodology, Glaser & Strauss fundamentally disagreed over the use of literature and the need to conduct the initial review. Strauss, in his later writing with Corbin in 1990, advocated reviewing the literature early in the study and as it progresses. They believed this review led to:

- a stimulation of theoretical sensitivity;
- the provision of a secondary source of data;
- a stimulation of questions;
- a direction in theoretical sampling;
- a provision of supplementary validity.

Glaser (1992) strongly disagreed and discussed several levels of literature required within Grounded Theory including professional literature related to the area under study. A fundamental question always within Grounded Theory is when should one consult the literature. 'There is a need not to review any of the literature in the substantive area under study' (Glaser 1992 p.31). This dictum in Grounded Theory, he stated, is very unlike other research approaches. The reason

for this is to prevent the researcher from being 'constrained' or 'contaminated', or otherwise inhibited from effectively generating categories, their properties and theoretical coding through prior reading of related literature. Glaser considered that such reading leads to a 'derailment' in the form of recognised or unconscious assumptions regarding what the data is presenting.

Avoiding a literature review at the beginning of the study means that the emerging theory is more likely to be 'grounded' in the data (Hickey 1997; Cutcliffe 2000). Hickey (1997) argued that if there is a clear lack of research around the area of interest, the literature review may not only yield insufficient information, but risks leading the researcher into making inaccurate assumptions about what is or is not important to the research being contemplated. He pointed out the risk, following an initial review of the literature, of the researcher focusing the research problem on areas that the literature has thrown up rather than that of the emerging data. In his study, 'on the effects of the NHS and Community Care Act on the role of nurse', Hickey found that he had incorrectly assumed that the issue of 'case management' was of the greatest importance to the participants. This assumption, he stated, was a direct result of being informed by the early literature and not from the emerging data. This epitomises Glaser's (1992) warning that 'derailment' can occur if the professional literature is consulted in any depth at the commencement of a study.

It was for this reason, along with my prior experience with, and knowledge of, the study group that I decided to adopt Glaser's position and not conduct an initial review of the subject literature prior to the study's commencement.

Having worked in the professional area associated with this study, I have read fairly widely in terms of what Glaser (1992) considered to be professional literature, both related and unrelated to the subject area. As suggested above, my greatest concern at this point was not to risk any possibility of ‘forcing the data’ through existing conceptual understanding arising out of my prior academic reading and, most significantly, my previous professional experiences brought from the field. Wherever possible reference to the literature was made in an effort to identify comparisons or contradictions within the categories and codes only after they have emerged.

Sampling – Theoretical versus Purposive Sampling

Grounded Theory requires non-probability sampling and, because of the requirement for concepts and categories to emerge during the analysis, specific data sources have to be sampled until saturation of the categories is achieved (Cutcliffe 2000). The process of data collection has to continue until the emerging categories have become saturated (Glaser & Strauss 1967). Within this methodology sampling decisions are made ‘theoretically’ and information gathered from any group that may be a source of relevant data, relevance being determined on the basis of the requirement for ‘generating, delimiting, and saturating the theoretical codes’ (Hutchinson 1993 p.203). This form of sampling is also referred to in the literature as purposive sampling where the informants have the necessary ‘characteristics or knowledge’ to inform the evolving theory (Field & Morse 1985 p95). Field & Morse (1985) considered that this type of sampling within Grounded Theory is termed theoretical sampling. Theoretical sampling involves the researcher, from his or her

emerging knowledge of the population, selecting participants who might be considered 'typical' of that population being studied (Becker 1993; Haber 1994).

Holloway & Wheeler (1996) drew a distinction between theoretical and purposive sampling, claiming the latter should not be used as this means that the researcher has decided on the sampling procedures before data collection begins. This is, therefore, when a researcher preconceives a sample group's characteristics prior to the study's commencement, and selects all participants from this group without any further thought as to selection criteria regardless of emerging data (Cutcliffe 2000). Theoretical sampling begins initially with a purposive sample but is more specific in that the researcher, having interviewed one or more participants, then decides very specifically what data theme to pursue next and which particular participant type would best provide that data, decisions informed by the emerging theory (Glaser 1992). Holloway & Wheeler (1996) stated that the researcher has to use theoretical sampling as a necessity due to the inductive deductive nature of the research.

Coyne (1997) considered that there was a lack of clarity within the research community regarding these two forms of sampling which only led to confusion for the researcher not experienced in Grounded Theory methodology. Theoretical sampling within the Grounded Theory methodology is dictated by the emerging theory and therefore should be classified as being 'theoretical' rather than 'purposive', a distinction not made by other qualitative researchers (Cutcliffe 2000). As pointed out by Glaser (1992), more is to be gained by conceptualising the data and that, while bias can be an issue, this is reduced in

Grounded Theory by the use of constant comparison, saturation and core relevance. While the risk of bias in theoretical sampling is acknowledged, this is most useful when the researcher wants a sample of 'homogeneous experts', as was the case in my study (Polit & Hungler 1987). This issue of sampling presented a particular impact upon my study and will be revisited within the following chapter and again also within chapter ten.

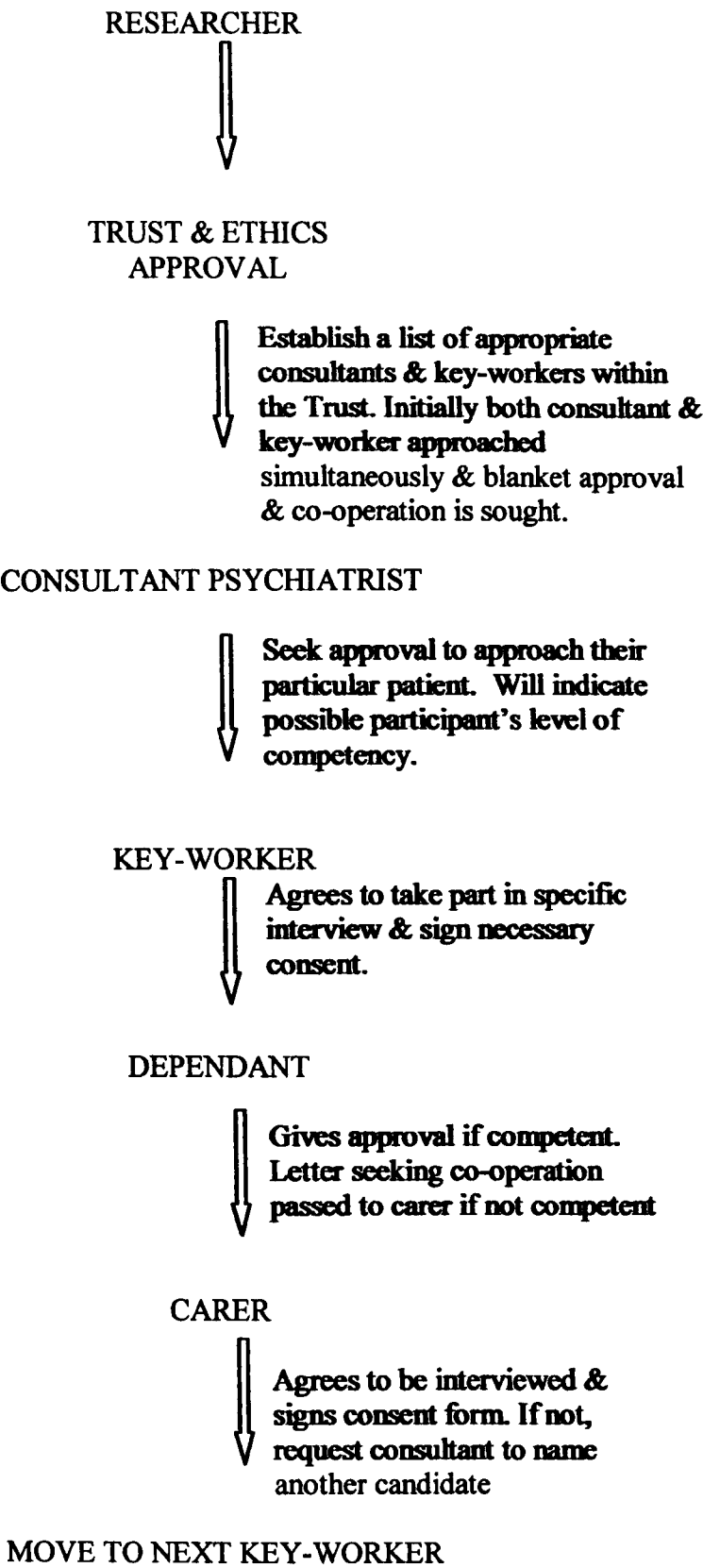
CHAPTER FOUR METHOD II – DESIGN AND PROCEDURES

THE POPULATION

Given the purpose of this study the participants had to have ‘specific characteristics and knowledge’ which was relevant to the study’s aim (Field & Morse 1985). I therefore selected a sample of carers who either lived with or were in daily contact with a person diagnosed with dementia, along with their associated key-worker who was either a registered health/social care professional, or a worker working under such a professional’s direct supervision. As discussed earlier, a dyad that included both the professional care workers, who had key-worker responsibility for the care of the dependant cared for within the home setting, along with the principal carer for that individual was utilised. Therefore, following identification of a suitable care situation, each was interviewed independently and the interviews analysed prior to moving to the next, most appropriate, care situation. This tandem approach was adopted throughout the interview phase of my study.

All professional care workers required to be appropriately registered under health or social work legislation, and could be selected for interview regarding more than one care-giving dyad. These dyads were selected from the Lanarkshire Health Board area and associated with patients currently under the care of Lanarkshire Primary Care Trust. Accessing the sample groups (See Figure 2) involved initially contacting the responsible Consultant Psychiatrist in order to gain his/her permission prior to contacting the key-worker. The advantages and limitations of this approach are laid out within Appendix 1a.

Figure 2. Accessing the Sample Groups Prior to Ethical Approval



ACCESSING THE SAMPLE GROUP

Initially I had intended to write out to participants directly, having been given a list of potential names of suitable caring dyads (carer and key-worker) by a consultant, this being the perceived quickest and most direct route to these participants. However after consultation with some experts in the field, I was advised that I should proceed by firstly contacting the identified dependant as this was the approach that was most likely to meet with the approval of Lanarkshire Research Ethics Committee (LREC) and the Trust's senior management. This presented the problem of how to communicate, by post, with a person suffering from dementia? Two important considerations presented here; firstly, what was the dependant's level of competence and ability to receive this mail and then pass it on to the appropriate carer? Secondly, how not to scare or intimidate the person receiving this correspondence?

After further consultation the following approach was selected. A suitable letter addressed to the dependant was constructed in a format least likely to alarm them and ensure their passing on the information to the carer. Having received this, the carer could then make a decision on whether or not to contact me. By adopting this approach I ensured that the dependant was consulted prior to interview, and if they were incapable of understanding the letter, the carer was the most likely person to open their mail and so receive the correspondence originally intended for them.

What seemed initially to be a fairly straightforward task turned out to be a difficult and frustrating goal, i.e. the writing of a short letter to a person experiencing symptoms of dementia and requesting their co-operation in informing their carer. Following the first draft I took advice from a CPN experienced in dementia care to greatly simplify this correspondence and present it in a softer colour of paper making it less intimidating and easier on the eye. Hague (1993) supported the suggestion that the colour of paper selected was significant. He claimed that the researcher would get a higher response rate if he or she used a yellow or pink colour paper in his/her research correspondence. Given these opinions the colour of paper was changed from white to soft yellow, a colour hopefully more appealing to the reader and more likely to produce a positive response.

After several attempts this letter was still considered too complex and so further advice was sought from the Dementia Centre within the University of Stirling. They concurred with the CPN and advised that I use the Flesch readability scale contained within the Microsoft (Word 98) word processing programme. The first letter drafted had a readability quotient of 55.0. To put this into some perspective, the letter drafted for the Consultant Psychiatrist was 44.1. The lower the figure the more complicated the narrative and consequently the more complex. I finally managed to produce a draft with a quotient of 79.9, considered by Stirling to be much more appropriate for a person diagnosed with dementia (Appendix 3).

RECRUITMENT AND THE INFLUENCE OF ETHICAL APPROVAL REQUIREMENTS

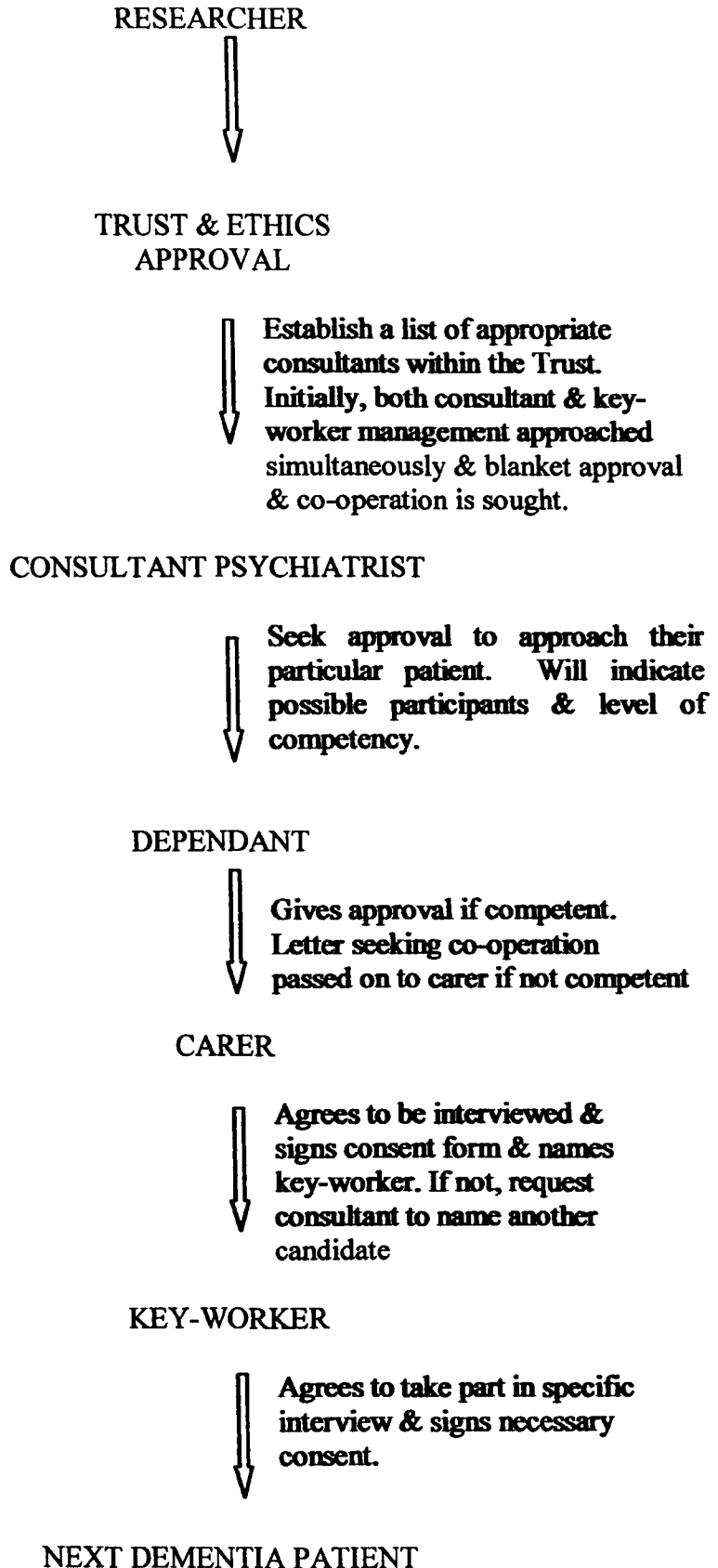
The gaining of informed consent within this study proved particularly challenging. Following consultation with the LREC, it was a requirement that the consultant psychiatrist must, independently from the researcher, identify all carer participants to be involved within the study. The consultant, by suggesting specific participants, was consenting to their inclusion within this research. As the consultant psychiatrist was the responsible medical officer for the care situation, it was not deemed necessary to inform the carer's general practitioner. A request for blanket permission was made to the Trust's medical director and lead clinician, as well as to the strategic service manager of the Local Councils prior to the inception of the study (Appendix 2).

Decisions made by LREC had such a significant impact on the recruitment of participants to my study that these are also addressed within this chapter. Accessing the sample groups involved contact with the consultant psychiatrist (see Figure 2), prior to contacting the carer. Other criteria required in the selection of participants was that the carer had to be living in residence with their dependant or, at least, be in daily contact and living in close proximity to them. This was essential as the study's aim and focus were best served by the inclusion of individuals who had an all-encompassing full time responsibility for the dependant and, therefore, possessed the specific characteristics and knowledge required for my study (Field & Morse 1985).

On requesting the participants for inclusion, the consultant psychiatrist was specifically asked to identify any individual who might be involved, currently or in the recent past, in any other research project. In addition I asked participants this question each time informed consent was being sought. As the data collection method involved a taped interview, I had to be able to clearly understand what was being said in order to accurately transcribe and analyse each conversation. It was vitally important that those included within my study could communicate in English. There was also a necessity that all participants could read and fully understand both the information sheet and the consent form. All potential participants within my study fully met with these criteria and all were therefore included.

The original proposal to LREC involved my receiving, from the consultant psychiatrist, a list of names of carers who would potentially be willing to participate in this study (Figure 2). This approach was not acceptable to the committee who requested a further meeting with me (Appendix 4). The committee would not allow me access to the names of any potential carer participants and so, following this meeting, the access route to the potential participants was altered (Figure 3). The study would now, having gained consultant approval, involve me providing the consultant's secretary with a pack that contained the letter and associated carer information placed within a stamped envelope. The consultant would then instruct his or her secretary to forward this information to potential participants. Therefore it was only when a carer wanted to be included in my study, and had contacted me directly, that I would know their identity.

Figure 3. Accessing the Sample Groups Following Ethical Approval



The advantages and limitations associated with this revised approach are contained within Appendix 1b.

Originally the study was to include only registered professionals as the entry criteria for the key-worker cohort. It was only after ethical approval of the study was granted that it became obvious to me that I was excluding a significant group of people whom the carers could consider to be key-workers. These were health and social care workers who were not formally trained or registered. It was important, therefore, that this group was included within the study. As these support staff had to operate under the supervision of the registered key-worker they therefore met the criteria of a professional care worker. The concept of professionalism, what constitutes a professional and how professional values are attained has received serious debate within the contemporary health care literature (McGhee 1995; Ruddy 1998; Van De Camp et al 2004). There is, however, no space to do justice to this debate within this thesis. The decision to include the unqualified group of staff was taken primarily because it was considered vital to the study's focus and philosophical underpinnings that the carers themselves selected who their key worker was. I would argue that the inclusion of this group did not, however, undermine the professional characteristics of the key-worker cohort as, by the fact that they worked under the supervision of the qualified professional, they are likely to reflect the values, ethos and professional code of that profession. Therefore, following writing to and gaining a further meeting with LREC, the proposal was amended to include this group on this proviso that they were working under the direct supervision of a registered health or social care worker (Appendix 4).

A total of 87 packs were distributed and 19 carers responded, 18 of whom met the study's entry criteria: 13 wives and four husbands, all living with their dependant, and one daughter living in close proximity to her mother. The carer identified who they considered to be their key-worker and, as some key-workers were involved with more than one carer, a total of eleven were included within the study. Of these 11, nine were health care staff: eight registered nurses and one health care assistant. The other two were social workers: one registered and the other a social work assistant. Seven of the key-workers were female.

This response rate to the request to take part in the study was disappointing. Although a total of 87 requests were sent out to the consultants over the two year period of the study it is not known how many actually reached carers. This relatively low number of responses could be attributed to my difficulty in accessing the sample group directly, a feature that was partly due to a lack of control over the contact process brought about by the requirements of LREC. One geographical area was placed totally out-with the bounds of this study when I was contacted by a consultant psychiatrist who, following a detailed discussion of the study, refused permission on the grounds that I would potentially upset her patients, and their carers, by interviewing them. This decision prevented access to any carers within an approximated general population of 75,000 people.

The problem over a lack of co-operation was also associated with organisations employing key-workers. One social work department asked me to apply using their established research approval process, despite having LREC approval, that involved the completion and submission of a detailed and lengthy application

request form. Following a three-month delay, I telephoned their personnel department and was assured that this was being processed. No further communication was received from them and, consequently, a significant group of potential participants remained unavailable for inclusion.

The low response rate also contributed to my suspicion that certain gatekeepers were not always fully co-operative in sending out all requests necessary to my gaining access to the sample. During the fieldwork the suspicion emerged that some consultants were failing to send out the request packages promptly or even at all. This doubt arose when I had no responses from certain geographical areas, despite repeated telephone and written reminders being sent out to these consultants.

Finally, two highly probable reasons for this low response rate could have been that these requests, having to go through the dependant diagnosed with dementia first, did not always find their way to the primary carer, or if they did reach them they were simply ignored.

It was not envisaged that the participants taking part in my study would encounter any specific risks. However it had to be considered and acknowledged that certain participants could possibly experience a degree of distress in discussing a potentially sensitive set of life experiences. Also, by discussing the issues that arose during the interview, existing relationships between a carer and the person with dementia, or with the key-worker, could become adversely affected. Every effort was made to minimise this and I was careful to listen for

any significant indications of distress or discomfort. The only other aspect to acknowledge with regard to risk was the obvious inconvenience to the participants in giving their time and effort to the interview process. Again I endeavoured to minimise this by conducting all interviews efficiently and effectively, keeping as close to the allotted time as possible.

The number of times that participants were interviewed varied depending on whether the participant was a carer or a key-worker. The carers were subjected to only one interview of approximately forty-five minutes to one hour's duration. The key-worker was interviewed more frequently depending on the number of suitable care scenarios they were currently involved with and which came into the study's selection process. It was not envisaged that each professional would be interviewed any more than three times. This proved to be the case in all but one instance when a particular key-worker required to be interviewed on four separate occasions. This case is discussed in more detail within chapter ten.

Throughout the fieldwork stage informed consent was obtained from both the carer and key-worker participants. For the carers, information sheets were sent out through a consultant psychiatrist along with the carer reply form (Appendix 5). On receipt of these reply letters the carer was contacted by telephone and a suitable appointment arranged. On meeting, and prior to the interview, the information sheet was again discussed and I reinforced the carer's rights contained within it. At this point they were asked to sign the consent form and to retain a copy. Following the interview, and only when the carer had identified and agreed to their key-worker being interviewed, the professional was contacted

in a similar fashion and sent the request for interview letter along with the appropriate information sheet (Appendix 5). On meeting the key-worker the same procedure was followed. It was only by them agreeing to the interview, and signing the consent form, that the name of their carer was divulged. Tables 1 and 2 contain a summary of both participant groups' biographical details. More comprehensive details are contained within Appendix 6.

Table 1 – Carer Biographical Summary Details

| Biographical Criteria | Carer Summary Detail |
|--|------------------------------|
| Total Number of Carer Participants | 18 |
| Gender | Male: 4 (22%) |
| | Female: 14 (78%) |
| Age (Years) | Range: 34 – 82 Years |
| | Mean: 69.4 Years |
| Relationship to Dependant | Spouse: 17 (94%) |
| | Adult Child: 1 (5.5%) |
| Time Spent Caring (Years) | Range: 1 – 7 Years |
| | Mean: 3.5 Years |
| Providing Personal Care | 13 (72%) |
| Providing Cooking Shopping | 16 (89%) |
| Providing Travel | 16 (89%) |
| Providing Safety Supervision | 14 (78%) |
| Providing Financial Support | 16 (89%) |
| Providing Supervision of Medication | 14 (78%) |

Table 2 – Key-Worker Biographical Summary Details

| Biographical Criteria | Key-Worker Summary Detail |
|--|----------------------------------|
| Total Number of Key-worker Participants | 11 |
| Gender | Male: 4 (36%) |
| | Female: 7 (64%) |
| Age (Years) | Range: 26– 55 Years |
| | Mean: 37.5 Years |
| Professional Group | Local Authority: 2 (11%) |
| | NHS: 16 (89%) |
| Time Involved with Carer (Months) | Range: 3 - 60 Months |
| | Mean: 15 Months |
| Providing Personal Care/Advice | 6 (33%) |
| Providing Cooking Shopping/Advice | 3 (17%) |
| Providing Travel/Advice | 6 (33%) |
| Providing Safety Supervision/ Advice | 11 (61%) |
| Providing Financial Advice | 6 (33%) |
| Providing Medication Supervision | 11 (61%) |
| Qualified/Unqualified Key-Workers | Number Unqualified 2 (18%) |
| | Number Qualified 9 (82%) |
| Qualified in Post (Years) | Range: 3 – 26 Years |
| | Mean: 13.4 Years |

THE PILOT STUDY

A pilot study has to command the same degree of care and attention to detail as the main study it precedes and, as much as possible, includes subjects that reflect similar characteristics to the main sample group (Polit & Hungler 1991). As this study focused upon both carers and key-workers, it was recognised that the pilot had to address both of these cohorts. When selecting subjects for this exercise a great deal of care was taken to avoid adversely influencing my main study. I decided therefore that the pilot study would include a carer who had been very recently involved in the care of a close relative, and the key-worker most involved in helping this individual. Both the carer and the key-worker were known to me and had willingly agreed to be interviewed. The carer had been caring for her mother for a lengthy period at home, but her dependant had been admitted recently to hospital due to deterioration in her physical condition. The key-worker was a senior community nurse and had been involved with the care and support of this relative for some time.

The selection of this key-worker participant had been, potentially, problematic as she had worked within the study's geographical catchment area and most certainly was eligible for selection into the main study. However, as my study examined the unique relationship between a carer and key-worker, each subsequent relationship studied was arguably likewise unique and unlikely to be unduly influenced by any earlier interview. Indeed, as already indicated, most of the key-workers within my main study were interviewed regarding more than one relationship.

The carer opted to have me interview her at home while the key-worker chose her office. Prior to each interview the subject was again reassured regarding confidentiality and that the aim of this research was not to look for right or wrong answers but at their views and opinions on their shared relationship (Chenitz & Swanson 1986). Participants were asked to complete the carer reply form and comment upon it as well as the contact letter, research information sheets and consent forms (Appendices 3 & 5). Both participants intimated their satisfaction with this correspondence and documentation.

When I transcribed the first interview I noticed that I could hear the participant but unfortunately I could not hear myself clearly on occasions. To overcome this I used two recorders on the second pilot interview, placing the second one closer to myself. This worked very well and provided a valuable backup recording that could be listened to when the main recording was unclear. The interviews were greatly assisted by the use of the interview schedules based on the initial research questions (Appendix 7). This allowed both the researcher and the interviewee to focus more precisely on a range of relevant issues and was a facility which greatly helped to cut down on the 'dross rate' that can be a feature of the semi-structured interview (Field & Morse 1985). The participants generally answered questions clearly, contributing greatly to the clarification and development of future interview questions (Melia 1982).

Following each interview a field note was written that reflected how I felt the session had progressed, my handling of the technique and any emerging general

theme or direction that could be pursued in subsequent interviews. I noted that I was not always in a position to write these field notes quickly following each interview, and therefore decided to dictate these views and impressions onto the small tape recorder used for the interviews. This was an exercise easily carried out in my car immediately following each interview, and this practice minimised the risk of losing important observations through poor memory recall.

The transcription of the interview tapes took place following each interview and the time taken to achieve this task, along with the volume of data produced, once again came as some surprise and reinforced the point made about minimising the 'dross rate' (Field & Morse 1985). This prompted me to purchase a transcription machine to help ease this burden of transcribing. However, even with this assistance, I still required an inordinate length of time to complete this task. After taking some advice on this matter I engaged the services of a typist who was familiar with the Data Protection Act.

The transcripts were analysed using the NUD*IST computer package. The analysis procedure was later discussed with a colleague who had some practical experience in the Grounded Theory research method and the use of NUD*IST software. She offered several very useful points such as separating each discrete idea within the narrative of the typed transcript, using a hard return on the keyboard, to allow NUD*IST to more effectively distinguish between emerging concepts.

The biographical questionnaire was considered reasonably clear and easy to understand. I noted that the first participant was unclear in what exactly I required by way of information within some questions. I concluded that it would be more effective, and efficient, if the biographical questions were asked orally at the end of the interview and recorded similarly. This information is best requested when the more intimate level of the interview has been established and the researcher has gained the participant's trust (Field & Morse 1985). Field & Morse (1985) described the progression of the interview from a 'shallow' and 'polite' phase, when the interviewee is deciding whether or not the interviewer can be trusted, towards a more 'intimate' phase, when richer more valid information could be gained. This was done on the second interview and worked very well. The NUD*IST software facilitated easy documentation and retrieval of this type of data, which allowed this information to be linked quickly and easily to other relevant data.

In summary, this pilot exercise helped to highlight the importance of putting the subjects at ease in order to maximise on the data that they could provide. The interview schedule was shown to be a valuable aid in highlighting important data that could then be explored more fully within the interviews. The pilot study also demonstrated the work effort and the associated time-scale involved in this research method. It highlighted the value of using two tape recorders and, finally, it has given me greater confidence moving into the main research study.

TRANSCRIBING AND HANDLING THE DATA

An important ethical requirement concerned the confidentiality of all research records. Participant names were not contained on or within the audiotapes or transcripts. Instead participant's audiotapes and transcripts were coded and any participant details were stored separately on computer floppy disk. All tapes, transcripts, computer disks and completed consent forms were held under secure conditions to be destroyed following the five year time scale considered necessary by the University of Glasgow.

Once I had received the transcription back from the typist, I again listened to the recording while reading the transcript carefully and correcting any mistakes or misconceptions contained within it. This exercise was made easier by using the second back up recording, suggested by the pilot exercise, which picked up any aspect of the conversation missed by the participant's tape recorder.

In his discussion of the transcription and analysis process, Glaser (1992) believed that the researcher should transcribe and analyse, in full, the first interview and field notes. Thereafter, this coding and analysis should provide guidance towards the process of theoretical sampling narrowing the range of future interviews and field observations. This provides an 'economy' to the generation of vast amounts of irrelevant and possibly repetitive data. However, Glaser (1992) cautioned that this approach:

'...should not be availed to until the researcher is certain of delimiting and selecting of data by the emerging theory. Better more than less transcribed data to a theory that fully accounts for the variations in the data.'(p.20).

Being a relative novice in the Grounded Theory method, I was sensitive to this warning and, consequently, fully transcribed and analysed all interviews and field notes. This was in fear of 'rushing past diamonds in the rough' and missing important data, a real possible risk during the analysis process (Strauss & Corbin 1990 p.76).

CODING THE DATA

I began to code the raw data with an initial conceptual meaning or explanation. I again deviated a little from Glaser (1978) by using a mix of both his and Strauss's approaches, an adaptation already suggested by Hickey (1997). He initially coded his data using detailed open coding, then moved more towards Glaser's (1992) view of selective coding whereby, through constant comparative coding and analysis of the data, higher order categories emerged. The labelling approach advocated within open coding allows for the diversity and nuances within the data to be preserved. This consideration is an important one when it comes to examining patterns within the codes and to 'hooking' the related literature around on the generated codes or categories. In marginally modifying Glaser's (1992) approach, I remained cognisant of the need not to over-conceptualise the data by coding every word and line, as he cautioned. From his arguments it was clear that I had to be careful, within the early stages of analysis, to search for patterns to conceptualise rather than highlighting numerous single unrelated concepts.

REFLECTION UPON THE RESEARCHER'S BACKGROUND AND THE USE OF FIELD NOTES AND MEMOS

I have already acknowledged my prior role as a CPN within this study's population area and my current position as a mental health lecturer. Therefore I had gained an existing degree of knowledge of the general subject area. The debate over the researcher's relationship with the research area, and their potential influence upon the associated participants and resultant data, has been highlighted by Reed & Proctor (1995) as a significant factor within the inductive research process. These authors explored the position of the researcher and how this could vary in terms of both their role and level of knowledge. They consider that the researcher occupies one of three positions; they are either an 'outsider', a 'hybrid' or an 'insider'. The 'outsider' is a researcher with no professional experience and a visitor to the area of study. The 'hybrid' is a researcher who undertakes research into the practice of other practitioners and is familiar with that research area. The 'insider' is the actual practitioner as researcher looking into their own and known colleagues' practice. Reed & Procter (1995) considered these positions as being on a continuum with the researcher moving backwards and forwards along it as he or she engaged with the research process.

In examining my circumstance, I would consider I was placed between the 'hybrid' and the 'insider' positions within my study. The 'insider' position has relevance in that I had an existing knowledge of the subjects from working directly within this field and, indeed, might know some key workers through my role as a mental health lecturer. This might influence the researcher/participant

relationship in that the key-worker might feel professionally defensive, due to my position as a lecturer, and avoid disclosing any information that they deemed reflected less positively on them (Reed & Procter 1995). Alternatively they may focus, in an effort to impress, on more abstract and theoretical constructs relating more to my background knowledge and professional status, thus losing the focus of the study. My intended approach to the carer, via the person with dementia, indicated my respect for the dependant and this largely derived from my professional background and experience. Additionally I introduced myself to the carer as a lecturer who was previously a CPN. These professional roles, particularly that of CPN, may undoubtedly have influenced the carer's view and subsequent acceptance of me as a researcher. This interpretation can only be made, however, if the carers' experience of this professional group has been a relatively positive one. My experience as a CPN most certainly was reflected in my approach to the carer and dependant, particularly when putting them at ease and in dealing with signs of distress during the interview itself.

As I had pre-existing knowledge of the study subject area but had been removed from direct involvement for some years, as well as having some exposure to the associated literature, I was also drawn towards the hybrid position (Reed & Procter 1995). This acknowledges that my existing conceptual framework could impinge upon the inductive nature of the study aim. This knowledge was a principal factor in my decision not to enter the literature directly associated with the subject area (Glaser 1992; Hickey 1997). The risk of being led by the literature and not allowing the theory to fully emerge from the data seemed, to me, highly possible. This viewpoint, however, is not universally accepted

(Procter 1995; McCallin 2003). Procter (1995) considers that the researcher was not any more likely to adversely influence the inductive research process by prior reading of the literature than they would from any knowledge gained from other less overt sources, such as that gained from prior professional experience. McCallin (2003) contends that in this more modern information era it is not possible for a researcher to be totally removed from the study literature anyway. In considering these positions I would still argue that the researcher has no control over what he or she already knows when entering the research field, but can exercise control over what is added to that knowledge base. So why therefore contribute to a potential risk? I considered that, as I occupied the hybrid/insider area of Reed & Procter's (1995) continuum, I was already somewhat theoretically sensitised to the research area. I considered therefore that additional direct reading on this area could, and would, unnecessarily influence how I approached, interpreted and reported upon the emergent data (Glaser 1992; Hickey 1997).

Some authors, however, argue that it is not advantageous or even realistic that a researcher enters the field with a completely blank or open mind on the subject area (Dey 1993; Reed 1995). Reed (1995) states that some research texts:

'... suggest that researchers should approach topics with an open mind, but an open mind is not necessarily an empty one. In other words, the issue is not whether the researcher knows something about the topic to be studied but whether they know what they know and whether they are prepared to regard this knowledge as provisional rather than fixed' (Reed 1995 p.60).

Dey (1999) added that ignoring the literature at the beginning of a study does not necessarily mean that it is discounted altogether. 'The issue is not whether to use existing knowledge, but how' (Dey 1993 p.63). Within these statements there is the recognition that prior knowledge, far from necessarily being a hindering factor, could in fact enhance the inductive research process. I recognised that, when entering the research field, I would be part of the culture under study and this could be useful in a number of respects. I should, as stated above, be more theoretically sensitised to the emergent data and my professional background could help me communicate more effectively with the subjects, particularly the key-workers, as I shared a similar background knowledge and vocabulary (Reed 1995). This could help in terms of the focus of questions and the speed of analysis (Reed 1995). However this might also be viewed negatively in that it could be construed that I was forcing the data by the use of my pre-existing conceptual framework (Glaser 1992). This is indeed a real danger and must be negated, as much as possible, by being open and honest in telling the reader of your background and reasons for any decisions made (Reed & Procter 1995; Cutcliffe 2000).

The 'hybrid/insider' dimension of this relationship could be problematic in other respects. Reed & Procter (1995) discussed the issue of an imbalance in power within the relationship between researcher and subject, and how this may adversely influence the research process. Rather than the researcher remaining inductive and 'telling it as it is', they may instead 'tell it as they see it'. I, when reporting on my findings, will use the actual data quotations from the subjects to

allow the reader to form their own judgements about how grounded these findings are within the data (Antle May 1986).

Given the above recognition of my background knowledge and experience of this study area, I addressed the potential for this to influence study through the process of reflexivity. Using tape-recorded field notes helped this process and, along with the written memos, these were transcribed and coded along with the interview data. I therefore commented upon my own background experiences and related decisions, derived from these memos and field notes, within the analysis and reporting of findings wherever appropriate. This helped ensure that I do not unduly bias any incoming data or, at least, acknowledge this aspect openly and honestly in the collection, analysis and reporting of developing categories (Reed & Procter 1995; Cutcliffe 2000).

Meerabeau (1995) considered ‘...that there is much more to be done in order to learn more about what we know and how we know it...’ (Meerabeau 1995 p.39).

Within qualitative research epistemological claims regarding the knowledge of reality must be viewed cautiously as such knowledge is coloured by the interpretations of the researcher (Porter 2000). In acknowledging my pre-existing knowledge and experiences, I intend to approach and carry out this study in a manner that is in keeping with the inductive requirement inherent within the grounded theory methodology and fully respect its ontological and epistemological underpinnings.

GATHERING THE DATA

Semi-structured interviews are an important data collection method in a Grounded Theory method and may be the only source of data in many of these studies. My study utilised interviews to effectively explore both parties' understanding of their relationship and associated activities. The literature on the research methodology suggested that formally arranged interviews should take place at a time and venue acceptable to the participant, and should last between one and two hours (Hutchinson 1993).

I anticipated that some participants within my study would be limited in terms of time and so the interview process was designed to create as relaxed an atmosphere as possible. This requires certain knowledge and skills (Chenitz & Swanson 1986); and an ability to display genuine interest in the participant; establish eye contact to aid the development of trust and to smile appropriately in an effort to put the interviewee at ease (Field & Morse 1985). The researcher must display good manners such as being punctual, courteous and to be neatly, but not too formally, dressed (Polit & Hungler 1991). Care also has to be taken in the selection of the interview setting to minimise common pitfalls such as being interrupted or having a situation with competing distractions on the interviewee (Field & Morse 1985). Such precautions are especially important when the interview is being recorded.

ANALYSIS OF THE DATA AND USE OF THE NUD*IST SOFTWARE

NUD*IST is designed specifically for qualitative research and is a particularly worthwhile and impressive tool when theory generating and hypothesis testing is

a requirement of the research process (Pateman 1998). This quality makes the NUD*IST programme particularly relevant to a Grounded Theory study and was therefore appropriate for adoption within my study. Its applicability was clearly supported by Pateman (1998) who stated that the ‘... main advantage of NUD*IST and similar inductive software, is the ability to go beyond indexing and retrieval and test out emerging theory in a procedure arguably similar to Grounded Theory’ (p.86). A very valuable property of NUD*IST, in addition to being easily able to store and code large amounts of data, is its ability to make memos of the researcher’s hunches, feelings and developing opinions during the analysis process. Within my study these memos were made and attached to the relevant code. Reflexivity was addressed as I consistently examined my views and potential to ‘contaminate’ the incoming data, thereby avoiding the previously referred to problem of forcing the data (Glaser 1992). It was also through this process of memo writing that I should have been able to view the incoming data and consider the next most appropriate participant. This was in an effort to follow the theoretical sampling approach that is so important to the Grounded Theory methodology, as discussed earlier.

The NUD*IST program contains two parts, a document system to attach required documents, and an index system made up of nodes that contain ideas and codes/categories. This latter aspect allows the researcher to identify concepts and code them accordingly. The index allows these nodes to be given a title, coded and/or a memo recorded. Nodes are basically the containers for coding and for ideas. When coding, the researcher can engage in several processes. As the text is coded they can store all the material where an unexpected theme,

within that text, is beginning to emerge. They could then browse it or rethink it. Once a theme has emerged the researcher makes a node containing this information. As the researcher begins to contrast and compare themes emerging, they then begin to organise these as they search for higher order codes to explain the variation. This is achieved, within NUD*IST, by the use of the index tree where themes and patterns emerging from the data can be organised and presented graphically to allow further consideration and analysis. In addition to this it is important to realise that nodes can also store biographical details such as gender, age etc. This allows the researcher, should they wish, to search and identify all parts of the data set or documents that contain specific information coming from one particular grouping, for example women. This was a real strength of the programme and again made its adoption within my study most appropriate.

Therefore, within my study it was through this process of memo writing, and the associated constant comparison of the data, that data categories began to emerge. During the compilation of these data categories each section of transcript, plus its associated memo, was grouped under a data category heading. This information was re-examined under each heading and again, by constantly comparing and contrasting these codes, patterns were looked for and the identification of 'higher order' codes sought, which would fit Hutchinson's (1993) criteria for a core category. By using this approach, higher order substantive codes emerged and these were similarly examined. Through this process higher order codes eventually collapsed into four major categories that were subsequently again

linked through theoretical coding and a core category emerged that explained all lower ordered codes and categories (Glaser 1992; Hutchison 1993).

USING THE THEORETICALLY SAMPLED LITERATURE

As mentioned within the preceding chapter, in this study the first real move into the 'professional literature related to the topic' was delayed until the emergence of data categories grounded within the data (Glaser 1992). 'References from the literature may be used here to enrich and show outside support for concepts or propositions...' (Antle May 1986 p.149). Literature was searched for using the emerging concepts through the range of databases available both within the University of Glasgow and Bell College libraries. These included:

- CINAHL
- ASSIA
- The Cochrane Library
- Medline
- Psych Info
- EMBASE
- PUB MED
- Zetoc.

In addition to these sources, I also found relevant literature through the university and college library catalogues and by extracting further references from the reference lists of literature already acquired, as well as through sources such as the Health Education Board for Scotland (HEBS) on CD.

As the study progressed, literature related to the topic area (theoretically sampled literature) was increasingly consulted as substantive codes, major categories and resultant theory emerged (Glaser 1992). It must be borne in mind, however, that emerging theories at the early stage of the study are tentative (Strauss & Corbin 1990; Fleming 1992; Glaser 1992). They are being commented upon at a preliminary stage of the research process, with the associated risk of 'premature disclosure' spoken of by Hutchinson (1993), and must therefore be viewed with a degree of caution.

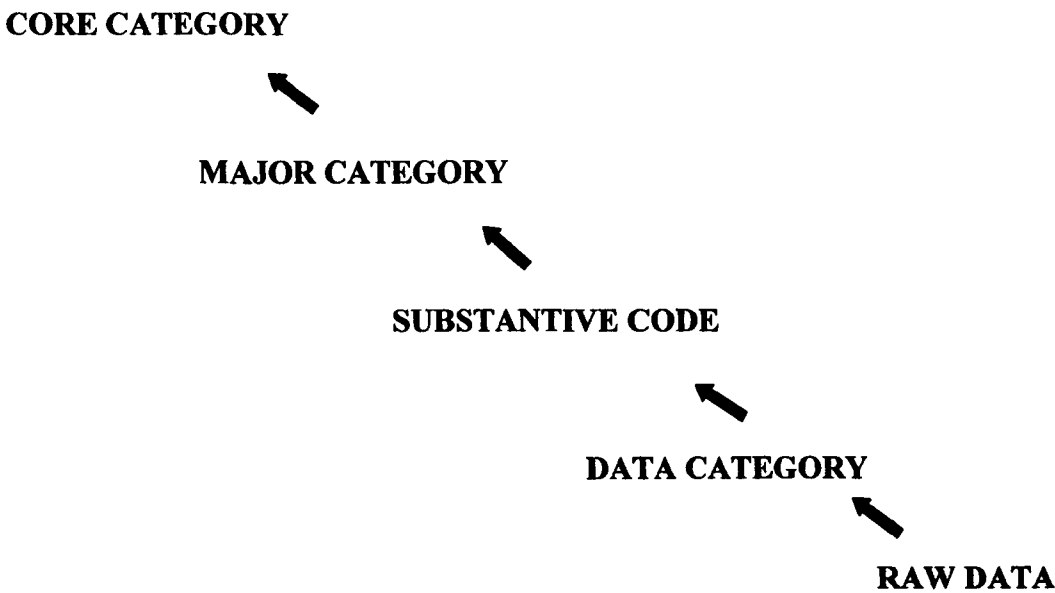
Many of the studies discussed within the following four chapters were qualitative in nature and often involved small sample sizes. As suggested above, the qualitative paradigm generally carries a realisation that, unlike quantitative studies, its results often lack generalisability to other cultures and settings (Parahoo 1997). Whenever possible, while reporting on these studies, I have identified the research method, sampling process, the sample size and the cultural setting in which the study was carried out. This was in an effort to avoid repetition of this generalisability issue each time such a study was being discussed.

Effort was also made within the following four chapters, in keeping with the Grounded Theory methodology, to critique the theoretically derived literature included. However, given the number of studies consulted, it was impractical to provide a review of each and every study. Critiques were primarily undertaken whenever studies contained either a particular strength or weakness important to the quality of its findings. Some of the literature consulted was not always

derived from specific research studies but was included as it derived from important sources of relevant information to this study's topic, such as Government policy, and provided further important data surrounding the concepts under examination.

The overall title of the thesis has been given the name of the core category representing the theory that has emerged from the study (See chapter 3, p.36). The following four chapters contain the results and analysis from this study, along with the associated theoretically sampled literature. Each of these chapters has been given the title that corresponds to the four major categories that eventually emerged from the study. Within each chapter the results are firstly presented under the headings that correspond with the substantive code followed by headings associated with the lower order data categories originally formed from the raw data through open coding. The headings contained within each chapter, therefore, present the developing concepts in a reverse order from their natural order of emergence from the data (Figure 4). The arrows contained within Figure 4 represents the natural, or chronological, order of emergence towards higher order conceptualisation. Tables 3–6 presented at the beginning of each of the next four chapters display all the codes and categories contained under that particular major category in the order that they naturally emerged from the data. Chapter nine will fully discuss the developed theory using analysis derived from these four chapters and will demonstrate how theoretical coding between these emerging codes and categories has led to the developed theory.

Figure 4 Presentation Order of Codes and Categories



RESULTS AND ANALYSIS

This major category chapter has been titled ‘Enhanced Relationship Drivers’, a title which recognises the potential within this major category area for either inhibition or enhancement of the Carer/Key-Worker relationship. Within the chapter’s first substantive code, ‘Unacknowledged Work’, certain important interactions and practices, leading towards more effective interpersonal interaction between the key-worker and lay carer, take place at an unplanned or hidden level from the perspective of both parties (Table 3). Interestingly, within the second substantive code, ‘The Determinants’, more overt qualities and activities are shown that can enhance and strengthen this relationship and are described under their respective data category headings. Finally the inherent qualities of the enhanced Carer/Key-Worker relationship, ‘Enhanced Relationship Properties’, are explained which demonstrate how this relationship benefits the parties involved, including the person diagnosed with dementia.

UNACKNOWLEDGED WORK

The Unacknowledged Role

Many of the carers and key-workers appeared to experience considerable difficulty when articulating aspects of their respective roles, or if they proactively undertook actions that positively influenced their relationship development. Just what did a key-worker do for the carer and why was their involvement viewed by many carers in such a positive fashion? For some carers, their views of the key-worker’s role, while somewhat obscure, remained highly valued by them. The following carers expressed this ambiguity associated with their understanding of the key-worker role:

Table 3 Enhanced Relationship Drivers: Codes & Categories

| DATA CODES | SUBSTANTIVE CODES | MAJOR CATEGORY |
|--|----------------------------------|--|
| <ul style="list-style-type: none">• The Unacknowledged Role.• Working with the Hidden Care Plan. | UNACKNOWLEDGED WORK | ENHANCED RELATIONSHIP DRIVERS |
| <ul style="list-style-type: none">• Carers Hold Realistic Expectations.• Carers Appreciate the Key-Workers Role.• Key-Worker Availability.• The Frequency of Contact & Time Spent with the Carer.• The Need for Shared Respect.• The Key-Worker Goes the Extra Mile.• Does the Key-Worker Proactively Shape the Relationship.• The Key-Workers Manner Makes Carer Feel Important.• The Effective Use of Humour.• The Key-Worker and Personal Disclosure.• The Key-Worker as a Credible Source of Support. | THE DETERMINANTS | |
| <ul style="list-style-type: none">• Carer Experiences a Real Psychological Benefit.• Friendly Informality.• Deep & Meaningful Communication. | ENHANCED RELATIONSHIP PROPERTIES | |

'It's really hard to explain it... it seems strange to say you rely on somebody who doesn't really do anything as such, they're only there and they talk to you.'

(Carer 15)

'It's nothing I can put my finger on, I just feel that he's good to talk to.'

(Carer 18)

Hill & Michael (1996) highlighted that, as a result of this 'hidden' work associated with the health care professional, their activities became impossible to 'describe, quantify, or measure' (p.246). While their research was not specific to dementia care it was reflective of mental health professionals generally and attempted to 'define the core activities of psychiatric nursing' (p.248). A phenomenological approach was adopted using an unstructured interview style on 12 residential psychiatric nurses and, while this was a small-scale qualitative study, an attempt was made to strengthen the results through member checks.

