

A COMPARISON OF CARERS' EXPERIENCES OF CARING FOR  
INDIVIDUALS WITH DEMENTIA OR INTELLECTUAL  
DISABILITY: A LONGITUDINAL GROUNDED THEORY STUDY

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By

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## **DECLARATION**

**I declare that this thesis is my own work and that no material contained in it has been submitted for another academic award.**

**Mei-Chun Lin**

## **ABSTRACT**

### **Introduction**

Increasingly the provision of care for older people with dementia or children with intellectual disabilities (ID) has shifted from institutions to the community. This has resulted in an increase in burden and a reduction in autonomy for those who care for these individuals.

### **Aims**

This study sought to identify, describe and explore the changes in the carers' experiences of looking after a relative living with dementia or adolescents with ID, and the effects of caring on the carers' autonomy and health over time.

### **Research Design and Methods**

A longitudinal, grounded theory approach in three phases was used. In-depth interviews were conducted with six spouses and seven mothers at the beginning, at six months and at eighteen months. A constant comparative analysis of taped and transcribed interviews was used.

### **Findings**

Four categories emerged: My Life Changed, Commitment, Responsibility and Duty, and Support. The core category My Life Changed was identified as representing the beginning of the caregiving journey; and the learning from experience that occurred as a consequence of that journey, offering a new perspective on the experience of carers. Of the other categories, Commitment refers to a deepened and sustained element; Responsibility and Duty increases over time and finally Support refers to the fluctuating nature of help provided by formal and informal sources. All participants experienced changes in the caregiving journey; the degree and nature of necessary adaptations varied.

### **Conclusions**

A Theory of Caring emerged: overall there is a great degree of similarity in the journey of caring, what changes were experienced did not appear to conform to any fixed pattern. All carers learned by experience to manage their situations although for the older group it is more rapid in the early stages of caring while the mothers experienced this learning more gradually. For all carers their autonomy and health was challenged.

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## **GLOSSARY**

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## GLOSSARY

- AD** Alzheimer's Disease is a brain disorder which results in cognitive impairment involving a progressive deficit in memory, the abilities of communication, thinking, making judgments, and actions or behaviour are also affected.
- ADLs** Activities of Daily Living is a term which refers to the basic things that people need to be able to do in order to look after themselves, such as feeding, bathing, dressing, grooming.
- ALs** Activities of Living is a term which has replaced ADLs since 2000 by Roper, Logan and Tierney.
- CINAHL** Cumulative Index in Nursing and Allied Health Literature which is a database covering nursing and allied health professions.
- DS** Down's Syndrome is a life-long condition in which extra genetic (chromosome 21) material causes delays in learning and development on those children who carry the material.
- EE** Expressed Emotion is an assessment of the affective relationship between two people characterized by levels of emotional involvement, hostility, or criticism.
- GP** General Practitioner is a medical doctor who provides primary care.
- ID** Intellectual Disability is gradually replacing the term learning disability, and refers to people with some impairment in cognitive functioning. To be diagnosed with the condition it must have been present from childhood and the intelligence quotient (IQ) has to be lower than 70-75.
- MEDLINE** MEDLINE is a database of largely medical literature.

SEN Special Educational Needs is a term which refers to children who have learning difficulties or disabilities which makes it harder for them to learn or access education than most children of the same age.

## **CHAPTER 1 INTRODUCTION**

The stimulus for this topic was previous experience of working alongside carers of individuals with dementia in my home country, Taiwan. I was also personally involved in caring for my friend's child, who had learning difficulties. The result of these activities was my realisation that the carers of such individuals have complex needs. In my MSc dissertation I made a comparison between caregiver burden and coping strategies in primary carers of elderly people in the Scottish and Chinese communities, and became increasingly convinced that the experience of family caring, and specifically of the changing needs of family carers over time, was appropriate for a longitudinal study. I also realised that my familiarity with two distinct health and welfare systems, at home and abroad, might enable me to bring a fresh perspective to such a study.

### **1.1 Background to the study**

The provision of health care in the UK has changed over the last three decades, with a shift in policy from institutional to community-based care, particularly in regard of individuals with dementia and intellectual disabilities (Walker & Ryan, 1995; Barodawala, 1996). In consequence of this shift, such individuals are increasingly being cared for at home, usually by a family member. Additionally, improvements in medicine have led to increased longevity for such individuals (Scottish Executive, 2000a), meaning that there is a higher number of frail and elderly people in the modern British population, and similarly an increased number of intellectually disabled adolescents surviving into adulthood (Patja *et al.*, 2000).

The Scottish Executive (2000b) estimates an increase of 1.2% a year between 1960 and 1995 of people with severe problems in the UK population, and National Statistics Online (2007a) further reports that the general population of people over sixty-five grew from 7.4 million in 1971 to 9.7 million in mid-2006. Moreover, a fall in the birth rate has resulted in an alteration in the ratio of young people compared to older people. In England and Wales, the birth rate has decreased by more than 15.7%. In 1996, 523,212 babies were born to mothers aged between twenty and thirty-four

years compared to 489,979 babies in 2006 (National Statistics Online, 2007b), which in turn suggests the likelihood that there are fewer younger able-bodied people available to help meet the increasing needs of the older population, both in terms of providing formal and informal care .

Family carers comprise a fundamental and essential element of community care. In the Working Group Report of the Scottish Executive (2001), carers are defined as being key partners in the provision of care. As a statistical category, they are now recognised as being of equal importance as cared-for persons. Various terms are used to describe people who are looked after by their relatives or friends, for example ‘care-receivers’ or ‘clients’. The term ‘cared-for person’ is consistently used in Governmental papers and reports, and is therefore the term I shall employ in the course of this thesis.

Helping carers may be one of the best ways of helping the people they care for. According to Strategy for Carers in Scotland (Scottish Executive, 1999), a number of new approaches for promoting the development of services warrant consideration: carer legislation, providing better information with regard to NHS support and carer-friendly employment; strategies specifically aimed at providing assistance to family carers (such as those initiated by Scotland Executive - also reported in Strategy for Carers in Scotland, 1999); the development of action plans for the modernisation of community care; consultation on all community care policy; the writing of an advocacy guide for carers; and housing and council tax reductions for carers of people with disabilities. Scottish Executive (2006) has further recognised the encouragement of younger carers, improved respite care, greater consideration of carer health and carer training as priority areas for development.

## **1.2 Justification for the choice of two groups**

There are various medical conditions as a result of which individuals need help with activities of living. These include dementia, stroke, terminal illness, arthritis, and breathing difficulties, as well as diseases and disabilities specific to children, such as intellectual disability (ID), cerebral palsy, and cystic fibrosis. For the present study,

two groups of carers were selected; these were carers of people with dementia, and carers of adolescents with ID. Further elaboration on each of these two groups follows.

### **1.2.1 Elderly people with dementia**

Dementia as a syndrome comprises the progressive loss of cerebral faculties. The most common variety of dementia is Alzheimer's Disease (AD). Other types of dementia arise from vascular problems, and include multi-infarct dementia, and alcohol-related dementias, such as Lewy body and Pick's disease (Alzheimer Scotland, 2004). The effects of the illness depend on the areas of the brain damaged. The commonest symptom is progressive memory loss. Other symptoms include mood changes, communication problems, decline in intellectual ability and self-care skills, and deterioration of personality (Alzheimer Scotland, 2004). The practical needs arising from this range of symptoms are help with dressing, feeding, bathing, and management of incontinence. In England, it is estimated that there are around 652,600 people with dementia. The prevalence of dementia in individuals aged between sixty-five and seventy is 1:50, rising to 1:20 for those aged between seventy and eighty. It is predicted that there will be over a million people with dementia by 2025 (Alzheimer's Society, 2007).

Numerous studies have focused on the experience of carers of elderly people with dementia (Pruchno & Potashnik, 1989; Young & Kahsna, 1989; Lewin & Lundervold, 1990; Robinson, 1990; Vitaliano *et al.*, 1993; Draper *et al.*, 1995; Fuller-Jonap & Haley, 1995; Russo *et al.*, 1995; Gallant & Connell, 1997; Clyburn *et al.*, 2000). The majority of these, however, have adopted a quantitative approach. Perhaps as a result of this, there remains a lack of understanding regarding the process of caregiving (Nolan *et al.*, 2002).



### 1.2.2 Adolescents with ID

A variety of terms, including mental handicap, mental retardation, and learning disability have been used to describe ID. Louhiala (2003) suggests that the respective terms reflect the era and context in which they were used, and recommends that ID is the most appropriate term to describe this group of people, explaining that intellectual and mental functions are not identical, and that individuals with intellectual disability may not always manifest specific mental retardation. For the purpose of this study the term ID will be used. In England, it is estimated that there are around 210,000 people with ID, of which approximately 65,000 are children and young people (Department of Health, 2001a). In the population of Scotland, it has been estimated that there is a ratio of 20:1,000 individuals with a mild or moderate ID, and that of that number, three or four people manifest profound or multiple disability (Scottish Executive, 2000b). In addition, around 15-20,000 people are thought to need help with understanding information, with communication, mobility, personal care, and in coping with daily living. Of these, about 25% (4,000-5,000) are children and young people aged under sixteen (Scottish Executive, 2000b). ID covers a range of disabilities, encompassing congenital, functional and intellectual difficulty (Twigg & Atkin, 1994) such as may result from Down's syndrome (DS), Turner syndrome, and Triple X syndrome (Watson, 2003). DS is the commonest biologically-based cause of mental retardation, affecting approximately one out of 1000 infants born each year in the United Kingdom (Rutter, 2002). However, there is no accurate figure for the number of people with DS living in Scotland. This is due to DS being subsumed into the general population of individuals with ID (Scottish Down's Syndrome Association, 2001).

Adolescence is recognised as a critical phase for individuals with ID and for their families (Thorin, Yovanoff & Irvin, 1996; Heslop *et al.*, 2002). However, the majority of studies have focused on parenting experiences of very young children or adults (Blacher, 2001) and less attention has been paid to the transition years between adolescence and adulthood (White & Hastings, 2004). There is also little longitudinal understanding of the experience of caring in this group. The main purpose of this study is to identify, describe, explore and compare the experience of carers in these two groups.

### **1.2.3 Similarities and differences between the two groups**

I recognised that, although the two groups comprising my sample represent very different sections of the population, there are important areas of similarity between them which are worthy of comparison – areas which, to date, have not been investigated. The two groups are similar in that each needs full time help with activities of living. As a consequence of increasing age, individuals in both groups are likely to provide increasing problems with regard to movement and handling – in the older group because of the effects on mobility, in the younger because of changes in body size. Moreover, in both groups the factor of increasing age must be taken into account for carers as well as cared-for persons; in both cases increasing age is frequently attended by negative effects on the carer's health (Wilcox & King, 1999; Clyburn *et al.*, 2000; Olsson & Hwang, 2001; Canfield, 2002; Gräsel, 2002; Emerson, 2003; Hedov, Wikblad & Anneren, 2006; Pinguart & Sorensen, 2007).

In both groups there may also be problems related to communication and response between carer and cared-for person; dementia is attended by a crucial and progressive impairment in cognitive and communicative faculties, while adolescence in individuals with ID often give rise to issues concerning discipline and obedience. Although, in these cases, the causes of difficulty are in many ways different, the outcomes provide similar dilemmas for the carer. Parents in general expect their children to develop communicative abilities; the extent to which this development is compromised or delayed by the effects of ID may be a cause of frustration in parents of such children. Inevitable deterioration in the communicative abilities of individuals with dementia is a source of similar frustration for their carers.