A further phenomenon identified within the dementia-care literature was that many carers did not even recognise their own significant role in caring for a dependant. This was considered to be a consequence of the carer becoming accustomed to continuous negative experiences with the professionals involved who generally ignored their own particular needs (Woods & Watson 2000). Within the literature it was recognised that, in order to be more effective in helping the carer cope with a dependant, and avoid the pitfalls associated with caring, the professional had to develop a clearer understanding of the carer's experience (Adams 1994; Webb & Morris 1994). In a similar fashion to the key-

worker activities quoted by the above carers, many of the activities carried out by the carers themselves were equally invisible to them, even under arduous conditions, and were undertaken principally to protect the integrity and dignity of their dependant (Bowers 1987). Hasselkus (1988) identified the importance of this invisible work while MacLean (1989) described the carer's experience as 'hidden' and 'shrouded in mystery'. Howcroft (2004) highlighted how the key-worker often had to help the dementia carer identify their particular role activities more clearly and, for example, see how their role has moved on from a husband, wife, daughter or son and now expanded into being a carer.

In contrast to the literature's more negative portrayals of the carer's experiences, the following carers held a more optimistic viewpoint on their key-worker. They, however, continued to be unable to identify the key-worker role in clear and unambiguous terms, or describe what exactly their key-worker offered them, or even what enabled them to warm to this professional. Their qualities were best summed up in general terms in the belief that the professional was simply 'made for the job':

'I think he is just the right kind of person for that kind of job.'

(Carer 5)

Limited literature existed that effectively explained the importance of the carer's need to more fully understand their key-worker's professional role and function. My study supported the results of Pickard and Glendinning (2001) who found that dementia carers generally failed to understand the role of their associated

CPN. However, in contrast to my study, these carers did not value their professional. This was attributed to a lack of role clarity and because the professional failed to provide them with 'hands on' help. This was a small but well conducted qualitative study undertaken within the UK. The sample size (12 carers and 24 CPNs) appeared to be appropriate for a qualitative design but curiously, given the method and small sample size, effort was made to introduce a randomisation framework into the recruitment process. Data was gathered by in-depth interviews utilising a semi-structured interview schedule. Unfortunately, no information was given as to the origin or design of this instrument or how the data was handled and analysed, omissions that could detract from the interpreted quality of the findings.

Some key-workers within my study shared this ambiguity with the carers over their own activities and, as well as demonstrating genuine surprise at being perceived so favourably by the carers, equally struggled to explain their own involvement:

'I've no idea, maybe I'm a good listener, I don't know; I don't think I'm anything special (laugh)... Well I'm struggling too (laugh) to see why as well.... God that's strange isn't it. You don't think, you just give out your normal daily tasks and you don't think people hold you in such high esteem (laugh).'

(Key-Worker 14)

'I think there's an area that, really, there's a lot of issues with, that really ourselves as practitioners, certainly from my experience, don't think about.'

(Key-Worker 18)

This key-worker clearly identified a hidden aspect when it came to the carer's understanding of both the key-worker role and the carer's own circumstances:

'She had, like, blinkers on for a while about that and I don't even know yet if she's actually lifted the blinkers to see, well this is the state of play and its not going to get much better than this...' *(Key-Worker 15)*

Working with the Hidden Care Plan

The importance of mutual role understanding was an essential element within this category and will be examined in further detail within the next substantive code: 'The Determinants'. The hidden perceptions associated with the key-workers' role became most obvious when it emerged that they held no explicit or formalised care plan to deal with specific carer problems, or even to improve their relationships with the carer:

'No you don't, you don't really care plan for them but you do care plan for them in an off hand way. But you don't specifically care plan for them... you don't care plan for them exactly, you're care planning for the patient if you like and they (carers) are influencing the care on the patient... It (planning for the carer) is off the record but its, I suppose it could be more formalised...'

(Key-Worker 11)

'... I don't think about it when I'm doing it (therapeutic involvement with carer).

I'm not aware of it when I'm doing it. ' (Key-Worker 12)

This sense of operating at a more ad-hoc or informal level was alluded to by most of the key-workers, however, overt care planning associated with the carer's needs on any formal documentation was not a feature of their involvement:

'Again I don't, I'm not conscious of, I respond obviously when anyone comes on the phone upset or disturbed, or what have you, but I'm not conscious of really doing anything (other) than my job, that's the bottom line you know.'

(Key-Worker 14)

This was surprising as the relationship between the carer and dependant was, to me, reciprocal and carer difficulties would impact upon the dependant. Nolan et al (1996b) discussed this issue of the professional working directly on carer's needs in their paper considering the Carers (Recognition and Services) Act 1995. They made explicitly clear the increasing need to have a reappraisal of this relationship between carer and professional. They went on to describe how any difficulties associated with meeting carer's needs was a result of the professionals having no 'real tradition of practice' in this particular aspect of care which resulted in the professional increasingly drawing upon 'implicit and tacit' forms of knowledge. While these views were not drawn from a particular

research study, they did represent the views of recognised experts within the field of dementia care.

The debate highlighted by key-workers within my study regarding the relevance of overt therapeutic approaches directed towards the carer were also evident within the literature (Brodaty & Hadzi-Pavlovic 1990; Eloniemi-Sulkava et al 1999; Pusey & Richards 2001; Marriott 2003). Marriott et al (2000) drew an interesting distinction between family intervention in dementia and in other forms of mental disorder such as schizophrenia. Family interventions in Alzheimer's disease did not, they claim, have the reduction of relapse or improvement in the symptoms of the condition as a primary aim. In the case of Alzheimer's disease the intervention was directed more towards the carer, and the reduction of carer stress, rather than any modification of the disease process itself. These researchers did however acknowledge that carers exercised a control over environmental factors to an extent, and did influence the behaviours associated with their dependant.

Brodaty et al (2003), in a meta-analysis of the psychosocial interventions for carers of people with dementia, found that despite limitations there was clear evidence that certain interventions were indeed effective. Such findings again pointed not only to the legitimacy of the key-worker directing treatment interventions towards the carer, but that such interventions were a vital component in improving the caring experience and, as such, should be overt and acknowledged. Carradice et al (2003) also made it clear that interventions directed towards the carer are justifiable in helping them to overcome any

problems they faced in their caring role. However in their overview of studies into this aspect of professional role, these authors identified that many studies lacked any real theoretical underpinnings. Pusey (2003) in citing Carradice (1999) speculated that such an absence of theoretical rigor could be a reason for any lack of professional effectiveness in the working with the carer. I considered that this could also be a factor in explaining why some professionals within my study were not wholly comfortable in viewing interventions directed solely towards the carer as being a legitimate and overt component of their overall role. Indeed within the literature some authors debated whether or not any intervention directed towards the carer was indeed worthwhile at all (McKee et al 1999; Cooke et al 2001).

Within my study, Carer 15 was particularly interesting in this last regard, as she was considered by her key-worker to be on her case-load on merit of her own needs and not those of her dependant's. Despite this acknowledgement the key-worker continued to strongly deny any suggestion that her intervention was overtly directed towards the carer as to do so would change the carer's status to that of patient:

'To develop a package round her (carer) would actually be giving her, she would be my patient rather than (dependant) being my patient ...' (Key-Worker 15)

This distinction reflected the contrasting models of the carer put forward by Twigg (1989), the carer as a resource, a co-client, or a co-worker. There was, however, an antagonism between Twigg's conceptualisation of the carer as a co-

worker and a co-client. Being viewed as a co-client rendered the carer as a non-expert who required their own treatment needs to be addressed, as a co-worker carers took on the mantle of care workers operating within a formal system and were viewed as visible participants within that system (Bond 1992). Clarke & Heyman (1998) considered that when it came to carer need versus dependant need, there was a threat to the process of 'family-normalising strategies' and carers overcame any potential conflict by way of a compromise between their own needs and those of the dependant.

Twigg & Aitkin (1994) raised the possibility of a divergence of opinion between the perceptions of social work and health care staff concerning carer involvement. They highlighted how the social work professional viewed their health colleagues as dealing with the family as an appendage, a situation that could create tension between these professional groups. This was viewpoint identified by Key-worker 15 (p.75), who arguably expressed a similar opinion concerning her own involvement with the carer.

I found it interesting as to why carer involvement was viewed so rigidly and inflexibly. To use Twigg's (1989) particular concepts, why was the carer either a 'resource', 'co-worker', 'co-client' or, as Nolan et al (1996b) later articulated, an 'expert'? Could not such boundaries be viewed in a more fluid manner over the carer's care-giving career? Why could the key-worker not work in partnership (carer as co-worker) and still be effective in meeting a carer's particular needs (carer as co-client) without this detracting from their partnership? This would appear to be fully utilise and not diminish carer expertise (carer as a non-

exploited resource and carer as expert). These questions will be further explored in greater detail within the discussion of the next major category, 'Models of Action'.

The question of 'who was the key-worker there for?' and 'changing the status of the carer to client or patient', as highlighted by Key-worker 15, were factors explored in greater detail within subsequent interviews. The following key-worker put a slightly different perspective on this 'hidden care planning' around carer's needs. She attributed a lot of the activity directed towards the carer as being undertaken at a more instinctive or tacit level, as suggested by Nolan et al (1996b), and only became apparent to the professional if their problem developed into a significantly difficult issue:

'...it's levels of complexity, you can have a very straight-forward (intervention), doing it almost in the back of your head without thinking what you're doing, till you get to something complex as that where it's very conscious control situation where you think I need to get this under some kind of control.' (Key-Worker 16)

Pusey (2003) also argued that dementia care involved a lack of overt recognition by the professionals in providing interventions directed at the carer. She cited Mathew's (1990) findings, which corresponded with Key-Worker 16's view above, that the professional held no systematic plan for dealing with carer needs and that such needs are only considered objectively if a crisis ensued. Certainly, the following key-workers indicated an inevitable degree of uncertainty

surrounding their working with carers, and advocated that the key-worker should not have any preconceived strategy of involvement:

'Well I think you've got to be adaptable. You've got to be able to think on your feet.' (Key-Worker 14)

'I just go in and I don't know whether it's my experience and just going in and you support them as they need it.' (Key-Worker 15)

'I think it depends on the person, I think we are all quite good at reading people and you know when you've sort of gone in the wrong direction... so there is this flexibility, it's about the response you get... I think you're constantly assessing, you spend all the time watching for responses... I think it's instinctive.'

(Key-Worker 16)

Key-Worker 17 however considered that professional approaches when working with the carer were much more of a blend of the ad-hoc and the preconceived response:

'I think if I can provide a mixture of ad-hoc and kind of deliberate interventions...I think it just seems to evolve. I think, its something you go in with..., a standardised kind of way to establish rapport, to establish relationships with people. And I think it obviously differs because individuals differ.'

(Key-Worker 17)

As seen from the following substantive code, overt practices consciously enacted had a considerable influence upon this developing relationship.

THE DETERMINANTS

Carers Hold Realistic Expectations

The more overt characteristics and behaviours of the key-worker and carer did appear to influence their relationship, an influence that led to either a positive or negative consequence. A significant property to emerge early on from the data was that of role expectation. In contrast to the preceding substantive code, the relationship was moved towards a much more positive and effective dimension (zone) when this 'Unacknowledged Work' was addressed, and both the 'Unacknowledged Role' and the 'Working with the Hidden Care Plan' data categories became more overt and visible. There was a necessity to establish a clear and unambiguous shared appreciation of what to expect from each other, particularly on the part of the carer:

'Yes he (key-worker) came and explained to us, em, what his role was.'

(Carer 3)

'(Key-worker) phoned me seven months ago and explained who she was... what she does, where she was based and that she was coming to see me.' (Carer 10)

The following carer demonstrated her appreciation over the key-worker's ability to share his knowledge with her in a way that she could easily understand and relate to:

'and he really was down to earth about the Alzheimer's.'

(Carer 18)

While the following key-workers highlighted the importance of helping the carer gain a realistic outlook upon their entire care-giving experience:

'... I think her (carer) long-term expectation of the medication is not, could be better... I've started the process and she has been warned about that...'

(Key-Worker 3)

'It's hard because she (carer) doesn't know what's expected of her. Its just the parameters aren't clear-cut for her.' (Key-Worker 15)

Some key-workers spent time, during the early contacts with the carer, 'setting ground rules' that were viewed as being advantageous to relationship development by both parties. The following comments demonstrated a much more positive position than those contained within the preceding substantive code's data categories (Table 3) by making it clear that some key-workers routinely made their role more explicit in an effort to develop their relationship with the carer:

'I think (carer) knew my role from the onset and I told him what I could possibly do or couldn't do. Normally from the onset it's good if you can get them to understand that this is what I am here to do.' (Key-Worker 6)

'... I don't know what role she (carer) saw me in. I think after I explained what my role would be with her I think there was a great sense of relief...'

(Key-Worker 7)

If the key-workers failed to establish a clear and shared understanding surrounding their respective roles, the impact on the carer's care-giving experiences could be more negatively interpreted. Keady & Nolan (1995) pointed out that an outcome from their study examining the experiences of family carers with community professional support, was that the carer and the professional did not share the same '... terms of reference and interpretative frameworks...' (p.35). These authors stressed the importance of the community practitioner making their role explicitly clear and understandable to both the carer and their dependant. The carer's belief in the professional role often exceeded realistic expectations and the quality of the relationship was dependant upon the inclusion of such shared aspects as inclusion, negotiation, openness and honesty. Such aspects ensured a more realistic level of understanding on the part of the carer (Walker et al 2001).

A carer's ability to cope more effectively was largely determined by their abilities of 'appraisal and perception' within their care giving environment (Adams 1994). Hocking (1994) pointed out that a dialogue between human beings was essential in the development of a sense of well being, and suggested that carers experienced more negative feelings when they held unrealistic expectations. When looking at management involving people with dementia, it

was considered vitally important that both the professional and the carer had a shared meaning, and understanding, of each other's knowledge of risk. 'Otherwise, professionals will not value carer's knowledge and family carers will dismiss professionals' advice as inappropriate.' (Clarke & Heyman 1998 p.239).

Adams (2000 p.792) examined the construction of identity by carers; a concept that included '... groups, statuses and roles, and also provided descriptions of individuals.' Like Hocking (1994), he considered that the concept of identity could only be fully understood through the process of social interaction. Indeed Parker 1990 believed that family expectation of the carer role often determined who from the family should provide care, especially when it came to issues such as gender. Carers were even considered to be so often confused over the role of professionals that they could not identify clearly who their own key-worker was (Walker et al 2001). The understanding of roles was of particular significance and this was not merely a product of experience but rather derived from a dialogue between both parties (Adams 2000). The importance of a shared expectation between the professional and the carer was essential to the success of any intervention requiring the involvement and co-operation of the carer (Zarit & Leitsch 2001).

Carers Appreciate the Key-Worker Role

In order to work effectively and develop a positive and durable relationship with the carer, the key-worker role had to be valued by that carer. This requirement particularly emerged during one particular interview where it became clear that

how the carer viewed the key-worker was of importance as he believed that he should be considered the central figure involved in the carer's support:

'I would imagine that, or I would hope that all clients that I deal with think of me as the main focus for everything.' (Key-Worker 14)

Even when the key-worker's practices did not meet with their approval, carers still appeared to accept that they had an effective relationship with the key-worker and continued to value the professional's knowledge and judgement. This carer, following her key-worker's decision to reduce his involvement with her and her dependant husband, demonstrated this sense of appreciation for the key-worker's judgement and expertise:

'... I thought it should be three months, but I was taking his judgement of that.' (Carer 18)

Within my particular study, when the emphasis was moved from the more negative aspects of the 'Unacknowledged Work' substantive code towards the more positive 'The Determinants' substantive code (Table 3), the Carer/Key-Worker relationship was in a much better position to flourish. Within this code an appreciation for the professional role and expertise appeared to be a significant factor in ensuring that the quality relationship developed. The following carer demonstrated her high regard for the key-worker, and value for his professional role, through not making unreasonable or manipulative demands upon him:

' ... I suppose I wouldn't demand and say, I've got to have it because, you know, I'm all myself or something like that. ' (Carer 14)

She did not want to present the professional with problems or to be considered a 'bother' to him. Carer 15 demonstrated her deep appreciation for her relationship the key-worker and suggested that their relationship was so strong that it helped to compensate for negative attitudes held by those close to her who failed to demonstrate an understanding of her circumstance:

'It's a hard illness for people to understand. You can talk to your friends about it but they don't understand. Unless they are in the same situation as you're in, it's just a waste of time. But that's where (key-worker's) team comes in. I can really relate to her. ' (Carer 15)

Hasselkus (1988), within an ethnographic study examining the meaning of care giving for families of the frail elderly, found that families contradicted this notion that the carer holds the professionals' knowledge in high regard, and indeed found such an acknowledgement surprisingly rare.

Key-Worker Availability

Key-worker availability was a further issue raised within my study as having significant importance to the development of a successful Carer/Key-Worker relationship. A strong relationship was ascribed to key-worker reliability and ease of access to them:

'Well I feel that, like today, I pick up the phone and spoke with him, I feel that I can talk to him about anything at any time... Oh yes and if he's not there whoever answers will get him to phone me back if it's necessary, excellent.'
(Carer 1)

'It's not even the access of them coming to see you, it's just the idea I think is good, just to be able to phone and if there's somebody there on the other end to answer your problem at that time... I was quite surprised that day he sort of dropped everything and just came up, because I didn't actually ask him to do that... I just feel he's not one of those, I'm awful busy don't phone me unless you have to, type of thing...' (Carer 17)

This need for easy, flexible and increased access to key professionals was acknowledged within the literature (Wenger 1994; Soliman 2003). Chenoweth & Spencer (1986) recognised this need within family carers who had experienced increased difficulties once their dependant was diagnosed with dementia. They highlighted that the key professional, in this case the general practitioner, could be of invaluable assistance to them if they made themselves more freely available to discuss worries and concerns over the illness. Such a simple effort would mean that the carers did not feel so abandoned or isolated, and felt confident in handling any associated problems. However, on the other hand, the carer could fail to take advantage of such an 'open door policy', as they may perceive this as them being a nuisance (Arskey 1998). Bruce & Paterson (2000) discussed this need for easy access to the key professional and highlighted that the carer often,

despite being well known to their general practitioner, found access to formal community support services problematic. Goulbourne et al (2002) made clear the importance of professionals maintaining contact with the carer and pointed out that carers themselves identified that ease of contact was essential in them effectively coping with a dependant with dementia. Soliman (2003) considered that improved contact with the key-worker, in this case the Admiral Nurses'¹, led to a significant reduction in carer stress.

The need for professional availability was also recognised, and considered necessary to the developing relationship, by most key-workers:

'... and I'm fairly accessible. I'm only a phone call away and she knows that, you know, instead of phoning her GP or consultant, you're not likely to get them most days certainly.' (Key-Worker 3)

'... I think certainly there's no point in saying, you know, give me a phone anytime and we can arrange something if you're not going to do it. I'm certainly very conscious of that. If I get a message I try to act as promptly as I can.'
(Key-Worker 18)

The following key-worker certainly concurred with this last sentiment and cautioned that the key-worker must be honest and not give a wrong impression to

¹ The Admiral Service is a community-based service that provides specialist nurses to work with families, carers and supporters of people with dementia throughout England.

the carer. They must clearly point out that being available to them is on a realistic basis:

'... but I think it would be unfair of me to leave them to think that I would be their best friend and would always be there for them.' (Key-Worker 9)

The need to allow for flexible and timeous availability to professional services was evident within the literature. A lack of such contact often led the dementia carer to believe that no-one had concern for their circumstances or how they coped with their dependant, a devastating development and potentially a severe drain upon carer morale. This had a severe impact upon the caring experience and added to their sense of burden and stress. This is discussed later in this thesis within the major category, 'Impact Upon the World of Caring'. Contact with the key-worker was often considered more important than the actual delivery of therapeutic interventions (Fottrell 1992). Carer difficulties were easily anticipated and often occurred out-with office hours, a situation that led to increased levels of stress and frustration for the carer. The maintenance of effective contact was vital and had not to be viewed as an ideal but as an essential provision (Walker et al 2001). The most effective time to intervene in a situation involving people with Alzheimer's disease and their carers was during periods when they were experiencing the most sensitive changes (Zarit & Leitsch 2001).

Brown (2001) agreed with this position when she pointed out that regular contact was especially important at what she considered to be such a sensitive period; the

early formative stages of the dementia process. While her views did not derive directly from a research study, they never the less represented the opinion of a qualified mental health professional with many years of dementia care experience. Keady & Nolan (1995) identified the theme of continuing support for the carer within the dementia care context. They highlighted that carers found it vitally important to have a key-worker with whom they could develop an effective and trusting relationship, a relationship that was continuous. These findings derived from a small UK study where 38 carers were either interviewed or asked to complete a questionnaire. The discussion surrounding the design of this qualitative study was however disappointingly brief, thus making judgement on the quality of the data more difficult.

Clarke (2000) highlighted how some professionals adopt a range of strategies to help carers cope with the increasingly complex and threatening environment of caring, one being a need to be available to the carer. This was a study in which the researcher clearly identified the inherent difficulty and complexity in identifying and selecting a sample of dementia carers, a realisation that I could readily identify with from my own experiences from this study. This research similarly used a Grounded Theory approach. The associated inductive-deductive process and constant comparative approach associated with the analysis, along with the continuous checking of the data against associated literature added to strengthening the quality of the findings.

A further study utilised focused groups, involving a small sample of family carers, found that services could improve carer experience by ensuring they have

more 'integrated and consistent' ways of working with care professionals (Dewar et al 2002). These included carers knowing who was available for contact, ease of accessibility to a key professional at mutually agreeable times, committed and ongoing contact that was flexible to both parties, and an alternative staff member made available should the key contact be unavailable. The discussion on the research methodology within this paper was however disappointing as it provided only a very weak outline of the design and nothing about how the sample was derived or how data was collected or analysed.

The Frequency of Contact and Time Spent with the Carer

An important and related aspect contributing to the enhancement of the relationship was both the frequency of visits by the professional and the length of time spent with the carer. The following carers identified the importance of time and its significance to this relationship:

'Well I'd say that she was my key-worker yes because that's the person I've dealt with most... I would say probably because I've had a lot more dealings with my (key-worker) than I have directly with CPN.' (Carer 9)

'She spent a good three quarters of an hour, well that's quite good, I didn't expect that. You don't expect a nurse to stay all that time.' (Carer 12)

'(Key-worker and healthcare assistant) to me are much closer to (dependant) than my nephews and nieces because we don't see much of them... you see the regularity does it too.' (Carer 16)

The importance of the key-worker having more opportunity to spend significant and appropriate periods with the carer was also recognised within the comments made by the following key-workers:

'... she probably would take on board anything the GP was telling her as well. It's just simply that they do not have the time to sit and give advice. I think it's as simple as that.' (Key-Worker 10)

'... they (carers) know you're busy, they know how hard we work and yet we still find the time to get them on the phone saying things like it's good of you to take all this time talking to me.' (Key-Worker 16)

For some carers, the strength and depth of the relationship with their key-worker developed in a surprisingly short time period, and with relatively few visits. Carer 12 considered that the key-worker established a strong relationship with her within a three-month period:

'That would be about 3 months now... About 3 months now and it's really been good.' (Key-Worker 12)

Carer 17 explained that a safe and relaxed relationship with her key-worker not only occurred very quickly, but also developed with relatively few contacts:

'...he's only been here 3 times... he's good at his job and he's always asking is there anything that you want to know or that kind of thing.' (Carer 17)

Her key-worker agreed that a significant depth of the relationship was achieved relatively quickly when the key-worker adopted the most appropriate approach for that carer:

'... I think when you go into each individual house you quickly gain, I don't know, you quickly gain some kind of insight into what, its hard to explain, how to react to these individuals as people, without sounding condescending or patronising...' (Key-Worker 17)

While Carer 18 voiced how she quickly relaxed in her key-workers company:

'I don't know I think he just it was more or less he just made me feel at ease...'
(Carer 18)

The amount of time spent with the carer was essential for both an effective assessment as well as the creation of a strong and open relationship between them and the professional (Nolan et al 1996b; Walker et al 2001). Clarke (1999c) considered that health care workers preferred to base activities involving the carer over a more prolonged contact period as this produced greater benefits. Care delivery was more profitable if it focused upon the developing relationship with the carer and their dependant rather than adopting a rapid 'hit and run' approach to care delivery.

The Need for Shared Respect

Carers within this study all articulated a compassionate, caring and positive attitude towards their dependant, as indicated by the following comments:

'But people will say I wouldn't put up with that. Just go and leave him. But I can't do that.' (Carer 15)

'She says (dependant) she feels not bad but she gets awful tired very quickly (dependant interruption), she's very tired.' (Carer 16)

Respect for the dependant was another common theme associated with the Carer/Key-Worker relationship. The following key-worker expressed an appreciation of the carer's positive attitude and the respect she demonstrated towards her dependant, in this case her mother. This positively influenced the relationship with the key-worker and helped to make working with that individual more successful:

'I've no doubt in my mind that she does have her mother's best interests at heart and she's doing the best that she can, and so that has made it easier (developing a good relationship) I think.' (Key-Worker 9)

The ability to care for a person with dementia within the home was dependent upon the carer's attitude towards that individual. Where they valued their dependant, and the care they provided for them, they coped much more -

successfully with the demands of their role (Kitson 1987). Kitwood (1997) strongly advocated the need to preserve the right of 'personhood' within the individual diagnosed with dementia. He made clear the serious consequences if those delivering carer failed to ensure such a level of respect for the diagnosed person. Approaches that failed to foster a sense of identity and worth in the individual greatly contributed to the creation of a 'malignant social psychology' that hampered any significant therapeutic benefits for that dependant (Kitwood 1997). An appreciation therefore by the key-worker of the carer's attitude towards the dependant was an important requirement that directly contributed to the dependant's health and well-being. By appreciating and encouraging such a level of carer respect, the key-worker would help to ensure a greater alliance between carer and dependant. This would, equally, provide an increased sense of satisfaction in the care being delivered within the home, correspondingly helping to reduce carer stress (Grant & Nolan 1993; Nolan & Keady 2001).

The key-workers themselves also demonstrated a high degree of respect for the carers, and this was a further important factor in their developing relationship. Many carers intimated how the key-worker demonstrated this respect in terms of ensuring carer involvement in decision-making in matters associated with their dependant. This was made clear by this carer's comments:

'...he just leaves it to me, as he says, I know more about that than he does, so he just leaves that bit up to me.' (Carer 17)

Some of the key-workers suggested that this necessity to respect the carers and their decision-making was a feature of their management of the relationship:

'... her decision has to be respected regardless of whether I think that's a right or wrong thing for her...' (Key-Worker 7)

'What I always said to (carer) was that I respected the fact that he wanted to care for (wife) and he wanted to keep her with him as long as possible.'
(Key-Worker 11)

'I really kind of try to stress that they know they're the ones that are in charge, and again what can I do for you?' (Key-Worker 18)

Lowery & Murray's (2003) paper, promoting the benefits of group therapy for people with dementia and their carers, highlighted this need for respect to be shown towards both parties, a respect evidenced by listening to their views and opinions. One aspect that influenced and impressed carers, thus improving the key-worker's influence within the care setting, was their attitude towards and response to the dependant. Carers described an appreciation of this response which included the key-workers apparent dedication in dealing with their dependant. This allowed them to further warm towards the key-worker and gave the carer a real sense of pleasure, satisfaction and perhaps even some security. What was apparent here was that the key-worker was being scrutinised and judged by the carer as they interacted with the dependant:

'... an extremely pleasant young lady, very professional and very helpful and very good with him (dependant). Treated him with respect. When you get to (dependant's) stage there are an awful lot of people... don't speak to him because they realise after a while that he can't communicate and doesn't understand what they are saying to him' (Carer 10)

'... she even got down on her knees in front of (dependant) when she was taking her pulse and her blood pressure, and that itself was a great thing because there's not a lot of nurses would have done that.' (Carer 12)

The importance of respecting and including the person with dementia was evident within the literature. Sweeting & Gilhooly (1997), within their paper on 'Dementia and the phenomenon of social death', further discussed the concept of personhood. Where this was not respected, and negative attitudes prevailed towards the person with dementia, the perception developed was that this person no longer socially existed. This paper unfortunately only gave the results of this exploratory study and did not discuss the research design at all making the task of judging the quality of the results rather more difficult. Crisp (1999) raised a similar issue of negative attitudes directed towards the person with dementia leading those involved in their care to view the dependant as being less than fully human, clearly a very derogatory and unhealthy attitude for care providers. Armstrong's (2001) article, that gave an overview of dementia and the problems associated with carers, described a range of factors which contributed to the development of the 'malignant social psychology' spoken of by Kitwood (1997). These included deliberate or unintentional exclusion, a consequence of using

complicated language or an inappropriate communication style such as speaking too quickly.

Adams (2000), in discussing the need for future research associated with CPNs working with families of people with dementia, highlighted the importance of professionals actively including the person with dementia in any decision making surrounding their care. Dementia carers wanted the professional to respect the level of 'loved attention' they bestowed upon their dependant while they were being cared for within formal settings. The professional had to reciprocate this within their own care by, for example, identifying what made their dependant content or discontent and giving the dependant quality time (Walker et al 2001). In this regard Soliman (2003), citing George et al (2000), made it clear that respect from the professional should manifest itself in the dependant being viewed as an expert in all areas of their lives.

For the following carers the importance of the relationship, between the dependant and the associated professional, was made even more explicit when they described the reactions of their dependant husbands towards others they had recently come into contact with:

'... he always talks about (key-worker), and she was the first one, the first carer who came to see him and she was spot on. I mean he related to her and she could get him to look at her and answer which he doesn't do with his family.'
(Carer 10)

'I mean there have been people in and he hasn't liked them, he doesn't want to them to come back. One... came in to shower him... He just wouldn't entertain the woman... I also decided I needed help with the housework... he didn't take to her either. So it can be difficult.' (Carer 15)

The following carer expressed the emotional consequences for her when the professional failed to respect her husband by not addressing him in conversation:

'See I get annoyed at that, they don't have a conversation with him and they talk to me. It's like, you know, you see people talking to folk over the top of a wheel chair. You get this and I think, ask him, he's sitting there. And sometimes I get really angry.' (Carer 17)

The data emerging from this study suggested an important realisation in that key-workers should be made aware, if they are not so already, that they are under scrutiny from the carer as they interact with their dependant. The importance of the professional's character, and their response to the dependant, was clearly evident within the following carer's account of a student nurse who demonstrated an unacceptable behavioural response towards her husband. While accompanying the key-worker the student exhibited a defensive response towards this carer's husband who was experiencing a severe early onset dementia:

'... she (key-worker) did bring with her a girl, a young girl, who was a trainee psychiatric nurse, and my God if that girl ever gets through God help the

psychiatric patients. She didn't project any personality whatsoever, any confidence. My husband goes about doing these sorts of things some times and she physically shrank back, and I thought if she does that one more time I'm going to land her one. So yes, you don't realise, I mean ... to me a good psychiatric nurse is one where you don't actually see what they're giving, but when you're not given it, as this girl did, then it's blatantly obvious.' (Carer 7)

What was interesting within this account was the remarkable relationship the carer had with her key-worker. Despite this rather negative encounter her confidence in the relationship allowed her to express her dissatisfaction regarding this student and to request that she not be brought back into the home. It was also important to note that her last comment related strongly to the earlier data code, 'The Unacknowledged Role' (Table 3). However, in contrast to this carer's view, the following key-worker found that if the carer perceived her as being too closely involved with the dependant, this could present problems in terms of their relationship. In her view this carer felt detached from her due to her close association with his wife:

'I always sit with (dependant) which is maybe why he sees this distance... he sits separately but I sit beside (dependant) and I often hold her hand... she does get a bit anxious so I do, you know, to reassure her.' (Key-Worker 16)

The Key-Worker Goes the Extra Mile

A further aspect that appeared to have a positive influence upon relationship development was associated with activities, undertaken by key-workers while

working with carers, which were perceived by the carer as exceeding 'normal' professional role boundaries. Here the carers expressed that the key-workers not only provided a quality service to them and their dependants, but also seemed to go beyond what was expected from their role in order to make their care experiences more manageable and less stressful. This was a concept that both improved the relationship and the quality of the care giving experience. Some carers were highly surprised by some key-worker actions:

'... when I was in hospital that time she'd (key-worker) come in and (son) had just been home for a few days then and he told her I was in hospital and she was very nice. She phoned ward 4 I was in and asked how I was keeping which I thought was nice of her.' (Carer 10)

'... she (key-worker) normally doesn't start work I think till about 9 o'clock, but what she did that particular morning knowing that I'm on my own, she came to the house at 8 o'clock in the morning and helped me to get (wife) dressed and (wife) up in the car and got her into (local) hospital, into ward, and I just followed up later on in my own car... She was very, very helpful.' (Carer 11)

'... when I went into hospital she (key-worker) organised care for my husband during the day and somebody came in and made his lunch and somebody came in and made his dinner... and (key-worker) came in on a regular basis to (dependant) in that 3 weeks and made sure he was all right... She probably put herself out I would say, aye.' (Carer 15)

When this idea of ‘going the extra mile’ for the carer was put to key-workers they had a rather different perspective. Some expressed surprise at this carer response, to them these were simply routine actions carried out in an effort to improve the home circumstance. Such activities were not exceptional but simply the key-worker doing their job:

‘It was the thought of making the patient’s life a bit more easy like... there was a lot of behavioural problems at the time so there was a lot of harassment, a lot of friction if you like with (carer) in that relationship with his wife. So to make life easier, or the burden to come off them then I could share the burden and come out and help with my expertise, with skills from years ago.’ (Key-Worker 11)

‘Is that not just a good way of building trust and relationships. If they think you’re going to go, we do go the extra bit if you think it’s going to benefit the person at the end of the day... it makes life a lot easier doesn’t it.’
(Key-Worker 15)

However Key-Worker 17 distinguished between himself and other care professionals. He considered that he was in the rather unique position of having operational flexibility that allowed him, in comparison to other professionals, to provide an enhanced level of input:

‘Other professionals won’t do that, they tend to have very strict demarcation lines.’ (Key-Worker 17)

The following key-worker concluded that this, him demonstrating a willingness to go out of his way for the carer and her dependant, was the principle reason why he was identified as being the key-worker:

'... she thinks I'm her key-worker and you know I've thought about it since you've spoken about that and you know I thought well, why does she feel that way. And you know to a certain extent probably I do feel as if when she does talk to me about things, you know, I will try my utmost to do something for her, you know, if I can.' (Key-Worker 5)

It was important for me to point out, in regard to this particular data category, that I could not find any relevant supporting literature. This particular aspect of the Carer/Key-Worker interaction would not appear, therefore, to be a recognised phenomenon currently within the dementia care literature.

Does the Key-Worker Proactively Shape the Relationship?

The varied practices of the key-worker somehow influencing the developing relationship with the carer emerged as a significant aspect within this study. Reflecting upon my own experiences, I had no recollection of coming into a care scene with any predetermined viewpoint aimed at improving my relationship with that carer. When I considered this objectively, it seemed that this could be a sensible and rational approach aimed at positively benefiting the Carer/Key-Worker relationship. Again, in keeping with the spirit of Reflexivity, I was careful in pursuing this concept to allow it to truly emerge out of the data. In exploring this further with the key-worker participants, I met with a diversity of

opinion. Key-Worker 15 denied that any attempt to consciously shape the relationship took place and left me with the distinct impression that to do so was a negative and possibly even a manipulative act:

'There's no hidden agenda... No it's (going the extra mile) basically to make life easier for everybody.' (Key-Worker 15)

To her, the relationship had to develop spontaneously in a less-contrived manner. In keeping with this view, Key-Worker 6 expressed that there was an element of fate associated with the quality of the emerging relationship that was not open to key-worker influence through their activities, a fate that could shape the emergent relationship for months ahead:

'... from the first time you chap (knock) the door I think probably the first five minutes you've sort of set out the way they are going to perceive you. If it's in a positive light you've probably, your 'quids' in for the next six months. And if it's not entirely positive then you can maybe build on it if it's on a negative light you're probably going to struggle from then on probably.' (Key-Worker 6)

Some key-workers quickly established a sense of psychological ease with the carer and considered this to be a result of proactive and deliberate actions on their part. Certainly, this appeared to be the case given the views of the following key-workers:

'...I do have a set structure because I do my preamble to (put) them (the carers) at ease and to prepare them for the questions that are going to be asked.'

(Key-Worker 14)

'... but basically I prepare them for the questions because there's nothing worse. I try to build a relaxed atmosphere... rather than make it seem like the Spanish Inquisition.' *(Key-Worker 14)*

'... to a certain extent engineering things, or having strategies in how to get in and make people feel at ease. (Key-Worker 18)

Again, as like the preceding data category, there was no literature identified that could be used to compare or contrast with these particular findings.

The Key-Worker's Manner Makes the Carer Feel Important

The question as to why the carer could communicate intimately with their key-worker, and to be put at ease so effectively, emerged as being significant to the quality Carer/Key-Worker relationship. For many carers the reason for the high quality of this relationship was attributed to the character and qualities of their key-worker. A general sense of appreciation of the key-worker's personality was evident from all carers and was best demonstrated by the following comments:

'To say very nice may be, that's another I used already, she's got charisma... maybe I shouldn't say it, she's not a beauty but she's a nice person.'

(Carer 16)

'He's just got that kind of nature, he's just got a big happy go lucky guy you know.' (Carer 17)

The key-workers appeared to share this belief in the importance of the professional's personality:

'I think its down to the individual personalities and how they relate to people.'
(Key-Worker 12)

'Personality is the screening issue, because not everyone would be suitable to do this.' (Key-Worker 15)

For many of the carers this quality came down to the fact that their key-workers simply cared about them and were approachable:

'Well I think he's got that caring quality that comes over if you talk to him... but to me just straight to the point that he was caring and I think that there is no other word for it.' (Carer 14)

'... really approachable, that's all I can say about him that he really was... because I felt somebody like that would need to be the approachable type. Somebody that you could sit and say, oh I've spoke to, I feel I've known him for a

while sort of thing. I felt that's what he was like... he just seemed to be that type (of) approachable person.' (Carer 18)

The following carers summed up more specific qualities associated with the more effective key-worker's personality. These qualities included kindness, a caring nature along with evidence of genuine concern for the well-being of the carer, leading to them feeling valued by that professional:

'... he still looks in yet (following the death of the dependant). You know he's still interested to see how things are going.' (Carer 6)

'Yes, it made you feel important, it made me feel really important... It makes you feel there's somebody taking an interest in what you're doing' (Carer 12)

'I don't think I can speak to anybody the way I do speak to her (Key-Worker)... I feel she is a genuine person... They care, they care about their job, I think they need to care about their job...' (Carer 15)

Key-workers shared this recognition of the professional needing to demonstrate genuine interest and concern. A level of interest and a positive enthusiasm was essential in nurturing the relationship to a more enhanced status:

'... he (carer) attends church and in his retirement he's taken up selling cards and different things. And I'm interested in the full of his life...' (Key-Worker 12)

'... and it's back to this idea of focusing on them rather than yourself... Just don't hurt them, they will always remember you positively even if you don't always get it right.' (Key-Worker 16)

Within the literature it was suggested that there was a lack of such qualities associated with care professionals (Rutman 1996; Nolan & Grant 1989; Walker et al 2001). Clarke (1999a) in citing Pitkeathley (1989) believed that professionals continued to hold one of three negative positions regarding carers: they ignored them, they felt guilty about them or they became impatient with them. The professional should commit him or her self to the carer if carer support was the principle reason for involvement. If loyalty shown towards the carer was in conflict with involvement with the dependant, then a dependant advocate should be considered (Woods & Watson 2000). Negative attitudes towards the carer were avoided when the professional genuinely valued the carer's involvement, and this was made explicit to the carer (Simpson 1997; Walker et al 2001).

The following key-workers believed that an improved relationship was brought about through the carer's recognition of the professional's role and responsibility:

'I think it's maybe pride on her part that it's confidential with me. It's, the relationships a kind of professional (one) really, you know it's not one that I'm going to blab to anybody else, or maybe she feels safe that this is confidential,

and I'm not judging her in anyway if she's telling me things. I'm really just there to offer help whereas friends would maybe be a bit more judgmental or something.' (Key-Worker 10)

'... this kind of idea, I think, is where the non-judgmental kind of thing as well, I think family and friends are quick to judge.' (Key-Worker 17)

The ability to be non-judgemental and maintain confidentiality were components of the professional role consistently highlighted as being essential to the relationship. Such qualities were widely recognised within the literature as being associated with the therapeutic relationship involving a service user. Empathy was particularly identified as being an important concept in being able to relate to and communicate effectively with a patient/client, principles that are essential to the development of the therapeutic relationship (Peplau 1987). This relationship is associated with the concepts of genuineness and respect contained within the interpersonal counselling model advocated by Carl Rogers (Stanley & Cantley 2001). The importance of being on a shared and equal level of understanding with the carer was evident from data discussed earlier within this substantive code section. When this was possible, the key-worker offered significantly more when dealing with the emotional trials and tribulations associated with the carer's role:

'I think I'm on her wavelength in the sense that over the visits (that) are done you get to I suppose... know them. You get to know their attitudes to the illness. Acceptance, denial at what stage they're at...' (Key-Worker 18)

Empathic understanding for the above key-worker went much deeper than simply making the key-worker/carer role more explicit. Empathy for the carer involved an understanding of what they were experiencing emotionally and communicating that genuine understanding to them. The Key-Worker 18 (p.107) stressed the importance of being on this shared and equal level of understanding with the carer. When this was attained he could offer more when dealing with carers' emotional problems.

The importance of empathic understanding of the carer's circumstance was evident within the literature. There was a recognised need on the part of the key-worker to demonstrate understanding and appreciation of the carer (Webb and Morris 1994). Bruce & Paterson (2000), within their study looking at the barriers to community support for the dementia carer, found that carers expressed difficulties surrounding the lack of understanding by the professional of their needs. This study appeared well designed and utilised an established interview schedule and analysis procedure. Walker et al (2001) considered the importance of a relationship characterised by honesty and openness, while Soliman (2003) stressed the importance of developing a therapeutic relationship involving both the person diagnosed with dementia and their carer. She, in citing Zarit (1985), pointed out the importance of maintaining a non-judgemental approach with the carer as being the most significant aspect associated with the quality relationship.

Walker et al (2001) attempted to refine guidelines for the involvement of carers in planning care for dementia dependants within the UK hospital setting.

Drawing upon autobiographical data, their findings demonstrated that empathic understanding between the carer and professional was fundamental to their relationship, and that communication between them had to reflect the professional's understanding of the carer's situation. This study used a qualitative workshop design involving three small focus groups (four/five carers and two project workers) to provide data. Among the strengths associated with the study was that the sample was selected from a wide variety of sources, saturation of codes/categories had been achieved and the findings underwent a series of member checks. By being sensitive to carer emotions key-workers were able to assist with perceptions of stress and isolation (Tebb & Jivangee 2000). Brooker (2003) made clear that empathic understanding was a key issue for both professional and family carer when caring for a person with dementia and that such an understanding enhanced levels of dementia awareness within the carer. Interestingly, this was achievable through training approaches directed towards both of the professional and carer. Such an improvement could include an effort to improve understanding between carer and key-worker and, along with the qualities associated with the personality of the key-worker, influenced the carer and helped to cement their relationship.

The need for more empathic understanding of carers was clearly expressed by the earlier comments Key-Worker 18 (p.107). Judging by the following data, this also appeared to be a product of the professional background and experience of the key-workers:

'The younger ones (key-workers) maybe understand less. (Key-Worker) knows what you're talking about because she's been there I would imagine.' (Carer 10)

'Is it coming from the fact that I have been doing it for 24 years? I mean I have always made a point of talking to carers.' (Key-Worker 12)

'... I think the more experienced you are you do it... you just read body language and it just becomes part of the skill.' (Key-Worker 16)

The Effective Use of Humour

For some key-workers the ability to create a positive atmosphere around the carer and dependant was facilitated by their use of humour. A sense of humour positively influenced the sense of social and emotional closeness between them, especially when the key-worker adopted a humorous approach while working with the carer's dependant:

'...she used to have a wee joke with the wife... that's good, I think that was good, makes you feel at ease too.' (Carer 12)

The literature associated with the use of humour around dementia carers was very limited. Walker et al (2001) described how key-workers could use humour when providing psychological support for the dementia carer as this helped them to maintain a sense of perspective. However its use with the diagnosed individual was much more recognised within the literature (Simon 1988; Summers 1990; Hulse 1994; Astedt-Kurki 1994; Townsend 1994; Buckwalter et

al 1995; Dowling 1997; Astedt-Kurki and Arja 2001). Pasquali (1991), while looking at carers of the chronically ill and frail elderly, considered that humour could help 'revitalise' the carer in both their physical and mental health. It has to be noted however that this viewpoint was from a theoretical perspective and did not derive directly from any empirical research study.

Bennett et al (1997), in a paper that explored the use of workshops to help support and train carers in their role, identified humour as a significant component of the professional's interaction with dementia carers coping with a dependant. For the carers of such frail elderly adults, humour served two vital communication purposes. It facilitated a more comfortable way to share intimate and sensitive information and provided a mechanism that allowed the carer to 'save face' when any adverse feelings and actions presented within their care-giving experience. Within a US based study it was claimed that humour provided an essential communication medium which allowed unresolved concerns, or conflicts, to be effectively addressed and resolved (Bethea et al 2000). This study used exploratory in-depth interviews on a appropriately sized sample group of carers (23).

The Key-Worker and Personal Disclosure

Some carers expressed a need for the key-worker to become more open with them and volunteer some information regarding their own life circumstance. This, they felt, was a facet that helped them relate to the key-workers and consolidate their relationship. A preference for professional disclosure was made clear within this carer's comments:

'... so I think if you're on that kind of level with them that it does help. They know all your business and you don't know anything about them.' (Carer 17)

As indicated earlier, the sharing of sensitive information by the carer was a positive feature when coping with the problematic aspects of caring (Bethea et al 2000). For carers more personal communication allowed them to warm towards the key-worker. This developing close relationship, resulting from the professional's revelations, was made apparent within the following carer's comments.

'... and I feel he's quite an open guy, you know, he spoke about his partner and that him and his wife were separated...the type of work the key-worker's doing, its quite important because he's building up a relationship so he's not just asking all about us, he's telling us a bit about himself you know' (Carer 5)

'She (key-worker) makes you feel more as if she's a friend coming in because she does talk about, I mean, I feel I know her family. I feel I know the children.' (Carer 15)

'Just saying well my son and my daughter were just coming up, I could talk to another woman about a daughter, I feel it would be beneficial, they would get closer to the person... I think they would get closer if they did that.' (Carer 16)

Key-workers valued disclosure, particularly around a shared interest such as family, when developing the relationship with the carer. It provided a mechanism to 'grease the wheels' of the relationship and helped to improve the sense of trust between carer and key-worker. This also put the carer at ease as well as generating that sense of being valued by the key-worker, spoken of earlier and highlighted by these key-workers:

'I think it's shared, shared interests, and it's allowing you to give a part of your self as well... I think it does help it, I think it does help the working relationship when you have something in common that you can relate to, or that just, you know, down loading a bit about yourself without going too deep.'

(Key-Worker 2)

'...so I think you always look for a common link... Commonality you can identify with that person that takes it (the relationship) forward. Obviously that was quite a good one the (both originating from the same village) one.'

(Key-Worker 11)

'... to make sense of that to me is like she's (the professional) human, you know, like you're a person... it's not like intimate details, it's like general things that you've got a family, you've built a house, you've moved, just general things...'

(Key-Worker 12)

However the belief that disclosure by the key-worker was always desirable was not a unanimous viewpoint held by the carer:

Aye, he stayed over in Airdrie and that, and in truth, we never had a good discussion about his family or anything, we never got to that stage. I felt it was kind of irrelevant at that time you know.' (Carer 6)

When considering this use of disclosure by the professional, I was curious about the issue of professional boundaries. It was noticeable from this key-worker's account that there was a boundary of disclosure not to be crossed, as to do so could be counter productive and potentially harmful to their relationship. Part of the caution related to the personal circumstances of the carer, and the key-worker had to use professional judgement with regard to when this strategy could be used to best effect:

'I think we always spend so much time talking about him (laugh). I just don't think he's got that far in the relationship, I don't think we've got to that (professional disclosure) because he's too busy, he's too focused, too distressed. This man has still not come to terms with his wife's condition... I think it's about timing, it's about that process in the relationship' (Key-Worker 16)

However, a close, less formal, relationship was not always viewed positively. The following key-worker highlighted a possible downside in this relationship where by this closeness might become too subjective to allow tangible therapeutic benefits:

Maybe the... carer... and the key-worker becoming so involved that they may be perceived to be not totally objective in their judgement or they in fact do become a wee bit close that they can't see the wood for the trees a little bit.'

(Key-Worker 18)

This tension between becoming too intimate with the carer and maintaining a professional distance is explored within the following major category. Studies associated with this data category's conceptual area were once again absent within the literature.

Key-Worker as a Credible Source of Support

A quality associated with the key-worker, and considered invaluable by the carer, was the belief that the key-worker was a very credible source of support. Importantly this viewpoint gave the carer a sense of confidence in the key-worker's ability and helped them cope with their own particular needs, especially in gaining knowledge about dementia. Credibility in the key-worker's knowledge base, and in the information they provided, was emphasised by these carers:

'We can talk about the illness and he gives you wee tips, or if I say about something, you know, that's happening he'll explain... but I think perhaps (key-worker) having a nursing background helps with the job he's doing.' (Carer 5)

'So the (key-worker) answered the key questions I needed to know, and the practical side of it as well as the progression of the illness...' (Carer 7)

She knows what she's talking about. She is the first to admit that she doesn't know the first thing about general nursing, but she knows plenty about psychiatric nursing. Which is what I'm dealing with.' (Carer 15)

This need to provide a consistent approach towards the carer, along with a high quality of advice and expertise, was evident within the following key-workers comments:

'I think when the advice turns out to be good advice em, it certainly does your credibility a lot, a lot of good.' (Key-Worker 1)

This perceived credibility was an essential ingredient leading towards a quality of Carer/Key-Worker relationship and an aspect of the relationship that required nurturing. Key-Worker 4, who expressed how she felt after interpreting that a senior colleague had undermined her relationship, brought the fragility associated with maintaining credibility within the relationship into sharp focus:

'It was in relation to looking for respite care. (Carer) had asked about respite care in the hospital, which to my knowledge was only available for people who had behavioural problems which this patient didn't fall in to... He (carer) then went to a talk done by the Consultant Psychiatrist in which the Consultant was saying about the support the health service could offer carers. And looking at respite care and after the talk (carer) went to Consultant and says I've been told that it's only for people that need psychiatric nurses to look after them. And the

Consultant says, oh no, that's not right, we'll just arrange for her to get into respite care. After that the carer didn't value my judgement as much. I felt my relationship had just been torn to bits basically by it. ' (Key-Worker 4)

This key-worker believed that her relationship with the carer had been irreparably damaged:

'I think it is a big thing that you know that this nurse is coming in and you trust them, you trust them, you trust their judgement and you telling them one thing and then somebody else, you know. I felt it almost as if I was a barrier, as if I didn't want the carer to get respite care in hospital, and that wasn't the case at all. ' (Key-Worker 4)

What was interesting about this account and worthy of note was that the carer, in his earlier discussion with myself, had maintained a strong belief in this key-worker and did not highlight any perception of the loss in credibility that she had assumed.

A need to preserve credibility in the professional was recognised within the literature and problems often arose when professional practices were inadequate, incorrect information was given or there was a lack of empathic understanding (Bruce & Paterson 2000). Tebb & Jivanjee (2000) claimed that there was an increase in carer isolation when the carer perceived a lack of knowledge on the part of a professional and subsequently lost faith in them. This lack of knowledge was most problematic when it related to either the dependant's

condition or to carer need. This US study utilised semi-structured interviews with eight elderly female carers to explore the carer's subjective experience. An effort was made to improve the 'trustworthiness' of the findings through member checks, peer review and audit trails.

What was a particularly important component of this credibility was the principle of trust, as mentioned by Key-Worker 4 (p.117). The following key-worker identified this, along with honesty and genuineness, as being essential to establishing a credible relationship:

'I think credibility is about trusting you and about you being genuine enough to say, well that was my mistake.' (Key-Worker 16)

Trust, openness and honesty were re-occurring concepts emanating from both the carer and key-worker when discussing their relationship:

'... in a way it's because I trust him... you know you build up a trust with them, you know.' (Carer 5)

'It's always important that you build up a trust and a relationship, but he (carer) trusted the relationship.' (Key-Worker 11)

'But I think we have a fairly open, very open relationship where I think she can trust me, and I think I can certainly trust her.' (Key-Worker 17)

For key-workers a trusting relationship was an important feature which they recognised had to develop when becoming involved with carers. An open, honest and trusting relationship had many direct benefits when operating alongside the carer and dependant, particularly when dealing with sensitive and/or unpopular issues:

'... to be able to tell people some, I don't know if it's home truths or some difficult decisions or whatever. They've got to have a relationship there, you would have to have that, and that, that if you like facilitates your ability to deal with more difficult issues.' (Key-Worker 14)

'... it's about developing skills and a confidence, it's about a confidence, and a lot of nurses maybe don't have that inner confidence. But I don't care if I look stupid at times, it doesn't worry me. As long as the carer continues to trust me and thinks, well (key-worker) says it, it will probably be right because she wouldn't kid me on or she wouldn't keep me going about this.' (Key-Worker 16)

Within these accounts the concept of credibility was once again considered to be more a product of the inherent qualities of the key-worker's character rather than being an 'engineered' outcome on the part of the key-worker. Key-Worker 17 identified credibility as a product of professional reliability and considered it to be a crucial ingredient to his successful relationship with the carer:

'... credibility if you can try and not let people down.'
(Key-Worker 17)

In 'not letting people down', the key-workers displayed certain qualities that led to a strengthening of their developing relationship and the emergence of the key-worker as a credible support to the carer. Highly significant amongst these qualities was this need for reliability and dependability. Dependability was an enhancing quality that helped solidify the relationship, as clearly demonstrated by the following carer comments:

'I think reliability is really important because of the amount of things you have to deal with when you're a carer of a person with dementia...' (Carer 9)

'She's a very valid and reliable person so that comes through, across, as well.'
(Carer 12)

'If she's not there she'll ring me back and she always rings me back.'
(Carer 15)

This quality was acknowledged as being significant by this key-worker and links to the earlier requirement of clarifying the professional's role:

'So I really felt it was really important that, as she said, if I said I was going to do something I had to do it. And I tended to follow things up quite a bit in writing so there's no confusion about who was doing what.' (Key-Worker 9)

When the 'Relationship Drivers', discussed within this substantive code section, become positively engaged, the more negative attributes of the preceding substantive code, 'Unacknowledged Work' (Table 3), becomes less influential. The consequence of this is an improved relationship between the carer and their key worker. The properties of this improved relationship are now discussed under the final substantive code associated with this major category chapter.

ENHANCED RELATIONSHIP PROPERTIES

Carer Experiences a Real Psychological Benefit

The shared belief by both the key-worker and carer, that there was a range of benefits derived from the strength of their relationship, quickly became apparent early within this study. The first benefit alluded to within the preceding substantive code discussion and highlighted by the following carer's comments, was the rapid emotional & psychological ease experienced by the carer as they become involved with the key-worker:

'I can't think of anything else just you feel really at ease when he's (key-worker) there.' (Carer 12)

'...I've never thought of it that way, when he (key-worker) has come in I felt at ease straight away... You're down enough without anyone else trying to put you down.' (Carer 14)

'But key-worker really was different, he really did help a lot, he put everything at ease... I don't know, I think he just, it was more or less he just made me feel at ease.' (Carer 18)

The key-worker's relationship with the carer provided a significant emotional and psychological benefit to the carer particularly when commenting upon their contribution to the care of their dependant. This gave the carer a tremendous uplift to often-flagging spirits:

'He (key-worker) gave me a wee boost, you know, that you're doing things right, you know, confirming to you that you're doing things right, which is a big, big thing.' (Carer 6)

Key-Worker 14, made it clear that the key-worker not only validated the carer's work by reassuring them that their efforts were appropriate, but also reassured them that key-worker involvement was not an indication of any failure on their part:

'Well yes that's it because I think that initially she was quite emotionally upset with regard to having to seek help and I tried to reassure her of the fact that because I'm here doesn't mean she's failed in any way.' (Key-Worker 14)

It was acknowledged within the literature that in caring for a mentally ill dependant the carer required their work to be valued and validated in this way (Badger et al 1990; Hocking 1994; Crisp 1999; Gall et al 2003). According to

Grant & Nolan (1993) professionals generally failed to provide sufficient emotional support, particularly by failing to recognise the carer's work effort. This finding came from a well-designed study that used both a qualitative and quantitative methodology, and incorporated steps to improve the inter-rater reliability of the qualitative analysis process. It was recognised that the sample utilised had a degree of bias both in terms of being self-selecting and by being predominantly female. Ross et al (1997) found that the professional giving such a boost to the carer was a vital aspect of support, particularly when the carer struggled to cope with a dependant's admission into formal care. While this study looked at a range of conditions that predispose to admission, a significant proportion of these were dementia related.

Friendly Informality

For many carers the relationship with the key-worker was characterised by a perception of 'friendly informality':

'Well that it's just that she's easy to speak to, em oh how can I explain it? She's not like any of an official capacity; she makes herself at home and that... Yes she came in and she was quite, you know, jokie and that...' (Carer 2)

'They don't wear uniforms now or anything like that, so it's not like anyone coming in that's, you know, here comes the nurse.' (Carer 7)

'... his manner yes, I think it's important, he's not like I'm the doctor and you're the patient, just like a big pal coming in'. (Carer 17)

The above comment by Carer 17 reinforced this perception of a more informal relationship. Here the carer's acceptance of the key-worker suggested an ease of comfort that was in keeping with the concept of 'adoption' that is discussed within the following major category chapter. This was a product of the key-worker's overt friendly manner, approachability and obvious demonstration of a genuine interest in the carer and dependant. The following carer again identified this sense of psychological comfort:

'Oh yes of course some folk you can speak to quite easily and others, you know, he really is easy to get along with.' (Carer 5)

Several key-workers shared this view of informality associated with their relationship and saw this as a positive development that greatly enhanced the effectiveness of their role. A sense of ease was significant in creating an environment that allowed both parties to forge a closer more intimate relationship:

'I would still say it's a nurse carer relationship, but in a more friendly, probably, manner than it was initially, probably more open because... she's probably more at ease saying her true feelings because she is always going to be a bit reluctant at the start. And probably I can be more truthful with her now.' (Key-Worker 1)

'No I think the relationship, over time, certainly is very much nurse patient, I'm using carer as patient here, also, em, certainly over time it does become probably more informal and more open.' (Key-Worker 3)

For these key-workers the level and character of relationship depended upon good communication skills, particularly in making the effort to listen, a factor that related directly to the preceding substantive code's data category 'The Key-Worker's Manner Made the Carer Feel Important' (Table 3):

'I think by listening and picking up on key points, probably, that's what she was saying. Probably that's the most important thing is actually listening to her.' (Key-Worker 10)

'I think it's just communication, it's basic communication skills. It's listening to her (carer), but it's also listening to (dependant) and not forgetting that (dependant) is your patient.' (Key-Worker 15)

'I might be the only person that actually comes in and listens. Everybody else will come in and do a bit, but I could be the only person that actually sits there and listens to what's going on, I think that's the difference.' (Key-Worker 16)

This ensured that the carer experienced a greater sense of support, reassurance and confidence in dispatching his/her responsibilities in caring for the dependant, as suggested by the following comments:

'I'll tell you this, if something was wrong you can tell her about it and she reassured you.' (Carer 12)

'Aye, that talk to him (key-worker) kind of eases it (stress) off a bit.' (Carer 18)

Key-Worker 18 demonstrated here the importance of the carer being at ease and therefore more able to communicate openly. In the following account, he set out to encourage this quality within the carer early on in his involvement with him/her:

'... he said I don't want you to feel you're strained to talk to me or anything like that, he says just answer me anyway you feel is right.' (Carer 18)

Deep and Meaningful Communication

A benefit from this level of psychological comfort between carer and the key-worker was an increased ability to communicate more freely, openly and at a surprisingly intimate level:

'... I felt I could talk to her without being embarrassed about it.'
(Carer 4)

This revelation led me to explore this phenomenon further within subsequent carer interviews. The quality Carer/Key-Worker relationship appeared to create a climate that facilitated an ability to communicate freely and intimately as suggested here by this carer:

Well the first place is you can sit and talk to her in person, there's some people you can't talk to.' (Carer 12)

'... it's someone for me to talk to, warts and all, and I mean warts and all...Oh no, I can talk to her, I can tell her things I can't tell you, personal things. I wouldn't tell you because I feel she's used to hearing people.' (Carer 10)

The following carer highlighted how this ability to communicate at a deeper more intimate level was associated with her key-worker and contrasted this to experiences with other care workers:

Sometimes you meet people right enough, and as you say, you're a wee bit on your guard with them...' (Carer17)

The quality of the relationship had a significant impact upon the role of the key-worker. An ability to effectively manage the variety of situations that arose involving the carer was improved by having a quality relationship with the carer. The following key-worker demonstrated this facet:

'... I think certainly just for her low mood, really quite negative thoughts, I think I need to have that kind of deeper relationship in order to explore that.'
(Key-Worker 18)

The carers experienced a sense of satisfaction and reward from being able to communicate at such a level with their key-worker and found this deeply reassuring. The confidence to explore explicit and sensitive matters with the key-worker was shown by the following carer's willingness to explore more personal matters, and this particularly interested me:

'... I get this problem; sometimes he goes to the toilet and forgets to take his underpants down. It's not happened a lot but it has happened. I would say to (key-worker), Oh God do you know what happened last week, you could never tell to anybody else. Even your family, you couldn't say to them.' (Carer17)

Even more surprising was a highly sensitive issue involving sexual behaviours. Carer 4 highlighted overt sexually related matters which he could not discuss comfortably with his family nor anyone within his social circle. This 77 year old man was being visited by a female CPN in her early 20s and, despite the generation and gender gap, both were clearly comfortable to discuss intimate sexual matters in an effort to solve a very troubling problem:

'I felt that I could speak to her (key-worker). When my wife went to 12 and 12 (drug dosage and time) there was a bit of nocturnal activity which eh, more or less (was) masturbation. And I spoke to (key-worker) and that and it was just, I didn't feel embarrassed talking to her about it and I explained to her what was happening. So she explained to me that some times these tablets, it does increase sexual activity so that's when they decided to cut from 12 and 12 to 12 and 8... it more or less disappeared. I could speak to her about that'. (Carer 4)

This carer took a very pragmatic approach to the problem he faced with his wife's behaviour and saw this as a problem that had to be faced up to, and his key-worker possessed the necessary qualities to make this possible:

'... I felt that she was a receptive person, that she would understand. I mean the thing was there was no point in trying to hide it, it had to come out and I felt that I could talk to her without being embarrassed about it.' (Carer 4)

The literature associated with this level of communication between a dementia carer and key-worker was limited. Carers required the opportunity to be able to talk about and explore their emotions with professionals in order to more effectively cope with the burdens of care they faced (Gilliard & Wilcock 1993; Allen 1997). People sought social support for one of two reasons, either for instrumental reasons that included advice, assistance or information; or for emotional reasons such as moral support, sympathy, or understanding (Carver et al 1989). Carson (1992), speaking about the carers of mentally ill people generally, was of the opinion that carers often experienced strong emotions associated with their negative exposure to health care professionals and their services. This left them feeling undermined, as services were not tailored to their individual needs. Franks & Stephens (1996) cited Cohen (1988) in claiming that evidence from both theoretical and empirical research indicated that support provided by others had a significant effect on the individual in receipt of such assistance.

This need to have a professional who improved carer emotional well-being, and did not compound their problems, was made clear by this carer:

'Well she's (key-worker) very calming; she had a very calming effect, she's very relaxed, not at all doom and gloom which I found a lot when he (husband) was first diagnosed. I was getting a lot of doom and gloom and it's not really the way of handling things.' (Carer 7)

The following carer derived a real sense of emotional reassurance from her key-worker's insight into dementia:

'When you get reassurance about it and somebody that understands the illness, it's really that's the big thing. It's somebody that understands the illness that's the difference than talking to anybody else.' (Carer 7)

Key-Worker 4 demonstrated earlier within this data category how she understood the unwanted effects from medications used within dementia care. She also had an ability to communicate with the carer at a deep and intimate level. The capacity to achieve this level of communication was a desirable, if not essential, ability associated with the more effective Carer/Key-Worker relationship.

Recognition of sexual issues in the older person and their carers, especially those associated with a dementia diagnosis, has historically been an area that has been lacking within the literature (Archibald 1994; Phanjoo 2002). According to Archibald many staff dealing with dementia, and supporting the carer,

demonstrated an ageist and stereotypical attitude that was a product of their own discomfort and inadequacy with sexual issues. Indeed Ehrenfeld et al (1997) considered that such professional awkwardness often resulted in the person with dementia being treated like a child and separated from their partners. While these were interesting discussion papers that provided opinion from dementia care experts, the general paucity of up-to-date research-based evidence on this topic was surprising. This lack of research attention was particularly associated with the impact dementia had on the marital relationship and the effects upon marital intimacy and satisfaction (Baikie 2002). This absence of study was particularly concerning given that, while this illness was in itself a tragedy, many dependants, and their carers, continued to enjoy and derive a sense of comfort and mutual support from their ongoing physical relationship (Oppenheimer 2002).

The professional's ability to comfortably deal with difficult issues such as sexual aspects was seen as a particularly positive attribute by the carer. The following carer, caring for a husband with pre-senile dementia, expressed this view after being able to discuss her worries surrounding her son's sexuality. She highlighted her appreciation at the professional's willingness and comfort in exploring a personal problem that went wider than her dependant's circumstance:

'... so (key-worker) was very easy to talk to and tell her these sort(s) of intimate details as well...' (Carer 7)

It was particularly interesting to note that Key-Worker 4, who earlier described dealing with a difficult sexual issue, also gained a great deal of personal satisfaction from this encounter. She expressed a sense of pleasure at being able to facilitate this level of intimate disclosure that resulted in her finding a tangible solution to a most difficult and sensitive problem:

'... being a different sex it must have been extremely difficult for him to talk to me about it. And he's not the type of man that would be blasé about things like that. It was quite, it made me feel quite good actually that he could confide in me about it. But as I say my initial reaction was, Oh my God, (laugh). I think we got over that yeah.' (Key-Worker 4)

As highlighted earlier, communication within this relationship appeared to go wider and deeper than simply discussing the immediate needs and issues associated with the dependant. The quality of the developing Carer/Key-Worker relationship facilitated a level of communication that directly benefited the carer and covered a wide variety of areas within their lives that were often unrelated to the dependant's situation. In being able to explore these diverse areas the key-workers facilitated a response that seemed to directly improve the carers own effectiveness and so potentially improved the quality of their day-to-day lives. Here the carer suggested that the key-worker subtly probed in order to open up areas of real concern to her:

'I feel he would keep on, I'm not going to say niggling, but I feel he would keep on talking until it came out.' (Carer 14)

This key-worker (social worker) acknowledged that getting the carer to open up into any issue within their lives was an important aspect of his role. It helped to uncover aspects within their lives that were problematic and, as a consequence of their strong relationship allowed them to express these difficulties in relative comfort and safety. The need to deal with the carer's problems, outwith the immediate concerns of their dependent, was not an aspect that was shared by all key-workers however. In contrast the following key-worker (CPN) failed to see this activity as having any real relevance. The key-worker she believed, given the seriousness of the illness, must confine him or her self solely to the issues relating to the individual with the dementia diagnosis:

'When I'm there I think he's so focused on this illness that we can't (discuss unrelated issues), we need to deal with illness when I'm there because that's what he sees as my remit.' (Key-Worker 16)

Key-Worker 16's views apart, there was an acknowledgement among key-workers that it was to their carer's significant advantage to be able to raise any concerns regardless of their nature. Here, as in the above situation, the Carer/Key-Worker relationship allowed for a deeper level of disclosure around sensitive non-dependant related issues:

'As far as private personal things me and (carer) discuss, I would say that she did divulge things about her own family that are maybe annoying her a wee bit. And she did have a few stresses with, you know, her daughter for example. Well

she had a marriage break up with a young daughter and her son is in and out of work and she's worried about him, and she quite often would maybe bring that into any visits that I have. Any worries like that would always come out... I wonder if it's because I maybe slightly probed or asked about, maybe took time to ask her how things were whereas other people wouldn't. ' (Key-Worker 10)

This ability, according to the following key-worker, was again related to the quality of their relationship and was in contrast with other professional relationships the carer may have experienced:

'... I think what you're doing is actually (at) a much deeper level, and other members of the care team aren't able to operate at that level.' (Key-worker 17)

The closeness the carers felt within this relationship was frequently contrasted with involvement with other care workers and served to typify the unique qualities associated with the enhanced Carer/Key-Worker relationship:

'... he suggested we phone the... the social worker to see what we could get from him, but it's like the Scarlet Pimpernel to get a hold of him.' (Carer 3)

'... but you sometimes get a doctor coming in and you feel, oh my this is, he's not approachable at all, not talking and just sit with their head down or that.' (Carer 18)

Within the literature it was expressed that dementia carers often experienced a disappointing level of service from health care professionals (Pickard & Glendinning 2001). Pickard & Glendinning's (2001) study not only supported the claim suggested by the above carer's comments, but indicated this was often the reality of care professionals as experienced by the dementia carer, as suggested by these key-workers:

'... I was talking to one of the nurses on the ward and they basically said that she (the carer) needs help more than he does. But it was in a sort of derogatory way. And that she's too stressed and she's tuned to the moon.' (Key-Worker 15)

'I would say my relationship with (carer) was quite good, quite solid. Fairly informal I would say... The impression I've had is the doctors are very much the kind of formalised, sometimes I get the impression (they) don't have the greatest amount of time for the problems that are most specific to them (the carers).' (Key-Worker 17)

At this point I was interested to consider why the carer felt so comfortable and safe with their key-worker, and in such contrast to other health and social care workers that they are involved with. Indeed this was often achieved after relatively few encounters with the key-worker. What was significant, however, was that this quality relationship existed and was established at an early stage of their association. It brought immensely positive and productive qualities; qualities that underpinned future care practice and contributed significantly to the avoidance of the concept of 'malignant social psychology' described by Kitwood

(1997). Such an enhanced relationship could improve significantly the quality of the environment in which such care was being delivered (Brooker 2003; Soliman 2003). The following chapter now explores just how this depth of relationship influences the care-giving practices of both the key-worker and the carer.

CHAPTER SIX MODELS OF ACTION

This chapter explores caring activities or ‘Models of Action’ as viewed by both the key-worker and the carer (Table 4). These perceptions vary in terms of the nature and strength of their relationship. At one end of the spectrum the key-worker operated as an expert professional exercising almost complete control and influence within the care setting. At the other end of the spectrum the carer exercised dominant control and possessed the necessary ‘expertise’ to deliver effective care to their dependant. Between these two polarised perspectives the carer and key-worker could operate within a therapeutic alliance. This chapter suggested that this stronger more positive interpretation of the Carer/Key-Worker relationship carried with it tangible benefits for all those involved within the care-giving environment. How this partnership was conceptualised, particularly by some carers, indicated a surprising depth of closeness and intimacy. Once again the literature consulted was not always directly related to dementia carers, but provided some insights into the emerging concepts and therefore its use was appropriate in the absence of more relevant and specific dementia carer literature.

THE KNOWLEDGEABLE PROFESSIONAL EXERCISES CONTROL

Carer versus Dependant: Who is the Key-Worker there for?

As demonstrated by the first substantive code within the previous major category chapter, there was an ambiguity surrounding the key-worker’s activity and focus (Tables 3). Concentrating activities on the carer, however, was not always seen as appropriate.

Table 4 Models of Action: Codes & Categories

DATA CATEGORIES SUBSTANTIVE CODES MAJOR CATEGORY

| | | |
|---|---|-------------------------|
| <ul style="list-style-type: none">• Carer versus Dependant: Who is the Key-Worker there for?• Educating the Carer• Preparing the Road Ahead• Key-Worker as a Resource to Other Professionals• Key-Worker Manages Dependent Better Than Carer | THE KNOWLEDGEABLE PROFESSIONAL EXERCISES CONTROL | MODELS OF ACTION |
| <ul style="list-style-type: none">• Carer Exercises Independent Control When Providing Care• Carer Provides Best Care Because of their Intimate Knowledge of Dependant | THE INDEPENDENT CARER | |
| <ul style="list-style-type: none">• The Adopted Professional• Carer Expresses Sympathy and is Protective of the Key-Worker• Key-Worker as a Partner in Caring: a Friend with Knowledge | WORKING TOGETHER: A THERAPEUTIC ALLIANCE | |

In keeping with this perception, some carers suggested that the supportive role of the professional was targeted principally upon their dependant and only provided them with peripheral support to enable them to engage in their caring role:

‘Although (key-workers) are there to give a feel, I got information from them on how to deal with issues, I think they seem to be there to assess my mum more...

Well I think she's very helpful in a professional capacity but her role is, I would see as what's she's doing, basically is helping me to provide the care and put in a review on how things are going, I mean I wouldn't see her, I don't see her responsibility as helping, dealing with my needs.' (Carer 9)

'... when he (key-worker) comes in and he works with (husband), you know, the wee tests and that to see if he has went back any or if he's improved any. But that's a good thing as well, him coming in to test that.' (Carer 18)

This viewpoint contrasted with the view of this key-worker who suggested that his activities included actions directed towards the carer:

'I certainly see the role as just not for the husband, although he is the most important in this kind of situation. But I think (what's) just as important, to a certain extent, is the carer because they are living through it as well and if I can be of any value, or any use to them, then all the better.' (Key-Worker 17)

What was significant in terms of the key-workers role, and subsequent activities, was the length of time the key-worker had been involved within the care setting. This carer gradually came to realise that her key-worker focused increasingly on helping her as their relationship became more established. This was a further argument in support of the need for time and availability to be given to the carer as highlighted within the preceding category (Table 3):

'In the beginning I felt that she (key-worker) was coming in for my husband, in the beginning it was really for him because in the beginning they spent a lot of time doing questionnaires and mini mental sort of thing... in the beginning it was all directed at him, as time has gone on she never even sees him... so I would say it's mainly support for me, but through the support for me it helps me to cope with our situation.' (Carer 15)

Indeed if the situation deteriorated, and the carer's health becomes compromised, some key-workers considered the carer as the primary recipient of care:

'We (key-worker service) would take them on as patients. We would actually take them onto the caseload. And we've certainly, recently one of our nurses has taken on a carer because the (husband) went into long term care and the carer became very depressed and was very distressed.' (Key-Worker 16)

Not all key-workers felt that this was their particular responsibility, but rather another independent practitioner should deal with the carer if their mental health becomes compromised:

'... but if there's something psychologically wrong, or we think there's some sort of mental health problem developing, then there's nothing to stop us getting another member of the team to see that person.' (Key-Worker 16)

When it came down to actually working with both the carer and dependant, the following key-worker reflected on the notion of the 'hidden care plan' alluded to

within the preceding major category chapter (Table 3). Here the professional worked with carers in a more concealed fashion but did acknowledge addressing their needs:

'You're responding to their (carers) needs in an informal way, or an unseen way, but you're still doing it. So your operating in a, it's not documented in the same way, it's not structured in the same way, but you're still doing it.'

(Key-Worker 15)

Twigg (1989) conceptualised differing relationships between service providers and carers, naming one 'the carer as co-client' model. She highlighted the difficulty in conceptualising this model, particularly in terms of social care, and questioned the appropriateness of attributing the status of client onto the carer. Twigg, as cited by Grant & Nolan (1993), believed that addressing the carer as a 'co-client' will:

'... risk the inherent danger that services will be swamped by ordinary human misery and take over the normal processes of life' (p.951).

It was important to note that these conceptual representations encompassed all carers and were not related specifically to dementia carers. Weiler et al (1994) discussed Volicer et al's (1988) view that the professional's practice activities in themselves could help establish a 'therapeutic alliance' between the professional and both the person with dementia and their carer. Stanley & Cantley (2001) reinforced Carer 9 and 18s earlier comments by highlighting how professionals

historically tended to view patients/clients and carers as totally separate entities, particularly in terms of assessment, which created the potential for a conflict of interest.

The following key-worker avoided any concern of a conflict of interest by viewing her carer's status as that of a patient/client, and in doing so justified the valuable commodity of time that was necessary in helping her:

'We'll take this lady onto the caseload and treat her as a patient, and give her that time, because that is what you need to think about, how much time is this going to take?' (Key-Worker 16)

However, for this key-worker it was not her fear of a conflict of interest between the needs of the dependant and the carer that influenced her approach. It appeared that she was much more reticent to take the carer onto her caseload as by doing so would mean labelling her with the stigma of mental disorder:

'... there's a big taboo about mental health which has given her (carer) a stigma, because as soon as you give them a label it still happens... So if I give her, take her onto my caseload, if you like, then I would be labelling her...'

(Key-Worker 15)

Educating the Carer

Education of the carer also emerged as a vitally important key-worker responsibility and was indicative of the professionally dominant sphere of the

Carer/Key-Worker relationship (Table 4). This aspect of practice was highly dependent upon the key-worker's expert knowledge being imparted onto the carer who was coping with a dependant with a diagnosis of dementia (Harvath et al 1994). The following key-workers clearly identified education of the carer as being an important aspect of their role:

'Yes I was the first contact for her with our service. She never had anybody before and I think she had very little support, you know as to what's happening, or she didn't have the understanding as to whether it's going to get better, (and) so there is a lot of education on her part as well.' (Key-Worker 10)

'(Carer) especially, (was) quite worried about (dependant) himself on a cognitive enhancer. And I just felt quite open and I felt that to work on her level was to tell her as much as I possibly, to could get as much literature as I could for her.' (Key-Worker 18)

The necessity to develop a sound knowledge of dementia was an area of significance to all health care professionals who required to incorporate such a understanding into their educational approaches (Department of Health 1994). The political recognition of making this requirement available to the carers was evidenced by the introduction of the Carers (Recognition and Services) Act, 1995. This was introduced to give carers the statutory right to have their own needs assessed, a significant need arguably being their requirement for education around the process of dementia. Despite this legislation, carers often remained

marginal figures who were rarely consulted or provided with the level of support (education) that they required (Brown et al 2001).

Allen (1997) found confidentiality to be one of the most difficult issues to consider when developing inclusive patient/client and carer-focused dementia services. As a result, the carer was often kept in ignorance of their dependant's condition, and if that situation were to exist for the professional they would have, quite rightly, refused to accept care-giving responsibility. This important point was brought out by Arksey et al (1998) who also found that carers wanted considerably more medical and practical information, a need that often conflicted with the professional's duty of confidentiality. They pointed out that unless more information was made available to the carer, they would continue to be critical of both health and social care services. While this study addressed carer issues it's important to note that it did not have a specific focus on dementia carers although it is likely to have relevance to this cohort. Unfortunately, the paper failed to give sufficient information on the study design making it difficult to judge the strength of its findings. Walker et al (2001) discussed the importance of the professional's ability to communicate, a requirement considered fundamental to the understanding of the carers' situation. A lack of information, coupled with poor communication, added to the burden on individuals striving to care for a dependant, a realisation that strongly links this data category to the 'Costs of Caring' substantive code discussed within the next major category chapter (Table 5).

The provision of a good educational grounding by the key-worker was an aspect of their role valued by the carer:

'Well, she told me things that I didn't know anything about, but that was a great help. Things that I knew nothing about and she is putting us wise to.' (Carer 12)

'I think he was yes, because there is a lot I have learned from him that I didn't know about before, you know.' (Carer 18)

Gilliard & Rabins (1999) identified this thirst for information on the part of the carer and stressed that there was a need for the carer to become increasingly involved in the provision of care to their dependant. Key-Worker 17 applauded the level of interest and enthusiasm of his carer as she strove to improve her knowledge of the condition and acknowledged that he was better placed than other professionals in meeting carer educational needs:

'I can try and make it... hopefully being able to put it more in terms that suits their individual needs. Whether that be more simplified... that's the kind of thing I would say mainly I could offer clients that a General Practitioner can't... She's very kind of hungry for information, and very much wanting to be part of things, and I think that's great, I'm quite happy with that' (Key-Worker 17)

Inherent within this educational role was an ability to impart quality information to the carer, a requirement that drew upon expert professional knowledge. The need to provide education and training for the carer was very well represented

within the literature. Eraut (1994), cited in Brown et al (2001), analysed the nature of professional knowledge in some depth and argued that the essential essence of professionalism centred on power derived from specialist expertise, and the more specialised that expertise the greater the power that resulted. Hasselkus (1994) acknowledged the power invested in the professional and stated that such professionals are viewed as the 'repository of expert knowledge' (p.95) and therefore would know what was best for care delivery. This, consequentially, led to them exercising greater control over the care environment. Harvath et al (1994), citing the views of Tanner & Benner (1993), argued that nurses' scientific knowledge did not constitute expertise. What distinguished nursing expert practice was an ability to combine professional knowledge with an in-depth understanding of the client group; this blend of scientific knowledge and understanding of the client group defined the expert practitioner. The belief that such professional expertise was inherently beneficial to the carer was challenged by the argument that recognised genuine expertise within the carers (Brown et al 2001), a theme that is examined further within the next substantive code. Brown et al (2001) cited research carried out by Tuckett et al (1985) on both doctors and patients, a study that was neither dementia nor carer specific. They found that consultations were often one-sided with little emphasis placed on the patients' understanding of treatment. Any attempt to clarify their understanding was often ignored and any advice given was seldom individually tailored. This study appeared to indicate that a lack of recognition of lay expertise led to problems affecting the quality of communication between these two parties.

The Government document, 'Growing Older' (Secretary of State 1981) saw an educational role for the health care professional directed towards the user of health care services but, surprisingly, failed to address this same need in carers. Kitson (1987) claimed that the educational role of nurses was vitally important when it came to training carers to care for their dependant more effectively. A study undertaken within the UK by Graham et al (1997) aimed at determining how much dementia carers from differing settings know about the disorder. They concluded that the level of education dementia carers receive should not come down to their ability to ask the right questions, but rather it was the responsibility of the professional to actively impart accurate and well presented information. This quantitative study drew from three distinct populations and the resulting sample groups were formed using specific selection criteria. It utilised a previously established questionnaire to gather the data. A particularly good response rate (95.6%) further added to the strength to these findings.

Hasselkus (1994), a US academic, considered the needs of carers generally and identified that while the professional was in control of the care setting the carer continued to strive for some meaning regarding the illness and changes in their dependant. Efforts to educate them represented the beginning of a sharing of expertise and responsibility between the professional and carer. Cooke et al's (2001) well conducted review of the carer literature concluded that while it was possible to raise the level of knowledge the carer had about dementia it did not necessarily follow that the carer derived any automatic psychological or social benefit. There was limited evidence to support the premise that interventions improved psychological well being in the carer or reduced burden. These

authors did acknowledge limitations within their review, such as the numerous designs which failed to use any control group, and advised that their conclusions be viewed cautiously.

The carers within my study agreed that they received high quality information from key-workers:

'That's (key-worker), that's her thing to listen to people and to advise, she gives you good advice.' (Carer 10)

'..and any sort of advice she gives me, she's been very very helpful.' (Carer 15)

'Well really, he's been awful good, very helpful in anything I asked him about, he explained it good to me, he really explained it good.' (Carer 18)

Some carers required information around financial concerns. Such advice from the key-worker contributed towards maintaining carer well-being, as suggested by the following comments:

'Well I think it, ... obviously you give her advice about benefits and they get a bit more money, which certainly, em it eases things, certainly it's a worry less if they know that they can go to Asda at the end of the week, so they are not worried about the money.' (Key-Worker 3)

'She will speak to me regarding finances. I mean I don't actually sit down with her and say, right this is how much is coming into the house or that, but she tells me her concerns about finances. She's very concerned that if her husband goes into care, you know... she's worried about, you know, she maybe has to give up the house. And to me that's causing a bit of stress...' (Key-Worker 5)

A study by Philip et al (1995) measured perceived financial burden and unmet needs in carers of both demented and non-demented dependants. It found that, despite increased demands on the carer, they did not report a corresponding increase in financial burden except when it came to domestic expenses. Significantly it reported that where financial hardships were found this was more likely to be related to a lack of awareness rather than a lack of financial support, a further argument in support of a more educational input directed towards this particular deficiency. This research was a comparative study that adopted a quantitative approach on two groups of carers, one with dependants with dementia and the other with non-dementia dependants. The sample group was sizeable (228) and was recruited from a wide range of sources adding to the strength of the design. The data was gathered using a previously established interview schedule based upon a variety of recognised assessment scales.

A further study elicited the experiences of patients/clients being cared for by an informal carer (McCann & Evans 2002). It found that more than half of the dependants expressed concern for both theirs and their carer's financial circumstance. While this study was not specifically focused on dementia carers, it used a randomly derived and representative sample of carers drawn from three

wide geographical areas. The distribution of income is considered a 'key determinant' associated with the health of any population (Kawachi & Kennedy 1997). For many dementia carers such financial concerns were a dominant issue as they often were not in receipt of a wage (Sutcliffe 2001). Woods & Watson (2000) stated that just having to provide care for a dependant created financial hardship that derived, not just from domestic costs but, because many carers had to give up paid employment.

In the more advanced stages of dementia advice from the key-worker was particularly beneficial when more extreme behavioural problems, such as aggression, became a feature of the dependant's condition. Straightforward suggestions from the key-worker significantly improved the carer's handling of serious behavioural outbursts:

'... but with (key-worker), if it was as you say like, if it was the aggression or something like that, I feel I could phone (key-worker) and say I've got this problem what do you think I should do, how could I handle it? And he could answer me, he could help me there. I think that is the good thing about the (key-worker).' (Carer 17)

With certain hostile behaviours the key-worker gave detailed practical advice that successfully helped the carer defuse potentially aggressive outbursts:

'I have a lot of bother getting (husband) in the... shower and I get all this shouting and bawling and so of course I said to (key-worker)...he was saying

that the reason... it's something like a psychological thing when the waters hitting him.' (Key-Worker 17)

'... sometimes watching television and he'll (husband) say, I saw that, and I'll say, no you didn't (husband). And he gets quite erratic and he'll say, (carer) I saw that yesterday... and I say to (key-worker) he gets quite erratic about something he's seen on the telly. I can't put the television on during the day, and (key-worker) said, ... the problem there, he says, if they (dementia sufferers) go up the stairs to the toilet, or put the kettle on, and were maybe watching it and it's went out of their mind, and when they see it again they say, I've saw this. ...Well now I just say to him you probably did see it, you probably saw a coming attraction on telly. And he said, well I knew I'd seen it anyway.' (Carer 18)

The professional's role in educating the carer to cope with extremes of behaviour was acknowledged within the literature (Marriott 2003). Within my study dependant behaviour was a professional concern that highlighted health and safety issues for both carer and dependant, as demonstrated by the following comments. The key-worker here believed that his advice had to be tailored to the particular situation as he found it, and his experience was of particular significance in this endeavour:

'... like you know she's very worried (husband) would sometimes walk out of the house em, you know, and through experience of maybe being in the community you've heard people, how they deal with that situation. You know maybe say they'll lock the door, you know... and then the next thing (husband) was like

arguing with her, where is the key for the front door. And I was saying maybe the best thing to do is just put another key in the door that's the wrong key. So it's not her fault that there is something the matter with the door, you know, at that moment of what's happening, maybe it alleviates the problem.'

(Key-Worker 5)

For some carers, their greatest educational need was simply to make sense of the condition:

'Oh aye because, in fact I'd say (key-worker's) the first person who explained to me exactly the difference between multi-infarct dementia and Alzheimer's.'

(Carer 4)

'The only thing I feel is that nobody has actually explained about (husband). I've got a book, and that. I just read through the book but nobody sort of just takes time to say' well this is going to happen, that's going to happen... I've not really got anybody that's actually sat down and said, now this, in detail... She gave me a clearer picture of dementia than anybody else has. I'm a person who likes to know how things work. I'm a nosey bugger'. (Carer 17)

The need for carers to understand the dependant's condition and associated behaviours was evident within the literature. Willoughby & Keating (1991), in a study designed to understand the process of care-giving from the perspective of the family, conceptualised a five-stage model of gaining and relinquishing control of care-giving. Within stage two of this model they considered that the

carer is more likely to become involved with the professional and to view them as a resource for information about the condition. This well designed Grounded Theory study used a small sample of ten participants, a sample whose selection was well explained and appropriate to the Grounded Theory approach, although surprisingly the saturation of the codes was not addressed. This important point aside, this study was well executed and the more intense analytical process associated with Grounded Theory made the findings worthy of consideration. Carers had to be provided with adequate information that would lead to a positive influence on care delivery. However, in order to ensure the highest standard of advice, care was taken to ensure that appropriately skilled and knowledgeable professionals dispatched this information (Arksey et al 1998).

Making sense of the dementia behaviours, and how best to respond to these, was a further aspect of the educational role frequently referred to as being encompassed within psychosocial intervention approaches. This term has been widely adopted in relation to carers of individuals diagnosed with schizophrenia (Vaughn & Leff 1976; Brooker 1990; Scazufca & Kuipers 1996; Winefield & Burnett 1996; Adams et al 2000). According to the Scottish Intercollegiate Guidelines Network (SIGN) for schizophrenia, psychosocial interventions includes educational programmes as well as family interventions and cognitive behavioural therapies (SIGN 1998). Adams (1996; 1997) cited several studies that also linked this educationally based concept to dementia carers although he considered the results from such studies as being 'equivocal'. Orford et al (1987) found that such carers experienced frustration and irritation arising out of their dependant's behaviour, but surprisingly failed to respond with high levels of

‘expressed emotion’, instead displaying compassion and understanding. However, Bledin et al (1990) countered this by concluding that higher levels of ‘expressed emotion’ were found in dementia carers who subsequently had higher levels of stress. Hall & Buckwalter (1987) highlighted that educating the dementia carer led directly to a health improvement for the person with dementia. They advocated teaching the carer to ‘listen’ to their dependant in order to evaluate their verbal and non-verbal responses. The concept of expressed emotion in the dementia carer was positively correlated to several carer characteristics which included psychological well-being, contact with friends and the nature of the relationship between the carer and dependant (Gilhooly & Whittick 1989).

Kobayashi (1993) believed that by educating the carer on the process of dementia the professional would ensure an improved stimulation and a keener awareness within the carer of their dependant’s non-verbal behaviour. This qualitative Japanese study involved forty-nine dementia carers who are interviewed using a semi-structured questionnaire. Unfortunately no information was provided as to the nature of these questions or how they were derived. It has to be highlighted, however, that this study involved a Japanese population and has to be viewed as being significantly different in terms of culture from the research papers reported upon within my study. This means that its results must be carefully interpreted with this realisation in mind. The sample was drawn from a variety of sources, however it was significantly skewed towards women and no clear explanation was provided regarding the analysis of the resultant data. Grant & Nolan (1993), in their review of the carer literature, identified the carers’ need for information

that ranged from that associated with the condition and its treatment through to the availability and choice over support services. Keady & Nolan (1995) discussed psychosocial interventions and pointed out the importance of realising that this concept revolved around diagnosis, assessment of the family, health education and family stress management. Whilst the exchange of information from the professional to both the dependant and the carer was regarded as crucial within psychosocial education, Keady & Nolan (1995) cited the Department of Health's (1994) finding that the provision of psychosocial interventions in dementia '...was conspicuous by its absence...' (p.38)

An ability to educate was a necessary requirement within more present day therapeutic approaches and inherent within the intervention strategies directed towards the carer. Marriott et al (2000) examined how carer burden was influenced by a cognitive behavioural family intervention strategy. They pointed out how this intervention, which consisted of three approaches, which included carer education, stress management and coping skills training techniques, significantly reduced stress in carers. Zarit & Leitch's (2001) review of the literature around community based social and behavioural interventions highlighted that while such interventions did not prevent the inevitable deterioration associated with dementia, family counselling was effective in reducing carer stress. Lowery & Murray (2003) agreed that approaches that involved education of the carer provided significant beneficial effects. However, in referring to the work of Brodaty & Gresham (1989) and Brodaty et al (1994), Lowery & Murray (2003) cautioned that such carer-based educational programmes had not consistently been found to significantly impact on carer

problems such as depression, stress and burden. Cognitive behavioural therapy approaches however offered a very positive potential benefit for carer related problems (Zarit & Leitch 2001; Soliman 2003).

The key-worker's ability to deliver quality advice to the carer was, however, largely dependent upon how they were perceived. The following key-worker pointed out that there is a consequence in being viewed in a more formal or authoritative manner. When this presented the professional risk of being bypassed for support and advice as the carer would approach less appropriate sources of information, a situation that a key-worker had to avoid in the carer's best interest:

'... he'll actually ask my students more than he would ask me. When I'm there I'm in my professional head, he sees me very much as this professional nurse in to help him and his wife... I think the role, is it because he also sees nurses up in the hospital for his diabetes? You know, so he's always, he's perhaps got a view of the nurse that's taking time to break down.' (Key-Worker 16)

Preparing the Road Ahead

This data category (Table 4) highlighted a further aspect of key-worker advice that aimed at preparing the carer for likely changes they may face regarding the progress of their dependant's condition, and possible future reactions they may have to these changes. These key-workers' demonstrated an appreciation that the carer's role was going to change significantly over time as their dependant's

illness progressed, and that involved them adopting different approaches towards the carer depending upon the progress of the condition:

'... I try to prepare them (the carer) for what stages that they'll go through, and highlight that it really is a, there is no getting better. It's a degenerative illness and things are only going to get worse.' (Key-Worker 14)

'I mean I think a lot of the stuff that's been done on carers, really obvious to us, the early part of the condition you'll get this sort of psychotherapeutic work to do lots of listening and counselling skills. And (as) the person's condition moves on they seem to lose the need for that, and it becomes more cognitive, it's much more problem solving and practical and there is less of this, it's still there but the balance shifts. And (at) the early stage it's not problem solving, it's emotional based. And he's (carer) still very much in that point as time goes on it's more about how we fix this, how do we make this easy to cope with.' (Key-Worker 16)

Whilst the following key-worker recognised the importance of this preparation, he advocated a more cautious and measured approach:

'It's quite a sensitive thing because you don't want to alarm them, but you want them to be (slightly prepared).' (Key-Worker 17)

The need to 'prepare the road ahead' was also recognised by carers. The following carer appreciated the key-worker's effort in making the changing

nature of her husband's behaviour more predictable and therefore less alarming to her:

'She explains things to me like if I say such and such, like that's what I'm saying he's walking behind me, she'll (key-worker) maybe tell me what the next stage is likely to be, you know... it doesn't worry me, or anything like that, because when it happens it doesn't come as such a big shock.' (Carer 8)

A good deal of such advice concerned the future likelihood of putting the dependant into care. In this case, the key-worker (CPN) and the social worker advised this man regarding this very unpalatable decision in an effort to prevent his health deteriorating under the strain of caring for his wife. Even with their strong concern, he remained very reluctant to acquiesce to their advice:

'She would always come on a day that (wife) wasn't at the day centre so she could see her, and even that (social worker), the social service worker, and they would sit there, you know, and they would say to me, you know (carer) you're not getting any younger. And then you have had this operation, you'll have to really be thinking about the long-term prospect. And I used to just put it to the back of my mind and I'd say as long as I'm able to carry on I'm going to carry on. I just hate the idea of putting her into a home, hate the idea.' (Carer 11)

This reluctance to accept respite help will be further explored within the following substantive code. Woods & Watson (2000) highlighted a need for professionals to ensure that, for example, carers understood that accepting respite

relief was not a selfish act but a necessary strategy aimed at improving their ability to provide care. Gilmour (2002), in a study of family carers, found that many could not recall receiving any preparation from their professional about risks in using in-patient hospital services. Unprepared use of these services could cause harm in terms of the additional stress resulting from the conflicting emotions experienced. This was a longitudinal qualitative study from New Zealand in which participants were interviewed over a three-year period. Effort was made to improve the validity of the findings through the careful and wide selection of the sample allowing for as varied a study group as possible, and also through constantly checking the emerging data within the subsequent interviews.

Hocking (1994) emphasised that carers need to feel in control of their situation and that their involved professional should be teaching them coping strategies. Braithwaite (1996), within her quantitative study, examined the health of 144 carers of frail elderly people, a study that included those caring for individuals diagnosed with dementia. She found that interventions aimed at increasing resources for carers and preparing both them and their dependants for what lay ahead are both feasible options of support. However, this Australian study presented a design weaknesses in that the sample of one hundred and forty four carers was based upon a self-selection approach that may have introduced a sampling bias into the participant selection. McErlean (2001), in a Grounded Theory study investigating the needs of younger people with dementia and their carers, also found this lack of preparedness in the carer, coupled with a fear of an unknown future. While the constant comparison method associated with Grounded Theory was a more rigorous way of analysing such qualitative data, it

was disappointing to note that McErlean failed to adequately explain this or indicate if saturation of categories was achieved. Such factors were important to the interpretation of the findings. Given that this is an extensive thesis, adequate time could have been spent to more fully explain these aspects.

A realisation about the unpredictability of the dementia process led Carer 8's key-worker to be more cautious about preparing the carer for any possible future developments:

'About getting almost a desire to know what the future's is going to hold for her (the carer) we don't particularly dwell on, I don't think anyway. I mean how things are going to be in a year's time. I've learned an awful lot but we don't do that because by the very nature of his illness it is unpredictable, you know, for me to say physically how he'll be, or mentally how he'll be, but that might not necessarily be the case, you know, six months from now. He might well be the very same, we don't know that. I think that's something you can't emphasise, try to put the positive things out, how he is at the moment, and try not to think too much about the future.' (Key-Worker 8)

A gradual exposure to the progressively changing difficulties faced by the carer was identified by Clarke (1995) who considered that one way in which the carer tries to cope with the demands of the caring role was to 'pace' their exposure to the difficulties they faced. This viewpoint derived from a UK qualitative study that examined the relationships between elderly people with a diagnosis of dementia and their carers. The study, which utilised a multi-sourced sample of

dependants and both lay and professional carers, used a variety of methods of data collection carried out over three phases. Arksey et al (1998) identified how carers within their study expressed the need for information on how their dependant would demonstrate signs of deterioration. In contrast to this Action's (2002) study suggested that some carers were reluctant to discuss or contemplate future developments.

A more measured and finely paced approach towards preparing the carer was evident within the comments of these key-workers:

'Obviously you don't want to go down that road too soon, and put the fear of death into her certainly, but I think, you know, you're obviously got to kind of touch on it and make sure the information is there so that if she wants to have a nose in the book and sort of read em about. Sort of going down that road with her when she's ready it, make sure its there for her, information.'

(Key-Worker 3)

'(I) tend to again, very much like we talked about earlier about bringing concepts and ideas in that might not be appropriate at this stage, but maybe be appropriate in the medium to long term. I tend to kind of bring up things up, well you realise, at certain points.' (Key-Worker 17)

In a study that adopted an action research approach aimed at assessing whether enhanced support at home would extend the length of time the dependant remained at home, Askham (1995) suggested that the future could not always be

accurately predicted and so could not be planned for. The sample of 166 people with dementia was drawn from two geographical areas. The criteria for selection was clear and they and their carers were interviewed using a semi-structured instrument. The design, however, was not fully explained. Several limitations to the study were highlighted including the difficulty of generalising the findings to all carers. What was most surprising was the author's considered limitation that the sample size is too small. Given that this is a qualitative design, such a sample size appeared rather sizeable in comparison to other similar studies.