In both groups, carers are faced with a prospect of unrelenting responsibility in the face of these problems. There are, of course, clear differences between the groups, the most obvious of which are the ages (and therefore the energy levels) of the carers, the quality of relationship between carer and cared-for person, the likely duration of the caregiving commitment, and the extent of available social support. It is also likely that carers of the older group may be confronted with a greater preponderance of personal health concerns, connected with the ageing process.

### **1.3 The structure of the thesis**

In Chapter 2 a Literature Review is presented in four sections. The first section examines the context of caring; the second describes the impact of care; the third discusses carers' resources; the last focuses on the issue of carer autonomy. Literature furnishes the broad context and outline to the current study, and provides the basis for research, enabling identification of the strengths and limitations of previous research in this area. Some literature, connected with considerations regarding the research approach, was used as a third source of data and is presented in the findings.

Chapter 3 describes the Research Design and Methods, providing a discussion of the methodological issues and procedures undertaken in this study, and the rationale which dictated the choice of an appropriate approach. The ethical considerations and limitations of the study are also explained.

Chapter 4 comprises a series of Life Histories, giving an overview of each participant. The purpose of this section is to illuminate the context of caring for these participants.

In Chapter 5 the findings are presented in four categories: My Life Changed, Commitment, Responsibility and Duty, and Support. This chapter also includes separate data sets, literature, and the reflexive daily journal.

In Chapter 6 the emergent Theory of Caring is presented and changes over time are shown, explaining inter- and intra-related relationships between the categories.

Chapter 7 contains the conclusions and highlights the outcomes of the study.

Chapter 8 contains the recommendations that have been identified from the findings, covering the areas of education, practice, and future research.

## **CHAPTER 2 LITERATURE REVIEW**

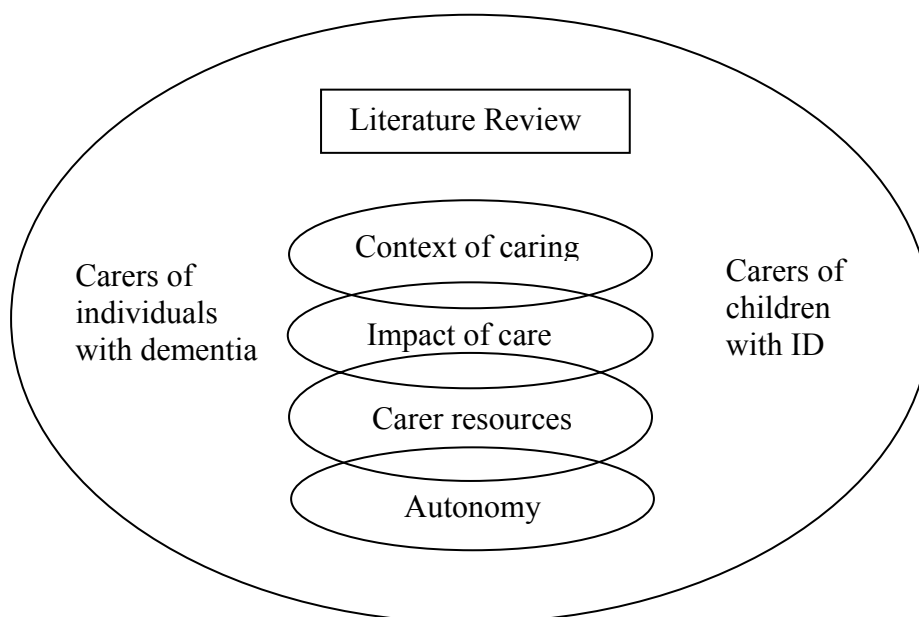
### **2. Introduction**

There is a vast body of literature on caregiving pertaining to many different types of populations, and including various demographics of carers and cared-for persons, under such headings as disease, age or gender groups. For the purposes of this study, the literature review mainly focuses on a comparison of carers of people with dementia and adolescents with ID. However, before designing a new study, it is important to review the previous literature, in order to address the key research questions which should be addressed in the new study, and to highlight methodological errors to be avoided. In accordance with a grounded theory approach, the function of the literature review will be both to furnish the context for research, and to point out gaps in existing literature with regard to viable research topics. At the same time, the majority of literature cited will be used as another data source in the findings chapter.

This literature review comprises four sections which are diagrammatically presented in Figure 1. The rationale for this division is that, whilst the four materials in each part are interdependent, their separation will present a manageable and clear review. The first section provides broad ideas related to the context of caring. The second section focuses on the impact of care on persons undertaking the caregiving role. This includes three subheadings: negative impact, positive impact, and personhood. Negative impact includes theoretical accounts of the concept of caregiver burden - encompassing definitions, categories, multiple theoretical models, and variables related to burden. Positive impact features positive responses to caregiving. Personhood investigates and discusses the ways in which carers view their relatives.

In the third section of this review there is an emphasis on resources which may help carers to maintain practical effectiveness and psychological equilibrium in managing their responsibilities. Discussion is organised under three subheadings: psychosocial resources, social support, and coping strategies. The final section focuses on the concept of autonomy in relation to carers and caregiving situations. This section includes material drawn from theoretical papers and research studies.

Figure 1: Conceptual model of literature review



Keywords for searching: carers (family carers, spouses, daughters, adult-offspring carers) of people with dementia or Alzheimer’s Disease, and parents (carers, mothers, fathers) of children with ID (or mental retardation or learning disability) written in English were included. The indices used were: Cumulative Index in Nursing and Allied Health Literature (CINAHL), British Nursing Index, and MEDLINE computerized databases. The CINAHL database is suggested by some authors (Vrabec, 1997; Hunt, 2003; Burns & Grove, 2005), because it is a comprehensive electronic database for nursing. Hand-searches were also used. Three lists of search results from these three databases are presented in Appendix 1.

The concept of caregiver burden was first proposed four decades ago in a study published by Hamilton and Hoenig (1966) and became common from the 1980s onwards. Most caregiving studies focused on one of two fundamental research articles: the first, published by Zarit, Reever and Bach-Peterson (1980) investigated the issue of burden in family carers of individuals with dementia; the second, which was published by McCubbin and Patterson (1983) studied family adjustment and adaptation to care for relatives with disability. Numerous studies succeeded these seminal works (Baxter, Cummins & Yiolitis, 2000; Knight, Fox & Chou, 2000; Miyamoto *et al.*, 2002; Saloviita, Italinna & Leinonen, 2003; Azar & Badr, 2006).

Therefore, this literature review started from 1980; it includes work published in English, and includes both research and theoretical papers which relate to the caring experience, caregiving, the impact of caregiving, caregiver burden, positive aspects of caring, and autonomy. On the other hand, material concerning experiences of care relating to other diseases, papers written in any language other than English or published before 1980, and commentaries were excluded from this review.

## **2.1 Context of Caring**

Caring may affect every one of us. Every individual may, at some stage in their life, either require care, or be called upon to provide care for another person. The caring situation arises in a relationship. It is intricate in both its physical and mental requirements, and may be crucially affected by the way in which the persons involved perceive that situation and their place within it. ‘Caring’ has been defined as “...doing things for people that they cannot do for themselves” (Twigg & Atkin, 1994, p.8). The context of caring is an important factor with regard to caregiving. In isolation from context, caregiving may be viewed as comprising practical help carried out for someone by another regardless of either the effects on the person being cared for, or on the individual(s) providing care.

The general concept of the context of caring involves four essential factors: carers, types of care demand and time spent, the dynamic nature of caregiving and feminist approaches to care. These will be discussed under separate subheadings below.

### **2.1.1 Carers**

As a consequence of improvements in medical treatment, people with chronic conditions are living longer. Also, allied to these improvements, the provision of health-care in the United Kingdom has altered, with a shift in policy from institutional to community-based care over three decades (Walker & Ryan, 1995; Barodawala, 1996). In relation to this policy shift, there is an expectation that the cared for person

will remain in their home for as long as possible. Given this altered healthcare context, it is far more likely that a cared-for person living at home for longer will be cared for and have their immediate needs met by a lay carer, rather than a healthcare professional. The carer is usually a family member (The Princess Royal Trust for Carers Centre, 2007).

The literature suggests that there are different titles accorded to those individuals who care for their relatives. These titles appear to be determined by different interpretations of their role, such as carer, informal carer, and primary carer. The Princess Royal Trust for Carers Centre (2007) indicated that a carer is someone who, without payment, provides help and support to a friend, neighbour or relative who is unable to manage care for themselves because of frailty, illness or disability. This view is reflected by Wiles (2003) who conducted thirty interviews with informal carers about their experiences of caring for a frail, ill, or disabled elderly person at home. Individuals providing care in the community are sometimes known as informal carers (Wiles, 2003). These may be defined as those who provide care on a lay basis, which means that they usually have no formal training.

These definitions seem to be somewhat limited, given that they do not make clear the complexity of the caregiving relationship. In addition, the literature seems to neglect the important but unrecognised point that caregiving is also facilitated by professionals or organizations and not necessarily by the lay carers alone. This may be at odds with current government policy of adopting a more inclusive approach to user and carer involvement in service provision, particularly in relation to mental health care provision (Forrest *et al.*, 2000; Masters *et al.*, 2002).

For the purposes of this study, therefore, the term carer is defined as being a family member who has no formal training, but is providing care and assistance to meet their relative's needs and life activities in the community. Spouses are often the main source of caregiving assistance for elderly people (Chappell, 1991). In the case of children with disability is generally accepted by parents, particularly mothers (Read, 2000). For these reasons, spouses of elderly people with dementia and parents of adolescents with ID were incorporated in this study.

In total, it is estimated that there are 6.8 million carers across the UK - approximately one carer in five of the total population - with carers devoting at least twenty hours per week or more to caring (Joanne & Green, 2000). Figures published by The Princess Royal Trust for Carers Centre (2007) suggest that around one million carers are looking after somebody for an aggregate in excess of fifty hours each week. In the Scotland's Census (General Register Office for Scotland, 2001), it was estimated that there were 115,675 people who had caring responsibilities for over fifty hours per week. Scottish Executive (2006) estimated that one in eight of the Scottish population is a carer. Such figures acquire added significance in the light of findings published by Henwood (1998) in which it was reported that three quarters of carers received no regular formal help with caring. The implications of these statistics are clear; we must consider the possibility that there is somewhere in excess of three quarters of a million people in Scotland alone confronted with the burden of caring for a family member without any formal assistance. The financial and personal cost implications to those individuals, and the implications for their own health cannot be ignored - particularly when, in all likelihood, they are unable to provide the level of care which is required of them (Henwood, 1998).

This last point deserves closer consideration. Unfortunately, it is evident that not all carers have the necessary experience or expertise to address the full range of their relative's needs. It is certainly true that many who might be defined as family carers having nothing approaching the skill-set required in trained professionals, such as nurses. This is perhaps one reason for the insistence that family caregiving should be informed by an understanding of burden as a central part of the carer experience (Greenberger & Litwin, 2003).