Clarke & Keady (1996) debated what path should be followed in this difficult debate. To give too much insight into the future might lead to despair while not to 'prepare the road ahead' may leave the carer with a series of unexpected shocks as their dependant's illness deteriorates. Clarke & Heyman (1998), in a paper discussing risk management for people with dementia, highlighted how the carers managed their dependant's difficult eventual deterioration by maintaining control over the information they were receiving, and selectively filtering out that which caused most difficulty. The authors considered that a middle route was probably best, as people required knowing what they faced, although such knowledge should not dominate their lives to the exclusion of more positive aspects of their caring role. In support of this more cautious approach, Hooker et al (2002) cited McCarty et al's (2000) contention that unlike the cognitive symptoms, which show a linear pattern of deterioration, the unpredictable progress of dementia's behavioural and psychological symptoms meant that the carer experienced more stress.

Key-Worker as a Resource to other Professionals

Within this data category many carers expressed satisfaction in their key-worker's ability to quickly elicit any necessary information from other sources, particularly medical staff, and pass this on in a clear understandable manner (Table 4):

'And if I want to find out anything from (the) consultant, the Consultant Psychiatrist, we can phone (key-worker) because he is in regular contact. If we can't get a hold of (the) Consultant so (key-worker) can get a hold of him for us, and find out if there's any information.' (Carer 3)

'... as far as, eh, what she (key-worker) would do is if I had any queries she would go back to the doctor and find out.' (Carer 4)

'Well I feel (key-worker), well I can turn to her when I've got problems. And even if it's something that she can't deal with she'll tell me who to get on to... she can point me in the right direction. You know, to get help or anything like that.' (Carer 8)

Willoughby & Keating (1991) pointed out that a professional who did not present to the carer as being an expert, but more of a Consultant, was considered most helpful. The tendency to be viewed more as a resource rather than an expert, and to honestly admit to not having all answers, appeared to be a quality that was appreciated by these carers:

'... if there was anything I wanted an answer to I wasn't frightened to ask (key-worker). I knew I would get an answer from him. And if he didn't know the answer he would find out the answer. You know he would go to (consultant) and find out the answer.' (Carer 6)

'Yes, and as I say, he gives me the impression that if it was a problem, and he couldn't sort it out, he'd find out for me. I get that impression.' (Carer 17)

This reflection on the need for openness and honesty links this code to the 'Determinants' substantive code discussed within the previous major category (Table 3). This resource person/co-ordination role was in evidence within the following key-workers comments:

'I was brought in at that point because there was an anticipation that there was more services required. It was to co-ordinate things maybe a wee bit better, take an overview of things... there's lots of different people involved, you know, care providers etc, oh you know, the usual sort of scenario, lots of people with potential for breakdowns in communications immense. And I really felt, well I'm the care manager.' (Key-Worker 9)

'... I took on this job Gerry and I tended to look upon it as, myself as the link if you like. The link in the chain between all the other disciplines, between the consultants, Psychiatrists, even their GP, even (dependant's) GP... I tend to kind of stress that I can be, if you like, that link. That I can do a lot of the kind of

correspondence with, or you know, the one in the middle if you like. I think that's very much my role. I'm the first in line if you like.' (Key-Worker 17)

Adams (1996) conducted a review of the literature on the provision of community psychiatric nursing services to elderly people with dementia and their carers. Within this review he cited the argument by Illife (1994) that too much pressure was placed upon GPs that led to them being perceived as ignoring carers' concerns. It was more appropriate for CPNs to develop approaches that would help bring carers into more contact with specialist services. An ability to collaborate with other disciplines was considered by senior politicians to be a particularly strong asset of mental health care professionals (Department of Health 1994). According to Ham (1988), the Department of Health had already issued guidelines to professionals that emphasised a need for inter-professional collaboration in the development of care programmes for patients and their carers. In a small exploratory study undertaken within the UK into the role of mental health nurses for people with dementia, Ho (2000) found that all respondents within his study saw the community mental health nurse as a vital link to other professional groups and agencies.

However not all carers viewed the key-worker role as simply one of a care co-ordinator or resource person. The following carer warned not to view the key-worker's input in such simplistic terms:

'And it's not just about someone who comes in and says we'll put this service in for you, or we'll put that service in, there's more to it.' (Carer 14)

This tendency to support or even protect the key-worker manifested on several occasions within my study and is more fully explored later within the following substantive code 'Working Together: The Therapeutic Alliance' (Table 4). Parker (1990) claimed that there has been limited development within present day service structures aimed at adequately supporting the carer. Walker & Dewar (2001) concluded that to only provide information and emotional support was evidence of a paternalistic attitude amongst professional staff. This UK study adopted a qualitative case study approach and drew on a sample of twenty informal carers and twenty-nine care professionals. The sample selection was based upon a self-selection approach and all participants were drawn from only the one hospital source. This sampling decision, coupled with the qualitative nature of the design, indicated that any findings had to be carefully interpreted. The study was strengthened however by the rigorous constant comparative approach to the analysis process and by the inclusion of independent outside analysis at certain junctures in the research cycle. Walker et al (2001) agreed with carer 14's above sentiment that the key-worker's role went beyond that of co-ordinator by stating that:

'The role should help establish a relationship with the carer that reflects continued commitment to them over a period of time, while the carer is the primary carer. The relationship between the carer and key contact therefore should reflect detailed understanding and knowledge of the carers' situation and the person they are caring for' (Walker et al 2001 p.86).

Key-Worker Manages Dependant Better Than Carer

This data category highlighted how the carer in particular considered that their key-worker could often handle the management of their dependant much more proficiently than they could (Table 4). In contrast to some of the literature identified within the preceding data category, the key-workers within my study provided this level of practical assistance whenever necessary. This carer viewed the help he had received as a very positive dimension to the key-worker role:

'Well it was quite good to see her (key-worker) because when she came in she would speak to (wife), and you know try to reassure (wife). For instance if (wife) wanted the toilet, or anything like that, when she was in (key-worker) would take her up to the toilet and things like that.' (Carer 11)

As mentioned above, there was an appreciation among some carers that the key-worker could deal with their dependants much more practically and effectively than they could. This carer who was experiencing extremely negative and resistant behaviour from her husband found that only her key-worker could gain his co-operation:

'(Key-worker) can also bully him a wee bit and I don't mean that in a bad way. She can sort of, now look (husband) if you don't take these tablets at the right time I'm going to see someone about them, and she can I don't mean bully him because probably (that's) a bad way to put it, but it's just that she seems to get things over to him.' (Carer 15)

Again, as with some of the preceding data categories, I failed to identify any relevant associated literature with which to compare and contrast the data derived from this data category.

In summary therefore, within this substantive code, the key-worker's role was viewed as a dominant feature within the Carer/Key-Worker relationship whereby 'The Knowledgeable Professional Exercises Control' (Table 4). In most instances this aspect of the key-worker's operational role was seen as a positive feature that carers valued, especially in terms of using their 'professionally' acquired knowledge to provide education around their dependant's situation and condition. However, the data within this substantive code provided an interesting dimension to this perceived dominant role of the key-worker, particularly when noting its stark contrast to the first data category associated with the following substantive code. If the key-worker role was to become inappropriately dominant, without any real or genuine involvement of the carer, could their relationship become problematical, potentially leading towards carer alienation, dis-empowerment and possible resultant damage to their operational partnership?

THE INDEPENDENT CARER

Carer Exercises Independent Control When Providing Care

In contrast to the carer's perception that the key-worker possessed greater ability in managing the dependant, there was consensus among the key-worker cohort that the carers themselves were highly able and capable providers of competent care:

'She (carer) was intelligent certainly, and she would articulate, you know, she knew, she knew what she, she wanted the best for him (husband), she was adamant she was going to get it you know.' (Key-Worker 1)

'... she's very independent, she's very focused on where she wants to go. She's made a very positive decision in caring for her husband.' (Key-Worker 7)

Some carers shared this perception of being in control and having mastery over, and confidence in, their own ability to manage any care independently:

'There's not really much because I feel so independent. I'm not turning and leaning as I say (key-worker) what should I do with this? I feel so independent that I don't need to ask for help.' (Carer 16)

Even when it came to medical treatments for the dependant some carers displayed a confidence by challenging the professional experts. As described within the preceding major category, when perceiving inadequate services the carer could and would challenge the professional service provider. Similarly, Carer 18 was so committed to ensuring her husband's well-being that she, when feeling concerned about the effects the drugs were having on him, had the confidence and determination to bypass the key-worker and confront her husband's doctor directly:

'They put him on tablets, put him on six point five milligrams twice a day, but I found that was too strong. I haven't been in contact with (key-worker) to tell him... so I went to the doctor myself and told him and I said look, he's just not right. But he got all the blood tests and everything at the doctors and everything was alright... I said do you think it's the tablets? And the doctor said it could be a build up now of the six point five milligrams twice a day, he says we'll drop him down to four.' (Carer 18)

Carer 7 considered that she was responsible for ensuring that the social environment within the home was conducive to her husband's well being and would challenge any individual who created a sense of negativity around her husband:

'And I don't want them all coming up going ooohhh he's terrible today. Well okay he's terrible today but he might be better tomorrow. He has his bad days and good days like every body else. And if I sink into it, which I easily could, you feel on the verge of it now, you could let go. I can't afford to do that because I've got to make his life happy and contented.' (Carer 7)

A negative emotional environment was recognised within the literature as having an adverse consequence on the health service user (Vaughn & Leff 1976; Brooker 1990; Winefield & Burnett 1996). The carer in this situation demonstrated an appreciation of this fact and indeed, should the key-worker have created a problem for her or her dependant, she would make her disapproval known. This was the case for Carer 17 who had no hesitation about bringing her

key-worker's behaviour back into line after he turned up at her home when she was out, a visit that caused some distress for her husband alone in the house:

'I phoned up and said if you're going to come will you phone me first, because (dependant) got into a panic, he thought you were putting him into hospital. Oh God, he says, I didn't realise, I didn't mean that, so now he phones...' (Carer 17)

Interestingly however Carer 18, who had earlier challenged the doctor over the medication her husband was on, displayed a contrasting less assertive manner regarding the decision by her key-worker to reduce his input. Despite receiving a decision that was desperately disappointing to her, she seemed resigned to this in the belief that, as he was the professional, he knew what was best:

'Because I felt, you know, I said well six months, he (key-worker) must feel that that's enough, you know, it's a gap but it should be enough.' (Carer 18)

This was a feature of the Carer/Key-Worker relationship that has been already highlighted within the preceding substantive code 'The Knowledgeable Professional Exercises Control' (Table 4).

Hasselkus (1994) stated that power and influence between the professional and the carer changed as the carer progressively experienced what caring meant within the context of their own lives. In the early stages, as diagnosis and care management was being established, the professional was the dominant influence. However, this switched progressively more towards the carer as they began to

manage the care of their dependant and doubts emerged about the 'professional knows best' belief. It was at this point that carers began to modify prescribed treatments to better fit with his or her approaches and home culture. As the carer gained in experience and moved towards providing longer-term care, the progressive transfer of power and influence ended with the carer becoming the predominant agent of care and the professional operating more in a supplementary role. Hasselkus's paper, however, was neither research based nor dementia carer specific and was, solely, based upon the professional's perspective. This tendency for the dementia carer within the US to go into negotiation with the professional regarding their involvement was also identified as being a feature within the UK context (Clarke & Heyman 1998).

Within my study a strong sense of independence led some carers to feel a sense of irritation, or even anger, when professionals tried to encourage them to accept support against their wishes. This was a significant area of conflict between the professional and carer which for Carer 7 below, while she accepted that the social worker meant well and had her interests in mind, still persisted in demonstrating her fierce independence in wanting to be her husband's main source of care. This strong desire to remain involved in caring for her husband linked this data category across to the data category within the next major category chapter, 'Caring is a Real Privilege' (Table 5):

'... the social worker dropped in last night as well, she wanted to make sure I was all right because I keep telling her that I don't need respite. And I don't

need respite. But they are so desperate to care for you, if you like, that they don't realise it. I'm handling it. I don't like it but I'm handling it. ' (Carer 7)

Gilliard (2001) examined the perspectives of people with dementia and their carers and found that the UK continued to be dominated by traditional models of service that have the user fit the system. This has resulted in the carer experiencing unnecessary stress levels, frustration and exacerbated guilt. Gilliard considered that alternative models should have been developed that offered more to all engaged in caring for someone with dementia. Such a model should acknowledge the abilities and potential expertise associated with the carer (Nolan & Keady 2001).

For Carer 7, her obvious tenacity and strong motivation to deal with matters concerning her husband became most apparent when she experienced considerable frustration over the lack of service provision prior to her key-worker's involvement:

'We had absolutely nothing. And I had to start digging out numbers to generate support. It was a long time before we got social work involved. I had contacted them a few days later and it was months before they became involved. And because he is a young onset he didn't fall into any category. He was fifty-three at the time and he didn't fall into any category for support. So we had to absolutely fight for everything. ' (Carer 7)

The following carer displayed significant resourcefulness when addressing deficits in her knowledge and sought out appropriate literature following a more limited input by her key-worker who had not addressed her educational requirements to her satisfaction:

'Well it's frustrating, frustrating in the sense that you have got to, I mean what I did was I went away and found a wee bit more about dementia and tried to read up on, get information and things like that, to help me understand what was happening. It would have obviously been a lot more helpful had somebody been there on a more regular basis.' (Carer 9)

The following carer also demonstrated a strong desire to learn and improve the standard of care he provided for his wife through a process of trial and error:

'She (wife) had an awful bother feeding. I just put it down to learn as you go. Don't give her anything, kind of cake or anything like that, she just stuck (that) in her mouth. You had to make sure her mouth was cleaned out before you gave her tablets or the tablets, you were finding them at the bottom of the tumblers.' (Carer 6)

Nolan & Keady (2001) recognised this tendency of carers to learn by a process of trial and error. They considered this to be a feature of the experienced carer and stressed that such carers had a far better grasp of the care situation than did the professionals involved. In keeping with this sentiment, the following key-worker

considered the carer as an empowered individual who held the dominant influence within the care scene:

'The carer, I think, dictates a lot of the time how the visit is going to go, dictates how much input she wants from me.' (Key-Worker 17)

Nolan et al (1996b), after examining more traditional conceptualisations of the relationship between carer and professional services, suggested an alternative model which they believed reflected the more contemporary issues inherent within the field of dementia care. They entitled this the 'carer as expert model' and claimed that such a model would assist the development of a shared understanding of the diversity of perspectives associated with dementia care and more fully reflect a partnership and empowerment approach. This model supported the carer's entitlement to remain as independent as possible and remain in control of their domestic situation. Unfortunately, this paper failed to present any research evidence underpinning this model. The authors, however, are recognised academics with an acknowledged expertise in this area of health care making their conceptualisation worthy of consideration. Their argument to consider the carer as expert was fully supported more recently by Dewar et al (2003 p.1) who stated:

'If involvement of relatives in carer processes is to become a reality, then attention needs to be given to helping staff to explore the meaning of involvement and to develop meaningful relationships with relatives which seek to value them as experts.'

The burden associated with caring was often reduced when the carer held a greater sense of self-esteem and mastery over the care delivered to their dependant (Braithwaite 1996). A key inhibiting factor in the carer's involvement in care planning was a failure to recognise their expertise (Walker et al 1999). Walker & Dewar (2001) considered that nursing staff viewed involvement with the carer as a reciprocal relationship in which the expertise of the carer and the contribution they made to care was highly valued. This finding came from a study well designed to determine how professionals facilitated carer involvement in decision making. The qualitative design used multiple sources of data collected from a group of dementia carers (20) and professionals (20). The study's sample differed in one important respect from my own in that the professionals were not identified as being the carers' particular key-workers. The validation exercises adopted helped to strengthen the findings. Walker et al (2001) considered that the term service-user was given to patients therefore the focus of involvement remained with them and, as a consequence, professionals had not viewed carers as having any legitimate expertise or that they had anything to offer the care planning process. The carer being viewed as an expert by the professional was a recognition and acknowledgement that this individual has been '... adjusting, thinking and coping long before services have become involved' (Shankland 2002 p.216).

Carer Provides Best Care Because of their Intimate Knowledge of Dependant

This key-worker expressed both satisfaction and appreciation of the carer's contribution to decisions associated with her mother, a contribution that was viewed as a distinct benefit to both the key-worker and the dependent:

'She was very open, she was also very clear about what would be helpful for her mum, very clear ideas about what her mum did and didn't want in terms of services. So it was very helpful for me because I could, you know, obviously I have limited knowledge of her mum, that was really helpful. I think her openness and the fact that she has given it quite a bit of thought.' (Key-Worker 9)

This view of the carer having expert knowledge not available to the professional had already been raised (Nolan & Keady 2001). There were two forms of knowledge recognised within the literature, the carer's detailed knowledge of the dependant and the professional's wider more general knowledge of the condition, and both forms of knowledge were presented as being mutually exclusive (Clarke 1997). These were labelled either 'local knowledge'- personal information held by the carer; and 'cosmopolitan knowledge'- more universal and generalisable information held by the professional (Harvath et al 1994). Clarke & Heyman (1998) agreed that the carers possessed a range of knowledge that was largely unavailable to the professional and consequently were able to provide a level of personal care well beyond the scope of the professional. Walker et al (1999) believed that the relationships between carer and professional had to reflect inclusion, negotiation, openness and honesty,

regardless of the context of that care. Carers, therefore, should be considered experts within their own sphere of caring. Brown et al (2001) claimed that the possession of experiential knowledge had given some legitimacy to carers being considered experts.

The sentiments expressed by Key-Worker 9 (p.177), that the carer knows the person with dementia best and was therefore in an optimum position to provide best care, also came out clearly within the following carer's statement:

'Yes I can do my crying in private, but as far as he's (husband) concerned it's everything to give him what pleasure he can get out of life. Because he doesn't get pleasure with food, now he used to like a drink, he couldn't care if you gave him water, milk or wine. So he's not getting any pleasure that way so the only thing he can get is pleasure from direct contact and lots of kisses, and he does respond to that, he'll give you a kiss.' (Carer 7)

These two forms of knowledge held by the carer and professional enabled the carer to derive some satisfaction from the realisation that no other agency or individual could provide the level of care that they could. Caring was more than simply meeting medical and physical needs, it meant really knowing the person being cared for and identifying subtle changes in their physical and mental well-being (McErlean 2001). The real desire to optimise the quality of life for the dependant was strongly evident within the above carer's comments, as was the intimacy associated with the care she provided and her ability to identify subtle cues associated with her husband's more emotionally based needs. Walker et al

(2001) considered that the carer often knew their dependant so well that they were the caring agent most likely to detect such subtle changes in their condition. Carers, in most cases, attended to the person they loved most and harboured expectations that this level of 'loved attention' would be respected by the professional involved and, whenever possible, ought to be reflected within the professionals own care practices (McErlean 2001).

The carer's ability to provide a deep and intimately loving care was welcomed by Key-Worker 7 who acknowledged that this was a level of care that was far and away beyond the scope of any professional carer:

'Yes definitely there's a, I don't say this to everybody but there is a lot of love in that relationship, I think that's when you've got the satisfaction of going in knowing that she dearly loves her husband one hundred percent and you can see the affection is still there. He still kisses her and he's still affectionate.'

(Key-Worker 7)

Qureshi & Walker (1989), in a study of young children providing care, found that such carers seldom cited love as the motivational factor for them providing care. They however stressed that this did not necessarily mean that love was absent from these caring dyads, but rather it simply meant that love was not perceived as an overt factor leading to care provision. Unfortunately this study was not specifically focused upon the dementia carer and by being based on young child carers, was not fully reflective of my sample group.

Within my study the strong motivation on the part of the carer to engage fully in all aspects of care delivery was evident. This man expressed his satisfaction in coping independently with all the domestic responsibilities within the home while those within his social circle expressed growing concern for his welfare:

'It's fortunate that, eh, I can cook, keep the house going, do the laundry and do the washing up, that I've been that bit independent, but eh the neighbours tell me that as well. I'm too independent. I should be getting help with, but up until now I felt able to cope.' (Carer 4)

Lea (1994), in defining the roles of lay and professional caring, accepted that lay caring characteristically involved 'carer's personal qualities and moral actions' which led them to provide individualised care. She expressed concern regarding such an intimate relationship as the carer could begin to believe that they are the only ones who could provide adequate care and consequently could refuse respite and other support services resulting in them suffering from an increasing level of unnecessary burden. Shankland (2002) also cautioned that many carers would experience guilt if viewed as not coping with their carer role, and that this would often keep them from seeking professional help when this was desperately needed. Unfortunately both of these papers were not premised on actual research studies nor were Lea's views particularly focused upon dementia carers. Pollitt et al (1991), as cited by Bruce & Paterson (2000), considered that the dementia carer would not always accept offers of help and that some may even be reluctant due to perceptions that this may produce a negative response from their dependant.

With regard to this tendency to blindly take on a caring role regardless of the consequences, the following carer expressed an intense desire to be the main provider of care for his wife. However, he did present a more balanced viewpoint with the recognition that this strong desire to care had to be reviewed realistically as circumstances changed:

'Well at the moment I can get my wife into the bath and use the shower, but there is going to come a time when I can't do that.' (Carer 4)

From the data presented here, along with the theoretically derived literature, it was evident that the carer possessed the potential to provide intimate and personal care that could not be emulated by any professional. However, there was also a potential negative connotation associated with the 'Independent Carer' substantive code in that the carer may strive to provide care regardless of the consequences and refuse all appropriate support. Jootun & McGhee (1998), following an examination of the dementia care literature, considered this important balance between professional and carer provision and claimed that:

'A balance has to be found between the sufferers' needs and carers' rights. If too little care is offered, needs are not being met, but if too much professional and state interference occurs, i.e. unnecessary and un-welcome admission to a nursing home, then rights of sufferers, and possibly their carers, are being infringed... Consequently there is an urgent need for community mental health professionals to learn from informal carers, especially as such carers have

expressed a desire to be involved in care management.’ (Jootun & McGhee 1998 p 125)

These views have been supported by the findings within this study. The following substantive code explores an apparently more harmonious model of these operational roles. This substantive code should be therefore sandwiched between the two perspectives already expressed within this major category. Here there is the potential for a blend of the more positive aspects of these preceding substantive codes, providing a more effective caring framework for all parties involved (Table 4). However, even within this more apparently positive substantive code, there is still the potential for more negative properties of the carer/key-worker role that can adversely influence the Carer/Key-Worker relationship. Therefore, in order to maximise the positive potential from the Carer/Key-Worker relationship, a blend of the positive influences from all of these substantive codes is necessary.

WORKING TOGETHER: A THERAPEUTIC ALLIANCE

The Adopted Professional

Many carers considered their relationship with the key-worker a particularly close one given its professional basis. For some the key-worker was more a friend than a professional there for service provision:

‘Yes, well it’s not like just you would say a purely business relationship as it were, he’s a friend, we consider him a friend.’ (Carer 3)

'Well I look upon (the) community psychiatric nurse as a friend now, and not a medical person, not a nurse.' (Carer 8)

'I don't think I really look on her as a nurse coming... I look on her as a friend coming in, although obviously we discuss mainly my husband's problems, but we also discuss other things.' (Carer 15)

Key-Worker 14, from a social work background, considered being perceived by the carer as a friend was not a problem for his professional role and indeed suggested that it indicated a measure of success on his part:

'No it wouldn't worry me, I actually feel quite happy, reassured that 'Christ', I'm doing something right.' (Key-Worker 14)

Some carers even considered their relationship as being closer than a friendship with the professional becoming 'adopted' by the carer and, surprisingly, perceived more as a family member:

'Yes, I feel (key-worker) (is) just like a big member of the family coming in... I've always (felt) like that with that boy from (when) he's come into the house, he's just been like a big member of the family since day one.' (Carer 17)

The following carer considered that this adopted family, or surrogate role, resulted from a lack of family ties coupled with the length of time the key-worker spent with them. Time once again is once again being raised as an important

issue and links this data category back to the preceding major category's 'The Determinants' substantive code (Table 3):

'I say again we don't have the luxury of a daughter or a son coming to visit us. A lot of the old ones here (sheltered housing complex), they get their daughter coming in maybe only once a fortnight... we don't get much visitors because my son's away and my nephews and nieces are all in Glasgow, some are further afield in Cumbernauld. So we don't see them regularly... to me they're (key-workers) more closer to (my wife) than my nephews and nieces because we don't see much of them.' (Carer 16)

Various explanations as to why the carer viewed their relationship on such intimate terms emerged from this study cohort. This key-worker considered that this could have been related to the carer more strongly identifying with them as they, the key-workers, belonged to the generation that their own children or grandchildren came from. Alternatively it could derive from reciprocity for the effort the key-workers have put into the home care environment:

'I'm not sure if it's maybe an age thing, if it was to do with some nurses being younger. I think there is an element of age comes into this. It has to, in old age to practice, we (can) get nurses of the same age in every other field of psychiatry, the nurse can often be of an age with the patients they're looking after, but none of ours are. So maybe this element of generational... but I think of it (as) reciprocity. They (carers) do feel you give them a lot a lot of the time, or energy.' (Key-Worker 16)

The following carer thought an ability to form this depth of relationship was more associated with the professional's organisation. She distinguished between the more instrumental role of her key-worker from social work as compared with a more emotionally supportive and intimate involvement possible from a health care professional. Availability, as discussed within the preceding major category's 'The Determinants' substantive code (Table 3), was once again highlighted as a significant factor within relationship development:

'... my social worker is my practical key-worker if you want, but I probably (would) have developed more of a different relationship with (a) CPN, but unfortunately she hasn't been available for some time. She'd been unwell and I think unfortunately that the service wasn't picked up for me. So I wasn't getting any service there.' (Carer 9)

Key-Worker 9 suggested that this deeper and more emotionally focussed level of the relationship failed to develop because of stereotypical attitudes associated with her professional group:

'I think a bit of it, I suppose, is perceptions of social work as well, you know, for older people who may be a bit anxious about the level of control you want to take off of them to some extent. You know, this vision of short term, coming in taking over and, you know, moving people towards nursing home rather than supporting them in the community and that's a, those sort of perceptions are harder, it takes a lot of time to build (or) to reduce those.' (Key-Worker 9)

The ability to view a key-worker as either a friend or relative was considered to present distinct advantages, particularly in terms of being able to communicate on matters wider than the immediate needs of their dependant. This ability has already been identified within the preceding major category's substantive code 'Enhanced Relationship Properties'. Here the corresponding data category, 'Deep and Meaningful Communication' (Table 3), highlighted how carers genuinely felt that they had a significant ability to communicate in depth with the professional on matters that concerned them most:

'... in a way he's like one of the boys (sons), he's like one of the family now, cause we talk about everything, not just Alzheimer's...' (Carer 5)

'And it's really important that he can get to a stage where you can feel free to talk to him.' (Carer 17)

The following carer made clear, as identified within the preceding major category's substantive code, 'Enhanced Relationship Properties', where the data category 'Deep and Meaningful Communication' (Table 3), suggested what it would mean not to view the key-worker in such an intimate way:

'I probably wouldn't speak to her. I'd maybe hold back a wee bit more. I'd probably speak to her as I do my GP.' (Carer 15)

A further dimension to this concept of adoption appeared when the following key-worker made an association between the carer and his own father. A realisation that his father could share a similar circumstance at some stage with that carer meant that he became even more motivated to fully help the carer. Viewing the carer in this way ensured that he dealt with the carer's needs with the an increased level of consideration and priority:

'... just when you go in to see people and you think, that could be my dad, you know.' (Key-Worker 3)

The literature failed to reflect this phenomenon of adoption associated with the Carer/Key-Worker relationship but did supported the need for more intimate communication being necessary for a positive and productive relationship. Moore et al (1993) pointed out that carers needed to communicate on matters more particular to themselves. Significantly they also stated that the dementia carer required to be fully involved in all aspects of decision making around their dependant and had an important part to play in informed choice. They further added that the carer required having their own issues taken account of by their associated professional.

Carer Expresses Sympathy and is Protective of the Key-Worker

Working together in this more intimate and informal manner also carried with it a potential to inhibit key-worker effectiveness, particularly their ability to communicate more deeply and openly. The following carers actually expressed genuine concern, as well as a degree of sympathy, for their key-worker:

'... I didn't go into personal problems or anything like that, I felt it was unfair to put them on to her (key-worker), it's not her job.' (Carer 4)

'They have a routine and a day they're busy, he's not the only patient they've got... (key-worker) comes in and finds someone she can't communicate with, (it) must be hard for her, she doesn't find that with me, I never shut up.' (Carer 10)

'... she must come in some days and think, what have I come here for? ...(the) job they do to be honest, I mean I wouldn't be a nurse for anything... I don't know, I really depend on her, I don't know whether I should depend on her as much as what I do, but maybe it's unfair to her, I don't know.' (Carer 15)

It was clear that such perceptions held negative consequences by presenting a barrier to the more open communication considered desirable within the previous major category, a risk already indicated by Carer 4 above. The following carers were even more defensive and indeed somewhat protective towards the key-worker:

'A friend of mine says community psychiatric nurses have a great job, they just go in and sit in people's houses. But that's how she thinks of them... That was a remark that really annoyed me... they don't seem to realise how much support you get from a short visit. Whether it's ten minutes or whether it's a phone call, even a phone call can be a big help.' (Carer 15)

'She suggested respite to (husband). (Husband's) first word was no I won't, he was always a stubborn old so and so... she really has done her best, so if you're looking to see what (Key-Worker) has done, she's done her best with him.'
(Carer 10)

For Key-Worker 10 the above carer's attitude was surprising in terms of identifying that the key-worker was frustrated over the lack of a positive response to her suggestions for additional support. Her lack of unawareness at being appraised in this way by the carer links this aspect to the preceding major category's substantive code 'The Determinants'. Here the associated data category, 'The Need for Shared Respect' highlighted this issue (Table 3):

'... that's strange she picked that up because, thinking about it at times I was frustrated that she won't, for example, take (patient) along to the diabetic clinic with her, and I was sort of say(ing) that to her.' (Key-Worker 10)

Adams (1999) cautioned that partnership between professional and carer could carry negative connotations for the dependant in that their power could be diminished as a result of the professional focusing too heavily upon the primary carer. He claimed that, as a result of the pessimism that surrounded the effectiveness of therapeutic interventions for dementia, the professional tended to focus upon the primary carer to the exclusion of the dependant. Brown et al (2001), in contrast, stated that a demonstrable acknowledgement and appreciation of the carer was essential for the development of a partnership between professional and carer. Walker et al (2001) considered that promoting

partnership with the carer and the professional would lead to better communication of care requirements and thus lead to an improved quality of care. In their qualitative study of dementia carers they concurred with the tendency on the part of the carer to show a sympathetic understanding for the key-worker's situation. They stated that the carer was realistic in what they expected from the key-worker and responded with gratitude rather than anger. This was a result of the carer directing responsibility for any inadequacies in service provision at the care organisation rather than individual professionals who, they considered, were doing their best.

The concern expressed for professional staff by carers was also identified within a study conducted on younger people diagnosed with dementia where difficulties faced by doctors who failed to make a correct diagnosis on the dependant was viewed sympathetically by the carers (McErlean 2001). Despite the strength of concern expressed by carers, and the view expressed earlier by Moore et al (1993), Lelliott et al (2003) remained convinced that carers were still excluded from decisions regarding care planning. While this view was derived from a fairly wide UK study, it was not particularly focussed on dementia carers but rather on those that had dependants with a severe mental illness, generally. It was not fully clear from the paper if dementia was an included diagnosis and this omission, along with the rather brief presentation of the method, made a judgement on the quality of the findings rather more difficult.

As indicated within the preceding major category chapter the substantive code 'Enhanced Relationship Properties' highlighted the ability to communicate more

freely with the professional and was an indicator that a significant level of trust was established (Table 3). This sense of trust improved the carer's ability to communicate with the key-worker at a more open and meaningful level therefore links this data category to the preceding major category:

'I believe he (carer) was, if he's more trusting he's more willing to tell you things that he would maybe hesitate if he hadn't known you... or was quite untrusting of you...' (Key-Worker 6)

'I think again it's just trying to get their (carer's) trust... and pick common things, things of interest to them and not just dementia.' (Key-Worker 12)

The following carer also expressed how the closeness she felt for the key-worker was a real source of confidence for her, similarly linking this data category to the preceding major category's substantive code 'Enhanced Relationship Properties':

'... I think it's just in (the key-workers) make up, as I say right from the first time she ever came she was somebody who I could accept she just, it's obviously her manner, her way of treating you, of speaking to you, that you just get confidence from her.' (Carer 8)

Key-Worker as a Partner in Caring: a friend with knowledge

Carer 17 clearly saw a benefit in having the key-worker as a 'friend' which she considered held an additional advantage over other friendships held. Having a

friend in the key-worker carried with it the real benefit of having expert knowledge freely available, a perception also shared by her key-worker:

'He's just a big (friend), the way he comes into your house with knowledge.'

(Carer 17)

'But they still have this knowledge part, you are a friend for, a friend but a friend with assets.' (Key-Worker 17)

Other key-workers described the relationship more in terms of remaining a friend to the carer but importantly not losing sight of the professional nature of their input. This comment suggested a tension between this more informal interpretation of the relationship becoming influenced by the more formal professional and authoritative approach, reflected within the first substantive code within this major category (Table 4):

'I think you've got to, I think you've always got to make the right decision based, your decisions (have) always got to be on professional based reason, em because you've always got to back it up.' (Key-Worker 1)

'I think he (saw) me as a friend but I think he also, at the end of the day, he knew I was a professional.' (Key-Worker 11)

The following key-worker captured this tension between the 'Knowledgeable Professional Exercises Control' substantive code and the 'Working Together: A

Therapeutic Alliance' code by highlighting that the key-worker possessed an ability to fluctuate from an informal level of involvement to a more formal, professionally focused, intervention style:

'I suppose that's where the line is drawn between a friend. What we are, it's just a slight cant towards professionalism. Always, I hope, because I would say that any nurse that hadn't got that had failed. If you don't have that professional cant then you probably aren't doing your job right. You've slipped from a kind of therapeutic role into a social one. I think that's the skill of this job is to be able to move often, in one visit, from a very social element to the visit and we can talk about Christmas and what we're getting the weans and move into something really personal... You seem to be talking about really something quite tense and the next minute you're having a sip of tea and talking about the price of milk. So it can go out and in the different layers quite subtly through the course of an interview' (Key-Worker 16)

Peplau (1952) developed a theory of psychiatric care built around therapeutic interpersonal processes between the professional and the mental health patient, a model that remains widely adopted within contemporary mental health care practice. Within her theory, Peplau considered that the health care professional adopted a number of roles during his/her professional interactions, one being that of surrogate (Aggleton & Chalmers 2000). As already highlighted within my study, the professional (key-worker) was considered by some carers to be likened to a friend or family member, roles that could arguably be viewed as being similarly surrogate ones. While this seminal work of Peplau focussed upon

patients/clients. I felt it was necessary to consider her theory here in order to provide a further insight and dimension into the key-worker role, given the absence of any similar carer literature. Pearson et al (1996) also described a surrogate role that involved the professional being perceived as a mother figure. Here the patient was required to gradually move away from this perception, as they became increasingly more independent. Therefore, by adopting the professional into such a family role, an unhealthy dependency could be created and, if this perception became protracted, it required to be rigorously addressed in order to ensure a more therapeutic outcome.

Jackson & Stevenson (2000) also recognised this changing level of the professional role but, unfortunately, again only associated this with patient/client involvement. Their UK study used an effectively designed Grounded Theory approach aimed at identifying why people needed mental health nurses. A rather large sample group (92) was utilised which was understandable given that the data was collected using focus groups involving between six and twelve participants all drawn from a of variety sources. Its findings were important to consider as this study provided some insight into how the professional's role could adapt within the care setting. Jackson & Stevenson (2000) described how professionals moved through a continuum involving different levels of knowledge and power, differing approaches to the use of language and to the use of time. These three levels they entitled 'the three me's'. At the most informal level, 'ordinary me', the professional shared more intimate knowledge with the patient and exercised any control through a position of friendship. This level involved a lay friendly language style and informal contact by the professional.

The second level was entitled 'pseudo-ordinary/engineered me' and involvement was described as semi-structured and the depth of knowing described as semi-intimate. Here control was exercised through deliberate self-disclosure and a language style was adopted that incorporated more professional concepts that were recognisable within everyday communication. The most formal level was 'professional me' where the depth of knowledge was more distant from the patient's understanding with a highly structured professional involvement. Here power control was centred upon professional status with a language style that was heavily jargonised. One conclusion drawn from this study was that psychiatric nurses had to establish and sustain friendly relationships with the patients/clients that were more intimate and went beyond a level of closeness that was customary. Indeed, Jackson & Stevenson (2000) claimed that nurses were more likely to prefer this 'friendly professional' status as it gave them an ability to more easily move between the more intimate and more distant professional role.

The following key-workers, however, warned that having an intimate involvement with the carer also carried with it professional and ethical costs in terms of creating a dependency that would require to be broken at some future stage, a viewpoint already raised by Pearson et al (1996) earlier:

'... the fact is that one day em, probably in the next month or two I'll probably discharge (husband) and (carer). You could say there's no need for CPN (community psychiatric nursing) input, that would maybe be debatable, em continued support maybe is a big role, but the demands on the service could be,

if I was doing that for (husband) and (carer) long term I would be neglecting other people.' (Key-Worker 3)

'It's you (that) are in some ways certainly breeding dependency which is a problem, but I think there is always going to be an element of dependency.'
(Key-Worker 6)

'... this is going to come to an end at some point, that's going to be incredibly hard, that's like saying to my pal I'm leaving you but there's no reason for it what-so-ever except see you later. You know that makes me query how's that woman (carer) going to feel, do you know, at the end of all this.' (Key-Worker 8)

Peplau (1994) believed it difficult for professionals to avoid communicating with patients/clients in a manner similar to how they spoke with family and friends. The professional had to stop and listen to how they communicated in order to determine their therapeutic appropriateness. She considered that 'a modicum of detachment' was necessary for the professional but also acknowledged that, given the nature of psychiatric work, without self-discipline on the part of the professional the ability to achieve and maintain such a level of detachment would prove almost impossible. Having explored this aspect of professional closeness she concluded:

'Professional closeness is an essential element in nursing situations. It is therefore incumbent upon the professional to be aware of its essential

characteristics and to be able to formulate these characteristics and know their meaning in nursing practice.’ (p.230)

She argued that professional closeness involved a complex set of behaviours taught within an educational context and differed from other forms of closeness such as ‘physical closeness’, ‘interpersonal intimacy’ and ‘pseudo-closeness’. Professional closeness had several points in common with physical closeness and interpersonal intimacy however, within professional closeness; the focus was exclusively on the interests, needs and concerns of the individual patient/client. The professionals remained aware of their own needs but kept these detached from those of the person receiving care.

The ambiguity surrounding the professional’s relationship with the carer was raised by Twigg & Aitkin (1994) who expressed difficulty in classifying their relationship as being one of caring. This view suggested a further link between this substantive code and the preceding one, ‘The Knowledgeable Professional Exercises Control’ (Table 4), where the question of ‘who the professional was there to care for’ was highlighted. Woods & Watson (2000) also recognised this ambiguity surrounding the professional’s role and considered that the potential to create an unhealthy dependency was a real risk that could lead to a conflict of loyalty for a key-worker. They concluded that if the professional was there primarily to support the carer then that is where their loyalty should lie and they should consequently reassign the dependant’s care to another organisation. As discussed within the preceding major category, I once again question this need to

view the dependant and carer as separate entities if the latter required additional or particular help and support from their key-worker.

The following key-worker raised a further factor that made a close relationship potentially problematic. She believed that on occasion it may prove necessary for the key-worker to challenge the carer's decisions and practices and that an inappropriately close allegiance might undermine this ability:

'The reality of it, and I think for carers, we have to be mindful sometimes we have to challenge as well. You know it may not necessarily be the interests of the carer and the person they're caring for might not be mutually compatible you know.' (Key-Worker 9)

Certain key-workers considered that if their relationships were to be perceived as being inappropriately close by the carer, then they were demonstrating an inequity of care provision when it came to other needy carers on their caseload.

'I would hope that my relationship was the same with everybody else, you know... (I) don't treat (Carer) any differently than any of the rest of my clients.' (Key-Worker 14)

A final potential problem associated with the close care/key-worker relationship involved the key-worker's standing with colleagues. If perceived as being too close to the carer, the key-worker's professional objectivity might be considered compromised:

'I think I get the distinct impression, certainly once or twice, that the GP's tone has been very final. And I've certainly come off the phone, going back to what you were saying, and feeling a wee bit of a loss or disappointment. Which, perhaps, I should be a wee bit more objective and a wee bit more professional in these situations, where as the GP says move on to the next thing, but I think I certainly sensed that certainly from the GPs anyway.' (Key-Worker 18)

The following key-worker considered that to work positively and productively with the carer required a sense of partnership that prevented the relationship being unhealthily close, or where either party more formally dominated the care scene:

'She, you know, she feels there's things that as if it's just as important she gets him out, she tries to do as much as much as she can, and to me that's what I try and do as well, so yeah that's, you know, going back to the two of us having a partnership, that's when I say a partnership okay so, and it's nice to see.'
(Key-Worker 5)

The partnership discussed here blended the more positive aspects from preceding substantive codes, already discussed within this major category, into a healthier and more productive therapeutic alliance between the carer and key-worker. This carer also shared the above key-worker's perception of partnership:

'Well we're both caring for the same thing, working to the same end hopefully....so we're all walking down the same path then that's got to make everything a lot easier.' (Carer 7)

Those diagnosed with dementia, and who lacked social support within the community, presented a significant burden to service providers (Draper 1990). Seaborn (1992) went further when she stated that without the involvement of carers the health care and social care services would be overwhelmed. Walker et al (2001) investigated what constituted a satisfactory level of carer involvement and considered that this varied from individual to individual. What was fundamental was that both parties discussed and negotiated a framework that was mutually comfortable, agreed on the principles of good practice and, finally, received overall support from the organisational and professional structures. The literature demonstrated appreciation of the development towards a state of partnership between the carer and their associated professional (Greenwell 1995; Clarke & Heyman 1998; Shepherd 1998; Armstrong 2001; Walker et al 2001). Following a review of the literature prior to presenting a small pilot study investigating dementia carers as equal partners with professionals, Simpson (1997) pointed out that most of the dementia literature around partnership focused on the patient and not the carer. Woods & Watson (2000) expressed the belief that such a partnership could be effectively formed but only when the professional both listened to, and learned from, the carer.

The Department of Health have, while emphasising the important need for 'inter professional collaboration', instructed that carers of mentally ill dependants

generally had to be involved in any care programmes devised for their dependant (Ham 1988). This carried the additional requirement that carers had to be fully involved in any assessment process and the given choice of where and when assessment took place. They had to know what was happening during the assessment while being encouraged to include within it as much detail of their own perceptions and difficulties as was possible (Woods & Watson 2000). Goulbourne et al (2002), as already discussed earlier under the 'Key-Worker Availability' data category' (Table 3), stated that the carer greatly benefited from having their efforts validated by the key-worker. This, they claimed, was brought about when the carer became involved in the care planning process, and that the carer must be involved whenever the review of such care programmes was undertaken.

Developing a partnership was not easy and carried with it 'complex and subtle' demands. In order to enhance this process the health care professional required to be both appreciative of and open to the limitations of care services. In addition, the professional had to point out any uncertainty surrounding solutions for carer difficulties and respond to their 'expressed needs' (Department of Health 1994). Partnership between the professional and carer was considered essential for effective and collaborative involvement, and no one person should be viewed as more important than another (Walker et al 2001). Dewar et al (2002) considered that partnership for the carer extended beyond the key-worker to include several professional groups, and where professionals valued the carer's expertise and knowledge 'appropriate, manageable and supported' care was assured. Such a partnership entailed the professional ensuring that carers

were asked if they wished to be involved in care, were involved in any decision making and held an expectation that the professional would understand if they wanted someone to support them. Such support could, for example, either involve a family carer or a carer support group. Dewar et al's (2002) findings derived from a small qualitative UK study that gathered data via focussed groups involving dementia carers. Unfortunately the authors failed to clearly describe and explain the nature and design of the study, nor the process of analysis, which compromised the reader's ability to adequately judge the quality of the findings.

Some carers within my study demonstrated a willingness to be involved more directly in all aspects of their dependant's care. This carer clearly articulated this desire and certainly she saw herself working alongside the key-worker in the management of her husband's medication:

'Oh yes, well we've got a bit each, he does the Risperdal and I do the largactil (laugh), we work it between us.' (Carer 17)

While this key-worker viewed their partnership, not as an equal one but, surprisingly, as one in which the carer was more in command:

'Again I think with (carer) also, she's very much a partnership, but with (carer) pulling the strings as it were, you know.' (Key-Worker 18)

Powel-Cope (1994) argued that partnership required a mutual exchange and that there had to be a respect for both lay and professional forms of knowledge

necessary when caring for a person with dementia, a point already discussed within the preceding substantive code 'The Independent Carer'. Clarke (1999a) highlighted a number of factors that inhibited a constructive partnership between a professional, a carer and a dependant. These included:

- Power through knowledge whereby the professional's (cosmopolitan) knowledge base usually carried a higher value, or status, over the lay (local) knowledge base.
- Power concentrated within the professional group demonstrated by the fact that those outwith the professional health and social care circles were largely constrained from being able to effect change.
- Professional-client relationships traditionally focused only on information exchange and failed to recognise the context of communication within this relationship that had resulted in a loss of its potential to provide therapeutic gains.
- Consensus and collaboration viewed as a superficial entity, whereby the need to forge an agreement was recognised but the inherent agenda rested only with one of the participants.

Clarke (1999a) also pointed out that this 'consensus, collaboration and partnership' was a complex phenomenon that did not simply happen because of a policy doctrine, but was wholly reliant upon practice and had to be regarded as an ongoing process. She cited Robinson & Thorne (1984) who supported the view that this relationship was a process that evolved and went through three distinct stages. Firstly 'Naïve Trusting' where the family carer and professional

did not share a common perspective due to their distinct but interdependent cultural backgrounds. 'Disenchantment' when they realised the diversity in their perspectives with both parties becoming adversaries and, finally, 'Guarded Alliance' whereby a gradual trust emerged and a mutually satisfying working relationship then became established.

The Department of Health (1994) advised that nurses treat all people who used their services as equal partners. An alliance between professional and carer was an essential element towards more effective care for the person diagnosed with dementia (Weiler et al 1994). Harvath et al (1994) pointed out that this partnership was necessary to more effectively deal with longer-term care needs. They added that when carers had an appropriate partnership with their key-worker, they would better manage their own care-giving responsibilities. Such a consensus partnership required an interactive preparation for both the professional and the carer that built upon 'adjustment, caring and knowing' and involved a judgement on appropriate timing and trust. Failure to do this resulted in an insubstantial partnership (Hurley et al 1995). Simpson (1997) pointed out that carers had to be considered service users along with dependants. Barker (1997) picked up on this theme of the relationships being based on mutual influence and stated that the reflexive nature of the relationship brought direct changes to the professional, the person cared for as well as 'significant others', a term suggestive of carer involvement. Barker pointed out the important distinction that professional caring involved caring with, rather than for, people regardless of the context of that care. His views, however, were unfortunately

not derived from any specific research study nor were they focused specifically upon dementia carers.

Twigg's (1989) model of the carers' relationship with the service provider, the 'carer as co-worker' model, recognised this partnership between carer and professional. She considered that while the two caring 'systems' between carer and professional did not link comfortably, the model did encompass the carers' interests and so maintained their morale. This also, in turn, improved the well being of the dependant. The nature of the carer's ongoing needs and changing educational requirements over their care-giving career necessitated the forging of much closer partnerships by the associated professional (Keady & Nolan 1995). Nolan et al (1996b) considered that the 'carer as expert' model was most appropriate within the contemporary care setting. Both of these conceptual models have inherent within them the principle of working in partnership with the carer. An important aspect of this last model was that it fully reflected the reciprocal nature of the relationship between the professional and the carer (McErlean 2001). Working in partnership with the family was the important and central tenet associated with the preservation of personhood in the person diagnosed with dementia. This was a significant factor in offering protection against the 'malignant social psychology' discussed within the preceding major category (Kitwood 1997; Brooker 2003). While this opinion did not derive from a specific research study, it was formed following a review of a wide range of contemporary dementia care literature and therefore worthy of consideration here.

Partnership emerged within this substantive code as being a particularly strong approach that appeared to blend the more positive qualities associated with this major category's three substantive codes. These more positive qualities lead towards a more effective level of shared operational practice. The following chapter now explores the impact the Carer/Key-Worker relationship has upon the care-giving environment and the associated experiences of, and responses to, the delivery of care involving a dependant diagnosed with dementia. It highlights how the quality and level of operational partnership that exists between a carer and his or her key-worker can influence these experiences.

CHAPTER SEVEN

IMPACT ON THE WORLD OF CARING

This chapter’s major category and three substantive codes reflected the perceived ‘Impact On The World Of Caring’ for the Carer/Key-Worker working within the home setting (Table 5). What was of particular note, when one examined these codes, was the conflicting and somewhat ambiguous way in which the care-giving experience was interpreted. The experience for the carer supporting the dependant through the arduous process of dementia appeared complex and presented the outside observer with contradictory, and at times, paradoxical accounts of how the caring role was interpreted.