The Carer (Recognition and Services) Act 1995 stipulates that carers have a right to address their own health and social care needs. 'Partnership for Care', the Scottish Executive White Paper on Health (2003), recognises the necessity of expert knowledge in the provision of care, and identifies the importance of proper resources for supporting and advising carers. Both the stipulations of the Carer Act, and the recommendations of the 'Partnership for Care' white paper represent formal recognition of the seriousness of the issue of caregiver burden. Moreover, the



Scotland's Census 2001 (General Register Office for Scotland, 2001) shows that households are getting smaller. It reports that there were 2.27 people per household in 2001, compared with 2.44 per household in the 1991 Census (General Register Office for Scotland, 1991). This means family carers are now less likely to receive informal support from other family members. In light of these facts, the findings of a study conducted by Seddon and Robinson (2001), which reported that, in general, family carers are ill-informed regarding the contents of the Carer Act, and are therefore largely unaware of their rights to assessment, or how these rights apply to their individual circumstances, suggest that our reflection on the true scope and importance of the caregiver burden is an urgent matter.

The Carers (Equal Opportunities) Act 2004 mentions that the local authority has a duty to inform carers of rights to assessment of their needs – necessities such as a proper break from caring, the opportunity to engage in paid work or pursue leisure activities, and the provision of formal training. However, it remains the case that many carers are ignorant of the rights attached to their role. For this reason, it seems important to investigate and understand that role from the perspective of carers themselves.

### **2.1.2 Types of care demand and time spent caring**

Daily care is categorised by Parker and Lawton (1994) by types and quantified in terms of time spent caring. Types of daily care provided broadly encompass personal and physical support. Personal care refers to help given in dressing, bathing, and toileting. Physical care includes assisting in getting in and out of bed and other types of lifting, help with walking, moving, feeding and toileting, general vigilance, and household activities, such as shopping, cleaning and cooking, as well as attention to financial matters. Personal and physical care are embraced by the term activities of daily living (ADLs) coined by Roper, Logan and Tierney (1980). The term was later amended to activities of living (ALs) (Roper, Logan & Tierney, 2000) in recognition of the fact that not all activities are done daily. Twelve ALs are defined: maintaining a safe environment, communicating, breathing, eating and drinking, eliminating, personal cleansing and dressing, controlling body temperature, mobilizing, working

and playing, expressing sexuality, sleeping, and dying. However, not all ALs are capable of being carried out by carers for their relatives, especially the process of dying. Time spent in addressing the care demands involved in these types of care was measured by National Statistics: Carers 2000 (Maher & Green, 2002). This study indicated that the majority of main carers spent more than twenty hours per week engaged in the specific tasks of caring, and over a third spent at least fifty hours per week. This clearly shows that providing care can be extremely time-consuming, and is therefore likely to affect many aspects of family life.

For the purposes of this study, the phrase providing daily care refers to participants' commitment to help with activities of living on a daily basis (Roper, Logan and Tierney, 1980). The domains covered by daily care include the maintenance of a safe environment, communicating, eating and drinking, personal cleaning and dressing, mobilizing, managing financial matters, and dealing with housework and social activities.

### **2.1.3 The dynamic nature of caregiving**

Perlick, Clarkin and Sirey (1995) point out that caregiving is a dynamic process, liable to change over time in response to prevailing factors in the individual care situation. Many of the previous studies of caregiver experience employed quantitative approaches with cross-sectional design in relation to the levels of caregiver burden (Pruchno, Peters & Burant, 1995; Chappell & Penning, 1996; Stuckey, Neundorfer & Smyth, 1996; Adams *et al.*, 2002; Emerson, 2003). The possible limitation of such studies is their exclusion of qualitative evidence regarding the subjective experience and perspectives of carers – an approach which is likely to underplay the negative aspects of carer experience. The significance of these limitations in method was recognised by Kellett and Mannion (1999), who criticised quantitative approaches as being restricted in their understanding of carer experience, particularly with regard to the emotions and perceptions of carers. Moreover, cross-sectional research design bases its findings on the evidence of experiences measured at a single point in time (Maurin & Boyd, 1990) - a methodological factor which ignores the dynamic nature of caregiving.

Wilson (1989) conducted a grounded theory cross-sectional study of the experience for carers of AD in a home care setting. She identified eight stages in the carer's perception of process of the disease: noticing; discounting and normalizing; suspecting; searching for explanations; recasting; taking it on; going through it; and turning it over. Keady and Nolan (1994) applying the same approach in a study of carers of people with dementia, identified six stages of the caring journey: building on the past; recognizing the need; taking it on; working through it; reaching the end; and a new beginning. Although these studies shed important light on the caregiving process for carers of people with dementia, there is still a lack of evidence and discussion concerning the nature of various longitudinal and individual changes during the caregiving process.

In the opinion of this researcher, there needs to be specific attention paid to caregiving as a changeable and changing process. This view is reinforced by George (1990) who suggests that there is a greater need for caregiving studies, as only a small amount of longitudinal studies have examined or researched the process of caregiving. A review published by Hatton and Emerson (2003) likewise points to the under-use of longitudinal and qualitative design in studies of families of children with ID. Other studies (DiBartolo, 2000; Brannan & Heflinger, 2001; Grant & Ramcharan, 2001) have recognised the importance of interpreting changes in the process of caregiving, and are unanimous in the recommendation of longitudinal design.

#### **2.1.4 Feminist approaches to care**

According to Walters (2005) the roots of European feminism lie in a religious framework. This happened because as far back as the 11th century, women who could not be married off either as a result of their not having a dowry or were 'unnecessary' (Walters, 2005, p.6). Men in the shape of fathers or husbands or sometimes brothers or other male relatives 'owned' women and they did not have any voice or 'rights' to their money even if they had earned it. The only way of dealing with these women was to send them for the rest of their lives to a nunnery. For many this was a total imprisonment and must have been hard for them to deal with while

doubtless for others it was a useful way to be safe, fed and in many cases get an education which they would not have had otherwise. The other benefit for at least some was that they found a 'voice' and we are fortunate still to have the writings of some of these women (Kempe, 1986; Hildegard of Bingen, 2001; Julian of Norwich in Spearing, 2002).

Others were given places of authority and so they were remarkable managers and found real strength and spoke against the views of the church both as individuals but also on behalf of the rest of their communities. Their argument with the church was that the men thought that it was improper for women to express views of how they saw relationships with God and how the female qualities fitted with a male deity. It is interesting to note that this argument has continued through the intervening 10 centuries and is still not resolved.

In the secular framework it took longer for women to find a public voice despite there having been a powerful monarch on the throne in the shape of Queen Elizabeth I of England, or indeed her cousin Mary Queen of Scots, in Scotland. This part of the argument, propounded by Makin, turns on the lack of education for women for it was argued that without this women (nor presumably men, despite it being accepted that their thinking was a 'given') could not make good decisions or form arguments (Wright-Hodgson, 2002). It was Bathusia Makin who began one of the first schools for women. Women wrote poetry which was presumably considered to be a feminine pursuit but in the main it expressed a personal view only, however others had the temerity to write plays and novels. Others were brave and wrote of their feelings about the bad ways in which women were being treated albeit informed by their own experiences such as Mary Astell, who is considered by many to be the first true feminist in this country (Perry, 1986; Wollstonecraft, 1992, 2003).

It was not however till the 19th Century that the great movement to bring women in the political arena really got going and finding a new role for women this of course was not at the expense of their 'domestic responsibilities' (Reid, 1988 [1843]). Interestingly, John Stuart Mill (Okin, 1985) was a strong champion of getting rid of the 'subordination of women'. He commented that 'it is their nature, to live for others'. Hence the view that caring for others is a particularly female attribute.

Despite this we know that in the current climate there are many men who take on caring roles for children, the ill and the elderly as well as immediate family members. Mill however did think that it was important for women to be able to express their views have access and rights over their finances, particularly within marriage.

In the late 19th Century the urge to allow women to work outwith the home and have a say in their resultant wealth, as well as having rights to education and better legal cover was campaigned for. The demand for the right to vote became central to the demands of women and so really have a very public voice. However, this was not achieved till 1928 when women could vote on the same basis as men. The First World War was the large turning point and indeed it was in 1918 that women could sit in Parliament but it was not till 1924 that Ellen Wilkinson achieved this goal.

War was an important impetus to various aspects of the feminist drive such as Florence Nightingale's impact on the role of women in the Crimean War. Margaret Sanger (an American) along with Marie Stopes in 1915 offered contraceptive advice to women to free them from the burden of having huge families for whom they could not totally provide. After the Second World War (in 1947) the United Nations began work on a declaration of Human Rights which was implemented two years later and so women were to have equal rights to men as to marriage during it and afterwards if it was to be dissolved while accepting that they 'needed special care and assistance' in their role as mothers. Though this made sense to the western world there were more pressing demands on those in the third world (Walters, 2005).

The role of women has changed greatly in the recent past though in the main these alterations are still seen as lying within the context of family life and ultimately tied up with caring. Certainly it is of interest that there still remains the central tenants of the matters which women have been fighting for in different ways from medieval times such as education, having the right to express views and being treated equally with men financially for equal work. However education at least in this part of the world has responded with a reasonable degree of equality and indeed there are more women who are going into medicine and law than men. Despite this there are still more men than women as Judges or Consultants.

It is also interesting that there has been an increase in women's unpaid domestic labour resulting from public spending cutbacks on welfare services (Smith BG (ed) 2000). Often women are still expected to go out of the home to work but still carry the major part of the caring and providing for their families. It is important to note that caring within families is still a matter of debate and is still seen by many as being the work of women who if they go out to work can be seen as being 'bad mothers', and indeed men are increasingly beginning to fight for what they see as being unequal rights (Mac an Ghail & Haywood 2007). Hooyman and Gonyea (1995) speak of the number of women who are expected to care for those with learning disability, the frail or elderly to the exclusion of men even in familial relationships. Now this is seen from an American perspective and things have changed in the intervening years. Here at least there are huge changes underway and though more mothers than fathers here still look after children or adolescents with intellectual difficulties this may well be the result of babies being looked after by their mothers predominately but husbands do look after their ill frail elderly wives though again in fewer numbers but this is a reality of men dying before their wives (Oakley, 1993).

Despite all this there are those who feel that it is vital to understand that uniqueness of women and how they see themselves, the world and how they speak of these things. de Beauvoir (1953) demonstrated using interviews with her companion Sartre that men and women do see things differently. In light of this there are researchers who want to make claims about how truth can be accessed and claim 'that people's sense of worth, moral values, intellectual development and vision of everyday experience' are the underpinning of what women know (Oakley, 1993, p. 220). This is an important issue if both men and women are carers and thus it would follow that their understanding of the reality of caring will be different.

Nicki (2002), based on in Susan Wendell's (1996) philosophical work, points out that a male bias emphasises ideals of autonomy and independence as opposed to the female experience which is based on notions of connectedness and interdependence. However she wants to further suggest that these are ideals which are widespread throughout human experience not just those with disabilities. And certainly it fits with the topic of this current work. Where both the carer participants as well as those they care for are dependent to different degrees and they can only care and be cared

for within a web of relationships as a way of managing vulnerabilities. However she does admit that within the world of psychological disabilities relationships can be destructive at worst or at least inhibiting and that the 'male' ideals of autonomy and independence can in fact act as 'guideposts'. She claims that in the American context the relationship between connectedness and interconnectedness has not been fully applied. This insight of coexistence of inside and outside was enunciated Carole Gilligan (Hekman, 1995, p.14). Though Nicki's idea may be useful when considering those whose cognitive abilities are challenged they may be less appropriate when considering the carers who are making decision for both themselves and those they care for. It does remain true that particularly in old age the circle of connectedness diminishes and so they may well have to become autonomous and independent.

So if equality is to be a reality there are still problems since though we have a schematic policy of equality in health in the sense of access to resources this has not actually brought such a utopia into being. Some want to claim that there is still a need to free people from the constraints of rigidly defined gender roles (Doyal, 2002). For example can we improve women's health without having men's health lag behind? There is no clear answer as to how this can be achieved. This is especially problematic for those men (and some women) who would need to make sacrifices which are not rewarded with any obvious gain (Saul, 2003). In light of this it seems true that women are still expected and probably will continue to remain being the primary caregivers within families. Though men may well contribute more financially to families there are changes afoot which mean that families vary widely and that individual groups make arrangements which work especially well for them, thus it is important to continue to hear the voice of carers as they are and not to make assumptions about their maleness or femaleness. It is also true that carers are becoming increasingly vocal about what they want and need and if individuals do not feel able to make their single voice heard the collective voice of carers (both male and female) in a variety of support groups is heard loud and clear.

## **2.2 Impact of Care**

The section Impact of Care is in three parts: negative and positive impact of care and Personhood. Carers of individuals with dementia or ID reported a relatively wide range of impacts of care, including both negative and positive aspects (Hatton & Emerson, 2003; Blacher, Neece & Paczkowski, 2005; López, López-Arrieta & Crespo, 2005). Negative impact of care is chiefly associated with caregiver burden, which may affect carers in numerous ways. Positive impact of care emphasises the potentially beneficial effect of caregiving on carers. The concept of personhood refers to the carer's perspective on the cared-for person, particularly as it is affected by the act of caring. Discussion of the treatment of these three issues in previous literature can be seen as follows.

### **2.2.1 Negative impact of care**

The caregiving experience often has material effects on carers' lives (Talkintone-Boyer & Snyder, 1994). It is frequently physically and emotionally draining (Lynch-Sauer, 1990; Greenberger & Litwin, 2003). Over the past two decades, gerontology literature has devoted a great deal of attention to the issue of caregiver burden and its psychological, physical, social, and financial costs to the carer. There is also a developing body of literature pertaining to caregiver burden in ID research.

#### **2.2.1.1 The definitions of caregiver burden**

In the context of 'caregiving burden' refers to role overload, emotional fatigue and disruptions to daily life, limited social functioning, and financial difficulties (Hunt, 2003). 'Burden', 'stress', 'distress' and 'strain' have been variously used to denote caregiver burden in previous research (Romeis, 1989; Pearlin *et al.*, 1990). These terms have similar meanings, and appear to be used interchangeably. Novak and Guest (1989) classified five types of burden, including time-dependence, developmental, physical, social and emotional burden. It has been shown that there are many types of burden on carers, affecting not only their physical and



psychological health, but also impinging on social life and free time (or time otherwise spent). Chou (2000) proposes a further conceptualisation of caregiver burden, identifying the carer's subjective perception of interaction between care demand and care provision, and further relating dynamic change and overload to multidimensional phenomena (the bio-eco-psycho-social continuum).

In the area of family caregiving for children with special needs or disabilities, parents have a key role. For this reason, literature devoted to this area tends to employ the term parental stress rather than caregiver burden. To avoid confusion, the term caregiver burden is used for both groups in the current study. Studies conducted by Kazak and Marvin (1984) and Baxter (1989) report that family carers of children with disability manifest high levels caregiver burden. Further studies have identified specific aspects of burden, including maternal depression (Hoare *et al.*, 1998; Veisson, 1999), and marital conflict (Kazak & Marvin, 1984). Caregiver burden in carers of children with disability also refers to a variety of crises in daily interactions, as well as the life transitions inherent in the developmental process (Crnic, Friedrich & Greenberg, 1983). Smith, Tobin and Fullmer (1995) have defined the developmental process as complex and dynamic, characterised by changes over time.

The task of defining a single clear concept for caregiver burden is problematic; previous literature abounds with broad operational or conceptualised definitions of it (Winslow & Carter, 1999). Such descriptions as have been generated tend to be limited in scope by their preponderance of attendant negative assumptions (Farran, 1997). Many studies in which caregiver burden is described or conceptualised have relied on quantitative methodology, favouring simplicity over complexity. Yet, as Vrabec (1997) points out, the consequences of caregiving relate to a multidimensional process. It seems clear that simple correlational studies are inadequate to explain the complex multi-causal relationships that characterise the caregiving situation and process.

This historical bias towards quantitative research methodology in this field tends to suggest that, to date, the concept of caregiver burden has been studied from the perspective of the researchers rather than from the perspective of the carer. Although there are notable exceptions, the majority of the research assumes that an 'outsider's'

interpretation of caregiver burden is more relevant and useful; evidence from the perspective of experiences is still under development. Further, most studies of caregiving have been cross-sectional (Vrabec, 1997); as a result, little is known about the changes of caregiver burden over time (Winslow & Carter, 1999). Longitudinal studies of caregiving are recommended (Kuhlman, Wilson & Hutchinson, 1991; Brannan & Heflinger, 2001; Grant & Ramcharan, 2001), if the dynamic nature of the caregiving process, and the degree to which it may be influenced by different life courses and at different stages, is to be fairly and accurately represented.

### **2.2.1.2 Categories of caregiver burden**

The concept of caregiver burden is first defined in research literature by Hamilton and Hoenig (1966) who carried out work on carers of psychiatric patients. They make a distinction between objective and subjective dimensions of burden. Objective burden refers to the negative effect of caring on a household, such as financial strain, disruption of family life, and limitations on social life and employment opportunities. Subjective burden is defined as comprising emotional reactions to the caregiving experience within the carers themselves. Prominent reactions include feelings of loss, fear, anxiety, and embarrassment. Many researchers have added further examples of subjective burden. These include anxiety about the future and about the nature of interactions with the cared-for person, feelings of distress connected with the prospect of loss, feelings of guilt about helping, feelings of entrapment, resentment, and embarrassment (Montgomery, Gonyea & Hooyman, 1985; Platt, 1985; Braithwaite, 1992; Vitaliano *et al.*, 1991; Reinhard & Horwitz, 1995; Borycki, 2001; Brannan & Heflinger, 2001).

The commonest emotion experienced by carers is guilt. This includes the feeling that the carer is not doing enough for his or her loved one; it may also be experienced if the carer has failed to keep his or her relative at home, has found it necessary to use external services, or to place their relative in a short-term care facility (Alzheimer's Society, 2005). Grief is also a common element of caregiver burden, particularly amongst parents of children with ID (Bruce, Schultz & Smyrnios, 1996). According to this study, loss and grief are concomitant with a range of ongoing challenges

confronted by such parents throughout the life-course of their children. They carried out a longitudinal study of grief in forty-nine parents - both mothers and fathers - over a three-year period and found that mothers' grief-scores were significantly higher than fathers', which decreased over two years. The conclusion drawn from this aspect of the study is that the parental grief-response alters over time.

George and Gwyther (1986) begin to broaden the concept of burden, defining it as a multidimensional process including physical, psychological, social, and financial aspects. Their concept of multidimensional burden is favourable, providing clear delineation of aspects of burden, and facilitating further discussion in relation to caregiving for individuals with dementia or ID.

### **2.2.1.2.i Physical burden**

Physical burden refers to the negative impact of caring on the carer's physical health. Pinquart and Sorensen (2007) report that meta-analysis of the physical health of family carers shows deterioration of health in carers with a spousal relationship to the cared-for person. It is suggested that, in such cases, the diminished health of the carer may be connected with age-associated physical decline. A number of quantitative studies report negative health effects in carers of relatives with dementia - identifying fatigue, elevated systolic blood pressure, sleep disturbance, weight change, arthritis, low immune function, ulcers, and anaemia (Pruchno & Potashnik, 1989; Kiecolt-Glaser *et al.*, 1991; Moritz, Kasl & Ostfeld, 1992; King, Oka & Young, 1994; Vitaliano *et al.*, 1995; Gallant & Connell, 1998; Ellgring, 1999; Wilcox & King, 1999; Canfield, 2002; Gräsel, 2002).

A study involving sixty-nine carers of spouses with dementia shows that they suffered significantly more days of infectious illness, primarily upper respiratory tract infections (Kiecolt-Glaser *et al.*, 1991). King, Oka and Young (1994) report discoveries made in the course of clinical monitoring which suggest that the systolic blood pressure levels of carers of people with dementia are significantly higher than non-carers. A further experimental study was carried out by Vitaliano *et al.* (1995), in the course of which the levels of triglycerides, low-density lipoprotein cholesterol and high-density lipoprotein cholesterol of carers were measured and compared with

similar measurements in a control group. The study found that the male carers suffered significantly higher triglycerides and lower high-density lipoprotein cholesterol than male controls, suggesting that the male carers studied were at greater risk of heart or blood disease.

Leonard, Johnson and Brust (1993) have also found that mothers of children with disability are at risk of physical health problems. Parents of children with DS reported deterioration in self-perceived health (Hedov, Wikblad & Anneren, 2006). In comparisons between parents, mothers of children with disability reported poorer health than their spouses (Hedov, Anneren & Wikblad, 2000; Allik, Larsson & Smedje, 2006). Raina *et al.* (2005) conducted a cross-sectional study investigating the health and well-being of carers of children with cerebral palsy and found a higher level of behaviour problems was associated with lower levels of physical health in the carers. It should be noted that these studies all used self-reported scales or questionnaires, which means there is no evidence of medical diagnosis or treatment. Also, in comparison with physical effects on carers of people with dementia (above), these findings show that there is less direct impact on the younger group. This disparity may be explained by the age of carers and the availability of support.

#### **2.2.1.2.ii Psychological burden**

Psychological burden refers to the negative impact of caring on the carer's psychological or emotional status. Findings cited by Pruchno and Potashnik (1989), and Clipp and George (1990) emphasise the importance of this aspect of burden, indicating that carers of spouses with dementia report greater use of psychotropic drugs, and a higher incidence of stress symptoms and physician visits than the elderly population in general. A number of cross-sectional studies have found that the burden on carers of people with dementia can lead to associated psychological ill health, especially symptoms of depression (Haley *et al.*, 1987; Gallagher, *et al.*, 1989; Moritz, Kasl & Berkman, 1989; Pruchno & Resch, 1989; Stommel, Given & Given, 1990; Schulz & Williamson, 1991; Grafström *et al.*, 1992; Tennstedt, Cafferata & Sullivan, 1992; Rosenthal, Sulman & Marshall, 1993; Gallant & Connell, 1997; Clyburn *et al.*, 2000). However, the results of cross-sectional studies may be difficult to interpret and generalise. The cross-sectional nature of the existing data makes it possible to

establish only 'a period of time' relation between caregiver health and various aspects of the caregiving situation (Baumgarten *et al.*, 1994).

Of greater significance, perhaps, than studies which apply cross-sectional design to their analysis, are quantitative studies, which consider the relationship between caregiver burden and depression over time. Eight such studies have been published in the last twenty years (Pruchno *et al.*, 1990; Schulz & Williamson, 1991; Shaw *et al.*, 1997; Goode *et al.*, 1998; Alspaugh, Zarit & Greene, 1999; Li, Seltzer & Greenberg, 1999; Glidden & Schoolcraft, 2003). Li, Seltzer and Greenberg (1999) investigated changes in depressive symptoms among daughter carers over an eighteen-month period, and found that higher levels of mastery were associated with reductions in depression. Similarly, Glidden and Schoolcraft (2003) conducted an eleven-year longitudinal study which investigated the variation in levels of depression in mothers of children with ID, and found that both birth and adoptive mothers reported diminishing levels of depression. They also identified a specific personality variable - neuroticism - as the clearest predictor of depression in birth and adoptive mothers. It should be pointed out, however, that quantitative studies exclude any consideration of evidence concerning the life experience of carers and the reality of their individual settings. Such studies are restricted in their understanding of the experience of caregiving, particularly with regard to the perspective of feelings and emotions of carers (Kellett & Mannion, 1999).