Table 5 Impact Upon the World of Caring: Codes & Categories

DATA CATEGORIES

SUBSTANTIVE CODES

MAJOR CATEGORY

| | | |
|---|-------------------------------|---------------------------------|
| <ul style="list-style-type: none">• The Emotional Stress of Caring• Just Being Able to Get a Diagnosis• Explaining Away Disturbing Behaviours• A Failure to Understand• Providing Care is a True Sacrifice• Regret for the Dependant’s Decline | THE COSTS OF CARING | IMPACT UPON THE WORLD OF CARING |
| <ul style="list-style-type: none">• Letting Dependant Down by Placing them into Care• The Loss of the Key-Worker• Involvement Beyond Admission or Death | THE ANGUISH OF LETTING GO | |
| <ul style="list-style-type: none">• Simply a Duty to Care• Caring is a Real Privilege | THE REWARDING CARE EXPERIENCE | |

For some carers the whole care-giving experience was fraught with tension, disappointment and dejection, whereas others considered it a development within their life that had to be accepted as a duty to be borne, or a reciprocal gesture in repayment for previous services received from their dependant. For others, this caring responsibility brought with it an intense fear of losing their dependant either to formal residential care or death, some even feared the eventual withdrawal of the key-worker. Interestingly, for a few, the opportunity to care was viewed as a real privilege, one which allowed them to look after the dependant in a more intimate and self-rewarding manner. The literature consulted within this category did not always refer to dementia carers but in the absence of any more specific literature this was considered appropriate in order to further explore the concepts that emerged.

THE COSTS OF CARING

The Emotional Stress of Caring

The level of commitment inherent within the carer's role was clearly appreciated by the key-workers within this study as they voiced their concerns regarding the well-being of the carer:

'... and it always comes back to the fact that she has had no sleep, she has been kept up at night with no sleep.' (Key-Worker 15)

'It was taking a toll on her, looking after her husband. And she was going to have to slow down.' (Key-Worker 17)

Indeed, even when the professional had to intervene to relieve a serious risk to the carer's health, the carer's commitment was such that they would not easily acquiesce to such actions, even when this could avert a serious health risk:

'We had huge problems sectioning² because this lady wouldn't give in to the inevitable, but she couldn't physically look after him, and since that she has actually kind of broken down and has got quite depressional about the whole thing.' (Key-Worker 18)

The following carer also indicated that in pursuing her caring role she would overlook her own health needs in order to continue to provide needed care for her dependant husband:

'I've now got angina... and I've had a couple of attacks but I had a bad one and I was getting put into hospital... I left (husband) in the house because it was an emergency appointment...I couldnae go (in) to hospital, had to go back up the road...' (Carer 17)

Scurfield (1994), in a paper exploring carer's needs, considered that the costs of providing care fell into the four main areas; emotional and psychological costs, physical costs, employment and financial costs, and finally social costs. This article was not however solely focused upon dementia carers. MacRae (1998) cited Baines et al's (1991 p.138) view that caring 'refers to the mental, emotional, and physical effort involved in looking after, responding to, and

² Emergency Detention using the Mental Health (Scotland) Act 1984

supporting others'. Caring for an individual suffering from dementia was considered to be a complex process that involved not only a great deal of work for the carer, but also required a range of differing kinds of work (MacRae 1998). The key-workers' sensitivity to the level of stress experienced by their carers, highlighted at the beginning of this data category section, sharply contrasted with the views of Nolan & Grant (1989). They considered that, due to a tendency to concentrate upon the 'dependant's objective functional status', the professional's input remained largely instrumental. Consequently this led to an inability to recognise the stresses inherent within the carer's role. Nolan & Grant, however, did not specify dementia carers only but suggested that this applied generally to all carers. Indeed, they claimed that in failing to recognise and respond appropriately to these stresses, the professionals contributed to an increase in carer stress levels. This was compounded by a tendency in many carers to become so preoccupied in their own caring role that they became unable to care for their own health (Tebb & Jivangee 2000).

Scurfield (1994), in citing Gilliard et al's (1984) study, highlighted how levels of stress and distress suffered by the carer led to higher psychiatric morbidity in carers. Within the literature there was widespread evidence of the link between dementia care giving and adverse psychological/emotional consequences (Brodaty & Hadzi-Pavlovic 1990; Keady & Nolan 1995; Donaldson et al 1998; Bruce & Paterson 2000; Clyburn et al 2000; Tebb & Jivangee 2000; Zarit & Leitch 2001; Aggarwal et al 2003; Marriott 2003; Thomson et al 2004). Within a review of research studies associated with the impact of dementia on carers, Donaldson et al (1997) found that throughout the literature the terms 'burden',

'caregiver strain' and 'stress' were all used to describe the same concept. These researchers, however, pointed out several limitations to their review including potential sampling bias within the studies selected, variation on the definitions of variables and an absence of critical examination of the findings within some studies. Allen (1997), within an article not specifically focused on dementia carers, considered that all carers were the 'corner-stone of community care' and their care involved a '24-hour burden with serious, often unacknowledged, consequences' (p.34). She stated that carers were rarely perceived as 'people in their own right' and if not so addressed, were vulnerable to becoming a mental health statistic. A study by Pickard & Glendinning (2001), exploring dementia caring, supported this viewpoint and stressed that if carers did not receive adequate support from the professional the likelihood of premature residential care for the dependant was most likely.

Often carers would not consider pushing their own health needs when in consultation with their general practitioner, despite being under considerable burden. The carer often experienced difficulty in expressing their own feelings to care professionals in an effort to reduce the level of emotional effort associated with their role (Walker et al 2001). These more negative portrayals of the care professional were in contrast to the experiences of the following carer who, having significant cardiac problems, found that her key-worker not only recognised this but made considerable efforts to get her to address her serious health needs:

'Well, she'll tell me that I've got to think of myself and think of your own health. And sometimes if I am really worked up she'll come back and she'll pop in and she'll say you were really angry on such and such a day when I wasn't aware that I was angry.' (Carer 8)

Within my study I interviewed one carer who did not reside with her dependant but lived close by in an adjacent house and was with her mother for most of every day. Despite not living with her dependant she described an extremely demanding role which had intensified over the preceding eight months:

'Oh there is difficulties definitely, I mean like it's only recently I've put a wee bit more care in, you know, like support from social work. But I mean it's, I've got a two year old and like, you know, my husband comes home and he's like 'is that your mother here again?' And sometimes it was seven days a week.' (Carer 9)

Dura et al's (1990) study compared distress levels of carers looking after a spouse with Alzheimer's disease and those caring for someone with Parkinson's disease. They found that the former carers had more time involvement with their loved one and therefore had to cope with higher levels of disability. This was a comparative study that used a quantitative design, gathering data using pre-existing instruments. The multiple source selection of the sample and the inclusion of a control group strengthened the design. However, two detracting aspects of the design were the sample size of twenty-three within each cohort, which appeared rather limited for such a quantitative design, and the fact that no process of randomisation took place within the sampling process.

Moen et al (1995) pointed out that the time spent caring was a particular issue for the carer. Following their literature review they hypothesised that 'Current caregiving is negatively related to well being, and the longer the duration of caregiving, the more negative its effects' (p.262). Myrra et al (1996), in contrast, claimed that the existing literature suggested more of a positive relationship between the duration of dementia and the carer's circumstances, a situation that supported the 'adaptive hypothesis' in terms of the carer's coping and well-being. They do, however, also acknowledge the 'wear and tear hypothesis' which proposes an ongoing deterioration in the circumstance of both the persons with dementia and their carers. This is an alternative perspective to the 'trait hypothesis' whereby the carer maintains a constant level of adaptation determined by their pre-existing resources. Clyburn et al (2000) considered that there was a dichotomy between whether the issue of time added to or reduced carer's problems.

Nolan & Grant's (1989) paper, drawing upon the literature associated with the needs of informal carers, highlighted the aspect identified earlier by Carer 9 (p.212) of the carer taking responsibility for their dependant along with raising a family, dealing with a home and possibly even holding down a job. Here they considered that, even when supported by other family members, dependant demands still meant ignoring other family member's needs. Where the carer held down a job, the literature was divided on whether this had a positive or negative influence on their stress levels. Gilhooly & Redpath's (1997) study of carers pointed out that this aspect lacked sufficient study across all carer groups

and cited Scharlach et al (1991) who highlighted a divergence in opinion as to whether employment increased stress or reduced it. Gilhooly & Redpath (1997) commented that, more recently, given the public attention given to carer burden over the past ten years, it was surprising that so few businesses in Scotland have given any real consideration to those individuals within their employ who had care-giving responsibilities. Even more concerning was their belief that this situation was a result of the current economic climate whereby the companies were confident that, should a stressed individual leave their employment, their post could be easily filled (Gilhooly & Redpath 1997).

Having experienced significant levels of distress, coupled with serious physical health problems, this carer described just how difficult it was to manage her husband without losing her temper:

'... I lose the place, I shout at him.' (Carer 8)

Matthew (1999), in her study of dementia carers caring for a wife, found that anger and guilt were features of the carer's temperament and that this was associated with loss. In Matthew's study the participants expressed two forms of anger: anger against the system and anger towards particular individuals. This emotional response was the result of a fear of the illness and its symptoms (Flannery 2002). Walker & Dewar's (2001) study also highlighted this aspect of displaced anger from the carer which they attributed to stress that led the professional to view the carer as 'guilt ridden and emotionally vulnerable' (p.334). Professionals accepted that this anger was inevitable and allowed the

carer to relieve stress in a relatively safe manner, and that anger may have been a consequence of difficulties in gaining an accurate diagnosis.

Just being able to get a Diagnosis

For certain carers gaining an accurate diagnosis was problematic. This key-worker highlighted the difficulty one of her carers had in getting to the root of her husband's difficulties:

'I mean she went through an awful lot with him as well. He was diagnosed as Parkinson's at one point when he was in (local hospital). She actually took him to a private consultation because this just floored her, Parkinson's; I've never seen anything like Parkinson's. I spoke to (GP) and he said no I don't really think it is (that) either, so we got a private consultation...' (Key-Worker 15)

Tissier (1993b) discussed a report on dementia carers from the Alzheimer's Disease Society that claimed that nearly a third of all respondents to their survey reported that it had taken doctors more than a year to identify dementia. The difficulties surrounding a diagnosis of dementia have been widely highlighted within the contemporary literature (Moore et al. 1993; Phair 1996b). Having to wait to discover what was wrong with the dependant was viewed as one of the most stressful aspects of dementia caring (Keady & Nolan 1995). Importance was placed on the professional carefully observing the behaviour of a likely individual to distinguish between dementia, depression or acute confusion (Chapman 1997). Depression, when it presented as dementia was sometimes

referred to as pseudo-dementia and depression was considered common in people over the age of sixty-five (Phair 1996b; Kitwood 1997).

Kitwood (1997) considered this association between dementia and depression, both of which involved neurological changes. These two conditions shared common symptoms, particularly when severe depression affected an elderly individual and a decline in cognitive ability became apparent. Kitwood (1997) believed that led to the possibility of a mistaken diagnosis of primary degenerative dementia when in fact the individual was amenable to treatment for depression. Goldsmith (1999) described this as 'misdiagnosis' where the dependant was initially diagnosed with another condition. Bruce & Paterson's (2000) study discovered that a lack of understanding over the diagnosis, even after it had been established, led carers to avoid assistance which compounded their difficulties. This was a realisation that linked this data category to the 'Educating the Carer' data category described within the first substantive code of preceding major category chapter (Table 4).

The following carer still awaited an accurate diagnosis on her husband's condition after five years of inquiry:

'I'd say my husband always had problems that were a bit different to lots of ones (key-worker) goes to, and I think you have dementia and you have Alzheimer's and you have schizophrenic, in the five years we have never had a definite diagnosis on my husband...' (Carer 15)

The following carer, however, found that even having been given the ‘feared’ diagnosis they still failed to receive a prompt input of services and were clearly angered by such a lack of support:

‘No, very late, we had absolutely nobody come in. We were given a diagnosis on the 19th of March last year... At that stage we had no support. We had absolutely nothing and I had to start digging out numbers to generate support. It was a long time before we got social work involved. I had contacted them a few days later and it was months before they became involved... I had to absolutely fight for everything.’ (Carer 7)

Tissier (1993b) highlighted how serious the consequences were for carers who experienced problems over the diagnosis. They could not make important financial decisions and missed out on early support. This claim, however, was not scientifically based and was more reflective of Tissier’s own professional anecdotal experience. Walker et al (2001) agreed that there were real difficulties in gaining an early diagnosis and further stated how a diagnosis of dementia was often the prerequisite to services acquisition.

In keeping with this link between getting an accurate diagnosis and service acquisition, the following carer held a contrasting attitude towards the uptake of such services. Indeed, the source of his emotional trauma derived from being offered such services. He experienced a level of guilt and even a sense of failure for having considered such an option:

'I was just aware that I had this to do and that to do and I wasn't capable of doing it, I mean quite honestly having a home help goes against the grain with me.... There was an assessment in the house with (wife) and the social worker said to me and how are you managing. And it really hurt me to say I'm not because I have so much washing and cleaning with (wife). (Carer 8)

Lea (1994) considered that the situation for the carer was made more difficult when they experienced such guilt. The carer, she believed, avoided admitting that they could not cope by refusing to ask for help, instead continuing to feel trapped and seeing their only relief as the death of the dependant. This increased their sense of guilt leading to emotional and physical exhaustion. Aneshensel et al (1995) believed that following the long process of care-giving to an end point of death, grief and relief were two emotions that occurred independently and, because you felt one, you were not precluded from experiencing the other.

So, within this data category the carer could experienced emotional trauma as a consequence of two contrasting situations. Some may not receive an accurate diagnosis for their dependant which results in stress deriving from not being able to plan ahead and difficulty accessing appropriate supporting services. Others, in contrast, could experience a sense of guilt at having to admit that they now require such supporting services. Both of these experiences contribute greatly to the 'The Costs of Caring' (Table 5) theme associated with this substantive code. This data code also links to the preceding major category whereby the inability to 'plan ahead' links to the substantive code, 'The Knowledgeable Professional

Exercises Control', and the guilt derived from having to accept outside support links to the 'The Independent Carer' substantive code (Table 4).

Explaining Away Disturbing Behaviours

The demanding nature of care-giving, associated with this substantive code's 'Cost of Caring' focus, was frequently alluded to and, for some carers, was even likened to caring for a young child:

'I sometimes feel mean about it, mind you, but I changed my mind because older men anyway, I don't know about young men, can get really childish and dependent even if there's nothing wrong, give me this, where's that, and so on...'
(Carer 10)

'... it's a bit like a child, you give a child a row, you say don't do that again or I'm going to take that off you. He doesn't listen, he does it again, he does it the next night, he takes the night sedation at a quarter to six which means that I'll know I'll have the whole night with him up and up and down.' (Carer 15)

This tendency to compare the dependant's behaviour to a child was also evident within this key-worker account:

'You can relate it to a kid, a kid playing up before you get out of the door.'
(Key-Worker 15)

This comparison of the demanding behaviours associated with the dependent and that of a child was also alluded to within the literature (Ungerson 1983; 1987; Askham 1995; McErlean 2001). The behaviours most likely to cause the carer problems were frequently identified as depression, incontinence; sleep problems and wandering behaviours (Wenger 1994; Donaldson et al 1997; Pickard & Glendinning 2001). The diversity of demanding behaviours that manifest in dementia was clearly described by Askam (1995). These ranged from an inability to deal with personal hygiene and dressing through to wandering away from home or turning night into day.

The carer became increasingly aware that their loved one had changed, as demonstrated by this carer who had witnessed her husband becoming more isolated and reclusive:

'It's a strange illness and he's now a strange man because he is quiet and never talks.' (Carer 15)

One elderly carer had been experiencing considerable problems in dealing with his elderly wife's behaviours:

'She was wanting to go out and she couldn't understand... one day she got on the bus but luckily enough somebody on the bus knew her and told the driver don't move the bus. Of course by this time I had run after her and out in my slippers (laugh) and we managed to get her off the bus, but she could be quite stern and very determined. She was always a quite determined person on her own when

she was okay, but she was even more determined, oh she would turn and batter me (laugh), but I knew it wasn't her it was just her trouble.' (Carer 11)

This inclination to separate difficult and aggressive behaviour from the individual and place it squarely at the door of the illness was considered a process that involved the carer 'normalising' their relationship with their dependant (Clarke & Heyman 1998). Clarke (1995) considered this concept of 'normalising' to be particularly important as she described how carers within her study used normalisation strategies to reduce the problems they faced in caring in an effort to minimise stress. Three strategies she highlighted were:

- Pacing the level of demands that they faced
- Confiding and gaining a perspective on their problems through dialogue
- Rationalising and making sense of their situation through, for example, relating the present situation they faced with past experiences

In the account given above by Carer 11, he was using the pathology of his wife's condition to explain away her difficult behaviours. This was a means whereby the carer used the dementia label to help protect their ongoing relationship with their dependant (Clarke & Heyman 1998). However, this process did not always protect the carer from adverse emotional responses resulting from these behaviours, as suggested by these further comments made Carer 11:

'No, no she went in to get treatment because, to let you understand, I was having an awful lot of bother because she was getting out the door at six o'clock in the

morning and at night time. She wanted to go back to her mother's and her mother actually only live(d) approximately about a mile away in this area. And she was desperate to get out and in fact she got out two or three times and I had to run after her and it was terrible you know. And she played up quite a bit, but this is all part of her trouble, which I understand but it was very depressing.'
(Carer 11)

Behaviours where the dependant became rude, over friendly or even aggressive, were usually changes well out of keeping with the person's previous personality type (Askham 1995). The literature generally acknowledged that such changes in the personalities of dependants occurred and led to significant problems within the care environment (Fares 1997; Sutcliffe 2001). Sutcliffe (2001), in a paper discussing the effects of dementia, described how the process of dementia resulted in bizarre behaviours from the dependant, for example, flushing personal items and valuables down the toilet. They then, as they had no recollection of committing such acts, proceeded to acrimoniously accuse others, usually close family, which undermined established levels of trust and loyalty. Given these changes it was not surprising that some carers often had difficulties handling such behaviours. McErlean (2001) considered that such changes presented an increased burden of caring as the carer saw their dependent in a more 'menacing' light with a greater possibility of aggression or other disinhibited behaviours possible. The carer's ability to tolerate such dependant behaviours was addressed in the 'Developmental Process of Care-giving' model developed by Kobiyashi (1993) and discussed further by Suwa (2002). In stage two of the process the carer would, as already indicated by Clarke & Heyman (1998),

attribute the behaviour to the condition rather than direct negative feelings towards their dependant.

As witnessed earlier from the Carer 11 example, such behavioural changes were made more problematic when they occurred in public. The following carer described the various problems associated with her husband's wandering and disinhibited behaviour that occurred during a foreign holiday and which caused her to experience considerable embarrassment:

'When we were away (on holiday) in June I lost (husband), I wakened up and immediately I knew there was something wrong. And no sign of him in the corridor so I thought I'll need to go down the stair... Here I sees him, I looked round the corner, here he's stripping ...And he speaks to himself in mirrors... well the hotel was full of mirrors, even in the lift... He'd go into the lift with three or four folk in it you know and (husband) would say "Oh Hello", you know and everybody sort of, you know. You shouldn't be embarrassed, you know, but you can't help it... But sometimes he would go into these moods he wanted to do something and get away on his own, and he was standing arguing with me in the hotel bar and everything, you know, and ... I would say you're embarrassing me, you're embarrassing me, you know.' (Carer 5)

One carer, however, put a rather different slant on the aspect as she deflected this sense of embarrassment back on to her dependant husband that, apparently, allowed her to avoid such adverse feelings:

'I thought maybe I would be a wee bit embarrassed, why should I be embarrassed I don't... He is embarrassed enough for me.' (Carer 10)

Sutcliffe (2001) discussed these anti-social aspects of behaviour associated with dementia and agreed that these were more difficult for the family to cope with when they occurred in public. He suggested that disinhibited behaviours may have been due to the changes in personality or, for some, they may have suggested aspects of the personality previously hidden that were now emerging as a result of the dementia process. What was clear from the accounts given within this data category, was that the carer often derived considerable stress and social embarrassment from behaviours exhibited from their dependant, emotions that contributed to 'The Costs of Caring' theme associated with this substantive code (Table 5). However, the carer often would attempt to mitigate such difficulties by attributing the problem not to their dependant, but rather to the condition itself thus helping to preserve their relationship with that individual. For some carers, however, the source of their greatest difficulty did not come from their relationship and association with the dependant, but rather derived from the wider community.

A Failure to Understand

Some carers expressed exasperation towards others in their communities who failed to show an appreciation for the circumstance and difficulties they faced:

'They don't understand. So because they feel they don't understand you get to the stage you don't talk to them about it. I just feel it's easier not to discuss it.'
(Carer 15)

This lack of understanding led to a sense of anger. The following carer found that she become annoyed even with close friends who failed to demonstrate any appreciation for her circumstances while caring for her mother:

'It's difficult with a friend because they don't quite appreciate her condition's deteriorated and what she needs and how you deal with somebody with dementia... it does annoy me...' (Carer 9)

Unfortunately similar attitudes led another carer to experience a sense of isolation:

'Yes, you definitely feel isolated. I think it is a very isolating illness.' (Carer 15)

Isolation in carers generally had been widely highlighted within the literature (Secretary of State 1981; Fitting et al 1986; Cameron 1993; Nicholson & White 1993; Walker et al 2001; Gall et al 2003). It was considered that the carers generally were more effective if they could turn to family and friends for support (Hatfield 1981). Homer (1994) recognised that the problems faced by carers, over and above the physical burden, were those of emotional strain, financial difficulties and isolation. Carers who were in contact with others from outwith the home suffered less from the psychological symptoms (Brodaty & Hadzi-

Pavlovic 1990). The loss of social contact was a consequence of the dementia condition in that the carer progressively lost contacts with friends and family (Harris 1993; Commissaris et al 1995; Tebb & Jivangee 2000). Male carers in a study by Parsons (1997) described how they missed the companionship and friendship of their dependant as they progressively deteriorated.

Neighbourhoods from which the carer and the dependent belonged have been viewed, particularly by those responsible for social policy, in more traditional terms that suggested ties of affection and harmony. Often, however, the experience for those reliant on such informal community support experienced a less romantic reality whereby their community presented more impersonal and dehumanising characteristics (Jootun & McGhee 1996). Matthew (1999) studied isolation in husbands who experienced a sense of loss while caring for their wives. One aspect of isolation involved the husband being separated from his wife following her admission to hospital, a phenomenon that will be further explored within the following substantive code. Within this study, involving six husbands, the problem associated with isolation took on another form, the isolation from those around them and a sense of feeling rejected by family and friends. This, when coupled with the loss of their wives, was considered a double loss. This was a small qualitative study that adopted in-depth interviews to generate fourteen categories around the experiences of carers. A disappointing aspect of this paper was that the discussion surrounding the actual design was rather too brief to allow an effective judgement on the rigor of the study to be made.

A Swedish qualitative study by Jansson et al (1998) examined carers' experiences of isolation and loneliness. While researching daughters' responsibility for a parent with dementia, the problem of isolation was linked to the fact that many of the carers had no siblings and, therefore, had no one to share their considerable responsibilities with. Again this study's finding required cautious consideration, particularly as its sample contained only daughter carers.

Providing Care is a True Sacrifice

In keeping with the theme associated with this substantive code, 'The Costs of Caring', this data category highlighted the level of sacrifice that this role demanded (Table 5). For some carers having family ties presented other significant problems. The following carer was clearly aware of a potential problem associated with bringing her mother to live in her marital home and was not prepared to 'sacrifice' her marital relationship:

'I think so because, I mean, there isn't a lot she can do and things now and, I mean, as much as I love my mum and things like that, I just couldn't have her live here, it would destroy my marriage (laugh), you know what I mean.'

(Carer 9)

Like the views identified within Gilhooly's (1984) qualitative study on the impact of caring on dementia carers, this carer was obviously torn and somewhat stressed at having made this most difficult decision. Jansson et al's (1998) study similarly highlighted this area of potential 'sacrifice' for the carer. They stated that often there was a conflict between a daughter's caring role for a parent and

her responsibilities towards other family members, a finding that was also highlighted within Gilhooly's study.

Carers within my study regularly raised the viewpoint that caring often required them making sacrifices within their lives. For some this involved giving up regular social events, a sacrifice which adversely impacted on life satisfaction:

'... quite a few times (husband) and I would get out a wee while and chat to the, you know, and people that know us say hello or how are you today, and it's a nice night and what not, but you're not in the same company now, the same because you can't... I miss it.' (Carer 5)

This reduction in the social life of dementia carers was found to be the commonest problem they faced (Argyle et al 1985). The Carer's National Association described carers as:

'... those whose lives are restricted by the need to take responsibility for the care of someone who is mentally ill, mentally handicapped, physically disabled or whose health is impaired by sickness or old age' (Bennet & Kingston 1993, p.25).

Harper & Lund (1990), in a study aimed at producing a model of carer burden, found that life satisfaction was a significant factor linked to burden, particularly female burden. This US quantitative study involved a strong design that utilised a series of self reporting questionnaires to gather data from a large sample of

carers (2,362) but had a slightly disappointing return rate (48%). Sacrificing occupational opportunities was also evident within the comments of the following carers:

'It was a huge wrench to give up my work. Money wise I didn't really worry about it, I just gave it up being honest... because I could never at one time imagine even the thought of retiring was dreadful to me because I enjoyed, I really enjoyed working but I don't have time to think about it. You know, going out to work.' (Carer 7)

'I thought he could have been knocked down and this kind of thing so that's how I had to give up my job. That was a life saver for me that two and a half hours a day but unfortunately that's had to go so I've had to give up my wee job.'
(Carer 17)

The level of sacrifice involved in the carer giving up their occupational role was also recognised and appreciated by the key-worker:

'... she spoke about having to retire to look after (husband), she had a lot of reservations about that. Feeling that she might not have a lot of time, time was a kind of key factor. She was wondering what she would be able to do with her time and all that but I think she found out that, you know, with (husband's) condition as it deteriorated, you know, she felt as if her time was taken up looking after (husband). Keeping him as they try to do things that he wanted to

do rather than what she wanted to do, which I felt was actually the most unselfish thing ever, you know, I felt that was really nice. ' (Key-Worker 5)

Barret (1992) discussed a study carried out by the Crossroads Care Attendant Scheme which contained the views of over ten thousand carers and reported that 54% had given up work to take on the caring role. Green & Acheson Cooper (2000) cited Niemi's (1988) finding that issues of quality of life, sense of life satisfaction, or sense of well being, were all derived from some form of activity or occupation. Younger carers of dementia dependants noticed that as dependants had to take early retirement many carers, due to their own poor health, also had to give up work and commented upon the financial implications of this decision (McErlean 2001). Action (2002) considered that carers also had little time for hobbies and often gave up on such interests. Respondents within this study quickly pointed out a lack of time to indulge in leisure pursuits. This descriptive study was conducted within the US using a small purposive sample of ten carers. The study was well conducted and an attempt was made to improve the credibility of the findings through a series of member checks. Lelliott et al (2003) summed up this sense of true sacrifice in their belief that carer responsibility came with a price. In comparison to the general population, carers were more likely to have a limited social life, be poor, be unemployed, and to suffer from both mental and physical ill health. However for some carers, just standing by and observing what was happening to the dependant was a torture in itself.

Regret for the Dependant's Decline

Some carers expressed a sense of regret over the changes in their dependant's health:

'... and I keep losing my head.. I can't get into my head that (wife) (is) not the (wife) I want, I want the (wife) that used to be active...' (Carer 16)

This focus on the deterioration of the dependant concerned this key-worker:

'It's difficult, I mean it's very, I think it's the antithesis of what we spoke about last week in the other relationship in that I go in there and sense, because we talk about this often, that (husband) is not (husband). (Husband) is not her husband anymore and (husband) is not the personality he once was. And she struggles to see this image of her husband sitting there, but who is not her husband.'

(Key-Worker 8)

Jackson et al (1991) studied the psychological well being of dementia carers and found that in addition to the problems of isolation, carers also experienced anticipatory grief as their dependants deteriorated. This quantitative design, involving a rather small sample (24) of carers, was strengthened by the inclusion of a control group. Hocking (1994) cited the view of Beck & Phillips (1983) that carers of older people generally experienced a prolonged grieving process if they held on to the identity of the dependant as they knew them in the past. Sutcliffe (2001) also highlighted this tendency by the carer to express regret over the deterioration in their dependant by focusing on the condition's effects, dwelling

primarily on what had been lost and not on what had been retained. This perceived deterioration in the dependant could hold significant consequences for the carer. The carer risked being vulnerable to depression largely as a consequence of 'anticipatory grief' (Jackson et al 1991). Some studies identified a significant correlation between perceived deterioration in the dependant and associated burden of care (Harper & Lund 1990; Almberg et al 1997). Such feelings of regret and loss were clearly articulated by Aneshensel et al (1995), who quoted the following carer's very moving interpretation of her emotional experiences, feelings which clearly corresponded with those of Carer 16 (p.231) quoted at the beginning of this data category:

'I feel that the person I knew has gradually been disappearing, little bits and pieces gone as she loses her ability to do things, loses memory. What are still left are memories of childhood. She remembers that. She loses track of the grand children. If I show her pictures from my childhood and mention names, I'll get a smile out of her. My mother's been dying for several years, bits and pieces gone. By the end it's not the mother I knew or that knows me.'

(Aneshensel et al 1995 p 45)

THE ANGUISH OF LETTING GO

Letting Dependant Down by Placing them into Care

Loss, as described above, was a significant feature of 'The Costs of Caring' substantive code theme (Table 5). The above carer quoted by Aneshensel et al (1995) expressed this sense of grief and loss while her dependant was still alive.

This response was further highlighted and explained by this carer's comments and those of her key-worker:

'I talk about it, I don't mean I talk about it to anybody, but refer to it at times as a living death, he's (husband) just still here.' (Carer 8)

'I mean you're involved, if you take (this) carer, you're involved with her, you supported her for (the) three years she's been through, she's actually telling you that this is a living bereavement, it's not (husband), and she's watched this happen.' (Key-Worker 8)

This phenomenon was also referred to by some commentators as a 'living bereavement' (Taylor 1987). Carers experienced 'anticipatory grief' through a process of adjustment to the eventual physical loss of the dependant (Sweeting & Gilhooly 1997). Matthew's (1999) study, discussed earlier within the preceding substantive code, compared the loss of a close relative to death and the loss suffered by husbands whose wives developed dementia. She discovered that, contrary to Aneshensel et al's (1995) view, the experience of numbness and shock so often felt upon the death of a loved one did not occur to the same extent within these husbands coping with progressive dementia. Jones & Martinson's (1992) examined the experiences of carers before and after the death of a spouse and found that they expressed 'pre-death' patterns of experience. These contained similar expressions of intense grief coming during the care-giving period, then feelings of death coming as a relief where the carer showed a readiness to let go and, finally, a readiness to get on with life. Aneshensel et al

(1993), within a survey of dementia carers (555) drawn from two dementia associations within the US, considered that while the placement of a dependant into care and the experience of death were very different transitions, they corresponded closely when examined within dementia carer populations. Therefore, survival to a death could be viewed in a similar manner as survival to placing a loved one into care.

The concerns and difficulties associated with putting a dependant into a formal care setting were clearly articulated in the comments given by the following key-workers describing the emotional effect upon the carer of such a decision:

'That's a painful experience and I've had a few lately, and some people just can't let go.' (Key-Worker 16)

'... and I think the letting go has been very, very dramatic.' (Key-Worker 18)

Stephens et al (1991) in contrast believed that the carers who institutionalised dependants experienced significantly less disruption to their family networks and fewer restrictions to their social activities. Stephens et al's study examined well-being and stress associated with carers who placed their dependant into institutional care. It involved a sample of carers (120) drawn from a variety of sources and utilised pre-existing data gathering scales. One strength associated with this study was the careful sampling process adopted and the significant effort to make the sample as representative as possible, however the scales adopted could have been explained more explicitly. Matthew (1999), following

on from her previously discussed findings that carer loss through bereavement was more traumatic, argued that this did not detract from the level of difficulty faced by the carer, but merely highlighted the nature of their particular loss. In her study she claimed that carers, who had experienced negative feelings of isolation, suffered such emotions as a direct consequence of institutionalising their wives, therefore such negative emotions were also a cause for concern when the carer was contemplating placing their dependant within an institutional setting.

Chenoweth & Spencer (1986) pointed out that 72% of people with Alzheimer's disease were placed into institutional care because the carer was overwhelmed by a twenty-four hour care demand. The difficulties precipitating such a crisis requiring subsequent admission have not been the focus for sufficient study (Argyle et al 1985). Morris et al's (1988) examination of the contemporary research surrounding dementia carers concluded that professionals had to make every effort to ensure that carers received adequate informal support from their own social network rather than attempting to replace this with formal care. This replacement of informal care by professional services was a feature of the 'Superseded Carer Model' described by Twigg & Aitkin (1994) and linked this code to the 'The Knowledgeable Professional Exercises Control' and the 'The Independent Carer' substantive codes discussed within the preceding major category (Table 4). Adams (1999) considered however that this model had limited applicability to older people and was really aimed at freeing disabled people from dependent relationships and removing the need for family carer involvement. The circumstance around why the person with dementia was

placed into formalised care by the carer was important to the carer's reaction to this decision. Webb & Morris (1994) considered that the stressful experience of lay caring within the home was closely related to an often premature institutionalisation of the dependant.

A concern for the carer, going through this process of 'letting go' of their dependant and allowing necessary hospitalisation, was voiced by the following key-worker:

'... it's very topical, Gerry, because I'm actually seeing a lady just now whose husband I administered the depot to for a good number of months and it was a huge problem. I'm actually seeing (carer) now but she's struggling to come to terms with her husband having to go into long term care.' (Key-Worker 18)

Here, having identified real emotional difficulties within the carer, the key-worker chose to remain involved with her following admission of her husband. This aspect of remaining involved with the carer after the dependant is no longer within the home will be explored in greater detail later within this substantive code. The following key-worker, also identified a sense of the guilt felt by the carer when placing the dependant into care:

'... and I know at the end of the day he's come to that decision and it's happened, and it's really quite guilt ridden and everything else, but the man's still to go through it.' (Key-Worker 12)

The literature supported the view that carers frequently experienced considerable emotional difficulties arising out of this decision to 'let go' and place their loved one into institutional care (Woods & Watson 2000; Hooker et al 2002; Nolan & Dellasega 2000). Guberman's (1992) study into why female carers choose to care found that some carers had inherent 'anti-institutional' beliefs and expressed a real lack of trust in the whole institutional care system. Armstrong (2001) considered that once a dependant was placed into care the carer often experienced a mixture of emotions including anxiety, relief, loneliness and a sense of guilt about whether their loved one would be alright within the new setting. More often than not the reality was that this decision did not constitute a rejection of the dependant but, rather, was the last act which demonstrated that the person could not be cared for safely at home (Kellett 1999; Tebb & Jivangee 2000).

While levels of burden for wives, husbands and daughters caring for an individual with dementia were higher when they co-habited with their relatives, those who did not live with their dependant experienced higher levels of guilt, including those who placed their dependants into care (Harper & Lund 1990). More alarmingly, when carers became exhausted they could experience a sense of unreality which led some to feel less guilty about abusing their dependant than they would if they had to place them in a formal care setting (Hocking 1994). More recent dementia care literature continued to acknowledge that the carer experienced guilt when agreeing to admission into residential care and could even be embarrassed as they expected to be harshly viewed by others within their community (Shankland 2002). It was also acknowledged however

that placing the dependant into institutional care was not always the solution to the carer's problems and instead might contribute to their problems (Almberg et al 1997; Colvez et al 2002). Nolan & Dellasega's (2000) study of carers within the UK and US identified that there was no real forward planning by professionals towards permanent placement into care and very limited carer involvement in the decision making within both countries. This lack of planning would once again link this category with the earlier substantive codes, 'Unacknowledged Work' and 'The Knowledgeable Professional Exercises Control', with the previous data category, with 'Preparing the Road Ahead' data code being particularly relevant (Tables 3 & 4).

Give the inclusion requirements for the participants within my study, carers had no experience of their relative being placed into formal permanent care. They had, however, experienced similar emotional difficulties when placing their dependants into formal care settings temporarily for either assessment or respite. For some, it was the reaction of the dependants that was most distressing:

'... she went into (hospital) for a, you know, to get assessed...but when she went in the first time she was like, don't leave me here, it was dreadful.' (Carer 9)

The following carer even experienced feelings of guilt, when placing his wife into day care for a few hours. Like the previous carer he found that with time, and positive feedback from the day care staff, the intensity of these feelings subsided and he would now contemplate placing her into a hospital setting in the future:

'I don't know, I feel a bit guilty, but I think with our experience something up in (Day Care Setting) and from feed-back from I get from them... she's quite happy in a group. She can hear folk talking and listen to them, and watch what's going on. So down in (hospital), she's been there before and they have seen it, I think the fact that there's other people round about she'll be okay.' (Carer 4)

This carer recognised however that, by sending his wife into an unfamiliar setting, he potentially risked adversely affecting her mental state:

'The fact that she's taken out of this environment. They tend to get into their own environment, she knows the house, she can walk round about if she feels like it where, if you take her into strange surroundings, she's lost.' (Carer 4)

However unlike the above carers, Carer 11 was contemplating that his wife would remain within institutional care. He had been dedicated to caring for her at home and had only initially sent her into care for respite. Unfortunately, as he described here, her physical health significantly deteriorated and it became increasingly unlikely that her care could be managed at home. He had, on his last visit, made the eventual decision to leave her there permanently and clearly was dismayed by this development:

'She only went in on the 13th of August and that was only for respite, Gerry. But then, because of this trouble so much so that now she can't walk because I think what's happened is she was so long off her feet, more than a month, and whether

she has lost her confidence or whether it's part of the trouble, I don't know because she was walking prior to that, although she didn't walk that fast... I can tell you something, Gerry, that day, that first day I drove home and the tears were tripping me because she couldn't understand why she was there. She knew she was in hospital but!' (Carer 11)

This dread associated with 'letting go' of the dependant, and the emotional consequences for the carer, was very evident from the comments of this key-worker:

'In the long term she's very, very upset over it, she feels she's let her husband down very much.' (Key-Worker 18)

Willoughby & Keating (1991) described how the carer, in making the 'cognitive shift' of accepting permanent care, underwent a 'process of adjustment' towards the psychiatric care environment. They considered that, despite experiencing an initial sense of relief in handing over caring responsibilities, the carer felt that they had let their dependent down and, consequently, experienced feelings of sadness and helplessness. Mackay (1993) considered that institutional care environments had to be seen as friendly, warm and welcoming in order to avoid intimidating individuals diagnosed with dementia and their carers. Gilliard & Rabins (1999) highlighted that the move from home to institutional care was a most difficult process and, as a consequence, the carer felt that they had failed the person up until then they had given so much time and devotion to.

The following carer described how the key-worker advised him on this most difficult decision making process:

'They told me it was my decision, but they were trying to advise me (that) what they were telling me was the real thing. I mean, they were only advising me for myself. I realise now that they did advise me that it was the proper thing, because at the end of the day it was going to come to that anyway. But, as I said again, it's the hardest decision I ever had to make in my life.' (Carer 11)

Fottrell (1992) believed that the professional, in advising the carer in the early stages of the condition, must ensure that they did not promise that they would not place the dependant into institutional care regardless of how the condition progressed. Such a promise could only result in future distress for the carer as, for many, this promise could not be kept. Gilliard & Rabins (1999) pointed out that carers often required to be 'given permission' to make this significant step by the associated professionals.

The following carer found advice from his key-worker had been a little too dictatorial although he recognised that it had been clearly identified that this advice was aimed at maintaining his own health and well being:

'(Key-worker) and one or two other people are saying that I have to. Well she says don't worry about that, you've got to get a break otherwise you'll fall ill and you won't be able to cope.' (Carer 4)

Nolan et al (1996b) considered that at the end point of caring, carers required a good deal of assistance to give up their role. They also acknowledged that, following admission, carers experienced a 'legacy of guilt and continued stress'. Fottrell (1992) claimed that respite was an important strategy in the longer-term management of the dementia dependant. It not only provided carer relief, but also allowed their dependent to become familiar with institutional care prior to permanent care becoming necessary. This service had to be sensitively managed as carers often feared that their dependant would be forcefully removed and placed into a hospital against their wishes. The carer required to be advised that while in hospital they could visit and take their dependant out for days or weeks and, should permanent hospital care become necessary, this was unlikely to be 'abrupt forceful or compulsory' (p.18).

The care professional not taking over but rather involving the carer in any decision making around whether or not to 'let go', and permitting the admission of their dependant into formal care, was identified as important by this key-worker:

'But then again I think nurses sometimes are very directive, and a lot of this is about being able to say, this is your decision. I'll support you, I'll be there, I'll help you. Personally... I might think you've made the wrong decision, but it's still your decision and I'll go with you and we'll do what we can to back that up.'
(Key-Worker 16)

This approach clearly links this data category with 'The Need for Shared Respect' data category contained within the first major category (Table 3), and 'Key-Worker as a Partner in Caring: a friend with knowledge' data category contained within the preceding major category (Table 4). The problem of not sensitively dealing with the carer in this matter was clearly highlighted by Chenoweth & Spencer (1986). They described the experience of one carer who, after being told by her doctor that she had no choice over the decision to place her husband into care, experienced a state of shock when these instructions were carried through. This issue of the carer holding the power to make such decisions has already been identified and discussed within the preceding major category chapter (Table 4).

The Loss of the Key-Worker

The 'letting go' process was not only confined to the loss of the dependant to institutional care or death. There was an acceptance from this key-worker that she could not remain involved within the care setting indefinitely and saw a natural point when she could detach from the scene:

'Once we sort, I suppose the medication, and how he is then that's, I suppose, naturally going to come to an end in terms of my involvement...' (Key-Worker 8)

This key-worker's viewpoint corresponded with Peplau (1987) who considered that all professional relationships were conceptualised into four overlapping phases of orientation, identification, working and, the area being discussed here, termination. Aggleton & Chalmers (2000), in their critique of Peplau's

development model for nursing practice, discussed this author's end stage of the relationship with the care recipient, which she entitled the 'resolution phase'. Within this phase Peplau considered that the end point of the professional's relationship could only be considered when the care recipient, the carer in this case, was able to act independently. This implied the open consent of the recipient to the ending of such shared involvement.

While this model was primarily aimed at 'nurses' caring for 'patients', the model put forward by Aneshensel et al (1995) described a three-stage care-giving process, but this time directed at the carer. The last stage of their process, 'disengagement from care-giving' closely corresponded to the 'letting go', process discussed here, and was described as entailing bereavement, recovery and the process of reintegration into the carer's social network following the death of the dependant. Willoughby & Keating (1991) earlier described this re-engagement process, whereby the carer picked up the threads of their social life following the dependant's death. Their model also outlined a multi-stage process of caring with the fifth and final stage labelled 'moving on'. In this stage, the theme was on the carer 'letting go' of caring and looking ahead to the future. This stage also involved the care professional withdrawing, but these authors pointed out that the professional often expressed disappointment at the carer not taken up any further helping services such as grief workshops.

The key-worker did not always necessarily see this process of disengagement as being a point of discharge, but rather one of limiting involvement. They could, even following discharge of the case, still remain involved with the carer:

'... you still have that relationship, so it's never quite terminated. I don't like that word at all, there's always a recognition I have is I'm still here and if they need me to pop back out, even if it's one visit, or they can leave it six months. Nine times out of ten the patients that we see are on some kind of medication, you know for memory, and we have a protocol which means we have to visit, you know, so many times and then we visit every six months. So he would be included in that even if they did terminate it I would be very sure I would be back there in six months anyway.' (Key-Worker 8)

For some carers, however, the thought of losing their key-worker, even for a few months, was a negatively perceived development:

'... at one point (husband) was doing really well (and) she (key-worker) said I think I'm going to try and leave it, I can't remember if it was three months or six, but I remember (the) panic feeling then, and I didn't want that. I wouldn't have said anything except what you have to, you know, what you can get me, lets face it it's the National Health Service, you've got to be reasonable. But I did feel panic then. I definitely did feel panic. Her coming in even half an hour once a fortnight.' (Carer 7)

Disengagement from the care scene seemed to present a problematic decision making process for some key-workers:

'I tried distance and tried (to) discharge; I know that doesn't sound very good. There came a point where he (husband) was fairly stable... he was more or less (at) the same stage. Although there was a recognition from me (that) wouldn't last for ever and it seems to come to a natural end for that, and I think I said to her (carer), you know, I said can we just leave things for a couple of months, you know, maybe six months come back, we'll see, you know, she seemed to be coping with present support, and that was fine, you know, we'll just leave things a wee while and come back, but in that time he did get worse, he got worse, he got remarkably worse.' (Key-Worker 7)

Another key-worker favoured discontinuing involvement and allowing another service to take over:

'... and I see a great desire that social work will take over an awful lot of that care as well. I can suspect the social worker will very much do what I'm doing at the moment in a lot of ways.' (Key-Worker 8)

Clarke (1999c) considered that the professional has two options once involved in care, either to remain involved and so over time move from a supervisory role to a more instrumental role, or make an effort to discontinue such involvement and pass the care onto another professional care worker. According to Adams (1999), CPNs prepared patients, and associated carers, for their eventual withdrawal by advising them on their initial visit that they would someday have to withdraw their service. This need to judge when best to inform on the

possibility of service withdrawal, or preparing the carer to let go, was of considerable importance.

For the following key-worker this whole aspect of 'letting go', including hospitalisation, involved them carefully outlining what might be in front of them or 'preparing the road ahead'. This aspect has been discussed within the substantive code, 'The Knowledgeable Professional Exercises Control', contained within the preceding major category chapter (Table 4):

'(I) tend to again very much, like we talked earlier, about bringing concepts and ideas that might not be appropriate at this stage, but maybe appropriate in the medium to long term. I tend to bring things up, well you realise, at certain points.' (Key-Worker 17)

This need to prepare the carer, in particular, was something that was considered a rather difficult exercise by this same key-worker who was commenting on how he felt when withdrawing his input:

'It's difficult (managing withdrawal from a care setting), I've certainly come across that situation a couple of times now where there is a difficulty.'
(Key-Worker 17)

Involvement Beyond Admission or Death

A further aspect involving 'The Costs of Caring' substantive theme again concerned overcoming the process of loss discussed within the earlier data

categories, particularly 'The Anguish of Letting Go' data category (Table 5). Here the termination process involved when, or whether, to withdraw key-worker services following the permanent admission or death of a dependant. This was an area of contention among key-workers and carers alike. The following key-worker clearly felt that her involvement should have ended, but not necessarily immediately following admission:

'What I tend to do is when they are in care, or they've died, is probably to phone them (the carer), I mean I immediately make a point of going down and having a chat... and again it's this, I'm not actively going to be involved with you but if you have, you know, any concerns or worries then ... I can come back out. I would do that, I would support them like that, I wouldn't say final, final.'

(Key-Worker 8)

The following key-worker had, up until now, believed that his involvement should end once the dependant was no longer staying within the home setting. Surprisingly he felt that, should the carer be experiencing continued problems, another service should take up the case despite the fact that he had an existing and possibly a stronger relationship with that carer, linking this code to the preceding major category's first substantive code's data category, 'Carer versus Dependant: Who is the Key-Worker there for?' (Table 4):

'... in my experience it is a tendency to discharge. If the carer is needy, if the carer has got problems, even though we have made a close relationship, (and) things like that, they would still be put elsewhere, whether that means the adult

team (or) say, for instance, under sixty five, or to social work, you know, they would certainly be off our case.' (Key-Worker 18)

In contrast to the policy of withdrawal after the dependant had left the home, what appeared to be a more compassionate spirit of remaining involved after the dependant's death was evident within the following key-worker's account. The carer's wife had unfortunately died following his agreement to take part in this study but, given his recent care experiences and strong desire to still be interviewed, his contribution and that of his key-worker was included within the study:

'But I would do that for, I've done it in the past and certainly you just maybe ran it past the General Practitioner to say, "I'll pop in every now and again just to see how he's getting on"... I think because you were involved certainly, I think its just good practice, well obviously he is more likely to run into problems over the next few months. You really don't want to think that, because his wife is dead now, that that's the end of (carer) and (wife). But he's got my telephone number and certainly he's took a big loss in his life because she was his life. Everything revolved round her over the last few years and now he's alone, it's certainly, you don't know which way it could go for him certainly... I've seen him once certainly since his wife died and he seems to be coping fairly well. And I'll probably pop down when I get another quarter of an hour, you know, just whenever I'm passing and see how he's getting on... It's looking after the carer. It is in some ways I would say, I think it's obviously the first three to four months is going to be a bit unadjusted for him certainly, and if he's doing okay over the

first three to four months I take it, you know, the natural healing process will do the rest. ' (Key-Worker 6)

Morris (1993) argued that Government Departments must monitor and review the 'terminal care' services available to dementia carers in order to promote their health through aftercare support and counselling for those who were bereaved. Watkins (1993) highlighted how the King's Fund (1989) ten-point plan raised the need for carers to have 'someone to talk to about their own emotional needs' both while they are caring, and once their caring responsibilities had ended. Aneshensel et al (1995) identified that following the admission or death of a dependent the carer often experienced an extended period of grief and social readjustment. Allen (2000), herself a former dementia carer for many years, agreed with this view when she summed up the carer's continued need for professional support. In an open letter entitled 'Where did all the people go?' Allen described her dismay at suffering a terrible sense of loss with the death of her husband, whom she described as her best friend. Tragically she highlighted experiencing the double blow of losing both her husband and also contact with those who had helped her through the arduous process of his long deterioration and subsequent death.

This willingness to remain in contact with the carer was also evident when a dependent had been permanently hospitalised. The following carer had been caring for his wife when he agreed to being included within this study, but since then her health had deteriorated and she had been hospitalised. Like Carer 6 he still wished to be included in the study and had a relevant contribution to make.

He expressed his satisfaction that his key-worker made the effort to visit him, even when his wife was no longer within the home:

'I think it's good because (key-worker) even told me, she said (carer), if there is anything you want to know or that, she says I'll even come up and have a cup of coffee with you and a wee talk, but I haven't required it.' (Carer 11)

A need to remain involved with the carer was also highlighted by Nolan et al (1996b). They considered that it was now more widely recognised that when the dependant finally entered into the formal care setting this was not the end of care-giving by the carer, but rather the beginning of a very different but equally stressful period. When the following key-worker contacted this carer by telephone, demonstrating continued interest and concern for his hospitalised wife, it was regarded as highly reassuring and beneficial:

'She did phone me up one day just to see how (wife) was getting on, and I said she's doing not to bad. I said she's a bit weepy when I'm coming away but, I'm, hopefully that's going to pass because the last three days now I've got away and she's okay.' (Carer 11)

Nolan et al (1996b) pointed out how 'sensitive and appropriate support' from the professional care worker could do a tremendous amount to ease this difficult transition in the carer's life. Macera et al (1993) argued that key-worker activity, designed to relieve the care burden, directly improved mental and physical health. This produced long term gains for the carer, even after their

caring responsibilities had ended. The design and execution of this study unfortunately was only briefly outlined. The sample of 82 carers was drawn from carer support groups and this raised a concern over how representative this group was in terms of the wider carer population. The researchers themselves highlighted several limitations including a weakness associated with the cross-sectional nature of the sample group along with the stability of the data-gathering tool.

Finally with regard to this aspect of discharging the carer once the dependant was no longer present, it was interesting to note a change of view from Key-Worker 18. He had earlier expressed his belief that the professional would, and perhaps should, discharge the carer once the dependent was no longer within the home. However, following on from this earlier position, he had since reflected upon this viewpoint and, at the end, made the following rather surprising comment:

'I've thought about it, but not thought about it too deeply till now, and it's quite unfair and I suppose you could go along the lines (that), it's a wee bit cruel... I've probably left a gaping hole in these individuals' lives.' (Key-Worker 18)

THE REWARDING CARE EXPERIENCE

Simply a Duty to Care

What motivated carers to take on such 'burdens' of responsibility was a particularly interesting theme within this data category. For many, their caring tasks were viewed as responsibilities that simply had to be shouldered. Indeed

for some it was considered a 'duty'. The following carer viewed this duty to care as being simply inherent within a husband's role:

'It's just the fact that (wife) is my wife, and somebody's got to do it, why shouldn't I do it if I can do it?' (Carer 4)

The following carer linked this spousal duty to the length of time she had shared her life with her husband:

'Well just because I'm his wife and I feel it's me that should be doing these things... Well we've had, we've been together for 53 years (laugh), it's just one of those things, I just take it for granted that I eh, when he's not well I've got to do what he cannae do now.' (Carer 2)

Harris's (1993) study of male dementia carers developed a theme associated with 'the sense of duty to care' whereby the men experienced an overly developed sense of duty associated with the care of their dependant. This qualitative study used a purposive sample of fifteen male carers drawn from a diversity of backgrounds. The group was subjected to in-depth interviews although the analysis of the resultant data was not explained adequately. Clarke (1999c) considered that this question of duty involved a web of complexity associated with the relationship between the carer and dependant. She cited several studies aimed at uncovering the emotional bonds that influenced the carer that included aspects such as 'kinship obligation' (Qureshi & Simmons 1987; Ungerson 1987), 'responsibility' (Finch & Mason 1993), 'reciprocity' (Pratt et al 1987),

‘affection’ (Cicirelli 1983) and ‘mutuality’ (Hirschefeld 1981; Montenko 1989). Ross et al (1997), in their study looking at what motivated wives to visit their husbands admitted into long-term care, identified similar motivational factors such as devotion, duty and obligation. In addition to these factors, they found that wives also visited to monitor their husbands’ well-being and provide assistance to both them and to staff as well as to seek feelings of personal satisfaction and enjoyment. While this was an effectively designed study that used both a structured and unstructured interview style. Unfortunately, its sample of wives (78) was drawn from only one source and did not involve wives caring for husbands with dementia. It therefore differed from my own study in this important respect.

Cicirelli (1986) in a study of adult child carers, saw ‘filial obligation’ as one of the important variables associated with attachment behaviours towards a dependant parent. Guberman (1992) saw such ‘obligation and duty’ as representing the darker side of family relationships. Speaking principally about ‘blood ties’, these authors found that the mixture of emotional bonds experienced by the carer varied from carer to carer, but tended towards more negative feelings of duty, obligation, resignation and guilt. They went on to state that the decision to care for a sick or handicapped relative was often made with no thought given to future implications, and that these feelings of obligation reinforced the guilt they experienced. McKenzie (1999) considered that this duty to care extended beyond those related to the individual and was ‘an implicit moral obligation’ incumbent upon the wider society to protect those who are vulnerable and unable to protect themselves (p.433). Although this paper was neither dementia nor

carer specific, its viewpoint appeared relevant to my study's results. Arber & McGinn (1990), cited in Clarke (1999a), conversely spoke of the expectation to care being placed firmly on the shoulders of family, who were considered obliged to care by societal expectation and a wider political agenda.

Some carers saw taking on responsibility for caring as part of their upbringing and character. This carer described her competing responsibilities towards other family members and why she has had to undertake such duties:

'I've been brought up to be very responsible for my whole family, there is my youngest daughter with M.S. (multiple sclerosis), and we do a lot for her. And I'm trying to stop my son smoking. So, I'm trying to be a responsible person and look after him (husband), I do the driving and everything else, I do everything.'
(Carer 1)

This responsibility also carried with it certain more negative connotations. Abel (1991), while studying the perspectives of adult daughters caring for an elderly mother, found that 'the chasm between women's overriding sense of responsibility and their ultimate powerlessness was one of the major difficulties carers experienced' (p.76). Finch & Mason (1993), as cited by Clarke (1999a), made the point that the carer took on the caring role due to their overwhelming sense of responsibility. These feelings were clearly highlighted within a qualitative Swedish study that gathered data using open-ended interviews. While studying thirty-five daughters caring for a parent with dementia, Jansson et al (1998) noted that even after the parent moved into the institutional setting, the

daughters continued to feel a strong sense of responsibility for their care and well-being. This motivated them into providing continued caring activities while their parent resided within the institution.

The following carer saw this 'duty to care' more in terms of reciprocity:

'Em, well I'd like to think if the positions were reversed (husband) would want to look after me.' (Carer 2)

George (1986) considered the term reciprocity as a competing norm with that of solidarity. Reciprocity, she contended, meant that the carer and dependant would both give and gain from that relationship in fairly equal measure, and that reciprocity was a 'fundamental and universal guiding principle of human behaviour' (p.69). Pratt et al (1987), as cited by Clarke (1999a), highlighted this sense of reciprocity in terms of what carers were doing for their dependant would be done for them if circumstances were different. Qureshi & Walker (1989), in their discussion of carers of elderly people, considered reciprocity as one of the principle foundations of the caring relationship. Wenger (1994) concluded, following a study conducted on 61 people with dementia and their carers, that most carers felt appreciated by their dependant and while they could see positive aspects involved within their caring, they were motivated to care more mainly in terms of duty, responsibility or reciprocity. A strength of this study's design was that the interviews involved specially trained researchers although it was disappointing that the paper failed to adequately explain the process used in the analysis of the data. In the study conducted by Parson (1997), discussed earlier

within this category, the concept of reciprocity was also identified. The caring sons within the study based their relationship around the fact that the dependant had once cared for them and they wished to reciprocate that care as a final act of gratitude.

The following carer's account agreed that a sense of reciprocity underpinned her rationale for caring and, similar to the earlier carer's viewpoint (p.256), she also identified the length of time they had been together as a couple as being significant:

'Well we've been married for nearly forty years, he was there when he was always (husband), would have gone from one end of town to the other for you, he'd have done anything for you, he was just that type of person...' (Carer 8)

George (1986) although not specifically discussing dementia care, named two theoretical perspectives closely identified with the concept of reciprocity as 'Exchange Theory' and 'Equity Theory'. The former denoted where humans work on the premise of maximising their gains while, at the same time, minimising their losses. The latter focused on the 'dynamics of social relationships' and, in particular, the factors which led these relationships to be stable and satisfying. Equity theory predicted that those involved within the relationship would experience different kinds of stress if they either 'over-benefited' or 'under-benefited' from their involvement. Those who 'over-benefited' would experience guilt due to undue rewards and unfulfilled

obligations, while those who ‘under-benefited’ would feel anger and resentment as a consequence of the excesses of their contribution (George 1986).

Caring is a Real Privilege

The sense of having a ‘duty to care’, for whatever reason, was not always seen by the carer as the principle motivational factor behind them taking on the responsibility to care for a dependant. The data supporting this particular data category emerged predominantly from only one interview involving the younger wife of the only dependant experiencing pre-senile dementia. The strength of this carer’s (Carer 7) viewpoint and intensity of her desire to care was not as strongly evident within other interviews. This may have been a feature of her being a younger spouse caring for a younger dependant. Due to the limitations surrounding theoretical sampling, discussed within chapter ten, I was unable to explore this aspect with other carers sharing similar characteristics and problems. However, her viewpoint was valuable and the supporting data that emerged from the theoretically sampled literature made its inclusion within this study appropriate.

Carer 7 simply desired to provide all the necessary care her husband required:

‘And it’s my duty, well not a duty, because that makes it sound like you have to do it, I want to do it.’ (Carer 7)

The experience of caring was often considered to be one of negative choices (Webb & Morris 1994). Buckwalter et al (1995) while discussing the

professional's relationship with the person diagnosed with Alzheimer's disease, also expressed the view that the caring experience carries with it special joys. Sutcliffe (2001) and Brown (2001) both argued that the caring experience could be a source of great satisfaction for the carer. In keeping with the above carer's viewpoint, Clarke (1999c) pointed out that, in contrast to most studies looking at the lay-caring experience, some studies have been more positive with regard to the carer deriving some reward or benefit from involvement. Nolan & Grant (1989) and Nolan et al (1996b) pointed out, however, that this is a general area of the literature that was relatively 'embryonic' and lacked 'conceptual debate'. Clarke (1999a) cited several studies which were indicative of this more positive outlook on the caring experience, studies such as those by Ungerson (1987) and Montenko (1989) who noted that some carers actually experience pleasure, or even joy, from their experiences of caring. Montenko (1989) identified four features that were associated with gratification in spousal caring:

- Continuing closeness in the marital relationship
- The carer giving meaning to their experiences
- The quality of the social support network
- Characteristics of the dependant's illness

Grant & Nolan (1993) made effort to examine the rewards and benefits derived from the caring role and contended that for many carers rewards and satisfactions co-existed with the more negative aspects of stress and strain. They argued, therefore, that the relationship between motivators, stressors and caring rewards required a greater research study effort. Action (2002) similarly found this

positive outlook within the caring experience when one carer in her study expressed the belief that 'life is better than she ever imagined' and another stated that she found 'joy in life' (p.27). Action also found that carers expounded the view that to care for a loved one made them stronger. Daughters, and daughters-in-law, caring for a parent with dementia, in the study carried out by Yamamoto & Wallhagen (1997), expressed similar positive views believing that the experience 'made them become more tolerant, generous people' (p.173). This Grounded Theory study undertaken in Japan utilised a small carer sample (26), recruited using theoretical sampling techniques, from a variety of sources. This more rigorous method of sampling, coupled with the fact that the study followed sound and well-recognised principles associated with Grounded Theory method, strengthened the credibility of its findings. However, its focus on a Japanese population requires the reader to interpret these findings with some caution given that this society is culturally rather different from a Western European culture, particularly in terms of family values and responsibilities.

For the following carer the fact that she and her husband still held each other in deep affection and the longevity of their relationship were two important components associated with her rationale to care:

'Eh, well we've been together a long time, I mean forty two years we've been married, and we're still fond of each other, you know.' (Carer 5)

George (1986) believed that reciprocity, when considering the issue of carer burden, was in direct conflict with the 'norm' of solidarity. She considered that solidarity meant that:

'... we provide our loved ones with all the support and assistance they need, without concern for a return on our investments or for the emotional distress consequences...' (p 73).

This response to the often demanding nature of the carer/dependant relationship suggested that involvement without direct gain for the carer involved a significant degree of affection, a factor identified earlier by Cicirelli (1986). The following carer was even more forthright in her declaration of love for her husband, and felt that what she was doing for him now was only an extension of what she did before the illness, and that such care was also a cultural expectation placed upon her:

'No, it's caring for somebody you love. I mean let's face it, (husband) is an old time West of Scotland man, if you like. He was never one of these new men. So it's only a continuation of what you were doing anyway (laugh). Most men would let you do anything for them anyway if you were going to do it, so to speak.' (Carer 7)

This emotional bond was also evident to this carer's key-worker who concluded that this level of affection had a very positive and strong impact upon her husband's emotional and mental state. This feature linked closely to the data

category, 'Carer Provides Best Care Because of their Intimate Knowledge of Dependant', contained within the substantive code, 'The Independent Carer', within the preceding major category (Table 4):

'The love she has for him is still very strong, and vice versa. You can see it in him, he recognises her you know its, give me a kiss, and he'll make all the motions to go towards her. This man is very impaired, you know, it's physically and mentally, so impaired (that) you (would) think he wasn't capable of that. I think when you see that happening, you know, it's a positive thing, this doesn't happen all the time.' (Key-Worker 7)

This ability for a highly incapacitated dependant to give back love and approval, thus providing the carer with a sense of reward, was acknowledged by Hocking (1994). Such deep levels of affection towards the dependant could, however, carry a more negative implication for the Carer/Key-Worker relationship. Twigg (1995) found that even the most heavily burdened carers could be so committed to their 'loving' relationship that to give up on their caring role would have been a total anathema to them. Twigg's views however were not based solely upon dementia carers but were generalised to a wide range of conditions which required informal caring. The aspect of the caring role being associated with a 'duty' and 'an act of love' were considered to be the motivational factors towards the carer providing care. It could, consequently, become difficult for the carer to allow others to become involved in the care setting as they believed no one could provide care equal to them (Gilliard & Rabins 1999).

The viewpoint that the carer provided the best care because they knew and loved the dependant has already been identified and explored under the substantive code 'The Independent Carer', contained within the preceding major category chapter (Table 4). Woods and Watson (2000) considered that many carers avoided alternatives to caring for the person they love, but cautioned that this assumption should not be made of all carers. They believed that previous levels of affection could see both members of the carer/dependant relationship through problematic times and would help make their experiences more rewarding. For some the fact was that they simply loved their dependant and just because they had developed a progressive illness did not alter their feelings for that person. This contention not to give up on caring for the dependant was closely associated with the 'Anguish of Letting go' substantive code explored earlier within this major category chapter (Table 5).

The provision of care to a close family member, as compared to carrying out such tasks as an employed care worker, was an area where some carers contrasted in their opinions. The following carer felt that this experience was much worse for the carer as they just could not escape the demanding behaviour exhibited by their dependant:

'Of course, yes, you could walk out, your shift is finished and (you) go home. But it's a hang of a difference when it's twenty four hours a day, and at night... he's like that, you can have weeks, he's up all day and for weeks he's up all night.'
(Carer 10)

This experience was, however very different for this younger carer caring for a husband with advanced pre-senile dementia. She had a much more positive viewpoint when she compared her caring experience to that of an employment scenario:

'It's a pleasure, I mean, it's like your work, everybody comes in and says, oh he's looking nice, or that's a nice shirt (husband), or, you know... he's all washed and dressed and changed, every item every single day. It's a pleasure to see him, you know, I feel it lets people not just look at the blankness in his eyes, if you catch something else first of all, then these things become secondary.'

(Carer 7)

However, this carer did draw a clear distinction between such work based comparisons in terms of her own motivational factors to care for her husband, caring for him was certainly was not a duty:

'It's a duty at work, it's definitely a duty at work.' (Carer 7)

Within the study undertaken by Harris (1993), some men involved in caring for wives diagnosed with dementia did so out of a sincere love and a sense of commitment, not duty. Clarke (1995) highlighted how carers interpreted their caring role and how they endeavoured to 'make sense' of their experiences in an effort to re-establish some control, and a sense of predictability, over their lives. Askham (1995) argued that an important feature of the carer's ability to cope was in being able to give meaning to their experience. In her study 106 carers were

asked to define what was happening to their relative and Askham elicited that their interpretations centred on a negative/positive continuum.

In contrast to the negative interpretations found within the earlier preceding substantive code, 'The Costs of Caring', Carer 7 felt strongly that she had experienced a very rewarding outcome through being involved in caring for her husband:

'Certainly his personal care, I never realised that he must have cleaned his ears all the time because they get dirty and I have to clean his ears, and this morning I was up his nose as well (laugh). I quite like nursing of any description, I feel its really rewarding... it's not all doom and gloom.' (Carer 7)

This sense of emotional gain for having provided care was also recognised within the comments of her associated key-worker:

'No she definitely reaps the rewards from him in regard to what stage he's been at. She's always picked up rewards from him.' (Key-Worker 7)

Montenko (1989), as cited by Clarke (1999a), addressed this aspect of gains and rewards in a study of 50 older dementia carers looking after a husband at home. Using interviews this researcher found that gratification within the caring role was linked to a greater level of well-being, while frustration centred more on distress. The risk of distress developing was associated with interpreting their world in a more negative way. This finding linked closely to the first major

category's substantive code, 'Enhanced Relationship Properties' whereby the data category, 'Carer Experiences a Real Psychological Benefit' identified that validation of the carer's role provided an important psychological boost to carer spirits (Table 3). Askham (1995) found that some carers, in their effort to give meaning to the caring role, adopted what Ungerson (1983; 1987) described as a 'mothering model' describing their responsibilities in terms of caring for a child. The use of this analogy described earlier within the discussion of the 'Costs of Caring' substantive code was interpreted in a more negative context, whereby the carers focussed upon the more difficult behaviours causing them distress. This interpretation, however, was in contrast to that of Carer 7 who continued to contradict other carers' accounts. She discerned a distinct 'silver lining' associated with providing care to her husband:

'... and I've been lucky enough to get the child from him, you know, most people, when they get married, don't know the child. I know the child again.' (Carer 7)

This surprising viewpoint could carry concerns in that this carer was infantilising her husband and perhaps held a rather faulty and even perverse outlook regarding him and his care. This couple, however, had two adult children who were both in regular contact and so such an interpretation was unlikely to be attributed to any pseudo-mothering role. In this particular situation, Carer 7 had discussed her very strong relationship with her husband throughout their marriage. She volunteered that they had, and continued to share, a strong and intimate marital relationship that helped her now provide a level of care that both amused and stimulated him. This was a feature that corresponded closely to the preceding

major category's data category, 'Carer Provides Best Care Because of their Intimate Knowledge of Dependant' (Table 4):

'And we can get a laugh out of him. Actually it's quite a lot. He laughs at sexual innuendo. He picks up on that. As a joke you know... He knows that's something naughty, if you like, and he always laughs at something like that.'
(Carer 7)

Carver et al (1989) believed that such optimistic interpretations were associated with active coping efforts, making the best of whatever comes the individual's way, while a more pessimistic outlook led to emotional distress and disengagement. Harvey (2001) agreed that while the life for the carer held many negative aspects, it could reward them by making them feel valued by both their dependant and the wider family. It could also bring them closer to the person they cared for and increase their confidence in their own abilities.

Despite initial concern surrounding carer 7's interpretation being potentially problematic, and recognising that her position still could carry significant difficulties regarding her 'Letting Go' process, her key-worker still strongly considered that this lady was both motivated and able to cope with her arduous care demand. Her husband was only 55 years of age, she 53, and he was severely affected by the dementia process to the point that he required virtually total care within the home, a demand that, to her key-worker, she appeared to deal with admirably. Carer 7's optimistic philosophy towards the care of her husband was highly admired by her key-worker who shared this positive

interpretation of her caring philosophy and considered that her approach should be a lesson for all care professionals. To myself, this viewpoint typified the essence of this 'Rewarding Care Experience' substantive code:

'I know she nurtures him in a way almost quite child like, but not patronising at all to him. She has it really down to a fine art that would make most nurses in our wards step back and look at themselves to be quite honest.' (Key-Worker 7)

CHAPTER EIGHT MEDIATING INFLUENCES ACROSS THE CARER/KEY-WORKER RELATIONSHIP

The following chapter addresses factors that created ‘Mediating Influences Across The Carer/Key-Worker Relationship’, and therefore impacted across the preceding three major category areas (Tables 3 - 5). These factors were external to the parties involved but did affect the developing relationship. Such mediating influences within this major category chapter were associated with the substantive codes ‘Organisational and Community/Family Influences’, ‘Carer Domestic Circumstance and Biographical Influences’ and, finally ‘Educational/Experiential Influences’ (Table 6). These forces had the potential to either positively or negatively influence the preceding three major category areas associated with the Carer/Key-Worker relationship and its resultant impact upon the care setting.

ORGANISATIONAL AND COMMUNITY/FAMILY INFLUENCES

Influences from the Employing Authority

One of the earliest factors to emerge within this data category area involved the professional’s employing organisation. Procedures and protocols associated with the employer influenced many practice initiatives and were significant in the creation of the ‘quality’ Carer/Key-Worker relationship. The following carer identified the problem of accessing resources quickly enough when circumstances became more stressful:

“But it was then when it was getting really bad (key-worker) said we’ll have to force this through she said but you understand that there’s, it’s hard to get a place in the hospitals at the moment. But she said the way (dependant) going now it’s really serious and we’ll get her in as soon as we can. But during that time, you know, I was having (problems) everyday, very stressful.” (Carer 11)

Table 6 Mediating Influences across the Carer/Key-Worker Relationship: Codes & Categories

| DATA CATEGORIES | SUBSTANTIVE CODES | MAJOR CATEGORY |
|---|---|--|
| <ul style="list-style-type: none"> • Influences from the Employing Authority • Carer Support Groups • Support from Neighbours, Friends and Family | ORGANISATIONAL & COMMUNITY/FAMILY INFLUENCES | MEDIATING INFLUENCES ACROSS THE CARER/KEY-WORKER RELATIONSHIP |
| <ul style="list-style-type: none"> • Domestic Circumstance of the Carer • Dependant’s Condition Influences the Relationship • Nature of the Carer/Dependant Relationship • Gender Influence • Age as an Influence on the Relationship | CARER DOMESTIC CIRCUMSTANCE & BIOGRAPHICAL INFLUENCES | |
| <ul style="list-style-type: none"> • Educational Influence • Life/Professional Experience Influences | EDUCATIONAL & EXPERIENTIAL INFLUENCES | |

This comment suggested two aspects that impacted upon the relationship. At one level, the development of the relationship was restricted when the professional was perceived as impotent and stress continued to build on the carer. At another level, this comment suggested a potential for enhancing the relationship whereby

key-workers were, in general, seen to 'fight' the carer's cause in a genuine attempt to gain available resources and this brought them closer to the carers as a strong ally. The following key-workers, as discussed within the proceeding category, suggested that this latter aspect was dependent upon the professional's ability to gain sufficient time with the carer in order to allow their relationship to deepen. Here the key-worker experienced a pressure to discharge prematurely and so was unable to spend sufficient time with the carer to maximise their association:

'... there's definitely a pressure to discharge people when people are coming in new to the system um because there's a limit to how many people you can see um within that week. Therefore, if you have Mr and Mrs A ongoing forever um Mr and Mrs B would not be getting seen...I know I may have provided something but um for the good of others you will have to stop contact.' (Key-Worker 1)

'Unfortunately because of the constraints on our service I've had to discharge her because it's come to the top of the protocol, finish the protocol to go to the memory clinic... I don't have the resources in the team to do that. You're talking about 3 nurses in the (local) area; it's like 1.5 nurse(s) allocated to the area. We don't have the resources to follow people through from beginning to end.'
(Key-Worker 12)

'... I think it's very important but the demands of social work at the precise moment in time are such that you're going in for supervision. And there are

cases that you would like to hold onto (that) you've been told to close because your team leader wants to allocate more cases.' (Key-Worker14)

Here the key-workers face the perennial dilemma of increasing caseload numbers threatening their developing relationship. A realistic balance has to be struck between demands placed upon the service and the provision of resources, including sufficient numbers of professionals. The issue of a lack of resources detracting from the relationship and impacting upon the care giving-experience was a consistent theme within this study:

'And the resources, sometimes the resources, people go to hospital and there isn't a bed, there's not a lot you can do about that sometimes.' (Key-Worker 6)

The literature widely reported a frustration associated with the bureaucracy and general lack of resources within the caring organisations (Tissier 1993a; Tissier 1993b; Badger et al 1990; Morris 1993; Nicholson & White 1993; Rutman 1996; Marshall 2001; Walker et al 2001). The following UK quantitative study examined two cohorts of elderly people and their carers, one being individuals with a dementia diagnoses. Philip et al (1995) found that dementia carers required additional support to those dealing with elderly dependants not experiencing dementia. It was worthy of note that a potential for bias existed in that the sample was not randomly selected.

McErlean's (2001) Grounded Theory study, already discussed within the second major category chapter, suggested that this frustration with resource provision

was recognised by professionals working with carers. This thesis claimed that the professionals held significant concerns over the health of carers due to this lack of adequate provision and a lack of adequate education and training. The professionals within this study felt that operating within a 'medical model' led to an under-resourcing of service provision which greatly inhibited their ability to provide 'consultation, training, counselling and support to carers...' (p.47).

Jones & Peters (1992) argued that care responsibility fell largely onto the carers of elderly people due to UK Government policy. Ultimately, and arguably, the most significant organisation within any society is its national Government who exercise overall responsibility for health and social care provision, be that through public or private means. Gannon et al (1990) believed that the Irish Government had to take measures to relieve carer burden if the policy of maintaining people with dementia within the community was to survive. The UK Government, through the Carers (Recognition and Services) Act (1995), brought much needed and belated political recognition to the plight of carers. However, in a critique of this legislation, Ratcliffe (1998) considered that far from rewarding the family carer the Act weakened their position. It made explicit for the first time the assumption that the 'primary responsibility' for providing care lay with the relatives (carers) and not the state, and the state reserved the right to withhold or withdraw services in light of the financial circumstances that prevailed at that time.

Twigg (1995) considered that these disagreements and areas of conflict between the parties involved in the care of people with a dementia diagnosis was an

acknowledged fact, including disagreements between care organisations and carers themselves. In a survey of self-selecting carers of older people, not necessarily with dementia, Smith et al (2003) highlighted that 93% of respondents felt that personal care for older people should be provided by the state. Caution had to be taken given the self-selecting nature of the sample within this study although the size of this sample (174) compensated somewhat for this area of potential bias. Iain Gray, the Deputy Minister for Community Care in Scotland, within his forward to the report, 'Strategy for Carers in Scotland' (1999), made explicit the Scottish Executive (Scottish Executive 1999) appreciation of the vital contribution made by carers. He stated that the Scottish Executive's aim was '... to ensure that all carers have access to flexible, quality services at a local level.' The lack of such political and economic support was, according to the study by Tebb & Jivanjee (2000), a major source of isolation linking this major category with the preceding chapter's substantive code, 'The Costs of Caring' (Table 5).

Kitwood (1997) believed that organisations associated with dementia care were largely immobile, bureaucratic structures resistant to development. The greatest challenge for health care systems was to ensure adequate professional resources to carers which were both evidence-based and achieved desired health care requirements, while providing value for money in a cost conscious political environment (Soliman 2003). This political/economic issue was a major obstacle for Bender (2003) who disagreed with the optimistic viewpoint voiced by Adams & Clarke (1999) on the likely future of dementia care. In Bender's opinion, the future was bleak for the person with dementia and their carers. He considered

that access to resources was an essential requirement in overcoming existing problems within dementia care, and that these resources were highly dependent upon effective political decision-making. Bender concluded that, as this level decision-making was highly unlikely, these resources would not be realised making any improvements within dementia care highly improbable.

The following key-worker considered that the consequences deriving from the more bureaucratic organisation posed a significant barrier to effective care activities and consequently meant that time with the carer and dependant was unnecessarily restricted:

'This is where I moan a bit, I believe that the amount of paper-work that we are now being asked to do is taking away from the actual social work, in no small way we're responsible for the decimation of the Brazilian rain forest. That's the way I feel about it, it's outrageous so and it's not just me, my colleagues feel the same that your getting more desk bound all the time. And to do social work you've got to be sitting face to face...' (Key-Worker 14)

Pressure of work was a factor that inhibited the professional from spending time with the carers of mentally disordered people, generally (Twigg & Aitkin 1994), and dementia carers specifically (Eaton 1995). The concept of requiring to spend time with the carer links this data code directly to the first major category chapter where the data category, 'The Frequency of Contact and Time', highlighted the importance of this to the developing Carer/Key-Worker relationship (Table 3). Within an Irish study of carers, McCann & Evans (2002) examined a statistically

representative sample of dependants and carers, although not dementia specific, using questionnaire and interview methods. The study's purpose was to gain data that would provide an insight into the dependants' views on their carers' ability to provide effective care. The study identified that healthcare authorities must acknowledge the fact that professional contact with carers must ensure a higher quality of care input by the carer which, potentially, will reduce existing tensions.

The following key-worker agreed that difficulties she experienced within the care setting were often a consequence of her management structure. Many associated problems came down to the inability of service managers to see the carer's needs and to recognise these needs as being sufficiently valid as to demand some priority in terms of resource allocation:

'... there are lots of services in England that support carers like the Admiral Nurses, but we've certainly asked for, you know, put bids in but they, nobody sees that as a priority, our managers thought it was further down the line.'

(Key-Worker 16)

Key-Worker 9 found organisational impositions and a lack of adequate resources led to unwelcome changes in her practice. While her intention was to become more involved with carer issues, dealing with any emotional problems they faced through counselling approaches, this was inhibited by the organisation's demands:

'... social work (has) been moved away to some extent from counselling roles, and that's probably about time constraints on the rest of it, you know.'

(Key-Worker 9)

Here, Key-Worker 9 clearly felt restricted from moving into more sensitive aspects of the carer's experiences and, due to the restriction upon time, was unable to adopt practices such as, 'The Key-Worker Goes the Extra Mile', data category spoken of within the first major category chapter (Table 3). This key-worker went on to express a rather more philosophical, if not resigned, viewpoint when it came to difficulties with employing organisations and their subsequent impact on the carer:

'I can think of another carer that I'm working with right at the minute and its been really, really very difficult and largely that has been because there hasn't been services there that this carer felt should have been there. And I absolutely agree with her in that but, unfortunately, as a representative of the organisation, I'm the person that's kind of you know to take the flak for that.' (Key-Worker 9)

The difficulties experienced here largely fell outwith the control of the key-worker but still had a significant impact upon her developing relationship with the carer. Here the key-worker, by taking overall responsibility for quality of service being provided, literally became a 'lightning-conductor' for all frustrations and shortcomings created by her employing authority.

Carer Support Groups

Many carers in this study were in receipt of additional support, outwith the Carer/Key-Worker relationship, aimed at assisting them deal with their dependant. Two important sources of such support came via day-care services for the person with dementia and/or carer support groups:

'Well, eh, it was the CPN service as well that got my mum in (local day care) which is in (the) day care service she attends. And they have a carers' group which is quite helpful... There is support there in the sense that you've got carers' groups and things like that...' (Carer 9)

The carers in this study regularly made reference to the carer support group. The following carer was not in receipt of this form of service but voiced how she felt that access to such a group would have been helpful:

'... there is not always somebody in the same position as you. It would be nice actually to talk to somebody whose husband was in the same position as yours. That kind of thing I don't feel there's enough of that kind of thing.' (Carer 17)

Carers have expressed the belief that carer groups have been a benefit when caring for someone diagnosed with dementia (Armstrong 1997; Walton 1999). Many authors have identified the need for the carer to avoid isolation by meeting up with other like-situated individuals where they can share views and experiences (Hettiaratchy & Manthorpe 1992; Cameron 1993; Harris 1993; Webb & Morris 1994; Gilliard 1997; Gilliard & Rabins 1999; Walton

1999; Woods & Watson 2000). Access to a carer group could significantly boost carer self-confidence, self-esteem and provide a significant level of emotional support (Parker 1990; Carson 1992; McErlean 2001; Shankland 2002). Russo et al (1995), in a study of 82 carer-dependant dyads, found that carers who had had a history of depression and anxiety showed no greater need for support groups than those whose emotional need derived directly from present care-giving demands. This suggested that the needs associated with caring for an individual with dementia were, in themselves, sufficiently demanding to indicate a need for such additional social support mechanisms. However, some bias may have been introduced through the self-selecting process used when recruiting the sample for this study.

However, for some carers within my study, carer groups and day carer services were not viewed in such positive terms. These carers felt that meeting with other carers risked unhelpful and negative comments being made to them, and the continual focus on the illness contributed to their sense of burden:

'... and I was going to support groups and things like that to find support. I didn't get it until the CPN was introduced into the picture... I just felt they were wallowing in it an awful lot these people, and you know my husband's got this and my husband's got that and oh wait till he's doing this and whatnot, and I can't handle it that way.' (Carer 7)

'You see I started going to the carers' group once a month... it was all ladies or should I say women and people were kind of nice and they would say is it your

husband and is he at home and this and that and the next thing... then a voice over here would say oh you don't know what's in front of you, oh wait until such and such happens and oh and this happened quite a few times and I thought no, I don't want to be there, this is not for me.' (Carer 8)

'... if I'm going to have anything... I'd rather have something outside the illness. I don't want to be totally immersed in this illness... I don't know, my feeling about it is that when I go out I want to get away from the illness, I don't want to be going into it.' (Carer 15)

'Well this is what I feel, I wouldn't really like to go to a group if you like... Everybody sitting around moaning.' (Carer 17)

Carer 15's above comments around the need to escape the illness was readily understood and encouraged by her key-worker:

'If she can free up any time then she wants to free it up to go and enjoy herself and go and see her friends, to go and see her relatives, to be able to go to the theatre, to be able to go and do this and that. She doesn't actually want to sit in a group and get more bogged down with (dependant's) worries and her problems. She needs a release from it if you like.' (Key-Worker 15)

However, Carer 15 had, when reflecting upon the function of carer groups, expressed a sense of guilt over her lack of involvement, and saw this as her being selfish. This was a rather negative and certainly unwanted effect upon a carer

that could only lead her to experience more stress in an often overly stressful situation:

'And maybe that's selfish, I don't know, maybe going to the carers' groups then I would have something to give other people, and they would have something to give me.' (Carer 15)

Little evidence of this more negative interpretation of carer support groups specifically, and other community support services generally, was evident within the contemporary literature. Nolan & Dellasega's (2000) survey of carers within the USA (54) and UK (48) identified a striking difference between these cohorts in terms of the availability of support groups and their beneficial effects on carers within the US. This could be the reason, it was suggested, why this cohort reported greater opportunities to talk about their emotional issues and having a sense of someone being there to listen.

The following key-worker summed up two possible outcomes from carer involvement with the carer support group:

'... yes they're great and they are of benefit, I'm not knocking them entirely. I don't have a great feeling about that; they are particularly supportive to some people. I think one-to-one working with people is more important because no one situation is the same. And there is nothing worse, and I explain that quite clearly, but she turned up (to the group), my husband's doing this, my husband's doing that, well if you think that's bad then wait to see what my husband did and

why he is in a nursing home now. And you know, and she's with all these really negative things and that takes away totally what I'm trying to do...'

(Key-Worker 8)

Carer 9 gave a further reason for a more negative interpretation of carer support groups. She considered age to be a factor, an issue to be explored within the following substantive code, where age may influence the Carer/Key-Worker's relationship development and the subsequent care-giving experience:

'... the other thing about that carers' group that although it is really good I haven't attended that many because they are all really old...' (Carer 9)

Support from Neighbours, Friends and Family

In keeping with the theme associated with the 'Organisational & Community/Family Influences' substantive code (Table 6), a further area of significant influence, that was out-with the Carer/Key-Worker relationship, derived from the wider community and involved close neighbours, friends and other family members. Several carers found this support invaluable to them and often paralleled the qualities derived from the more effective Carer/Key-Worker relationship, qualities such as listening, being easily available, demonstrating empathic understanding or 'going the extra mile' by undertaking tasks seen by the carers as benevolent acts. Having this alternative level of support made the requirement to develop a deeper relationship with the key-worker less of a necessity. This was a factor that particularly influences the preceding two major categories in that it enhanced 'The Rewarding Care Experience' substantive code

(Table 5), thereby making the need for the stronger carer/key-worker relationship 'Working Together: A Therapeutic Alliance (Table 4) less of a requirement. A good and supportive relationship with friends was all that was necessary:

'Well obviously buying clothes, I've got to buy but friends are quite good at that, they help me out... We're quite fortunate in that sense, really plenty of other help without having to (put) it on to the CPN or anything like that.' (Carer 4)

'I do have one other friend whose husband has Parkinson's and we have a good relationship because we can relate to each other. She is the only one because I honestly don't feel that people understand mental health problems.' (Carer 15)

'Well I've got a friend, one of my friends she listens, she's a good listener... Very important, and she doesn't say much, she just listens.' (Carer 16)

Some carers experienced this level of support from within the family:

'And my brother-in-law, that's (wife's) brother, they were very good at the time... It was just her trouble, so he used to come down in the car at 6 o'clock in the morning with his wife to try and give me support and to calm her down.' (Carer 11)

'And financially I'm independent because (son's) been good to us, my son.' (Carer 16)

'My son does because he's seen quite a lot... I couldn't leave (husband) so we'd to take him, so my son says I'll come as well and I'll have a beer with my dad while you're going out with the wee one and that, so he's been really brilliant.'
(Carer 17)

In this circumstance a strong positive input from the family member would likewise influence the other preceding major categories. Keady (1996) cited studies by Green (1988) and Parker & Lawton (1994) which discovered that the families had a tendency to draw upon one member, usually a spouse or adult child, for such support. This tendency was criticised by Adams (1999) who believed that this focus on the primary carer was problematic as it contributed to the burden placed upon that individual. When a person developed dementia, this model of family care was 'conceptually inadequate' as the whole family suffered and not just one member of the family. Social contact and support for the carer was viewed by several authors as being a positive requirement that improved their ability to cope more positively with their role (Tebb 1994; McCarty 1996; Mills 2000; Adams & Manthorpe 2003). In keeping with these findings, Harper & Lund's (1990) study found that both male and female carers cited a lack of social support as one of the principal reasons why they had experienced increased levels of stress.

In an Australian study by Brodaty & Hadzi-Pavlovic (1990), a large sample of family carers were surveyed using a pre-existing questionnaire. Significant effort appeared to have been made to minimise any risk of bias. The results demonstrated that more contacts outwith the home, and a satisfaction with the

number of people in contact, meant that carers suffered significantly fewer psychological problems. They postulated that support coming from those around the carer was inversely proportional to the 'psychological morbidity' derived from the caring role. Carter (1999) pointed out that the results of a 1985 General Household Survey found that spouse carers had a greater need for social activities to be available rather than any form of practical help. Grant & Nolan (1993) found that friends and family provided the carer with the sense of appreciation denied them by their dependant. Clyburn et al (2000), in a well designed study strengthened by its use of a large randomly selected sample group of people diagnosed with dementia and their carers, found that caring with lower levels of social support significantly increased carer burden. They pointed out that those experiencing higher levels of behavioural problems from a dependant were less likely to receive adequate levels of social support.

The wider care literature, generally, highlighted that social cohesion was significantly important to the carer and its availability helped to mitigate against the variety of negative health care outcomes associated with isolation (Kawachi & Kennedy 1997; Wilkinson 1997). Clair et al's (1995) well designed quantitative study of 110 family carers found that the size of the carer's household was significant in determining the level of social support available to them. The larger the household, the greater the number of social support options, a factor that linked this data category to the next data category, 'Domestic Circumstance of the Carer', contained within the following substantive code (Table 6). Tebb & Jivangee (2000) identified several studies in their initial review of the carer literature that suggested other family members and friends

withdrew from the primary dementia carer due to their inability to deal with a dependant's deterioration. Within their subsequent qualitative study involving in-depth interviews with a small sample of care-giving wives, they highlighted that friends and neighbours were unable to provide help to the carer because they did not understand the behaviours of the person with dementia and did not know what to say. This subsequently led to them withdrawing from the scene.

Within my study the data category, 'The Adopted Professional' spoken of within chapter six (Table 4), was a more likely development when there was less support emanating from other family members, or when the carer wanted to protect the family from the realities of the condition:

'I suppose I could talk to the family but I feel, how would you put it, you're betraying their dad to them.' (Carer 17)

'But that's the difference isn't it? If they (carers) tell the family that's very much a social relationship, but they're placing a burden on somebody else.'
(Key-Worker 16)

For some of the carers, when they approached other family members, the response was not always a positive or supportive one, as indicated by the following carer and her key-worker:

'You wouldn't want to tell the family that's happening really, because my daughter actually doesn't think her dad is as bad as he is. She keeps saying to

me, mum you're making it worse, you're making it worse but I know it's not. '

(Carer 17)

'Well certainly this kind of idea I think is where the non-judgemental kind of thing as well, I think family and friends are quick to judge. ' (Key-Worker 17)

A need to avoid utilising support from other family members, in an effort to avoid burdening them with the problems associated with the caring role, was also recognised within the literature (Twigg & Aitkin 1994). However, the need to look to family and the wider community for emotional support was not universally viewed as a positive development. Robinson & Steele's (1995) study, looking at the relationship between health and social support in dementia care-giving wives, concluded that further research into the factors that led to an increase in social support from families and communities was vitally necessary. A well designed Dutch study by Myrra et al (1996) looked at dementia carers' sense of competence and, using a quantitative design, they uncovered an absence of positive influences emanating from either their formal or informal social networks. This finding, they claimed, indicated the complexity of the social care network associated with the dementia carer, a complexity that was also highlighted within a large quantitative study by Franks & Stephens (1996). They considered that their results, including the finding that carers of older people generally did not always derive benefit from social support, further highlighted this complexity.

CARER DOMESTIC CIRCUMSTANCE AND BIOGRAPHICAL INFLUENCES

Domestic Circumstance of the Carer

While commenting on her relationship with the key-worker, Carer 9 indicated that she had a more formal and distant relationship with the social worker who she identified as being her key-worker. This more distant relationship was attributed to her lifestyle and domestic circumstance rather than to any particular issue or characteristic associated with the key-worker:

'... I just want to get on, you know, it's quite busy basically because I've got a 2 year old. But I just want to get on and get things organised... that's probably why it is slightly (more formal) ...' (Carer 9)

What was of particular interest in this interview was that she had named her social worker as her key-worker but went on to describe her relationship in more formal and somewhat distant terms. The key-worker was there to arrange solutions to practical problems and not to provide her with emotional support. Surprisingly, during the interview, she expressed regret at not having a deeper level of support and felt that this more emotionally based help could have developed with a CPN, if only her contact with the CPN had not been so limited. This carer again raised her domestic circumstances as being significant to her relationship development with the key-worker as, in addition to caring for a young family, she did not live under the same roof as the dependant. Again, the issue associated with 'The Frequency of Contact & Time' data category came

through as an important factor linking this to the first major category, 'Enhanced Relationship Drivers' (Table 3):

'I think probably if the relationship was to develop further it would be with the CPN as opposed to the social worker... if the CPN was coming in on a regular basis or whatever then you could probably develop more of a relationship because they are coming into the (dependant's) house as well.' (Carer 9)

Nolan & Grant (1989) identified this aspect of the carer taking total responsibility for their dependant along with managing a home and raising a family. They considered that, even when supported by other family members, there was a 'Catch 22 situation' for the carer as the demands of their dependant still meant ignoring other family members. Lea (1994) discussed the nature of the dementia carer's role in terms of the time spent caring. She believed that negative effects of caring were influenced by whether or not the carer lived in the same household as their dependant. If they lived in a different domicile they would consequentially spend less time in the caring role and their dependants would receive more input from community professional services.

This particular data category was derived solely from one carer, and for similar reasons highlighted in the preceding major category chapter, I was unable to find supporting or contrasting data from other participants in similar circumstances. However, it was important to include and reflect upon this data as it derived from the only carer involved with a parent and not a spouse. Due to ethical/methodological issues, discussed fully within the chapter ten, I was

unable to access similar carers to fully compare and contrast findings around this issue within the study. The literature, however, clearly recognised this data as being significant and, therefore, worthy of note in light of other findings within my study.

Dependant's Condition Influences the Relationship

Some key-workers saw the level of carer and dependant need as being important to relationship development. The more desperate the circumstances were for the carer, the more this strengthened the relationship, as demonstrated by the following key-worker's response to the question of why the carer appeared to adopt them as a family member or friend:

'I think it was because he (carer) was quite needy at the start certainly, and his fear was that she would probably go into hospital and she wouldn't be back out.'
(Key-Worker 6)

This suggested that the level of need being experienced by the carer influenced the quality of the relationship and motivated the carer towards investing in this relationship with the key-worker. The following key-worker also suggested that a level of need helped relationship development:

'I think initially, I generally find our relationship a bit more open. I don't know whether that's because when I first saw him there was such a wide spectrum of problems...' (Key-Worker 8)

For Key-Worker 12 the reason for her team's involvement arose specifically out of the dependant's treatment requirements, which led to them being involved with this carer earlier than they would have been otherwise. The nature of the dependant's treatment regime may have also possibly influenced a longer involvement with the carer:

'... the reason they were referred to the team was for the cognitive enhancers which maybe 2 years ago they wouldn't have seen him, they knew that maybe they would have seen him a wee bit later on in the more advanced stages of dementia and there was a problem arising.' (Key-Worker 12)

Harper & Lund (1990) found that general deterioration in the dependant directly increased the burden on the carer. Clair et al's (1995) US study, using a pre-existing data gathering instrument, examined carer distress using a psychosocial model and found that along with the carer's age and life events, the level of functioning of the dependant affected the carer's sense of control over their situation. Brown (2001) made it clear that the professional must develop an early rapport with the carer, particularly when the dependant was commenced on anti-dementia drugs. Such studies suggest that the level of disability associated with the dependant, and their presenting circumstance, directly impacted on the carer's level of need, which consequently could be a significant factor in their developing relationship with their key-worker.

More recent studies have continued to acknowledge the relationship between the dependant's presenting condition and the level of carer burden (Vetter et al 1999;

Colvez et al 2002). However, paradoxically, the increasing level of need associated with the progression towards the more debilitating stages of dementia might have positively influenced how quickly and deeply the Carer/Key-Worker relationship developed, as suggested by the following key-worker:

'... if you maybe have a patient who was a bit more deteriorated, less able to engage, you might find you spend less time engaging with them and more time with the carer.' (Key-Worker 16)

While such a development might be a positive one in terms of increasing time spent in communication with the carer, it was important to ensure that time and attention directed towards the dependant was not compromised in the process.

Nature of the Carer/Dependant Relationship

The only participant involved with caring for a parent within this study indicated that the daughter/mother relationship was influential on her subsequent relationship with the key-worker. This Carer/Key-Worker relationship would, however, be different if she was either a spouse, shared the home with her mother or if she was older. This relationship differed significantly from all the other Carer/Key-Worker relationships in this study as it was described as being the most formal and somewhat distant:

'I think probably it would be different if I wasn't married and I lived with my mum... I think maybe the relationship with me is different in the sense I'm not like, a spouse is more a partner or part of the individual who has dementia

whereas I'm a part but I'm not there all the time... There's a wee bit of a difference there, you know, there isn't a lot of support and maybe there isn't a lot of carers that are as young as me. So there isn't but their approach to me might be quite different from their approach to maybe a spouse.' (Carer 9)

The nature of the relationship between the carer and dependant was, like gender, significantly reported within the literature. Some authors considered that two-thirds of dementia carers were spouses and, of the remaining one-third, the majority of these were either daughters or daughter-in-laws (Gilliard 1997; Adams & Manthorpe 2003). Spouses were more likely to care for each other longer than would child carers, including adult child carers (Nicholson & White 1993). Brodaty & Hadzi-Pavlovic's (1990) Australian study found that spouses caring for dependants with a diagnosis of dementia were more likely to suffer from psychological problems. In contrast, however, Donaldson et al's (1998) UK study found the opposite in that, while women were at a higher degree of risk of psychological morbidity, being a spouse provided a degree of protection against stress and burden. This contrast was interesting given that both of these studies appeared to have used a well designed method and the only obvious difference between the studies was the different cultural settings in which they took place.

Penrod et al (1995) considered that the adult child carer was at an advantage over other forms of relationship in that they often had the comfort of a secondary support network of spouse, siblings and children. However, Sutor & Pillemer (1996) cautioned that the impending care requirement for a parent often led to conflict between siblings even when their relationship prior to this was strong

and non-problematic. Neal et al's (1997) US study supported this earlier premise when they found that caring for a spouse was the only relationship that was more burdensome than caring for a parent. In a qualitative US study, Beach (1997) used a Grounded Theory approach to examine the positive impact of caring on adolescent relationships. Their findings supported Penrod's (1995) study, in that caring for a relative with Alzheimer's disease led to more beneficial interactions with other siblings. This study must however be viewed in the knowledge that it involved very young adolescent carers and was not, therefore, representative of the sample used within my own design.

Gender Influence

In the following account, gender appeared to be an issue for this carer when it came down to who should work with her dependant:

'... the first one (key-worker) was a lady, they couldn't give us a man and that was all right, it worked quite well but I wasn't happy with it really...' (Carer 5)

In this case the carer's gender preference of key-worker was to address more effectively the needs of her dependant husband. Here the carer exercised some control in decision-making around the dependant and, as indicated below and linking this category to the 'Independent Carer' substantive code (Table 4), she was more familiar with his needs than the professional was:

'(Dependant) likes a pint so he (key-worker) took him up to the bar on the corner and he'd have a pint and have a game of pool...' (Carer 5)

Gender also arose within the comments made by the following key-worker. She similarly identified the benefit associated with the key-worker being of a particular gender, but in this case it was for the benefit of carer herself. However, she also raised the issue of gender in a different context by claiming that the female carer was subject to a different set of cultural expectations than a male:

'I think I'm also mindful of, and this is probably a kind of woman to another woman; I'm kind of mindful of the expectations of her as a female as well... but I think expectations possible on her brother are less.' (Key-Worker 9)

There was considerable amount of literature on gender and it was generally considered that females made up the majority of informal carers (MacInnes 1998; Hettiaratchy & Manthorpe 1992). Many authors identified a gender bias within dementia care claiming that females were generally considered to be more disadvantaged than male counterparts (Maclean 1989; Pruchno & Resch 1989; Miller 1990; Miller & Cafasso 1992; Braithwaite 1996; Dalley 1996; Ingersoll-Dayton et al 1996; Donaldson et al 1998; Clarke 1999d; Clyburn et al 2000). A study by Livingston et al (1996) described a greater risk of depression being a particular risk for female carers and similarly Yee & Schulz's (2000) study, on carers generally, found that females reported more psychiatric symptoms than did men. In contrast, a study by Beach (1997) identified that younger female carers were more successful in developing relationships with dependants during stressful times and could develop a greater level of empathy with them.