Cross-sectional quantitative studies consistently indicate that female carers are more likely to experience burden or depression than male carers (Gilleard *et al.*, 1984; Eagles, *et al.*, 1987; Anthony-Bergstone, Zarit & Gatz, 1988; Pruchno & Resch, 1989; Pruchno, Peters & Burant, 1995; Chappell & Penning, 1996; Song, Biegel & Milligan, 1997). However, it should be pointed out that these findings may reflect gender bias; female carers have been shown to describe their perceptions of burden, and to express their emotions in general, more readily than males (Zarit, Todd & Zarit, 1986). Further, there are methodological limitations in the use of a scale; such an approach may restrict the scope of answers, and adversely affect expression of feeling, or cause confusion in the participants – particularly when a level-rating scale is employed. There is a degree of doubt regarding some of the questions posed in the establishment of a self-reported health score, and representative samples. The necessity of caution

in interpreting such results is confirmed by Rosenthal, Sulman and Marshall (1993) who could not replicate this finding.

A number of studies have investigated the possible reasons for caregiver depression, and identified lack of social support, income, self-rated health, perceived stress, and effects of caring on levels of life satisfaction. These factors were mainly linked to problematic behaviours in cared-for persons, such as aggression, hallucination and anger (Pruchno & Resch, 1989; Boss *et al.*, 1990; Aneshensel *et al.*, 1995; Schulz *et al.*, 1995; Gonzalez-Salvador *et al.*, 1999, Shua-Haim *et al.*, 2001; Hooker *et al.*, 2002). A year later, a large scale survey investigating characteristics of 5600 people with dementia and their carers identified some key characteristics for carers who are at greatest risk of suffering depression, including age (less than sixty-five), education levels (lower than high school education) and low income (Covinsky *et al.*, 2003).

Studies conducted by Hirst (1985), Romans-Clarkson *et al.* (1986) and Singhi *et al.* (1990) have identified a significant risk of mental health problems for mothers of children with disability. Depression, in particular, is specified by further studies (Carpiniello *et al.*, 1995; Blacher *et al.*, 1997; Scott *et al.*, 1997; Olsson & Hwang, 2001; Emerson, 2003). Emerson (2003) found that two hundred and forty-five mothers of children with ID reported significant psychological impact. Ireys and Silver (1996) conducted a longitudinal study over the course of a year to investigate the impact of caregiving on maternal health. The study reports that carer perception of psychological impact had direct effects on maternal health (using Psychiatric Symptom Index), in the case of one hundred and sixty-nine mothers of children with chronic illness. The limitation of this finding is that it merely indicates the number at risk, eschewing any detailed exploration of the extent and nature of the impact on the mothers in question. Singhi *et al.* (1990) conducted a comparative study in fifty families with a physically disabled child, fifty families of children with ID, and fifty families with normally able children (a control group). The study found that parents with disabled children perceived greater negative effects on their mental health as compared to the control. However, in this study, negative effects were assessed against a Social Burden Scale – a measure not specifically related to health effect. A study conducted by Hill-Smith and Hollins (2002) reported that there is no significant difference in mortality rates between parents of children with ID and parents of

normally able children, but offered no explanation of the increased incidence of mental health problems in the former group.

Methodological issues may account for the equivocal findings as reported. Donaldson, Tarrier and Burns (1997) identified two possible areas leading to equivocation: inconsistency in the definition and measurement of burden, and different approaches to the measurement of mental status. Many researchers have sought to investigate the health effects of caregiving by defining caregiver burden, but there are variations from one study to another in the modes of measurement. The Hopkins Symptom Checklist for Self-rated Health (SCL-90), the Centre for Epidemiological Studies Depression Scale (CES-D), Beck Depression Inventory (BDI) and General Health Questionnaire (GHQ) are the most frequently used (Boss *et al.*, 1990; Cohen *et al.*, 1990; Cattanach & Tebes, 1991; Baumgarten *et al.*, 1992; Deimling, 1992; Aneshensel, Pearlin & Schuler, 1993; Pruchno, Peters & Burant, 1995; Chappell & Penning, 1996; Gonzalez-Salvador *et al.*, 1999; Glidden & Schoolcraft, 2003). The common element of all these modes of measurement is that they are self-reported health rating scales, an approach which admits the possibility of personal bias, and may thus lead to inconsistent results. The problem here is not the inclusion of subjective judgments in the assessment of burden, but the fact that those judgments are misapplied – deployed against formally scaled criteria of health assessment. The subjective perceptions of carers could surely be most usefully applied in a qualitative investigation of the effects of the informal caregiving experience on individual carers, enabling us to establish a relationship between individual experience and types of caregiver burden over time.

### **2.2.1.2.iii Social burden**

A number of studies (Pruchno & Potashnik, 1989; White-Means & Chang, 1994; Bedini & Guinan, 1996; Heiman, 2002) have found that carers experience great difficulty in attempting to balance time spent meeting their own needs, such as looking after their own health, engaging in leisure pursuits, against their caregiving responsibilities and duties. The demands of providing care often give rise to negative impacts on carers' social lives. Wimo, Winblad and Grafström (1999) refer to the danger that family carers will let friendships lapse, or find friends and social

acquaintances drifting away from them; Seltzer *et al.* (2001) identify social isolation as a predominant negative effect experienced by parents raising a child with ID; Tebb and Jivanjee (2000) warn of similar effects in spouses caring for partners with AD. Tebb and Jivanjee (2000) explored four dimensions of isolation: biophysical, psycho-emotional, social, and economic isolation – a model based on Rathbone-McCuan and Hashimi's (1982) framework of elder isolation in eight female spouse carers. Several social isolators were identified, such as lack of knowledge about the disease, disparity between caregiving needs and resources, changes in marital relationship and retirement expectations, loss of companionship and social relationship, and financial problems. These findings demonstrate the fact that carer isolation is not only a consequence of social changes, but may be the result of multiple interrelated isolators characteristic of complex caregiving situations. Isolation, or stress in social interaction, may also derive in the social stigma attached to disability (Goffman, 1963), both for parents of children with ID (Baxter, 1989) and carers of relatives with dementia (MacRae, 1999). Baxter's (1989) quantitative study of parental experience of stigma identified a number of stressors specifically associated with negative effects on the social life of carers ( $n=131$ ); they include: the conspicuousness of the child's appearance, speech or behaviour, the tendency of others to stare, the tendency of others to display discomfort, and the tendency of others to ignore or draw attention to the child.

Several studies have investigated reasons for diminished leisure time in carers of relatives with dementia (George & Gwyther, 1986; Moritz, Kasl & Berkman, 1989; Miller & Montgomery, 1990; White-Means & Chang, 1994; Bedini & Guinan, 1996; Dunn & Strain, 2001). Their findings point to externally imposed factors resulting from caregiving demands and lack of time, as well as internal obstacles such as tiredness and anxiety. The negative impact most obviously associated with restricted leisure time, both for carers of relatives with dementia or children with ID, is a clear reduction in opportunities for social interaction, and reductions in personal time and family leisure time (Singhi *et al.*, 1990; White-Means & Chang, 1994; Croog *et al.*, 2006). This again may lead to feelings of isolation. Dunn and Strain (2001) further investigated the relationship between leisure participation and characteristics of carers ( $n=517$ ). Their main finding was that carers who have higher education are more



conscious of the restrictions on their leisure time than carers with lower levels of education.

Caregiver burden is also directly influenced by family conflict, disagreement, and aspects of social hardship (Scharlach, Li & Dalvi, 2006). Family conflicts have been prominently identified amongst adult offspring who care for a parent, and are particularly associated with the carer's dissatisfaction with the attitude or behaviour of siblings (Strawbridge & Wallhagen, 1991; Semple, 1992; Fisher & Lieberman, 1994; Scharlach, Li & Dalvi, 2006). The findings of these studies suggest that such carers are at an increased risk of depression, and that conflicts regarding family members' attitudes and behaviours toward the cared-for person are most likely to result in anger (Semple, 1992). Fisher and Lieberman's (1994) study investigated the cases of ninety-seven families of relatives with dementia, but could identify no important negative impact on spousal carers. They suggest this finding may be explained by the strong feelings of responsibility which generally characterise spousal relationships.

A cross-sectional study of five hundred and twenty-seven carers conducted by Skaff and Pearlin (1992) defined a correlation between the subject's feelings of self-loss and the sense of being trapped in the caregiving role. The study also suggested that carers may become subsumed by their responsibilities – a tendency related to social restriction, a lowered sense of self-esteem and mastery, and increased levels of depression. Specific focus on the gender and age of carers in this study yielded further significant findings; for example, younger carers and adult carers of disabled parents tended to experience a greater number of conflicts than older carers, particularly in connection with loss of autonomy, and the subsequently reduced opportunity for cultivating social relationships. Especially female carers displayed higher levels of self-loss than male carers. The reason advanced for this disparity was that female carers might feel more restricted in social life outside the family than male carers (Skaff & Pearlin, 1992).

A study conducted by Todd and Shearn (1996) investigated the experiences of parental carers. The study defined two contrasting states deriving in the parental attitude to caregiving, which were summed up as 'captive parents' and 'captivated parents'. Captive parents describe those who find the tasks of parenting restricting;

captivated parents are those who identify positive aspects in the parental role. Four years after this study, Walden, Pistrang and Joyce (2000) conducted research into parental experience and quality of life for carers of children with ID. This study picks up on Todd and Shearn's definition of the captive parent, reporting that parents who fall into this category experienced a higher level of behaviour problems – a finding which probably accounts for their negative reaction to the caregiving situation. Importantly, the three major elements of burden outlined above - loss of self, role engulfment, and captive status – may all be traced to a common root, namely, diminished carer autonomy. This issue will be further discussed in section four of this chapter.

#### **2.2.1.2.iv Financial burden**

Financial burden refers to the negative impact of caring on the carer's economic status. The provision of care in the home, both for parents of children with disability and spouses of partners with dementia, is inevitably attended by considerable extra financial strain, including, for example, the costs of professional help, external services, and institutionalisation. Wolstenholme *et al.* (2002) investigated the cost of care for people of dementia in Britain, and reported a mean annual cost between £8,086 and £22,267 depending on the severity of the disease and its stage of progression. Long-term care was identified as comprising the largest proportion of total care cost, at 68.8%. The cost of bringing up a disabled child in Britain was estimated at an average of £7,355, which is approximately three times more than amount required to bring up a normally able child (Dobson & Middleton, 1998). A further element of caregiver burden which impacts importantly on the carer's financial situation is the inevitable restriction of employment opportunities. This restriction is, again, relevant to the issue carer autonomy, and will be discussed more fully under that heading.