McErlean (2001) concluded from his study of younger people with dementia and their carers, that professional staff had to recognise that the caring held different interpretations in terms of gender. He added that professionals had to ensure that female carers were not required to carry out their caring role in isolation from the rest of the family group, a comment that links this data category to 'The Costs of Caring' substantive code within the preceding chapter (Table 5).

Age as an Influence on the Relationship

As highlighted earlier within this chapter, Carer 9 considered that her age was a significant factor in her developing relationship with her key-worker. The key-worker agreed that age was important as, due to her being comparatively younger than most carers in a similar situation, she considered her to be in a better position to challenge the professional and assert her wishes:

'I think it probably affects us in terms of her attitude to professionals I think. I mean I don't think she really had, I expect older people would tend to accept what professionals said, they know best kind of thing.' (Key-Worker 9)

Along with marital status and education, age was considered by Moen et al (1995) to be a significant moderator in the psychological well-being of female carers. Its significance has been recognised within associated literature (Hettiaratchy & Manthorpe 1992; Kilstoff & Chenoweth 1998; Gilliard & Rabins 1999; Marriott 2003). Twigg & Aitkin (1994) commented that, across conditions, younger carers tended to receive less support from CPNs than did older carers. Clair et al (1995) found that carers who felt least capable of

undertaking their role tended to be white and older. A large longitudinal US study identified that two important factors associated with carer stress were the carer age and problematic dependant behaviours (Seltzer & Wailing Li 1996). Unfortunately, this sample was not drawn from a dementia specific group but the results were strengthened by the large sample size (2750) as well as the sampling technique adopted (randomised probability sampling). Braithwaite's (1996) Australian study used a mixture of qualitative and quantitative methodologies and found that burden was significantly higher in younger female carers. As in the preceding study, there were limitations within this study design in that the sample group was not specifically drawn from dementia carers and, as the sample was selected from volunteers, a risk of bias was potentially introduced.

A further aspect of age, highlighted within the literature, concerned discrimination, a phenomenon that younger people with dementia were also subjected to along with their carers (McErlean's 2001). It was recognised that many older carers, caring for ageing dependant spouses, had dreams of a happy, relaxed and shared retirement destroyed by the onset of dementia (Tebb & Jivanjee 2000). McErlean's (2001) study of younger people with dementia and their carers discovered that the impact of dementia upon children caring for a parent was equally devastating, particularly if the behaviour of the dependant became increasingly irrational and threatening.

Within my study the age of the carer and dependant was raised on several occasions as being an influencing factor affecting decisions made by key-workers:

'I think I've kept (dependant) on my case probably longer than I would have done if he had been 75 or 85, you know, for the simple reason (that) I think that the (carer's) problem is needing more support, em psychological support rather (than) physical support...' (Key-Worker 3)

'...she is a carer who's a bit younger than those we normally deal with, she's only 53, he's only 55 I think, and ... I think there's a bit of a difference between (carer) and the other carers that I have.' (Key-Worker 7)

The issue of carer age being an influence on the level of carer need and the subsequent relationship with the key-worker, highlighted earlier, appeared to be a feature alluded to within this carer's comments:

'I think that possibly it could be that I'm young and I can find out lots of things and I can, I mean I don't need maybe as much support.' (Carer 9)

It was disappointing, as discussed within chapter ten, not to explore these issues in greater depth with other younger non-spousal carer's within my study because it was not fully possible to adopt more of a theoretical sampling approach.

EDUCATIONAL/EXPERIENTIAL INFLUENCES

Educational Influence

As highlighted within the data categories, 'Key Worker as a Credible Source of Support' and 'Educating the Carer' discussed within major category chapters five

and six (Tables 3 & 4), expertise derived from the professional's knowledge-base was of significant value to the carer. The following key-workers suggested that their educational preparation was one of the most important factors impacting upon their ability to work effectively with carers:

'But does that not come round to the mental health background and the training that I've actually came through? ...I don't know, maybe I had good teaching, I don't know along the way.' (Key-Worker 15)

'But a lot of real skills were in the business of trying to train, and as quickly as possible bring people to a standard where they can operate at that level... For the carers it's about you having the knowledge-base that you can answer questions that they ask.' (Key-Worker 16)

'With the carer it's, I think again I think we've got quite a good relationship. I think again (the) carer probably feels (that) she can rely on me for my knowledge base.' (Key-Worker 18)

For this carer the educational preparation of the key-worker was the factor that increased her value and made their relationship more meaningful:

'I would say it's just the fact that she is very qualified in what she does.'
(Carer 15)

The importance of the educational preparation of the professional was a feature evident within the literature (Department of Health 1992; Carers National Association 1998). Within Winefield & Burnett's (1996) study, professional care workers expressed the view that they had not been trained adequately in the necessary skills required to prepare them to work with families. This study, however, involved a sample of carers with schizophrenia and not dementia dependants, although its findings could also be applicable to the latter cohort and so worthy of consideration here. The study involved a postal survey with follow up interviews and involved a reasonably sized sample (134) for a survey method. However the handling of the data and its analysis was very poorly explained. In Packer's (1999) UK study, a similar finding was discovered within the dementia setting. Using a smaller sample (23), she adopted a questionnaire and follow-up interview approach to investigate attitudes towards dementia care among health-care professionals. A significant finding in Packer's study was the value placed on education, with the professionals recognising the value of increased training and education into specific areas of verbal and non-verbal communication.

Life/Professional Experience Influences

While discussing the professionals' educational preparation, the following key-worker voiced that this, in itself, was not enough to assist their developing relationship with the carer. Her own life experiences and values had to come into this process as well:

'Through training and experience I suppose, and my own sort of values as well.'

(Key-Worker 10)

Therefore, the previous experiences of both the key-worker and the carer were a further factor that appeared to have a bearing upon their relationship and its subsequent impact upon the care-giving experience. The following non-registered key-worker, when asked about factors that influenced his dealings with carers and their dependants, considered that a lot of his style of approach to the carer/key-worker relationship derived from his own socialisation process and the experiences within his own family:

'I am saying that their relationship is what I would see in my own family. So it's more like em, I'm not seeing it from a professional's point of view, I'm seeing it from, you know, what more like a family is in situations. And I would probably do what I do even in my own family what I do with (carer and dependant) you know.' (Key-Worker 5)

Professional life experience, as distinct from educational experience, was also a factor commonly referred to as an important element shaping the attitude and character of the key-worker:

'I think maybe my spell in residential care has helped me.' (Key-Worker 14)

'I think that I actually had a good basic grounding. I was promoted in '86, so from '86... 8 / 9 years as a ward sister before I actually went into the community.' (Key-Worker 15)

'I think for nurses it only comes with practice. And I think they need to do it if they can teach them all the theory, but they need lots and lots of practice with people, all sorts of people at every level.' (Key-Worker 16)

The following key-worker highlighted the importance of experience and suggested that this was perhaps even more significant than professional education:

'Life experience as well. It's like the fact that students you often find the more mature students are the ones that tend to be bit more in touch with what's happening because they are more in touch with themselves as people, who goes back to confidence as well. It goes back to self-awareness which I think I did a great essay on, self awareness as a student and how training kind of lacks, nurse training lacks that component, that certain aspect...' (Key-Worker 7)

Life experience was an important requirement within dementia care as it corresponded with the carer's more 'local knowledge' spoken of earlier (Harvath et al 1994). Within this study it has already been proposed that a blend of this more experiential or 'trial and error' based knowledge with the more formalised 'cosmopolitan knowledge' associated with the professionals' education and training, maximised the care given to the dependant with dementia (Harvath et al 1994). This was best achieved through an effective working relationship between professional and carer (Brown et al 2001). McErlean (2001) agreed with the experiential nature of the carers' expertise when he stated that '... this expertise was acquired informally, through day-to-day experiences and taken for

granted knowledge' (p.23). In keeping with this view, the following unregistered care professional, who had not undergone a formal professional training, suggested that the educational background of the key-worker might not always be an asset and could create a barrier to relationship development. A significant theoretical preparation could lead to the professional viewing the carer's situation in a manner that failed to clearly identify their needs; education 'blinded' the professional with theoretical constructs which could get in the way of dealing practically with carer problems effectively:

'... a nurse or a doctor would say yes this is part of the diagnosis you know so all of a sudden there's a clinical side of it you know whereas you're (key-worker) looking at it, it's not a clinical side but everyday side of things you know, they (the professional educated staff) just see changes you know...' (Key-Worker 5)

Again, the inability to theoretically sample the study population, along with other inherent design limitations associated with this study, inhibited my following up on these views with key-workers from a similar background. This more critical view of the educational preparation given to the key-worker was evident within the literature. Bond (1992) believed that health care professionals had over medicalised the care of those with dementia and that this has resulted in negative connotations for the person with dementia in terms of the concepts of power and social control. He believed that this created a tendency, even within the family carers, to attribute relatively normal behaviours to disease processes. The opinion of the above key-worker supported the comments made within the study by Clarke & Heyman (1998). Their research addressed the issue of risk

management for an individual diagnosed with dementia, and they also cautioned over the potential for the professional's practice to become obscured by this phenomenon of overmedicalisation, a development that derived from their professional education:

'If professional carers, sometimes blinded by an overmedicalised training, only see the person with dementia as a source of risk to family carers, they will fail to consider the risks their professional response to the condition creates for family carers.' (Clarke & Heyman 1998 p238)

The following key-worker went on to make the point that her ability to enter into a relationship with the carer, and to judge the subtleties of such a relationship, was more a product of her life and professional experiences than a consequence of her educational preparation:

'I think it's not my training, it's my experience, it's not my training at all. Because you know that 6 years ago when I qualified I've not done the same job that I do now. I think through my experience from working, you know, the long term wards and seeing, you know, I've actually just progressed from working in long term wards to day hospital to community and I see the wider picture now. I see it very much from the family's point of view what they must be coping with but that's not been my training, that's been my experiences... I'm sure there must be life experience shapes who you are and your personality and I suppose there's an argument about whether you bring your personality into the job or not, but I think you probably do.' (Key-Worker 7)

This account suggested that such experiences influenced the key-workers character and attitude towards the carer and consequentially to an improvement in their relationship. This clearly linked this category to the substantive code within first major category chapter, 'The Determinants' (Table 3). However, experience exerting an influence on the relationship was not confined solely to the key-worker. In the following example Key-Worker 18 found that the carer's previous work experience as a health care support worker greatly assisted him in being able to more readily relate to her and enhanced her understanding of their expected roles. This once again impacted particularly upon the substantive code 'The Determinants' contained within first major category chapter:

'I think it makes a difference for (carer) in that she's very insightful I think into her husband's condition. Very insightful in terms of kind of how to manage things. Very used to being about medications and quite comfortable about medications.' (Key-Worker 18)

CHAPTER NINE DISCUSSION OF THE DEVELOPED THEORY

In order to fully reflect the ongoing process and immediacy associated with the emergence of this theory, I will present some of this chapter in the present tense. Within the later discussion, explaining the selective coding, no further acknowledgement of literature sources is made as these have already been outlined and discussed within the four preceding chapters dedicated to the analysis of study's results.

EXPLANATION OF THE THEORY LEVEL

In keeping with Glaser (1978; 1992; 2001) the theory emanating from this study, and the corresponding relationships between categories and codes, was explained by the emergence of the core category (chapter 3 p.36). The core category was fully representative of this theory as it explained the relationships between the major categories, substantive codes and data categories, and as such became the title to the thesis (Glaser 1992; Hutchison 1993). My original intention at the commencement of the study was to produce a conceptual theoretical model that more fully explained the Carer/Key-Worker relationship. However, according to McCann & Clarke (2003) this level of theory, in terms of nursing, was considered beyond the scope of a single Grounded Theory study as such a conceptual model provided a broader and more generalisable outlook on the nursing meta-paradigm. Theories in general are not definitive explanations but simply interpretations of phenomena and can be classified at three distinct levels and the terms used to label these levels can vary. At the highest theory level terms used include grand theory, formal or scientific theory and laws; middle-

range or substantive theory are at the intermediate level; and tentative theory is at the lower level of the hierarchy (Parahoo 1997; Kearney 1998; Burns & Grove 2001; McCann & Clarke 2003).

Grand theory is at the broadest and most abstract end of the range and involves a synthesis of both the theorist's ideas and those of other researcher's (Parahoo 1997). Within Grounded Theory, research studies at this level can also be classified as 'Grounded Formal Theory' achieved through the synthesis of findings surrounding particular phenomenon gained through a series of more narrowly focused individual Grounded Theory studies (Kearney 1998; McCann & Clarke 2003). Such grand, or formal, theories offer a broader conceptualisation of the phenomenon under consideration (Parahoo 1997). Laws are a very defined form of theory and are particularly associated with the natural scientist's (positivist) desire to explain, predict and control phenomena. These are, therefore, less applicable to the more socially orientated aspects associated with the health care culture where more middle-ranging theories are considered to be most appropriate (Parahoo 1997).

McCann & Clarke (2003) cited Morse (2001) in claiming that middle-range theories could also be termed substantive theories and were the most common form of theory to emerge from the Grounded Theory research methodology. Their value lay in the provision of a knowledge that was both relevant and understandable to those who lived in the real world (Nolan & Grant 1992). Burns & Grove (2001) agreed that while such a theory level did not carry the same degree of validity as a more formal scientific theory, the knowledge

derived from it was never-the-less of significant practical use and application within health care settings. These authors however added a further lower level of theory to the range, that of 'tentative theory'. This level occurred when any newly proposed theory had minimum exposure to critique from the wider academic community, and when it had not undergone any substantial testing. The theory developed from my study appeared to fit some of the criteria for a substantive or middle ranging theory, as the data produced underwent a degree of testing through the constant comparative method associated with the Grounded Theory analysis process (Glaser 1978; 1992; 2001). However, due the lack of wider academic critique and a failure to fully saturate all data categories, as highlighted within the analysis of the result's chapters, this theory fell short of the full middle-range theory criteria. Its position therefore was more appropriately placed somewhere between mid-range and a tentative theory.

The debate regarding theory level aside, this study produced a recognised theory that provided some explanation of the development and impact of the Carer/Key-Worker relationship. This assertion was given additional support by the words of Homans (1967), as cited in Parahoo (1997), who claimed that:

'...not until one has constructs (concepts) and propositions stating the relationships between them, and the propositions form a deductive system - not until one has all three does one have a theory.' (p.101)

McCann & Clarke (2003) explained how concepts derived from open or in vivo coding (level I coding) were linked and clustered under data categories using

theoretical coding, referred to in the literature as Level II coding. Such data categories were further examined for relationships and linked to form substantive codes, and a similar exercise carried out to form the major categories. These authors supported Glaser's (1978; 1992) explanation of the links or relationships between major categories, substantive codes and data categories, termed selective coding, which involved the examination of the respective properties of all codes and categories that naturally emerged from the data. The process of identifying the core category, and its links with and between the other major categories and codes as mentioned above, was often referred to as level III coding or selective coding. Within this process, theoretical coding and memo writing were the main processes involved and were derived from both an academic and clinical knowledge-base (Hutchison 1993; McCann & Clarke 2003). Level III coding was, therefore, arrived at when the core category emerged to explain the relationships between all the subordinate codes and categories and provided a central conceptual term that explained the theory (Glaser 1978; 1992; Hutchison 1993; McCann & Clarke 2003).

The process of level II theoretical coding, linking the codes and categories, is demonstrated within the diagrammatic representation of the theory (Figure 9 p324) by a series of arrows. As highlighted already within the methods chapter, the ability to carry this exercise out effectively relied upon the principle of theoretical sensitivity. The following section identifies these relationships between data categories, substantive codes and major categories within this study and demonstrates how these all articulate with a central core category. In keeping with Glaser's (1978; 1992) interpretation of the Grounded Theory

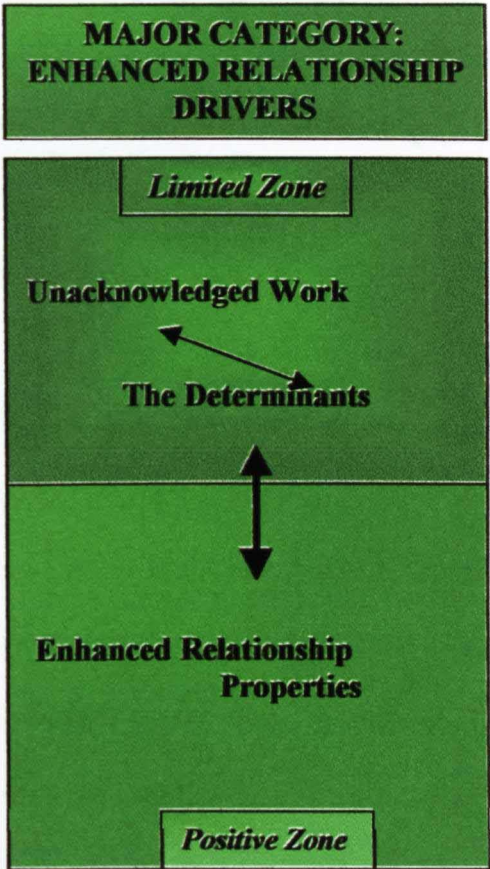
method, these relationships were allowed to emerge naturally from the data and great care was taken to avoid any ‘forcing of the data’, caused by preconceived interpretations, through my striving to maintain the principle of Reflexivity.

EXPLAINING SELECTIVE CODING: THE RELATIONSHIPS BETWEEN THE CODES AND CATEGORIES

Enhanced Relationship Drivers


The first substantive code associated with this major category is titled the ‘unacknowledged work’ of the key-worker and the carer (Figure 5). Several carers had great difficulty understanding what the key-worker actually did for them, or sometimes what they themselves actually did, in caring for the dependant. As for the key-workers, they equally were unclear and somewhat ambiguous regarding their involvement with carers. Clearly, such factors are contained within the limited zone of the diagram and, if not drawn towards the positive zone, will contribute to holding the substantive codes outside the positive zone associated with a more enhanced relationship (Figure. 5). Despite the more negative aspects associated with this code, many of the dyads expressed that they had a good working relationship that simply just happened. The activities associated with the key-worker towards the carer seemed to occur at a more intuitive level and pull this code towards the positive zone of the relationship in a more surreptitious manner. In a more overt action, this code is positively influenced and brought into the positive zone by factors contained within following substantive code, ‘The Determinants’ of the enhanced relationship.


Figure 5. Theoretical Framework Development - Stage I




This second substantive code highlights important factors that, when appropriately engaged, move this major category into the positive zone. This is arguably, therefore, the most significant of the substantive codes and, if appropriately engaged, has the potential to significantly drive the relationship into the positive zone. Avoidance or restriction of these characteristics, qualities and behaviours holds the code in the more restrictive zone thus significantly inhibiting relationship development. It is clear that aspects such as role clarification, shared meaning, the appropriate use of personal disclosure, along

with an appreciation of what each other could contribute towards care, drive the relationship towards the positive zone. Role clarification and shared meaning articulate this code directly with the preceding substantive code's hidden element pulling these more limiting characteristics into the positive zone. The diagonal arrow between these codes indicates this relationship (theoretical coding, p.30)

 . The arrows here (Figure 5) are double headed demonstrating the reciprocal nature and tensions between the codes.


A further range of more overt behaviours or actions drives this code into the positive zone of relationship enhancement. Much more practical and visible actions by the key-worker, such as spending more time and/or providing flexibility of involvement with the carer, or carrying out activities that carers considered go beyond their expectations, contributes to a process that further strengthens relationship enhancement. Interestingly many of the key-workers were often totally unaware that their involvement with the dependant was being scrutinised by the carer, and they simply considered all such activities as them simply doing their job. Such perceptions provide a link back across to the previous code, again demonstrated by the above diagonal arrow  holding it within the limited zone, this perception being more associated with the 'Unacknowledged Work' aspects of their role. If the key-worker fails to see the value of such behaviours, potentially important relationship development opportunities can be lost. The key-worker also displayed certain personal characteristics and qualities that drive the relationship toward the positive zone. Through their affable personality, demonstration of respect for both the carer and their dependant and being perceived as credible professionals by the carer, their

relationship developed more positively. The carers themselves also contributed to this positive development process by demonstrating their true commitment to the dependant, a quality much appreciated by the key-worker, as well as showing overt appreciation for the key-worker's contribution to the care environment.


When factors such as these occur, the relationship moves into the positive zone, and the third substantive code 'Enhanced Relationship Properties', therefore, lies very firmly within this positive zone. The relationship between this and the preceding two codes is once again demonstrated by an arrow, this time vertically positioned.  (Figure 5). This arrow is again double headed to demonstrate the tension between the codes but is also thicker to indicate a more positive and desirable direction for this relationship as this tension also exists between the two zones. When in the positive zone the carer finds that they are more inclined to experience a psychological boost from this relationship giving them more confidence to undertake further care-giving responsibilities. The interaction with the professional is on a much more friendly and informal basis that provides a positive influence on the level of communication between them. The carers generally found that they could divulge issues and talk about worries that went well beyond those associated with the dependant, a significant feature in the creation of that conducive psychological climate mentioned earlier. The ability to raise the level of the relationship was also perceived as being beneficial to the professional as it allowed them to operate more effectively in supporting the carer and creating a climate for optimum care provision.

When the carer and key-worker experience this enhanced level of the relationship, they both derive benefit from its range of positive features. These relationship dynamics, represented by the use of the arrows within Figure 5, is indicative of the theoretical coding that exist between these substantive codes. The process towards relationship enhancement is not only shown by the vertical arrow between the zones but also the colour shading going from the dark within the limited zone to bright within the positive zone, thus representing the preferable movement into relationship enhancement. This major category, given its nature and 'driver' dynamic, has this theme inherent within it: 'Enhanced Relationship Drivers' indicating its importance in launching the enhanced relationship cycle.

Models of Action

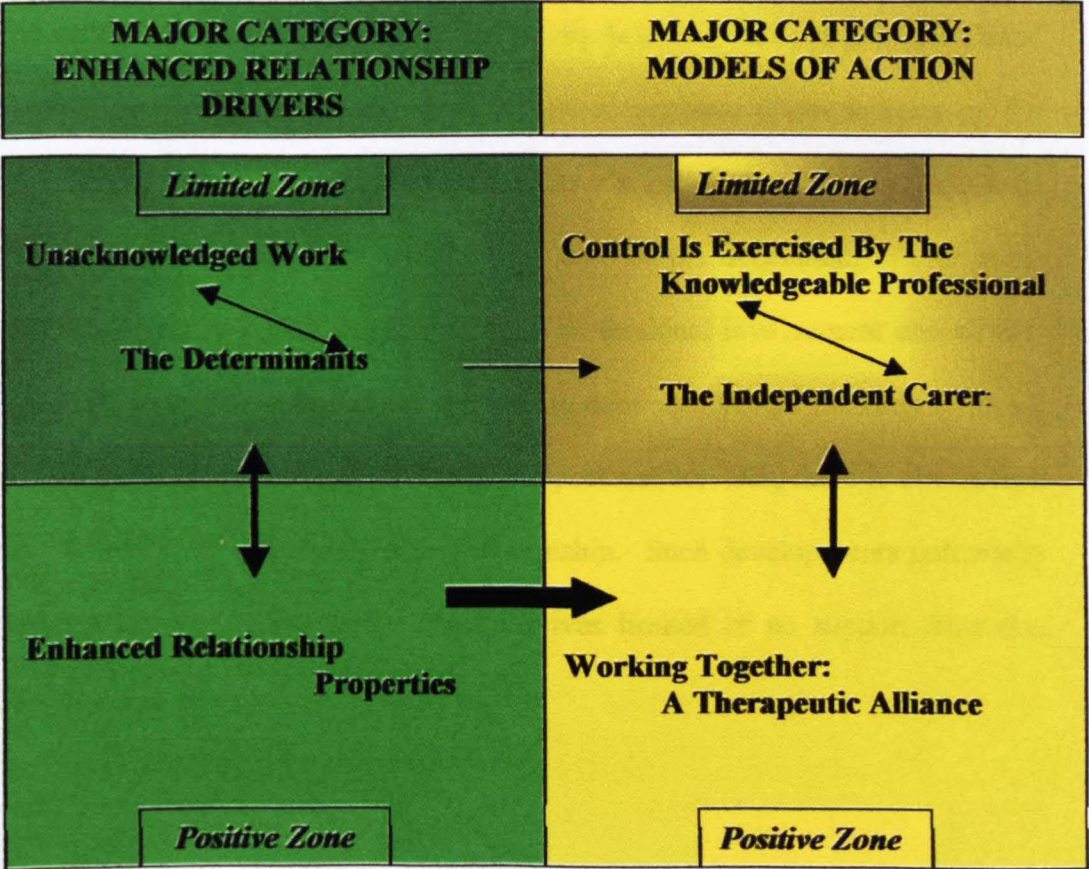
The qualities of the 'Enhanced Relationship' provide a powerful 'driver' into and through this next major category and this relationship is represented by a thick black arrow  (Figure 6). The codes within this category explain the activities that surround the care of the individual diagnosed with dementia, and the associated working arrangements between the carer and key-worker, and so contains the theme of action: 'Models of Action' indicative of such actions and activities.

The first substantive code within this category, 'Control is Exercised by the Knowledgeable Professional', explains the professional activities of the key-worker. The ambiguity created from the influence of the previous limited zone contributes to a dilemma for the professional in identifying whether or not their

role really involves the carer at all. At its most restricted level, this code potentially creates a situation whereby a key-worker ignores and bypasses the carer altogether and is indicative of power, control and expertise all being concentrated exclusively within the key-worker remit. A single headed horizontal arrow represents this more negative influence across the limited zones .


When influenced towards the positive zone, a shared recognition of the importance of the professional's role allows the key-worker to more effectively utilise his or her 'cosmopolitan' knowledge in educating the carer into aspects of the condition, as well as any entitlement/resources available to them. Associated with this educational role is a potential to 'Prepare the Road Ahead'. This allows the carers to pace themselves and deal more effectively with forthcoming developments and any difficult decision making.

Figure 6. Theoretical Framework Development - Stage II




A further property associated with this code, and drawing it more towards the positive zone, is the key-worker acting as a central resource and co-ordinator for other services and products, as well as playing a significant role in validating and appreciating the carer's work effort. This later action clearly contributes to the sense of carer confidence and increased morale associated with the positive zone of the preceding major category. Some carers considered the key-worker's practical ability, while working with their dependant, as also having an influence on relationship development signifying, to some carers, that the key-worker could manage their dependant more effectively than they could. This interpretation led to either an admiration of the key-worker's ability and positively influences the relationship or, for others, it highlighted their own inability to cope and negatively influences the relationship containing it within the limited zones.

The next substantive code within this category is that of the 'Independent Carer' (Figure 6). Under the influence of the more negative characteristics of the limited zones, this code highlights the carer's belief that they are the only relevant individuals to be involved in the care of the dependant. At its most extreme level this leads the carer to resist professional involvement and advice, instead assuming total responsibility for care delivery. Where the carer takes on such a 'siege' mentality and refuses all support and services, there is obviously a breakdown in the carer/key-worker relationship. Such developments potentially create a situation whereby the carer receives limited or no support from that professional.

A further aspect, holding this code within the limited zone, concerns either a lack of realisation or appreciation for the circumstance of the carer by the key-worker leading to them ignoring this person, as discussed within the preceding code. A diagonal arrow  between these two codes demonstrates this link (theoretical coding). When a professional exercises total dominance within the care setting, and fails to demonstrate any appreciation for the carer, then the carer is considerably more likely to withdraw from their contact. So the carer can either consider the key-worker as superfluous, in the belief that they alone can provide the necessary care, or a threat to their continued involvement and control over the care for the dependant. As this code becomes more influenced by the positive zone, actions such as the carer being able to appropriately challenge care decisions, while not becoming unnecessarily belligerent with the key-worker, is a more likely outcome. This, along with having carer 'local knowledge and actions' recognised as being legitimate and essential by the key-worker, pulls this code towards the positive zone. Within this zone the more beneficial characteristics associated with the code greatly contributes to maintaining the next substantive code's position within this positive zone and thus enhancing the relationship.

As indicated above, the 'Working Together: A Therapeutic Alliance' code is a product of the blend of the more beneficial qualities derived from both the 'Knowledgeable Professional' and 'Independent Carer' codes (Figure 6). At this level of the relationship the carer can become so relaxed and comfortable with their key-worker that they speak of them as being either adopted within their family or friendship circle. This phenomenon, if more strongly under the

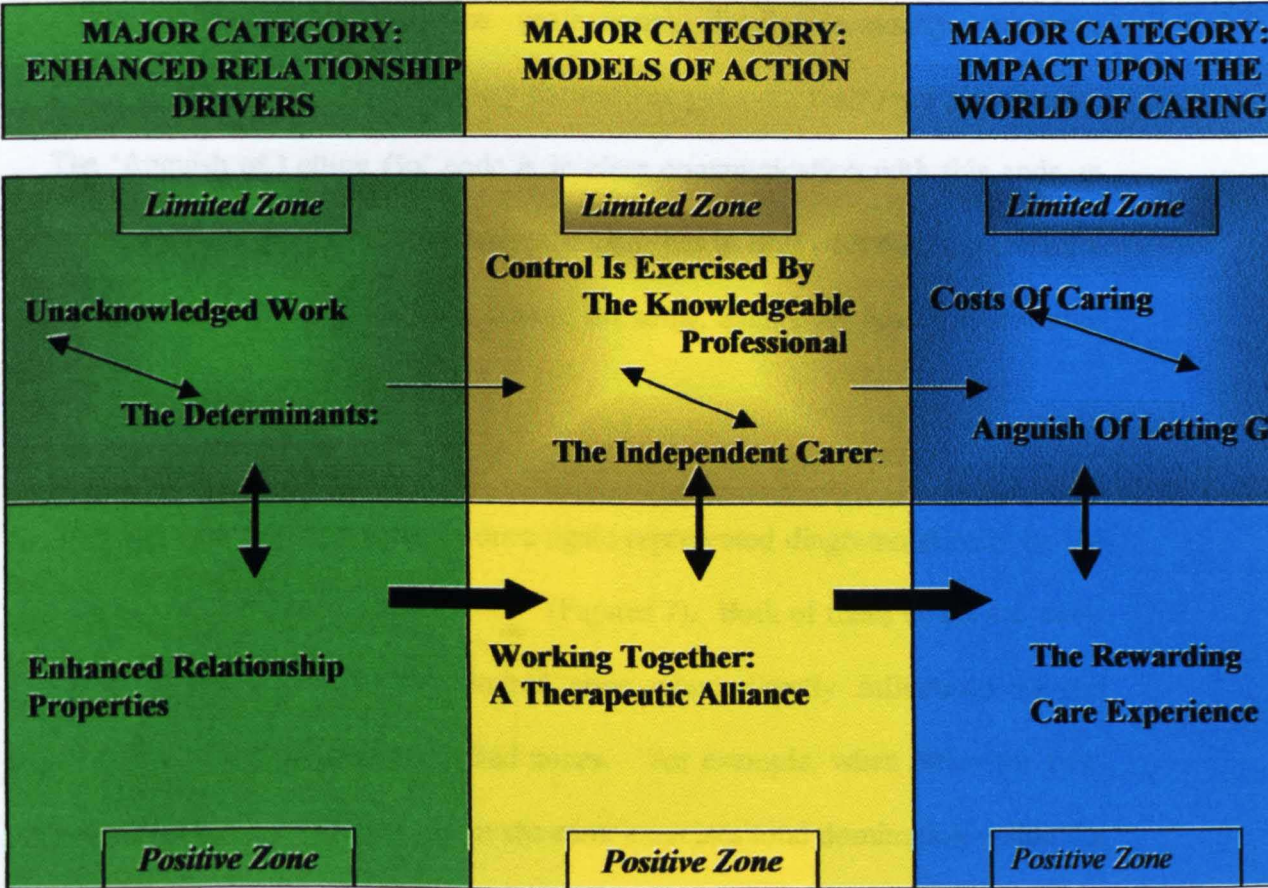
influence of the positive zone, further develops the enhanced relationship improving the depth of communication, trust and disclosure. This produces significant therapeutic and care management gains by creating a strong and robust partnership. Here, the positive qualities of the key-worker's educational role clearly feature and are fully valued by the carer. They greatly benefit from this 'cosmopolitan' knowledge, and from having their role validated, while the key-worker significantly gains from the carer's more 'local knowledge'. Under the influence of the positive zone, this code fully addresses the valuable contributions derived from both parties and the qualities they each contribute to both relationship development and the overall care-giving environment.


However, when drawn towards the more restrictive influence of the limited zone the 'Working Together: A Therapeutic Alliance' code becomes adversely influenced by the 'Independent Carer' code's more negative characteristics whereby the carer becomes inappropriately protective towards the professional and avoids burdening them with their worries and problems. They instead become overly, and inappropriately concerned for the key-worker's welfare. Alternatively, this inappropriately close relationship potentially creates a dependency associated with the limited zones of the following major category. Here 'The Anguish of Letting Go' code (Figure 7) predominates within the limited zone and resulted in a loss of any therapeutic gain for the carer and potentially exposes them to increasing and unnecessary stress, burden and guilt. This more negative aspect links these limited zones and is represented by the narrow single headed horizontal arrow  (Figure 7).

For the key-worker, too close a relationship with the carer can also prove problematic when fellow professionals consider their involvement inappropriately close and too subjective for the creation of any health gains. This then potentially results in the key-worker's role as a centralised resource, described within 'The Knowledgeable Professional Exercises Control' substantive code, becoming restricted as they increasingly become unable to positively draw on and influence associations with fellow professionals. This, therefore, similarly adversely affects their relationship with the carer and negatively impacts upon the following category's limited zone (Figure 7).


Impact Upon the World of Caring

Figure 7. Theoretical Framework Development - Stage III




This close relationship and strong alliance creates an influence upon the next category, 'Impact Upon the World of Caring', as the enhanced relationship's positive zones impact upon the total care-giving experience for both the carer and the key-worker, consequently contributing positively towards the care environment for the dependant. This impact is demonstrated by a thick bold single headed arrow  (Figure 7).

The codes 'Costs of Caring' and 'Anguish of Letting Go' are the two codes most significantly associated with the more limited aspects of the Carer/Key-Worker relationship. Within both codes, carers clearly expressed views that are heavily dominated by the concepts of stress, burden, guilt and even grief, all associated with a more negative interpretation of the care-giving experience. Within the 'Costs of Caring' code such feelings were often associated with the lack of support/understanding from the professional, family/community, or even unreasonable expectations that they themselves put onto their care-giving role. The 'Anguish of Letting Go' code is in clear communication with this code as stress, guilt and grief all feature when the carer has to deal with their dependant's eventual death or hospitalisation which, for some, even stretches to an eventual loss of contact with the key-worker.

This link (theoretical coding) is once again represented diagrammatically by the diagonal double-headed arrow  (Figures 7). Both of these codes are more likely to remain within the limited zone when directly influenced by the preceding major categories' limited zones. For example, when either the key-worker totally ignores the carer or the carer exercises total domination within the

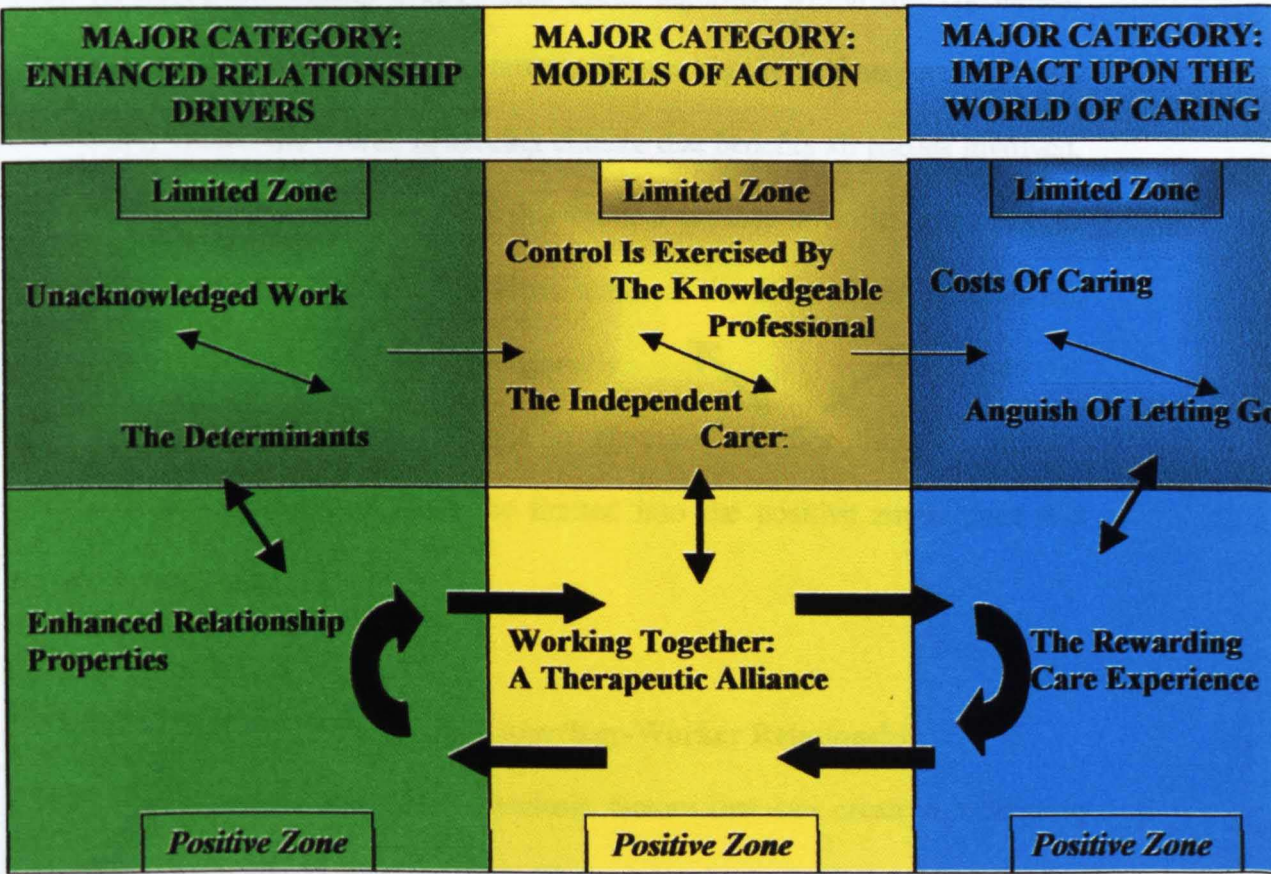
care setting refusing all necessary support in a misguided belief that they alone can provide all appropriate care. When these limited zones dominate, an unhappy and unhealthy caring experience is the most likely consequence for the carer.


When the qualities of the enhanced relationship enable a strong working alliance and partnership between carer and key-worker, this creates a positive force within the 'Impact Upon The World of Caring' major category, demonstrated diagrammatically by the bold arrow  (Figure 7). The codes within this category are then increasingly drawn towards the positive zone and sees carers begin to view their experiences in less problematic terms. For example, when considering the 'The Anguish of Letting Go' substantive code, a more positive aspect of this code sees the key-worker remain involved with the carer beyond admission or death, an enhancing feature that produces a positive effect upon the carer's overall caring experience. This brings this code into the positive zone where a rewarding experience for the carer is more of a possibility. When the 'Cost of Caring' code moves towards the positive zone, carer's perceive their care-giving role less as a duty that has to be undertaken out of a sense of responsibility for the dependant, and more associated with the principle of reciprocity. They are simply repaying the dependant for actions carried out by them for the carer's benefit at some earlier period.


At this level of the relationship carers also attempt to explain away the more disturbing behaviours their dependant display by either firmly attributing these to the condition and/or viewing the dependant as a child and so absolving them of

any blame for such problematic behaviours. The code most associated with the positive zone of this major category sees the carer expressing that, far from being a ‘duty’ or a ‘pay back’, care for the dependant arises out of their sheer love for the person being cared for. This rationale for caring brings its own considerable satisfactions in simply being able to provide unconditional care for this person. They can, therefore, in association with support from the key-worker, provide the highest level of care and see being able to do so as a true privilege and a highly rewarding experience.

Figure 8. Theoretical Framework Development - Stage IV



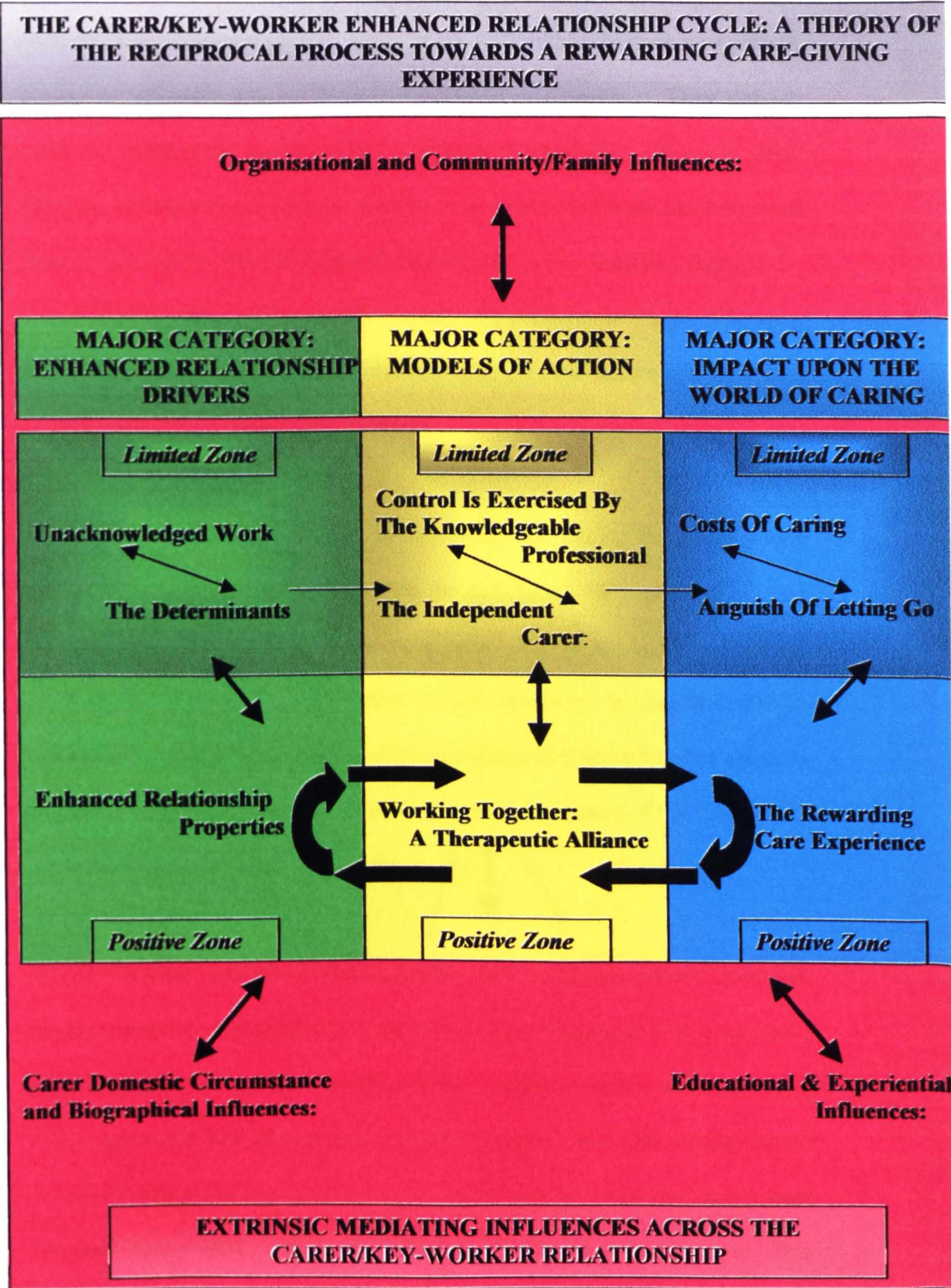
This positive care-giving experience feeds into an enhanced care-giving cycle by creating a reciprocal and enhancing influence back through the preceding two major categories, further strengthening their enhancing qualities. This enhanced relationship cycle is diagrammatically represented  (Figure 8), showing the bold arrows pushing across the positive zones now forming a cyclical process pushing back through the preceding two categories.

This cyclical process demonstrates that when both parties experience this very positive and rewarding care-giving experience their overall partnership is further strengthened, as are positive qualities arising out of their enhanced relationship. All of this is brought about by an exposure to the positive influence derived from this enhanced relationship cycle. This cycle, signified within the Theoretical Framework by the bold cyclical arrows (Figure 8), is self-perpetuating and ultimately creates the overall rewarding climate that benefits all parties involved. The influential pull associated with this cyclical process now changes the bold arrows, between the limited and positive zones of the first and third categories, from being vertical to being pulled diagonally  into this centralising process. This change in direction signifies the even greater tendency for enhancement from the limited into the positive zones once this cycle is established.

Mediating Influences across the Carer/Key-Worker Relationship

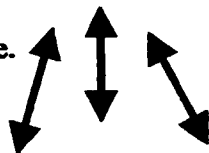
There are, however, other more extrinsic factors that can create a mediating influence across this cyclical process. The above enhanced relationship cycle has the potential to be influenced, either towards the positive or limited zones, by a

Figure 9. Theoretical Framework Development - Stage V

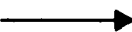


series of factors external or extrinsic to the Carer/Key-Worker relationship cycle. These mediators, demonstrated within the red area (Figure 9), either positively compensate for a non-existent or poor Carer/Key-Worker relationship or present a negative influence upon an already established relationship. They can act upon the substantive codes within 'Enhanced Relationship Drivers' major category, pulling them towards the positive zone thereby initiating this reciprocal process, associated with the enhanced relationship cycle, cascading through the following categories (yellow and blue areas). Similarly, by acting directly upon these other two categories, the mediators can produce an enhancing effect independent of these relationship 'drivers'.

Conversely, the mediators can act by negatively influencing the codes within each category and restrict them to the limited zones, thus creating adverse influences upon the enhanced relationship cycle. The links (theoretical coding) between this category and the other major categories is diagrammatically represented by one of three bold double-headed arrows (Figure 9). The selection of a double-headed arrow again reflects the reciprocal nature of the relationship between this category and the other three.



The first of these mediating codes highlights those influences derived from both the key-worker's employing organisation and those associated with community and family structures. Factors such as work overload, possibly resulting from a real or perceived lack of resources, adversely impact upon 'The Determinants' code by limiting the key-worker's ability to be flexibly available, or to spend adequate time with the carer, thus restricting relationship development. This,

consequently, pushes through the other two categories containing these within their limited zones, a situation that is brought about by a failure to positively engage these 'determinants'. The employing authority can therefore ultimately contribute to an often premature engagement of residential care which directly impacts upon the 'Cost Of Caring' and the 'Anguish Of Letting Go' codes, again demonstrated above by the horizontal arrows  (theoretical coding). This again holds these codes within the limited zones of the 'Impact On The World of Caring' category.

For some key-workers, such failures associated with their employing authorities are considered to be a significant detrimental factor to their developing relationship. When this occurs, they see themselves as 'lightning conductors', absorbing the 'flak' for the organisation. However, in contrast to this perception, there is also a more positive side to this failure when the carer perceives the key-worker as an ally 'fighting their cause' against a distant bureaucracy in an attempt to gain whatever resources possible for the carer and their dependant. This positively influences the determinants when aspects such as respect and credibility are pushed into the positive zone and, therefore, into the enhanced relationship cycle. At a higher organisational level, National UK and Scottish Governments have also made more of a recent effort to promote the welfare of carers through a variety of Parliamentary Acts, discussed within the preceding chapter. These have particularly influenced the 'Enhanced Relationship Drivers' major category by positively addressing many of the more subordinate data category issues contained within the 'The Determinants' substantive code such as

role recognition, respect and appreciation, time, flexibility and availability of the key-worker (Figure 9).

The involvement of community-based services such as respite care and carer support groups creates a more ambivalent relationship between this major category and the others. When the carer experiences a positive effect from such support groups this leads to a perception of support for the carer and confidence-building will result. This contributes to a pulling effect on the 'Impact Upon The World of Caring', major category' bringing its substantive codes towards the positive zone and into a more rewarded caring experience where factors such as isolation and loneliness are more likely to be minimised. However, if the carer becomes exposed to any unnecessary alarmist warnings about future potential developments associated with their caring responsibilities, raised by members within these groups, this category's substantive codes become more associated with the more limited zone.

Neighbours, families and friends all have the potential to create a mediating effect across this enhanced relationship cycle. In a similar way to carer support groups, family support structures can compensate for an absent or poor Carer/Key-Worker relationship and directly influence the 'Impact Upon World of Caring' category, pulling its substantive codes towards the positive zone. However, problems associated with such social structures can produce an opposing effect and can even counteract, to a certain degree, the beneficial aspects of the enhanced relationship cycle. The phenomenon of carer adoption discussed within the 'Models of Action', if contained within the limited zone, is

suggestive of this poor level of social support. Here, an unhealthy and inappropriate over-dependence on the key-worker can develop and, if this is not recognised and effectively managed by the key-worker, can lead to a more negative outcome for the carer by pulling the relationship into the limited zone. If the level of community and social support is at a significant and appropriate level, it is possible that the need for the Carer/Key-Worker relationship is significantly diminished to that of a more distant professional, perhaps only required as an advisor/resource person or even negated altogether.