#### **2.2.1.2.v Impact of adolescent transition**

This area of burden is obviously unique to carers of disabled children, referring to that point in the child's development when the emotional and physical effects of late puberty bring significant and often stressful changes, both for the child and the

parents. A number of studies have focused on this area: Blacher (2001) refers to it as a time of change and challenge, Beresford (2004) recognises it as problematic, Wikler (1986) and Townsley (2004) report that it brings increasing levels of stress to family and child alike. A study conducted by Konanc and Warren (1984) focuses on the issue of graduation from school, pointing out that this is a period of crisis, in particular, for families of children with developmental disability. The challenge presented by this aspect of the transition has interested many researchers in recent studies (Knox *et al.*, 2000; Read, 2000; Blacher, 2001; White & Hastings, 2004; Todd & Jones, 2005). The issues highlighted by these researchers include: the ‘adult-sized body’ (Read, 2000; Blacher, 2001), the increased incidence of behaviour problems (White & Hastings, 2004), lack of social skills (Blacher, 2001), problems of discipline (Read, 2000), the restructuring of the family (Todd & Jones, 2005), diminishing levels of formal support (Knox *et al.*, 2000) and mid-life transition for parents (Todd & Jones, 2005).

Thorin, Yovanoff and Irvin (1996) explored the dilemmas faced by one hundred and three families during their children’s transitions to adulthood through a self-devised questionnaire, and indicated some prominent dilemmas associated with parental wishes at this time: parents described the hope that their child would become more independent, but expressed concern that their needs should continue to be met; parents explained their desire to fashion a life for themselves separate from the care of their child; parents continued to express their commitment to do all they could for their child, but at the same time described their fears of ‘burning out’. These findings seem to suggest that parents above all want to maximise their child’s potential, but are uncertain how best to help in this way, or how far they can realistically push their child. These dilemmas demonstrate several complex processes at work during the transitional period; they might be summed up as the difficulty parents face in letting their child go set against a degree of ambition for themselves, and the pursuance of their own independent adult lives – a conflict between protective parental instincts, and individual adult needs.

Schneider *et al.* (2006) conducted a qualitative study, based around interviews with twenty families of adolescents with disability, investigating the issue of family restructuring. The study reported that restructuring is most problematic at the stage

when other normally able siblings begin to leave home, and also at the point when the disabled adolescent transfers from child-based to adult-based sources of formal external support. Presumably, the stage at which siblings begin to leave home and achieve greater independence is a pertinent transitional issue for families in general, liable to affect the younger siblings who are left behind whether they are disabled or not, although the ramifications of such changes are liable to be more keenly felt in any family which contains a child less likely to be able to make a similar transition. However, the issue of transference from child-based to adult-based external support is specific to families of disabled adolescents, and the subsequent factors regarding family restructuring likewise unique and challenging. The specific challenge identified by Schneider *et al.* (2006) is related to an important ‘falling-off’ in the level of support as the adolescent moves from one service to the other. The study summarised this problem by referring to the notion of ‘discontinuity’ in support. Similarly, Hudson (2006) suggested, on the basis of interviews, that the transitional period was predominantly characterised by a sense of discontinuity for the families in question, adding that this experience lead to frustration and confusion, both for the young persons and their parents.

Transition planning is recommended to meet many of the likely areas of difficulty, including living arrangements, social and leisure opportunities, further education, training, careers, information about benefits and the transfer to adult health and social services (Heslop *et al.*, 2002; Ward *et al.*, 2003). Interestingly, two types of transition were also identified by Hudson (2006): visible and invisible transition. Obviously, transition from school and child-based health provision was recognised as being a visible transition; transition post-college and between external services, perhaps because the intermediate steps they comprise are less clear, were defined as invisible. They are nonetheless time-consuming, and thus worthy of being considered real elements of the transitional phase.

A qualitative study conducted by Todd and Jones’s (2005), investigating the caring experience in twenty-two mothers of adolescents with ID, identified dual associations in transition, as adolescents reach the threshold of adulthood, and mothers found themselves in their mid-life transition. They reported that the dual transition brought extra pressure to bear on the mother. The basis of this finding is that the major

element of self-identity in the mother is associated with the role of lifelong carer; the process of transition thus confronts her when her identity is threatened, and the necessity of identity reinforcement occurs when there is biographical disruption (Bury, 1982). This disruption is related to a major event such as birth of a child or the acceptance of a diagnosis of a significant condition which alters one's perception of oneself forever. The study by Todd and Jones (2005) is important in shedding light on the complex challenge facing parents at the adolescent transition phase – a challenge which brings into question not only the identity and future prospects of the young adult, but of the mother as well.

In spite of the obvious importance of the adolescent transition, as confirmed by the evidence of the above studies, it remains the case that, in practice, young adults with ID are accorded little priority by the health service (Hudson, 2006). Problems continue to be experienced by young adults and their parents in managing the transfer from separate branches of formal support provision, in terms of the services available, their prompt delivery, and the furnishing of appropriate and useful information to families (Beresford, 2004). Reviews by Beresford (2004) and Morris (2002) both point out the importance for parents of involving the young adult more fully in the process of decision-making in relation to these issues, adding that the continued reluctance to do so is likely to lead to ongoing disparity between the wishes of parents and young adults concerning their future, which may lead to tension and conflict between parent and young adult.

It should be pointed out, however, that parents' views of the transition phase are not exclusively negative. The study conducted by Heslop *et al.* (2002) identified a few reasons for optimism: the formal planning package proposed by the authors was found to be a welcome and useful source of support and encouragement in preparing the young people to move into work placements, and at the same time enabled parents to feel actively and positively involved in the transition process.

### 2.2.1.3 Multiple theoretical models of caregiver burden

Three major theoretical and conceptual models, or frameworks, of caregiver burden, in relation to carers of individuals with dementia and children with ID, have been identified in the studies reviewed (McCubbin & Patterson, 1983; Haley *et al.*, 1987; Pearlin *et al.*, 1990). They show this field of research to be open to widely varying interpretations – a fact which Given and Given (1991) suggest may account for the controversy surrounding the concept of caregiver burden.

The most frequently adopted theoretical model for the study of caregiver burden, in the case of people with dementia, is the stress model proposed by Pearlin *et al.* (1990). Four domains of the stress process are identified: the background and context of stress, stressors (primary stressors and secondary role strains), mediators of stress, and outcomes of manifestations of stress. This model was applied and evaluated in numerous studies, and in a variety of settings, including carers of people with dementia, cancer, or rheumatoid arthritis (Hurwicz & Berkanovic, 1993; Patterson *et al.*, 1998; Ho *et al.*, 2003; Gaugler *et al.*, 2004; LeBlanc, Driscoll & Pearlin, 2004). The limitations of this model derive in its application as an explanatory framework, regardless of a variety of subsidiary circumstantial considerations which may crucially affect the perception of caregiver burden, such as the fluctuating emotions and responses of the carer. Hooker, Frazier and Monahan (1994) criticised the model for its ignorance of such person-centred research data, suggesting that, if the model is to provide a valid explanatory framework, it must be extended and modified.

Haley *et al.* (1987) were the first to apply Lazarus and Folkman's (1984) stress and coping theory to the issue of adaptation in carers. In general, stress and coping models comprise five categories of variables: (a) context variables (i.e., characteristics of carers and cared-for persons); (b) demands on the carer, (i.e., objective caregiver burden, including the cared-for person's behaviour problems and functional ability); (c) the carer's appraisal of demands as stressful or satisfying (i.e., subjective caregiver burden); (d) potential mediators between appraisal and outcomes (i.e., coping styles and social support); (e) consequences of caregiving demands (i.e., emotional distress and health outcomes). The study reported that subjective appraisal was a significant contributory factor to positive adaptational outcomes. This clearly suggests that

acknowledgement of variation in the carer's perceptions of caregiving over time provides a valid and practically applicable data resource – one which was conspicuously absent from the stress model advocated by Pearlin *et al.* (1990).

McCubbin and Patterson (1983) extended the ABCX model (Hill, 1958), proposing a Double ABCX model, which focuses on family events, family stress and adjustment over time. The main difference between the earlier and later models is the emphasis on the evolution and resolution of stressful phenomena over time, which is featured in the Double ABCX model. Family responses to stressful events are viewed in relation to three basic phenomena: the stressful event, the outcome of the stress, and intervening factors between these two. In the Double ABCX model, intervening factors include aggregation of stressors (Aa), family adaptive resources (Bb), family perception of the situation (Cc), and family perception of the outcome (Xx). This framework was later adopted by Rankin, Haut and Keefover (1992) and used to develop an integrated family-assessment inventory for carers of people with AD. The study found the longitudinal focus of Double ABCX valuable, facilitating both an explanation of the chronic nature of dementia, and multiple crises in the care of cared-for persons. This model has also frequently been applied to the caregiving experience of parents of children with ID (Bristol, 1987; Shapiro, 1989; Lustig & Akey, 1999; Baxter, Cummins & Yiolitis, 2000; Saloviita, Italinna & Leinonen, 2003). These researchers have found that the Double ABCX model provides an effective approach in conceptualising the process of family adaptation. However, Orr, Cameron and Day (1991) advocated a causal ordering of the model as ACBX, rather than an ABCX, suggesting that the latter ordering is mistaken in placing the resource before the need.

Three models of burden were examined by Montgomery, Gonyea and Hooyman (1985): (1) cross-sectional; (2) causal flow; (3) dyadic over time. They commented that cross-sectional view of burden ignores dyadic interaction, while causal flow of burden invites the danger of overlooking the concomitant variable, concluding that the dyadic interaction model over time presents the most appropriate model for describing the dynamic process of caregiving. In addition they made certain clear recommendations for caregiving research, for instance the need of more longitudinal studies, and attention to comprehensive interactions within the caregiving phenomenon.

Furthermore, many other researchers have developed the model of caregiver burden in relation to additional relevant factors, including caregiver burden and well-being (Stoller & Pugliesi, 1989), caregiver health (Miller, McFall & Montgomery, 1991), employment (Scharlach, Sobel & Roberts, 1991; Kramer & Kipnis, 1995) and social support (Robinson, 1990).

A true recognition of the multidimensional nature of the caregiving burden needs to take account of stressors, mediating resources, and subjective appraisal, amongst other factors. Many authors have attempted a systematic explanation of it. To date, there is a lack of consistency in the proposed theoretical models, in the perception of concomitant variables, and in resultant definitions. Consequently, there remains a significant degree of confusion regarding the concept of caregiver burden.

#### **2.2.1.4 Variables related to caregiver burden**

Many researchers have explored and described in different ways the individual demographics of both the carer and the cared-for person as they relate to caregiver burden. It continues to be the case that disagreement over the relevant variables leads to correspondingly inconsistent findings with regard to caregiver burden. It is therefore important to look more closely at the nature and range of concomitant variables if a clearer conception of caregiver burden is to emerge.

##### **2.2.1.4.i Demographics of carers**

Regarding the carer, studies have focused on gender, age, education, and relationship types and co-residents within the caregiving situation. These demographic areas are discussed here. Traditionally, care has been provided predominantly by women, with a particular emphasis on the notion that housekeeping tasks are seen as the woman's responsibility (Chafetz & Barnes, 1989). Fisher (1994) suggested that where relatives of both genders were available, the female relatives were selected to undertake caring responsibilities. It is important that, despite the willingness of women to undertake the role of the carer (Monahan & Hooker, 1997), numerous studies have shown that, amongst family carers of people with dementia, female relatives report higher levels



of caregiver burden than male carers (Morris *et al.*, 1991; Parks & Pilisuk, 1991; Miller & Cafasso, 1992; Kramer & Kipnis, 1995; Collins & Jones, 1997; Beeson *et al.*, 2000; Yee & Schultz, 2000; Adams *et al.*, 2002; Scharlach, Li & Dalvi, 2006). Two other studies, however, have identified no such gender-burden relationship (Hinrichsen & Niederehe, 1994; Takano & Arai, 2005). This disparity may be explained by the use of variant research methodologies – variations, for instance in the number of subjects studied, or in the types of measurement employed. It should be pointed out that, perhaps in response to the common view of caregiving as a predominantly female preserve, the weight of research in the last two decades has focused on the issue of female carers (Brody *et al.*, 1987; Robinson, 1990; Kramer, 1993b; Irvin & Acton, 1997; Rose-Rego, Strauss & Smyth, 1998). Comparatively little attention has been paid to male carers (Mathew, Mattocks & Slatt, 1990; Fuller-Jonap & Haley, 1995; Kramer, 2000). Nonetheless, it is worth reflecting on the potentially rich field of evidence to be drawn from a comparison of the issue of caregiving as it pertains to two genders: male and female carers may have different relationships with the cared-for person, they may be affected by different role-expectations, employ distinct modes of expression, develop different coping responses, and advocate different degrees of reliance on formal and informal support. Interestingly, Lutzky and Knight (1994) attempted to explain gender differences in perception of caregiver burden, and identified two significant factors: namely, gender-specific roles of emotional attentiveness, and coping styles. They further explained that men and women differ in their response to burden, and react to stress with different coping strategies.

Parents are usually the main care resource for children with disability. However, as suggested above, the specific responsibility of care is, in many cultures and societies, regarded as the preserve of the mother. It is perhaps for this reason that, in many studies, levels of caregiver burden are found to be higher for mothers than fathers. A study conducted by Bristol, Gallagher and Schopler (1988) investigating the experience of caregiver burden in fifty-six mothers and fathers of children with developmental disabilities, reported that all fifty-six mothers displayed higher levels of burden, leading to subsequent symptoms of depression and family disruptions. Beckman's (1991) quantitative study supports this finding. He related the disparity to the lower level of involvement in care demonstrated by the fathers in his study. His

explanation accords with the point made earlier concerning the influence of cultural and societal gender expectation regarding the responsibility of care. It is also possible to suggest a further application of this notion, in that the male parent is still by and large regarded as the chief source of income, and is therefore more likely to spend a significant portion of time out of the home. A further possible explanation for the disparity between genders regarding caregiver burden may be a difference in the sources of burden experienced by mothers and fathers. A study conducted by Brubaker *et al.* (1989) investigated this area, and reported that stress in mothers of children with ID related to the child's levels of mental ability, while fathers expressed concern about the child's physical disability and their future. However, these findings, while interesting, are inconclusive, and unreliable, since the study questioned a total of three hundred and thirty-four mothers, as against only fifty-four fathers.

Two further studies have focused on a comparison of caregiver burden in male and female parent carers. A study conducted by Noh *et al.* (1989) reported that 168 mothers and 127 fathers of children with disability (conduct disorder, autistic and DS) experienced similar levels of caregiver burden. Dyson's (1997) study was consistent with the findings published by Noh *et al.* (1989), reporting that there was no significant difference in levels of stress amongst mothers and fathers of school-age children with developmental disabilities. The findings of these two studies tend to highlight the anomalous nature of Brubaker *et al.*'s (1989) results, confirming that, although mothers and fathers of disabled children may experience caregiver stress for different reasons, the levels of stress are equivalent in both genders.

Another demographic variant, age, is of particular relevance to the current study, since there is obviously likely to be fundamental differences in life experience, relationships, and socialization patterns between the older and younger groups of carers. Carers of partners with dementia are themselves often elderly, while it is generally assumed that carers of adolescents with ID will be pre or early middle-aged – a supposition based on the likelihood that the carers in question will either be the parents or siblings of the cared-for child. It is probable that the experience of caring and managing care for people with disability brings with it a maturity that bears little relation to chronological age. However, the chronological age of the carer may well affect the different types of burden experienced. A quantitative study

conducted by Cook *et al.* (1994) reported that family burden ( $n=238$ ) increases with age. This was thought to be because the older parents (average age sixty) were more liable to suffer from emotional and physical strain than the younger parents (average age thirty). Studies from Haley *et al.* (1987) and Cain and Wicks (2000) report that older carers suffer poorer health than younger carers. This should not surprise us; with age comes a lowered resistance to infection, decreased energy levels, reduced mobility and other difficulties associated with the ageing process. It is perhaps also reasonable to add that the older carer may be less emotionally resilient, and more prone to anxiety in the face of stressful and unexpected events. On the other hand, a number of studies, however, cast doubt on these findings. Pickett, Greenley and Greenberg (1995) and Greenberg *et al.* (1997) reported high levels of anxiety in younger carers regarding the possibility of social stigma, and fears concerning their own safety, as well as the safety of the cared-for relative. Stephens *et al.* (1988) and Stueve, Vine and Struening (1997) suggested that higher levels of burden in younger carers related to the probability that, as distinct from older carers, they have multiple roles, with a concomitantly wider range of responsibilities. There are, however, a number of studies which have investigated the issue of age-related burden, and found no correlation between levels of stress and chronological age (Croog *et al.*, 2006). These contradictions may be explained by the fact that, in reality, age has nothing to do with how burden is experienced, or by the possibility that measurement and definition of burden are variable from study to study.

Education, types of relationship and co-resident are other demographic variables of carers in relation to caregiver burden. A study conducted by Kramer (1997) investigated the cases of husbands who care for wives living with dementia. The study identified predictors of negative and positive aspects of caregiving specifically related to levels of education in the husbands (lower education and appraisal of gain). Meshefedjian *et al.* (1998) further reported that carers who have lower education levels experienced a greater degree of negative psychological impact than carers with higher education levels. Papastavrou *et al.* (2007) proposed an explanation, suggesting that carers with higher education were less liable to stress because they are both more likely to be financially comfortable, and have a greater potential to develop appropriate and effective coping strategies in the caregiving situation. Interestingly, Scharlach, Li and Dalvi (2006) published findings which seem to run counter to these

suggestions, reporting that family carers with higher levels of formal education experienced a greater degree of burden. These findings were explained by reference to the notion that the better educated carer may have higher expectations of other family members, and are thus more likely to experience conflict. This seems a somewhat tenuous argument; it is possible that the disparity in these findings is rather a result of different research settings and measurement scales for caregiver burden.

A study by Chappell (1991) reported that family carers of people with dementia are predominantly marriage partners. A number of studies (Grafström *et al.*, 1992; Gallicchio *et al.*, 2002; Scharlach, Li & Dalvi, 2006) have found that amongst this group higher levels of caregiver burden were reported than amongst offspring who care for parents with dementia. Against this, it should be pointed out that one study (Nagatomo *et al.*, 1999) identified no disparity between the groups. Gallicchio *et al.* (2002) explains his findings by suggesting that spousal carers have higher levels of obligation to their partners than offspring. Although, in the light of the social contract which exists within marriage, there may be some value in this explanation, the proposal is difficult to verify; different types of relationships may be characterised by a wide and complex range of interactions, which do not submit readily to such simplified comparisons.

In the case of children with disability, to focus on parental carers, it should be noted that parents are not always the sole source of care in such cases. A report published in 2004 by Dearden and Becker entitled *Young Carers in the UK*, included in its findings statistics for brother or sister carers (all aged 18 and under) of disabled siblings, estimating a figure of 31%, (n=2142/6178). Furthermore, the UK Census (Office for National Statistics, 2001) reports that there is an estimated 175,000 young carers. This is a considerable figure, and makes the findings of studies which have focused on the challenges for young carers worthy of note; studies published by Dearden and Becker (1998), Cree (2002) have identified a range of important concerns, including effects on education, and problems with drug or alcohol abuse, as well as physical, emotional and social issues.

There is a more important body of literature devoted to the matter of grandparent carers, including studies from Force *et al.* (2000), Janicki *et al.* (2000), McCallion *et*

*al.* (2000), as well as a review, published by Hillman (2007). The commonest issues identified within this literature concerned problems regarding restrictions on time, difficulty with meeting physical demands, lack of support, and the increased incidence of depression. It was also reported that many grandparents expressed anxiety about the future, anticipating a time when, due to frailty and deteriorating health, they would no longer be able to provide care.

A number of studies have reported that, in care cases involving people with dementia, a co-resident relationship between carer and cared-for person increases levels of carer burden (Brodaty & Luscombe, 1998). This is an ambivalent finding; it is entirely possible that co-residence of carer and cared-for person will lead to an increased level of care demands (hence stress), but at the same time, it is possible that a home care situation may provide the carer with support from other family members.

#### **2.2.1.4.ii Characteristics of cared-for people**

Many studies have investigated the issue of burden with specific regard to the variety of diseases and conditions necessitating family care (Pearson *et al.*, 1989; Charkrabarti, Kulkara & Verma, 1992; Draper *et al.*, 1992; Williams, 1994; Scholte op Reimer *et al.*, 1998). Amongst the range of afflictions studied are physical disability, mental impairment, behavioural problems, dementia, and cancer. Draper *et al.* (1992) investigated caregiver burden in forty-eight carers of relatives with dementia, reporting high levels of perceived burden, with a significant incidence of psychological morbidity, associated with carer dissatisfaction concerning their life activities. A number of studies (Schulz *et al.*, 1995; Gonzalez-Salvador *et al.*, 1999; Robinson, Adkisson & Weinrich, 2001; Shua-Haim *et al.*, 2001; Gallicchio *et al.*, 2002; Hooker *et al.*, 2002; Rymer *et al.*, 2002; Croog *et al.*, 2006; Papastuvrou *et al.*, 2007) suggest that certain problematic behavioural traits typically associated with people with dementia - for example, aggression, wandering and disorientation - significantly contribute to caregiver burden. This should not surprise us; such traits not only present the inexperienced carer with the practical challenge of attempting to control the cared-for person, but also the emotional distress of witnessing such irrational behaviour in a loved one.

Such behavioural manifestations may be characteristic in a number of related illnesses. However, where the particular focus of researchers has been the nature and pattern of specific illnesses – diagnosis, duration, and number of hospitalisations in addition to behavioural problems (Anderson, Linto & Stewart-Wynne, 1995; Solomon & Draine, 1995), no direct correlation has been reported between illness and caregiver burden. This is perhaps understandable; although much of this literature has focused on the association of generic symptoms with effects on carers, the specific types of illness investigated, and their degree of severity may be too varied to furnish consistent findings.

Among carers of children with ID, behaviour problems are similarly reported as a major contributory factor to caregiver burden (Cameron & Orr, 1989; McIntyre, Blacher & Baker, 2002; Hassall, Rose & McDonald, 2005). Frey, Fewell and Vadasy (1989) make a specific relation, reporting that the ID characteristics displayed by the children are associated with the level of problems that may affect the parents caring for them. Reddon, McDonald and Kysela (1992) reinforce this view, suggesting that levels of caregiver burden are significantly associated with the characteristics of the cared-for child's functioning. There is little doubt that children with special needs may increase both the level of demand and the time expenditure of their carers. Frey, Fewell and Vadasy (1989) further suggested that the gender of the cared-for child has a significant influence on levels of parental adjustment to care demand, reporting that parental carers of male children experienced greater difficulty in this regard.