A variety of other factors surrounding the circumstances of both dependant and the carer can influence this enhanced relationship cycle. These include the level and nature of the dependant's condition which potentially can adversely influence the 'Impact Upon The World of Caring' major category, holding its substantive codes within the limited zone. However, this situation also appears to provide compensation for the enhanced relationship cycle by positively influencing the other two categories thereby strengthening the 'Enhanced Relationship Drivers' and the 'Models of Action' major categories where certain key determinants are enhanced and a stronger partnership established.

The strength and nature of the pre-existing carer/dependant relationship and the type of relationship, i.e. spousal or child/parent, along with gender and age all are significant mediating factors. Again, as evidenced within the literature, the progressive process into dementia often exacerbates pre-existing tensions between the carer and dependant. Along with this feature, the limited zone associated with the 'Impact Upon The World of Caring' code is also more likely

to dominate if the carer was an adult daughter carer. However, the carer literature adds that this is also true of female spouses. Within my study the single daughter carer being of a younger age, despite arguably being more physically able, was seen as potentially more problematic to the relationship cycle. This is a finding that is largely upheld by the available literature. Age, like gender and relationship type, appear to potentially adversely influence the enhanced relationship cycle by holding the codes across all major categories within their limited zones. This is evidenced by an impaired quality of Carer/Key-Worker relationship, leading to an ineffective working partnership creating a more adverse care-giving experience.

The final mediator substantive code explored the educational and experiential influences across carer/key-worker cycle. As evidenced within the discussion on 'The Models of Action' major category, the key-worker's cosmopolitan knowledge, effectively transmitted to the carer, was an essential component of the positive zone associated with this major category. Within the positive zone of 'Enhanced Relationship Drivers' category, the educational preparation of the key-worker strengthens and enhances the credibility of their input, so important to the carer's ability to respect and appreciate the professional's role. Within this code, life experience on the part of both the key-worker and the carer is also highlighted as being significant. Within the 'Models of Action' major category, the positive zone is seen to blend the more enhancing qualities associated with the key-worker and the carer. A significant factor leading towards this positive zone is this coming together of the formal knowledge of the professional derived from an educational preparation (cosmopolitan knowledge) and the more

experiential (local) knowledge of the carer. It must be noted, however, that these two forms of knowledge are not entirely mutually exclusive to either party. Indeed, one key-worker had not received any professional education and considered his life experience to be more important and, indeed, voiced that any formal educational preparation was potentially restrictive to his overall professional role. Conversely, some carers possessed a degree of a cosmopolitan knowledge, gained through previous employment practices, which key-workers considered an asset to both their ability to provide effective care and in enhancing the Carer/Key-Worker relationship.

Despite such views, 'cosmopolitan knowledge' remains largely the predominant feature of the key-worker's knowledge base and 'local knowledge', the carers. It is the blend of these two that creates the positive zone within the 'Models of Action' category. A formal education versus life experience tension, therefore, plays a significant part in forging this aspect of the carer/key-worker enhanced relationship cycle. A conclusion from my study is that an educational input directed towards the carer and/or the key-worker, based on results presented within my study, can significantly contribute to the development of the enhanced relationship cycle. The complete diagrammatic representation of this theory, featuring the core category displayed as an overall title contained within the grey rectangular box, appears in Figure 9 (p324).

ETHICAL APPROVAL

This study was limited by the near impossibility of establishing effective theoretical sampling of participants. This was brought about by the changes required by Lanarkshire Local Research Ethics Committee (LREC). By specifying the group to be targeted within the initial application for ethical approval, it could have been argued that I had elected to use a 'purposive sampling' approach. Once the data had begun to emerge I endeavoured to move quickly on to more of a 'theoretical sampling' basis by specifying the next most ideal person to be interviewed (Becker 1993). However, due to the limitations placed on me by the ethics committee, this proved to be one of the most difficult challenges associated with this study's design. I did, however, manage to exert some influence upon the selection process but the ethical requirement to be distant from the selection process made this frustratingly problematic for me on most occasions (Appendix 4). Therefore, to gain ethical approval for this study, I had to alter my intended approach in accessing the sample group, already discussed within methods chapter four (Figures 2 & 3). This change was highly significant making the selection of participants much more problematic as they were further removed from my influence and control. This consequently made theoretical sampling of participants almost impossible to achieve, as I could not gain any biographical details of the carer until they themselves made contact with me. If, in the spirit of theoretical sampling, I wished to interview a man or woman, or a wife or husband etc, I had to request that the Consultant identify

relevant characteristics and direct the request package to appropriate individuals. In reality, this was extremely difficult to accomplish and so some groups, such as younger adult carers caring for a parent or those caring for someone with pre-senile dementia, was under-represented within my sample. This decision created a potentially problematic ethical dimension for my study. An ability to theoretically sample arguably could have resulted in a more rapid and efficient saturation of the emergent codes and categories. Being able to select particular participants with characteristics relevant to the emerging issues could have meant that fewer interviews were necessary in order to reach a point of saturation. By utilising a less precise and broader purposive sample, more participants and more time was probably required to capture the range of characteristics necessary for new emerging issues.

The only example of my successfully pursuing a particular participant with appropriate characteristics, in the spirit of theoretical sampling, involved me having to re-contact the ethics committee to request approval to interview a particular key-worker for a fourth time (appendix 4). In the original application I stated that I would interview the key-worker a maximum of three times. The need for this change of decision arose during the third interview with Key-Worker 15 when she brought up a significant issue with regard to a specific carer being visited purely for her own needs and not those of the dependant. Without my knowing the identity of the participant, the key-worker requested the Consultant forward a request pack to this carer who, consequently, made contact and was interviewed along with the key-worker. This was a particularly important insight for the study and I was very keen to have this dyad included within the interview

process. This example provided evidence of the difficulty in sampling participants theoretically within my particular study's design.

PARTICIPANT DATA CONTRIBUTIONS WITHIN RESULTS CHAPTERS

It was interesting to also note the frequency of the contribution from each of the dyads (Table 7). With a few exceptions these figures demonstrated an increased general frequency and a growing intensity of richer data as the study progressed, particularly when examining the key-worker responses.

Exceptions were noted in the carers from dyads 7 and 13 in particular, who all deviated from this general trend. The first of these dyads demonstrated a considerable carer increase in the number of inclusions when compared to the neighbouring dyads. Carer 7 was a younger spouse looking after a husband diagnosed with pre-senile dementia. She provided important data into her caring role and attitude, as discussed within chapter six and was therefore a very rich source of such data, as evidenced by the frequency of her inclusion. Again, accessing other carers with similar characteristics would have been desirable at this juncture.

Table 7 – Frequency of Contribution from all Dyads

| <i>Dyad</i> | Carer Contributions | Key-worker Contributions |
|-------------|----------------------------|---------------------------------|
| 1 | 2 | 3 |
| 2 | 3 | 3 |
| 3 | 5 | 7 |
| 4 | 13 | 2 |
| 5 | 12 | 7 |
| 6 | 6 | 6 |
| 7 | 21 | 11 |
| 8 | 11 | 9 |
| 9 | 16 | 10 |
| 10 | 14 | 6 |
| 11 | 11 | 6 |
| 12 | 11 | 7 |
| 13 | 0 | 0 |
| 14 | 8 | 13 |
| 15 | 22 | 19 |
| 16 | 13 | 20 |
| 17 | 39 | 15 |
| 18 | 16 | 17 |

The other dyad was noticeable for the opposite reason; the carer had no contributions for this stage in the interviewing process. With this carer I

experienced significant difficulty focusing her directly onto the Carer/Key-Worker relationship. This carer, despite having a very positive relationship with her key-worker, began to display signs of distress suggesting that she was experiencing significant emotional trauma associated with her care situation and the condition of her husband. This resulted in her interview becoming increasingly superficial and socially orientated in nature. This led to vague and unfocused data that resulted in her comments not appearing within the result's chapters. This was a natural occurrence of the coding and analysis process and was not a deliberate attempt to consciously exclude this carer.

Table 8 – Aggregated Contribution Frequency across Dyad Groups

| <i>Dyad Groups</i> | <i>Carer Contributions</i> | <i>Key-Worker Contribution</i> |
|----------------------|----------------------------|--------------------------------|
| <i>Dyads 1 – 6</i> | 41 | 28 |
| <i>Dyads 7 - 12</i> | 84 | 49 |
| <i>Dyads 13 - 18</i> | 88 | 84 |

It was noticeable, when comparing the first six dyads with the final six, that there was a significant increase in both frequency of contribution and in the richness of data from the later group (Table 8). This increase in intensity was a particularly significant and desirable feature of this study and was in keeping with the Grounded Theory approach, whereby data was constantly being compared and contrasted within subsequent interviews, around progressively emerging categories and codes (Glaser 1978; 1992; Melia 1982; Strauss & Corbin 1990;

Hutchison 1993). It was noticeable that this trend was less obvious between the carers in the middle six dyads and final six of the carers' contribution. This balance was exacerbated particularly by Carer 13's non-inclusion as discussed above. This trend of increasing richness and intensity of data was much more uniform across the three key-worker groups.

SATURATION OF CODES AND CATEGORIES

As discussed earlier, a consequence associated with not being able to theoretically sample the participants was the inability to saturate all codes and categories leading to a failure to achieve that 'finer grained theory' which ideally should be the end point of a Grounded Theory approach (Strauss and Corbin 1990).

Strauss and Corbin (1990) emphasised that data collection should continue until saturation of the categories was fully achieved. With a sample size of eighteen dyads, possible premature closure risked a level of saturation that could be considered inadequate for dense, well-integrated categories (Glaser 1978; Hutchinson 1993). I was disappointed that I had failed to fully saturate all of the data categories emerging from this study. On reflecting on this disappointment I felt that, to some extent, a degree of saturation had taken place towards the later interviews when no new data appeared to be emerging within most of the data categories. It is also important to note the argument presented within the methods section, that it was not always essential to report at the more developed stage of the analysis.

In using the Grounded Theory method, the researcher can stop and report at an earlier more descriptive level of the process on one or several related categories (Chenitz & Swanson 1986; Swanson 1986; Strauss & Corbin 1990). This aside, however, I still would have preferred the reassurance of conducting several more interviews, gained through theoretical sampling measures, to reach a more satisfactory level of saturation recognisable across all of the emergent data categories. Following the coding and categorisation phase, I was able to identify a core category and the associated relationships between the codes and categories. These relationships were demonstrated diagrammatically within the preceding chapter in order to facilitate the explanation of the emergent theory. However, this diagrammatic representation also required an accompanying narrative to more fully explain how and why such relationships between categories exist (Donaldson 2003). The core category was consistent with the requirements of a Grounded Theory study in that it occurred frequently within the data, linked categories together and was central to the emergence of the Grounded Theory (Holloway & Wheeler 1996).

As discussed within the methods chapter, a validating exercise using member checks (face or expert validity) on these results was not to be contained within this thesis for a variety of reasons. Reflexivity already provided this study with an inherent degree of validity and, therefore, the use of such an exercise is not always considered necessary (Koch 1994; Webb 1994). Within the analysis of the data, by using the constant comparative method of checking emerging concepts with existing literature and in subsequent interviews, the issue of validity was already addressed (Melia 1982; Hutchison 1993; Glaser 1992;

2001). Following the analysis of the data, the emerging codes and categories progress the data to a more theoretical level and, therefore, exposure to this higher ordered theory that may not be recognisable to the research participant (Morse 1998; Horsburgh 2003). Finally, and for much more pragmatic reasons, this exercise was not reported due to the very real need to contain this consistently growing thesis to a manageable length. However, out of interest and as part of a post-graduate educational session involving students studying for a post graduate certificate/MSC who had relevant expertise in this area, I took the opportunity to conduct a small expert verification exercise which examined the resultant theory generated. As already indicated, this was not planned to take place nor be included as part of the study design at the commencement of this research. However, its results are reported within this thesis as these provide some insights into how this study may be interpreted by experts within the field (Appendix 8).

THE IMPLICATIONS OF THE DEVELOPED THEORY

The study provided an interesting and valuable insight into this interpersonal process and should prove to be of particular interest within both the educational and managerial circles of health and social care. The theory developed has been described as being between a substantive and tentative level. Developing this theory involved demonstrating relationships across data concepts and emergent categories. Determining relationships required a degree of creative speculation and interpretation on my part, an activity that is inherent within this Grounded Theory process (Glaser 1978; Patton 1980; Glaser 1992; Webb 1992; Parahoo 1997; Donaldson 2003; Pellat 2003). However due to the relatively small sample

size, along with the qualitative nature of the study, I suggest caution be exercised when interpreting the strength of relationships within this theoretical framework. Further empirically generated research evidence is required to more fully support or refute these links and render this theory more generalisable to wider care settings (Donaldson 2003).

A central and dominant hypothesis deriving from this study is that, through a process of increased awareness and education, the alliance between carer and key-worker can be improved to the extent that the carer has a much more positive and less arduous care-giving experience (Figure 9 p324). In particular, the developed theory suggests that the Carer/Key-Worker relationship will be improved if efforts are made to clarify and promote the determinants that lead to an enhanced level of this relationship (Figure 9). This hypothesis must be examined utilising, as mentioned above, more empirically based research methods in order to determine the strength of these code and category relationships. It follows on, therefore, that such awareness raising and/or educational programmes must be rigorously and systematically examined in an attempt to clearly establish the relationship between the 'Enhanced Relationship' (drivers) being improved, leading to more effective partnership (action) and a resulting improved care-giving experience (impact). In order to do this effectively a quantifiable measure of the quality of the caring experience will require to be established and the strength of the relationship linking this to such a programme clearly demonstrated. Only following on from such empirically based evidence regarding this relationship, can these results be confidently

utilised to underpin and strengthen any future educational and training programmes.

This theory, therefore, has implications for the future preparation of health and social care workers through its incorporation into relevant training and educational processes as well as publication within appropriate journals. In addition, insights gained from an exposure to this theory should benefit carers themselves and should be made available and understandable to them, again through appropriate publications and by its incorporation into training sessions delivered through carers voluntary groups or professionally run programmes. This should better prepare them to more fully exploit the potential from their relationship with the key-worker.

As was evident from the preceding chapter, organisations exercise a considerable effect upon this relationship. In facilitating educational activities, and having established stronger evidence associated with the Carer/Key-Worker relationship and the quality of the caring experience, efforts should be made to further disseminate the results regarding the importance of this relationship to senior health and social care managers and educationalists. This important alliance will only be fully recognised, and nurtured, by reaching those with the ability to influence the wider care culture. It is important, therefore to expose academics and senior managers to the potential from this theory, in order to ensure their appreciation of the importance of this relationship and the determinants that lie behind its development. Once again this can be achieved through appropriate

publications as well as in-service educational programmes directed towards these important and influential groups.

In conclusion, this study has allowed me to examine, in greater detail and more depth, the psychosocial processes associated with the Carer/Key-Worker relationship. By interviewing these carer/key-worker dyads using a grounded theory approach, I have been able to develop a theoretical framework that provided some explanation of the inherent processes associated with this relationship. The framework exposes aspects that appear to be important in determining this relationship's development and subsequent depth and strength. When enabled, these 'determinants' can potentially enhance the quality of the relationship and may lead to a stronger working partnership or 'therapeutic alliance'. When established, this 'alliance' can produce positive and potentially beneficial effects upon all of the parties involved in care delivery within the home, as well as improve the care-giving climate for the dependants themselves.

This level of partnership may help to reduce, for the carer, the more arduous aspects associated with the 'costs of caring' for a dependant diagnosed with dementia. Finally, this relationship is potentially influenced by a series of 'mediators' existing outwith the immediate Carer/Key-Worker relationship, which can exert either a positive or negative effect upon its development and strength. A greater recognition and understanding of the implications arising out of this study, potentially, will provide important insights for those who work with, or around, a person with the diagnosis of dementia. Following further research into this theory, these insights may provide the carer and key-worker

with a greater ability to more successfully develop, or positively exploit, 'the enhanced carer/key worker relationship' and derive the potential benefits its creation suggests.

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APPENDICES

Appendix 1a Advantages and Limitations of Research Approach

(Approach Before Ethical Approval)

PROS

You can get overall consultant & key-worker permission up front.

Reduces the chances of refusal during the progress of the study.

Will receive accurate indication of the competence of the dementia sufferer from responsible medical officer.

Consultants indicating & approving participants may give increased credibility to the study & improve recruitment.

Reduces the time needed to repeatedly seek consultant permission on a case by case basis. Will still inform consultant on each individual subject, by letter, prior to approaching the carer to ascertain if my involvement potentially may cause complications for the care situation.

Possibility of identifying the 'key' worker as seen from the consultant perspective.

Follows appropriate protocol.

Key-worker will already know & have a relationship with the carer.

Knowing carer details before interview aids theoretical sampling

Ease of access to key-workers.

CONS

Consultant disinterest or interference in research design.

There are still stages within the research process where a refusal could setback many hours of work.

Possible lack of knowledge/ interest around Carers issues by Consultants.

Perceived lack of credibility in non-medical researcher.

A fairly time consuming process involved.

Limited number of key workers within Lanarkshire.

The carer is not consulted regarding who they consider to be their key-worker.

Possible bias in the Consultant selection.

May have to use the same key-worker several times.

Appendix 1b Advantages and Limitations of Research Approach

(Approach Following Ethical Approval)

PROS

You can get overall consultant permission up front.

The carer is consulted regarding their perception of key professional worker involved.

Will receive accurate indication of the competence of the dementia sufferer from responsible medical officer

Consultants indicating & approving participants may give increased credibility to the study & improve recruitment.

Reduces the time needed to repeatedly seek consultant permission on a case by case basis.

Possibility of identifying the 'key-worker' as seen from the carer perspective.

Follows appropriate protocol

Key-worker will already know & have a relationship with the carer

Ease of access to key-workers.

CONS

Consultant disinterest or interference in research design.

There are still stages within the research process where a refusal could setback many hours of work.

Possible lack of knowledge/interest around carers & carers' issues by consultants.

Perceived lack of credibility in non-medical researcher.

A fairly time consuming process involved.

Limited number of key-workers within Lanarkshire .

Possible bias in the consultant selection.

May have to use the same key-worker several times.

Not knowing carer details limits ability to theoretically sample the participants

Letters of Permission

18th October 2000

Ref: SN/TAK

If telephoning please ask for: Dr Novosel

Mr Gerard McGhee
Research Student
Bell College Health Ltd
Almada Street
HAMILTON
ML3 0JB

Dear Gerard

Re : Developing a Conceptual Model of the Lay Carer/Key Worker Relationship

I write to confirm my consent for you to carry out the above study within the Old Age Psychiatry Services of Lanarkshire Health Care NHS Trust.

I wish you every success and look forward to receiving a copy of your final thesis when you have completed the study.

Yours sincerely



 **Steven Novosel**
Director of Mental Health/Learning Disabilities



SOCIAL WORK RESOURCES
EXECUTIVE DIRECTOR SANDY CAMERON CBE
Strategic Services

Our ref: SMcL/MC
Your ref:
If calling ask for: Sam McLean
Date: 8 March 2001

Mr Gerard McGhee
6 Woodlea
Blackwood
South Lanarkshire
ML11 9SY

Dear Mr McGhee

Developing A Conceptual Model of the Lay Carer/Key Worker Relationship

Thank you for your letter of 7th February and the copy of your research proposal. The proposal has been considered by representatives of the Research Advisory Group in Social Work Resources and agreement can be given for the inclusion of a sample of social work staff within your research study.

It is noted, from your correspondence, that you have agreed a proviso with Lanarkshire Health Board that you will not access the names of carers but that information will be anonymised before you receive it. This is a proviso that is also suitable for Social Work and I would propose that we agree it.

I will inform relevant managers in social work resources in the event of your contacting them regarding your research and wish you every success in the research you are carrying out. South Lanarkshire Council would be interested to receive a summary/synopsis of your research and in particular would be keen to learn any lessons which you learn from this which can assist us to deliver a better service. I look forward to hearing from you.

Yours sincerely

A large black rectangular box redacting the signature of the Strategic Services Manager.

Strategic Services Manager

**Social Work
Headquarters
28 Muir Street
MOTHERWELL
ML1 1BN**



**Contact: George McNally
Our Ref: GMcI/MW
Your Ref:
Date: 12 July 2002**

**Telephone: 01698 332555
E-mail: McNallyG@northlan.gov.uk
Fax: 01698 332550
Web Site: www.northlan.gov.uk**

*Director of Department
Jim Dickie*

**Mr Gerard McGhee
6 Woodlea
Blackwood
Lanarkshire
ML11 9SY**

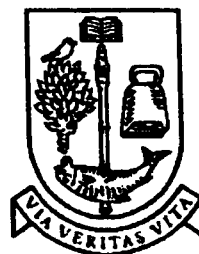
Dear Mr McGhee

Research Request

Thank you for your letter of 10 July 2002. I have passed your request to Michelle McClung, Research Officer, she will consider your approach and advise you if the Department is able to be of assistance to you. Michelle can be contacted on 01698 332055.

Yours sincerely

**George McNally
Manager Social Work Strategy**



UNIVERSITY
of
GLASGOW

Dear

I am a nurse doing some work at Glasgow University.

Your doctor has kindly agreed to send this letter to you and I have not been given your name.

I am writing to you to ask for your help.

I would like to speak to the people who help you manage from day to day.

This would include the nurse (or other professional person) who visits you at home and also the relative or friend who knows you best.

I will only meet with them if both you and they agree.

The reason for the work is to try to understand how best these people can work together to help you.

The work is confidential. I will not write down any names, or tell anyone else who you are.

I hope this work will help improve training for nurses, and that the University will give me a qualification for doing it.

If you agree for me to meet the people who look after you, please give them the envelope that came with this letter.

If you do not want me to meet the people who help you, you can tear up this letter and the envelope. This decision will not affect the help you are getting now or in the future.

Thank you very much for reading this letter.

Yours sincerely,

Gerry McGhee

Correspondence with Lanarkshire Research Ethics Committee



LANARKSHIRE HEALTH BOARD

OUR REF: MM/BC

14 Beckford Street

Hamilton

ML3 OTA

YOUR REF.

If telephoning, ask for

Telephone(01698)281313

Ms. M Macleod

Fax No (01698) 423134

23 February 2000

Mr. G. McGhee
College Lecturer
6 Woodlea
Blackwood ML1 1 9SY

Dear Mr. McGhee

**DEVELOPING A CONCEPTUAL MODEL OF THE LAY CARER/KEY-
WORKER RELATIONSHIP:A STUDY OF THE RELATIONSHIP
BETWEEN THOSE INVOLVED IN CARING FOR INDIVIDUALS
DIAGNOSED WITH DEMENTIA**

I refer to the above study which you submitted to the Lanarkshire Health Board Ethics of Research Committee for approval.

This was considered at a meeting of the Committee held on February 2000, when Members raised the following issues:

- As a matter of courtesy GPs should be informed when their patients are participating in a study.

- Members were concerned about you directly approaching the Carers/Key-Workers. Instead it was suggested that a letter should be sent out from the Consultant asking them to contact you if they were agreeable to participate in the study.

A member of the Committee, Dr. Gordon, Research & Development Manager has

offered to assist you with any concerns you might have on the issues raised by us.

Please feel free to contact him if this would be of assistance to you. He is based at

Beckford Street and can be contacted on 01698 281313.

Following clarification on how you will recruit members further consideration of your study will be given.

Yours sincerely,

M. MACLEOD

ASSISTANT ADMINISTRATOR

LANARKSHIRE RESEARCH ETHICS COMMITTEE

NOTIFICATION OF APPROVAL

NAME OF PROPOSER : MR. GERARD McGHEE
COLLEGE LECTURER
6 WOODLEA
BLACKWOOD

TITLE OF STUDY : DEVELOPING A CONCEPTUAL MODEL OF THE LAY
CARER/KEY WORKER RELATIONSHIP: A STUDY OF
THE RELATIONSHIP BETWEEN THOSE INVOLVED IN
CARING FOR INDIVIDUALS DIAGNOSED WITH SENILE
DEMENTIA

REFERENCE NUMBER : ER 101/2/2000

DATE OF MEETING : 15TH FEBRUARY 2000

MEMBERS PRESENT : DR. G.A. VENTERS, CONSULTANT IN PUBLIC HEALTH
MEDICINE (CHAIR)
REV S. COOK, CHURCH OF SCOTLAND MINISTER
MISS M.M. TAYLOR, CONSULTANT IN DENTAL PUBLIC
HEALTH
MRS. H. DAVIDSON, WARD 18, LAW HOSPITAL
DR. D. GORDON, RESEARCH AND DEVELOPMENT
MANAGER
DR. L. McALPINE, CONSULTANT PHYSICIAN
MRS. M. RUSSELL, CLINICAL SERVICE CO-ORDINATOR,
WILLIAM SMELLIE UNIT
MR. G. PICOZZI, ENT CONSULTANT, LAW HOSPITAL
DR. P. SHERIDAN, GENERAL PRACTITIONER
DR. C. GODLEY, GENERAL PRACTITIONER
MS. M. MACLEOD, ASSISTANT ADMINISTRATOR

The above study was considered and approved by Lanarkshire Research Ethics Committee at a meeting held on 15th February 2000.

As a consequence of this approval there are a number of obligations which we expect of you and are that:

You will notify the Research Ethics Committee immediately of any information received or of which you become aware which could cast doubt upon, or alter, any information contained in the original application, or a later amendment application, submitted to the Research Ethics Committee and/or which would raise questions about the safety and /or continued conduct of the research.

■ You will require to comply with:

- The Data Protection Act 1984
- Good clinical research practice standards

You will submit any amendments proposed to the protocol to the Research Ethics Committee for further review and each will require further specific approval.

You will furnish the Research Ethics Committee with details of the progress of the research project periodically, and of the conclusion and outcome of the research project, and inform the Research Ethics Committee should the research be discontinued or any subject withdrawn.

I trust these conditions are acceptable to you.

Signed [REDACTED] :..... Secretary

Date..... 8/5/00.....

Please note that our Reference Number given to project must be quoted on all correspondence.

NOAMCGHEE21F.DOC



**UNIVERSITY
of
GLASGOW**

6 Woodlea
Blackwood
South Lanarkshire
ML11 9SY
8th of May 2000

Dear Mrs Macleod

**DEVELOPING A CONCEPTUAL MODEL OF THE LAY CARER/KEY-
WORKER RELATIONSHIP: A STUDY OF THE RELATIONSHIP
BETWEEN THOSE INVOLVED IN CARING FOR INDIVIDUALS
DIAGNOSED WITH DEMENTIA.**

Thank you for your letter dated 23/2/00. I note your feedback from the Ethics Committee with interest. As suggested in the letter I met with Dr Gordon to discuss the suggested amendments. The following areas were considered.

- The informing of GP's of the involvement of their patients within the research.
- The Consultants passing on to me the names and addresses of suitable patients for the study.
- The need to make clear, within the Carer's information sheet that no information divulged by them will be made known to the Key-Worker.

The first issue relates to the notification of the patients GP. Whilst I fully understand the courtesy of informing a GP of a patient's involvement, there is a question within this study of who the involved person is. Is the Committee suggesting the GP of the frail elderly person be informed or the GP of the Carer, who is possibly different. In this study it is the Carer and not the patient who is the subject of the research.

In the former case, I would need your permission to access the name of the GP from the hospital records. In the latter case, the information as to who the GP of the Carer is can only come from the Carers themselves. At interview, therefore, I would need to ask the Carers who their GP is, and presumably, if they will permit me to inform them of the nature of the research and their involvement within it.

On discussing this with Dr. Gordon he agrees that the GP does not require to be informed on this occasion.

On the second and third issues I fully understand and agree with the committee's position on this and I have amended the study guidelines and letters accordingly (see enclosed).

Thank you for your help in this matter.

Yours sincerely

Gerard McGhee

Request to Ethics to Allow Unqualified Key-Worker Inclusion



UNIVERSITY
of
GLASGOW

Dr. Gordon
Member of Ethics Committee
Lanarkshire Health Board
Beckford Street
Hamilton
South Lanarkshire

6 Woodlea
Blackwood
South Lanarkshire
ML11 9SY

5th of February 2001

Dear Doctor Gordon,

Developing a Conceptual Model of the Lay Carer/Key-Worker Relationship

On February of last year I received ethical approval to conduct the above study within the Lanarkshire Primary Trust area. It has been only recently that I have been able to begin the fieldwork phase of the study. It has become apparent to me now that I may have mistakenly and unnecessarily restricted my sample group of Key-Workers.

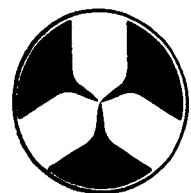
Within my proposal and ethics application form I stated that the target sample of Key-Workers would require to be drawn from professionally registered individuals. The study also requires that I interview the lay Carer in the first instance and get them to identify the Key-Worker. In the reality of contemporary practice it would seem that a significant number of these 'lay Carer identified' Key-Workers will not be on any professional register. They are, however, the principle people supporting the lay Carer, and the ones who may have the most significant relationship with the Carer. Therefore, if I stayed within the boundaries of my original sample requirements, I

could lose a significant number of important cases, particularly within the social care environment.

Given that these Key-Workers are under the direct supervision of either a registered social work or health care professional, I intend to amend my proposal (enclosed) and interview these individuals if they are identified as Key-Workers. I would be most grateful if you could acknowledge this correspondence, confirming that the committee would have no objections to the amendment, as soon as possible to allow my study to quickly proceed.

I look forward to hearing from you soon and thank you once again for your assistance in this matter.

G. McGhee
Research Student



LANARKSHIRE HEALTH BOARD

OUR REF:

YOUR REF:

NJA/PMcM

14 Beckford Street.
Hamilton
ML3 0TA

If telephoning, ask for:

Telephone: (01698) 281313
Fax No.: (01698) 423134

Mr N J Agnew

07 February 2001

Mr G McGhee
Research Student
6 Woodlea
BLACKWOOD
ML11 9SY

Dear Mr McGhee

DEVELOPING A CONCEPTUAL MODEL OF THE LAY CARER/KEY WORKER RELATIONSHIP

I refer to your letter of 5 February 2001 to Dr David Gordon, concerning the above matter.

Dr Gordon has discussed with Dr G A Venters, Chairman of the Ethics Committee, your proposed amendment to the study proposal, to include additional key workers, e.g. social work assistants, who are under the direct supervision of either a registered social worker or health care professional. I am pleased to confirm that Dr Venters, in exercise of his Chairman's authority, has approved the amendment.

Yours sincerely

N J AGNEW
CORPORATE AFFAIRS MANAGER

CARER INFORMATION SHEET

DEVELOPING A CONCEPTUAL MODEL OF THE LAY CARER/KEY-WORKER RELATIONSHIP: A STUDY OF THE RELATIONSHIP BETWEEN THOSE INVOLVED IN CARING FOR INDIVIDUALS DIAGNOSED WITH DEMENTIA.

Dear Carer,

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives or your relative's/friend's Consultant if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you would like to take part.

Thank you for reading this.

What is the purpose of the study?

The purpose of this research is to understand more clearly the important relationship that develops between the relative or friend who cares for someone suffering from dementia, and the care worker (Key-Worker) allocated to help them deal with their care responsibilities.

Why have I been chosen?

As you are currently involved in caring for someone with dementia, you're relative's/friend's Consultant has put your name forward as someone who may be willing to assist me in this research study. If you agree to take part in the study, I will arrange to visit you at home or, if you prefer, at a mutually convenient location.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form a copy of which you will be given to keep. You are still free to withdraw at any time without giving a reason. Your participation will neither affect the standard of care your relative/friend is receiving nor the level of help & support that you are entitled to.

What will happen to me if I take part?

The study will involve interviewing you on one occasion only for approximately forty-five minutes to an hour. The interview will focus upon the help you receive in caring for your relative/friend from the professional involved, and what you feel about the support they provide for you. The study will also involve interviewing your Key-Worker to allow me to more fully understand what they see as being important in effectively helping you to cope with your day to day care. With your permission the interview will be tape recorded to allow me to study our discussion along with those of the other Carers and Key-Workers. This is important as it allows for a more detailed and careful investigation of the important aspects of the relationships.

Will my taking part in this study be kept confidential?

Apart from your Key-Worker and myself no one else will know your identity and all the interviews, both taped and written, will not at any time carry your name or address and will be destroyed at the end of the research. The Key-Worker will not be approached until and unless you agree to take part and they will not be informed of anything that you discuss with me at any time. They will not know if you refuse to be involved. Neither your, the person you care for, nor your Key-Worker's identities will be revealed at any time during or following this study and all information given will be treated in the strictest confidence.

What are the risks of taking part?

While there are no obvious risks involved in this research study, discussing their particular circumstances may be difficult for some Carers. If this proves to be the case you can terminate the discussion at any point and withdraw from the study.

What are the benefits of taking part?

Participating in this research will not bring either you or your relative any direct benefit. However, by agreeing to take part in the study you will help to improve the understanding of the relationship between people who care for relatives and friends suffering from dementia and the visiting professional care worker. This understanding could help greatly in the training of professional care workers, such as nurses or social workers, allowing them to more effectively support Carers such as you. It could also allow health and social services more effectively plan support services for family Carers which are more useful in helping them deal with the day to day difficulties they face.

What will happen to the results of the study?

I am carrying out this research for a Ph.D. degree at the University of Glasgow. At no time will your identity, or that of your relative/Key-Worker, be revealed in the research report or any published work

Who has reviewed the study?

Lanarkshire Health Board's Ethics of Research Committee have examined this research and permitted the study to be undertaken within the Lanarkshire Health Board area.

Contact for further information?

If you require any further information on this research study please contact myself directly on:

***** any weekday between 9am and 5pm.

Once again thank you for taking the time to read this information sheet.

Research Carer Reply Form

Dear Carer,

If you would like to help me with this work please fill in your details below and post this form back to me in the attached envelope. (No stamp is needed)

Your Name
.....

Your Address
.....

.....

.....

Telephone Number
.....

When is the best time to phone you (Please Tick)

| |
|------------------|
| Morning |
| Afternoon |
| Evening |

Once again thank you for considering my request for help.

Yours sincerely,

Gerry McGhee

PATIENT OR VOLUNTEER CONSENT TO PARTICIPATE IN RESEARCH STUDY

Project Title

DEVELOPING A CONCEPTUAL MODEL OF THE LAY CARER/KEY-WORKER RELATIONSHIP: A STUDY OF THE RELATIONSHIP BETWEEN THOSE INVOLVED IN CARING FOR INDIVIDUALS DIAGNOSED WITH DEMENTIA

You should have been given a complete explanation of the research study in which you are being invited to take part, including details of the procedures and treatment you would undergo as part of the study.
You should have had the opportunity to ask questions.
You should have received the information sheet on the study, which has been approved by Lanarkshire Health Board Ethics of Research Committee, which you should have read and should keep.
There is no obligation to take part in the study and you need not give any reason if you do not wish to take part in the study.
You may withdraw from the study at any time without the need to give a reason and without any effect upon your normal care.

Consent

I (name in block capitals)

of
.....
.....

.....(address in block capitals)

agree to take part in this research project, the nature, purpose and possible consequences of which have been described to me

by(name in block capitals)

Subject signature

..... dated
.....

Researcher signature

.....
*This form has been approved by Lanarkshire Health Board Ethics of Research
Committee*

KEY-WORKER INFORMATION SHEET

Dear Colleague,

A Study of the Professional Health Care Worker's Developing Relationship with Those Lay Carers Involved with Individuals Suffering From Dementia

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you would like to take part.

Thank you for reading this.

The aim of this research is to more clearly understand the important relationship that develops between the relative or friend who cares for someone suffering from dementia, and the care worker (Key-Worker) allocated to help them deal with their care responsibilities.

As you are currently involved with clients diagnosed with dementia and their Carers, you are being asked to assist in this study. The client's Consultant Psychiatrist has provided their name and you have been identified as the Key-Worker associated with this care situation. If you agree to take part in the study, I will arrange to visit you at your base or, if you prefer, at a mutually convenient location. In carrying out this research I hope to interview around twenty-five Carers along with the Key-Workers involved with each of them.

The study will require interviewing you on each occasion that one of your clients is selected for the study and will last for approximately forty-five minutes to an hour. You may therefore be interviewed on two or three occasion depending on how many of your clients are selected. The interview will focus upon the help you provide for that specific Carer and how you feel that individual responds to your involvement. With your permission the interviews will be tape recorded to allow for study of the discussion along with those of the other Carers and Key-Workers. This is important as it allows for a more detailed and careful investigation of the important aspects of your relationship with the Carer.

This research methodology requires the researcher to type out, in full, all of the narrative that has taken place, which is then studied to determine any similarities or differences between them. This type of method is usually referred to as 'Grounded Theory'.

It is up to you to decide whether or not to take part. If you do decide to become involved you will be asked to sign a consent form, a copy of which you will be given. You are still free to withdraw at any time without giving a reason. This

decision will not be made known to either the relative nor the Consultant involved.

Apart from myself and your client's Carer, no one else will know your identity and all the interviews, both taped and written, will not carry your name or address and will be destroyed at the end of the research. Neither your, the client's, nor their Carer's identities will be revealed at any time during or following this study and all information given will be treated in the strictest confidence.

By agreeing to take part in this study you will facilitate a clearer understanding of the important relationship between people who care for relatives and friends suffering from dementia and the visiting professional care worker. This understanding could help greatly in the training of professional care workers, such as nurses or social workers, allowing them to more effectively support Carers in difficult domestic circumstances. It could also allow health and social services more effectively plan support services for family Carers which are more useful in helping them deal with the day to day difficulties they face.

This research is being undertaken in pursuit of a Ph.D. and is being supervised at the University of Glasgow. Neither yourself nor your client's Carer will be identified in either the full research report or any of the published work.

If you require any further information on this research study please contact myself directly on:

***** any weekday between 9am and 5pm.

Once again thank you for taking the time to read this information sheet.

KEY-WORKER CONSENT TO PARTICIPATE IN RESEARCH STUDY

Project Title

DEVELOPING A CONCEPTUAL MODEL OF THE LAY CARER/KEY-WORKER RELATIONSHIP: A STUDY OF THE RELATIONSHIP BETWEEN THOSE INVOLVED IN CARING FOR INDIVIDUALS DIAGNOSED WITH DEMENTIA

You should have been given a complete explanation of the research study in which you are being invited to take part.
You should have had the opportunity to ask questions.
You should have received the information sheet on the study, which has been approved by Lanarkshire Health Board Ethics of Research Committee, which you should have read and should keep.
You will be asked to give asked to give consent in principle prior to commencement of the study and on each specific occasion. There is no obligation to take part in the study and you need not give any reason if you do not wish to take part in the study at any stage.

Consent

I (name in block capitals)

of
.....
.....

.....(address in block capitals)

agree to take part in this research project, the nature, purpose and possible consequences of which have been described to me

by(name in block capitals)

Subject signature

..... dated
.....

Researcher signature
.....

Appendix 6 General Biographical Details Forms & Details

Carer

GenderMale/Female

Relationship Son/daughter Grandson/Granddaughter Husband/Wife

Son-in-law/Daughter-in-law Niece/Nephew

Brother/Sister Mother/Father

Friend Neighbour

Length of Time Caring

4 – 6 mths 6mths – 1 year 1 – 2 yrs

2-3yrs 3 – 4yrs 4 – 5yrs

5 – 6yrs 6yrs+

Care Responsibilities Occasionally/Full Time

Personal Care

Cooking/Shopping

Travel

Personal Safety & Supervision

Finances

Medication

Other

Age Range (15 – 25) (26 – 40) (41 – 55) (55 – 65)

(66 – 75) (76 – 90) (90+)

Carer Biographical Details

| Carer No. | Gender | Age | Relationship | Time Caring | Personal Care Provided | Cooking/Shopping Provided | Travel Provided | Safety Supervision | Financial Support | Supervise Medication |
|-----------|--------|-----|--------------|-------------|------------------------|---------------------------|-----------------|--------------------|-------------------|----------------------|
| 1 | F | ↑76 | Spouse | 5-6yrs | No | Yes | Yes | Yes | Yes | Yes |
| 2 | F | ↑76 | Spouse | 1-2yrs | Yes | Yes | Yes | Yes | Yes | Yes |
| 3 | F | 60 | Spouse | 5yrs | No | Yes | Yes | Yes | Yes | Yes |
| 4 | M | 77 | Spouse | 4-5yrs | Yes | Yes | Yes | Yes | Yes | Yes |
| 5 | F | 63 | Spouse | 7yrs | Yes | Yes | Yes | Yes | Yes | Yes |
| 6 | F | 74 | Spouse | 2.5yrs | Yes | Yes | Yes | Yes | Yes | Yes |
| 7 | F | 53 | Spouse | 1.5yrs | Yes | Yes | Yes | Yes | Yes | Yes |
| 8 | F | 67 | Spouse | 4yrs | Yes | Yes | Yes | Yes | Yes | Yes |
| 9 | F | 34 | Daughter | 4yrs | Yes* | Yes* | Yes* | Yes* | Yes | Yes |
| 10 | F | 74 | Spouse | 2.5yrs | Yes | Yes | Yes | Yes | Yes | Yes |
| 11 | M | 75 | Spouse | 3yrs | Yes | Yes | Yes | Yes | Yes | Yes |
| 12 | M | 81 | Spouse | 2yrs | No | Yes | Yes | No | Yes | Yes |
| 13 | F | 75 | Spouse | 4yrs | Yes | Yes | Yes | --- | Yes | --- |
| 14 | F | 74 | Spouse | 5yrs | Yes | Yes | No | Yes | Yes | --- |
| 15 | F | 62 | Spouse | 5yrs | Yes | --- | Yes | Yes | --- | Yes |
| 16 | M | 82 | Spouse | 2yrs | No | Yes | Yes | Yes | Yes | Yes |
| 17 | F | 65 | Spouse | 2.5 | --- | Yes | Yes | --- | Yes | No |
| 18 | F | 68 | Spouse | 2.5 | Yes | No | No | --- | --- | --- |

* Services provided by external organisations

General Biographical Form

Key-Worker

GenderMale/Female

Length of Time Qualified/In Post

Organisation & Designation

Length of Time Involved

4 – 6mths 6mths – 1 year 1 – 2 yrs

2-3yrs 3 – 4yrs 4 – 5yrs

5 – 6yrs 6yrs+

Care Responsibilities Occasionally/Full Time

Personal Care

Cooking/Shopping

Travel

Personal Safety & Supervision

Finances

Medication

Other

Age Range (15 – 25) (26 – 40) (41 – 55) (55 – 65) (66 –
75) (76 – 90) (90+)

Key-Worker Biographical Details

| Key-Worker No. | Gender | Age | Professional Group | Time Involved | Personal Care Support/Advice | Cooking/Shopping Support/Advice | Travel Provided Support | Safety Advice | Financial Advice | Medication Advice | Years Qualified |
|-----------------|--------|-------|--------------------|---------------|------------------------------|---------------------------------|-------------------------|---------------|------------------|-------------------|-----------------|
| 1 ¹ | M | 26-40 | NHS | 4-6mths | No | No | No | No | No | Yes | 14 |
| 2 | F | 41-55 | NHS | 4-6mths | Yes | No | No | Yes | No | Yes | 6 |
| 3 ¹ | M | 26-40 | NHS | 12mths | No | No | No | No | No | No | 14 |
| 4 | F | 34 | NHS | 7mths | Yes | Yes | No | Yes | No | Yes | 12.5 |
| 5 | M | 34 | NHS | 30mths | Yes | No | Yes | Yes | Yes | No | N/A |
| 6 ¹ | M | 26-40 | NHS | 6mths | No | No | No | No | No | No | 14 |
| 7 ² | F | 30 | NHS | 8mths | No | No | No | No | No | No | 9 |
| 8 ² | F | 30 | NHS | 36mths | Yes | Yes | Yes | Yes | Yes | Yes | 9 |
| 9 | F | 44 | SW | 18mths | Yes | No | Yes | Yes | Yes | No | 3 |
| 10 | F | 32 | NHS | 5-6mths | No | No | No | Yes | No | Yes | 10 |
| 11 ³ | F | 41 | NHS | 24mths | No | No | Yes | Yes | No | Yes | 20 |
| 12 ³ | F | 41 | NHS | 3mths | --- | --- | --- | Yes | --- | Yes | 20 |
| 13 ³ | F | 41 | NHS | 3mths | No | No | No | Yes | No | No | 20 |
| 14 | M | 50 | SW | 24mths | Yes | Yes | Yes | Yes | Yes | No | N/A |
| 15 ³ | F | 41 | NHS | 60mths | --- | --- | Yes | Yes | --- | Yes | 20 |
| 16 | F | 47 | NHS | 12mths | --- | --- | --- | --- | --- | Yes | 26 |
| 17 ⁴ | M | 32 | NHS | 4mths | No | No | No | No | Yes | Yes | 9 |
| 18 ⁴ | M | 32 | NHS | 5mths | No | No | No | No | Yes | Yes | 9 |

Note: The superscript numbers alongside the key-worker number identifies those key-workers interviewed on more than one occasion

Appendix 7 Interview Schedules

Carer

- **Who is your Key-Worker/professional?**

| Name | Designation | Contact Number |
|-------------|--------------------|-----------------------|
|-------------|--------------------|-----------------------|

- **How would you describe your relationship with them?**
- **What is it that this person does that helps you cope better when providing care for your relative/friend?**
- **Is there anything about this person that makes talking with them and working with them easier? What, if anything, do they do to make it easier for you to talk and share problems with?**
- **Is there anything that you do for your relative that you feel should be done by this professional or other agency? Why?**
- **Is there anything you feel prevented from doing by the involvement of this key professional?**
- **Can you identify any reasons why you have these views and attitudes towards your caring role and its associated responsibilities? i.e. previous experiences with the health care services, previous life experiences, social up bringing, media influences etc.**

Interview Schedule

Key-Worker

- Do you consider this particular person to be the principle Carer of your client? How would you describe your relationship with this Carer?
- What is it that this person does that helps you cope better when providing care for your client?
- Is there anything about this person that makes talking with them and working with them easier? What, if anything, do they do to make it easier for you to provide effective and relevant care?
- Is there anything that you do for your client that you feel should be done by this Carer? Why?
- Is there anything you feel prevented from doing by the involvement of this Carer?
- Can you identify any influences, out with your training and professional experiences, which contribute to you having these views and attitudes towards your caring role and its associated responsibilities? i.e. previous life experiences, social up bringing, media influences etc.
- Are there any other important aspects about your relationship with this Carer you think is important to appreciate?

Appendix 8

Verification Report – Verification of the Generated Theory

Group 1 – Enduring Mental Health Cohort

| Enduring Mental Health Group | Age | Gender | Qualifications | Length of Health Care Experience | Length of Speciality Experience |
|------------------------------|-----|--------|----------------------|----------------------------------|---------------------------------|
| Verifier 1 | 36 | Male | BSc (Hons) RMN. | 18years | 15years |
| Verifier 2 | 48 | Male | BA, Dip N, RMN, RGN. | 30 years | 20years |
| Verifier 3 | 39 | Female | BSc, RMN CPN Dip. | 22 years | 14 years |
| Verifier 4 | 42 | Male | BA, RMN, CPN Dip. | 4 years | 3 years |

Summary of Comments:

This group considered that the concepts generated were key to their professional role. Nothing that emerged surprised them and that, they considered, was a positive aspect. They were experiencing these aspects but were not consciously categorising these areas of practice. One member believed that the discussed theory reinforced her belief that this relationship was absolutely crucial, especially in terms of the present day tendency to move towards a more task-orientated, mechanistic and highly outcome-orientated approach to care delivery where such relationship development would become very problematic. The group felt that the professional, operating at a strategic level, requires to be made aware of this theory as the key-worker needs to operate within a system that

recognises and appreciates the importance of such a relationship being established. Generally, they considered that the theory had a lot of merit but one member voiced that an onus placed on the professional to foster this level of relationship with a carer might bring added pressures arising out of becoming too involved, particularly around the aspect of ‘letting go’.

Group 2 – Older Persons Cohort

| Older Person Mental Health Group | Age | Gender | Qualifications | Length of Health Care Experience | Length of Speciality Experience |
|---|------------|---------------|-----------------------|---|--|
| Verifier 1 | 47 | Female | RGN, RMN | 30 years | 6 years |
| Verifier 2 | 50 | Female | BA, RMN | 16years | 13 years |
| Verifier 3 | 46 | Female | BSc, RMN | 29 years | 12 years |

Summary of Comments:

This group felt that this theory was understandable and will bring out aspects of practice that require examination as this was an area that has not been adequately examined in the past. They considered that there was a need to understand relationships and that this theory would help generate some important questions that would help in this regard. This understanding would help in the professional getting the effective balance right in not being either too close or too distant from the carer. Like the first group they voiced the need for senior managers to

understand the importance of this relationship, necessitating a more flexible operational approach by the key-worker, particularly at the 'letting go' stages associated with either permanent admission or bereavement. They group identified with the need for the key-worker to be more overt in their assessment of the relationship with the carer and that this theory may provide an awareness-raising benefit and possibly an assessment mechanism to assess the quality of this relationship.

They all felt that this theory had real potential to help future practitioners through education and training initiatives and this would keep the professional much more focused upon carer issues and their importance within the totality of dementia care giving. They all expressed an interest in seeing how this can be taken forward into practice with one emphasising that, to her, the carers are hidden people and their profile requires to be raised in this country. They finished this exercise by claiming that this exercise, to them, had been very useful and had raised the profile of the carer relationship which will now be more in their thoughts in any future contact with this group.