### **2.2.2 Positive impact of care**

Hunt (2003) confirms the importance of assessing and understanding the caregiving process in terms of carer appraisal. This might prompt us to reflect that the experience of caregiving is not exclusively distressing. There is no doubt that in order to arrive at an understanding of the carer's experience, one must take into account the negative responses it often provokes. But it is equally important to acknowledge and investigate both the positive reactions of carers to their responsibilities, and the beneficial outcomes which they may derive.

Many researchers have demonstrated the positive rewards of caregiving for relatives of those who live with dementia or of children with ID. These include gratification; learning; enhanced self-worth; finding meaning; and caring as a source of companionship, strength, happiness and family closeness (Doty, 1986; Kinney & Stephens, 1989; Motenko, 1989; Pearlin *et al.*, 1990; Lawton *et al.*, 1991; Kramer, 1993b; Grant *et al.*, 1998; Stainton & Besser, 1998; Sheehan & Donorfio, 1999; Butcher, Holkup & Buckwalter, 2001; Sherrell, Buckwalter & Morhardt, 2001; Hastings *et al.*, 2002; López, López-Arrieta & Crespo, 2005; Greer, Gret & McClean, 2006). Cohen, Colantonio and Vernich (2002) further reported that carers who described such benefits manifested low levels of burden.

Caregiving satisfaction is defined by Lawton *et al.* (1991, p.182) as “subjectively perceived gains from desirable aspects of, or positive affective returns from caregiving”. It is the most commonly described benefit. In their study, satisfaction is associated with the degree to which the carer feels he or she is providing real support. Talkington-Boyer and Snyder (1994) described an association between perceived benefit and caregiving effort, and reported that high satisfaction related to lower depression and burden.

Sources of satisfaction for carers of relatives with dementia and children or young adults with ID were identified by three cross-sectional studies (Kinney & Stephens, 1989; Grant *et al.*, 1998; Lundh, 1999). In these studies, the majority of carers referred to the satisfaction of tending to their relative’s needs, preserving their dignity, seeing them well turned-out, giving responsive or affective feedback, and seeing improvements in their condition.

The positive impact of caregiving was recently investigated by López, López-Arrieta and Crespo (2005) in a study relating predictors of benefit to scaled levels of satisfaction. However, the scale employed was specific to carers of physically dependent elderly relatives, limiting the relevance of their findings (it seems likely, for instance, that different results might emerge for carers of relatives with dementia). Scaled responses are also unlikely to include qualitative experiential evidence. Tim and Hilde (1998) explored the positive impact of rearing children with ID, questioning six fathers and nine mothers under nine headings: source of joy or

happiness; family unity; personal growth and strength; increased spirituality; tolerance and understanding; sense of purpose and priorities; expanded personal and social networks; positive impacts on others; and interaction with professionals and services.

Some studies have investigated positive impact in carers of relatives with dementia (Kinney & Stephens, 1989; McConaghy & Caltabiano, 2005). Kinney and Stephens focused on carers of individuals with AD, and reported that a greater number of female carers than male described it as an uplifting experience. McConaghy and Caltabiano identified no such disparity, either in older or younger carers.

Existing literature makes little acknowledgment of possible changes in the positive consequences of caregiving. Researchers have focused exclusively on quantitative measurement of subjective responses to caregiving, which may limit descriptions or interpretations generated within the research process. Greer, Gret and McClean (2006) concluded that longitudinal research was necessary in order to relate positive impact to the availability of support services and coping resources.

### **2.2.3 Personhood**

Over the past decade, there has been an increasing focus on the concept of personhood in palliative care. Persons are unique but do not exist in isolation. Each has a context in which their personhood is articulated - for example, spirituality and religious roots (Kitwood, 1997; Nelson, 2000). Persons and personhood are related concepts, but there are no clear definitions of the terms. The concept of personhood and debates on the topic are explored in this section.

The fundamental work on the concept of personhood and dementia has its origins in the mid-1980s with Tom Kitwood, founder of the Bradford Dementia Group, England (Baldwin & Capstick, 2007). For Kitwood, the conceptualisation of personhood was more than an academic, philosophical debate, as the stance he adopted on this issue had serious implications for his practice (see over).



There is much philosophical debate about what it means to be a person. The concept 'person' is important because it relates to interaction with other people. The idea that an individual with dementia or ID is thought to be a 'shell' or not a person by his or her carers, represents a devaluation of status, potentially accompanied by a lessening of caregiving effort. The term 'person' tends to signify membership of the human species – a being accorded integrity and rights generally denied to other creatures (Frankfurt, 1989). Gress and Bahr (1984) describe a philosophical view of the person - an individual defined by possession of body, mind, and spirit, and by recognition of their personhood. Hughes (2001) confirms this emphasis on the importance of recognition by others. Clearly, the concept of person derives both from within the individual, and from their relationships to others – a notion summarised by Kitwood and Bredin (1992) - 'persons exist in relationship'. The perception of an individual by others contributes fundamentally to the idea of who that person is.

Hughes (2001) summarises two views of a person: the Locke-Parfit view of person and the situated-embodied-agent view of a person. The Locke-Parfit view proposes that the key element of a person is individual identity, which refers to psychological continuity and connectedness. The idea of being a person, from the Locke-Parfit view, is focused precisely on the competence of mental activity, which means that a person need only exemplify certain embodied psychological states. In contrast, the situated-embodied-agent view of person proposes that the embodied psychological state must be embedded in a history and culture.

It certainly seems reasonable to suggest that personhood derives equally in a variety of factors - character, history, family environment, culture, and experiences (Cassell 1992). Jenkins and Price (1996) add to this the importance of action within moral constraints. The link between personhood and moral status is commonly emphasised. Kitwood (1993) defines it as a complex concept based on social psychology, deriving from interaction with others. Warren (1973) focuses exclusively on the capability of psychology, identifying six elements: consciousness, reasoning, self-motivation activity, the capacity to communicate, the presence of a self-concept, and self-awareness. Personhood is defined by Kitwood (1997, p.8) as:

“...a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust”.

Kitwood (1997) states that there are three types of discourse in the concept of personhood: transcendental, ethical, and social-psychological. Transcendental discourse refers to respect accorded to an individual on the basis of their possession of a ‘soul’ – i.e. personhood comprises being-in-itself, as opposed to being derived from the context of other persons. Ethical discourse refers to personal value accorded on Kantian principles; i.e. persons are an end in themselves, and should always be treated the same. Social-psychological discourse refers to the view that a person is not an object, and focuses on a network of relationships with other people. In other words, personhood consists in being respected by, and respecting, others. Kitwood (1997) refers us to the Kantian ideal notion of persons as ends in themselves, reinforcing his notion of the social being by appealing to the importance of ethical value in the relationships of the individual with others.

Personhood comprises relationship, context, place, and self (Kitwood, 1997). Personhood obtains in relationships; the person is a social being, duly recognised, respected and trusted within the context of life. Bahr (1992) echoes these sentiments, defining personhood as a continued developmental process involving one’s physical, psychological, sociological, and spiritual aspects. In other words, personhood stems from the individual in relationships with others. Relationships can be built on love, trust, friendship, admiration, communication, sharing, as well as negative interactions, such as conflict and argument.

Three objections have been voiced against Kitwood’s theory of personhood. Adams (1996) refers to a lack of empirical support for Kitwood’s theory, and criticises Kitwood’s research methods, alluding to a confusion between data and assumption, and a corresponding lack of validity and reliability. Nolan *et al.* (2002) suggest that the needs of family carers have been overlooked in the cause of maintaining personhood in people with dementia, arguing that understanding the carer’s needs would help sustain them in meeting the demands of care. Davis (2004), challenges Kitwood’s belief in the value of maintaining ‘personhood-without-memory’ or ‘personhood-without awareness’. In such cases, he argues, preservation of

personhood in people with dementia increases the burden for carers confronted with a progressive condition. However, this objection is based on a conflation of the notion of personhood with that of identity. One may lose one's identity, in the sense of losing one's social role, previous interests, memories and so forth, but this does not necessarily mean that one loses the status of personhood.

### **2.2.3.1 Relevance to research on carers**

Dementia is a progressive degenerative disorder characterised by multiple cognitive deficits that are sufficiently severe to cause impairment in general living functions. There is evidence that people with dementia are affected in the course of the disease, in such a way as to destroy the perception of self or body image, and additional aspects of identity and independence associated with the facility for communication, and the capacity to plan events (Neisser, 1988). Autonomy implies recognition of an individual's personhood – their right to respect, to make choices, and to make decisions. According to the Locke-Parfit view of person, an individual who lives with dementia is no longer a person because his or her psychological state is not functioning as normal. This is arguable; people with dementia are whole persons who face barriers in interacting with others. The situated-embodied-agent view of person considers a person to be one situated in an historical context – i.e. defined, in part, by the fact of their existence in the past, present, and future, based on the perception of others. By this argument, an individual with dementia retains the right of respect as a person.

Kitwood (1997) cited Martin Buber's (1937) work as an approach which may contribute to an account of personhood – i.e. personhood as it arises in an interaction between at least two people. Buber suggests there are two fundamental relations of being in the world, 'I-It' and 'I-Thou'. The I-It model includes implied relationships, such as coolness, distance, detachment, and instrumentality. The 'I-Thou' model embraces openness, tenderness, personal intimacy, going out towards the other, and self-disclosure. It should be noted that the 'I-It' and 'I-Thou' models exist in social interactions. Obviously, Kitwood applied Buber's work of relationship and promoted the 'I-Thou' relationships among people and individuals with dementia. Many

research studies suggest that dementia is accompanied by progressive self-loss (Kitwood, 1997; Post, 1998; Vittoria, 1998). Kitwood (1993) relates this process to malignant social psychology, i.e. interactions tending to depersonalize the person with dementia.

There is a growing body of research focused on the Kitwood's notion of preserving personhood in people with dementia. Cowdell (2006) conducted a review of literature on this subject published from 1982-2005, identifying twenty-two articles covering such aspects as: ethical issues, sensitive consideration, informed consent, preserving personhood of individuals, and the credibility of studies. A common weakness identified in these studies is the lack of researcher-subject interaction.

An important concept, with regard to the issue of personhood, is precedent autonomy. This refers to the actions of carers in making decisions based on prior understanding of the cared-for person's interests and wishes. This is often necessary, since people with advanced dementia progressively lose competency in decision-making (Dworkin, 1993). As Moore and Hollett (2003) point out, this is a potentially problematic area, leaving the carer open to accusations of excessive paternalism, an attitude based on an assumption of diminishing personhood in the cared-for person. This is one reason why an effort to investigate the carer's view of personhood is important; doing so may enable the carer to arrive at a clearer understanding of his or her own actions, and the nature of interaction possible in the caregiving situation, potentially decreasing caregiver stress. In general it must be recognised that the issue of personhood is of fundamental importance, because, as Kitwood (1997) pointed out, the maintenance and promotion of personhood is the primary aim of person-centred care.

To date, there is no specific investigation of personhood in the literature devoted to the care of persons with ID. Nonetheless, the fundamental concepts of person and personhood are highly relevant to this area. It is commonplace of any civilised democracy that people with disabilities have the same rights as people without disabilities, yet such individuals are often the subject of social deprivation and discriminatory attitudes, which may both implicitly and explicitly devalue their status as persons (Harris, 2000). There are many studies investigating parental or familial stress and coping strategies in the care of children with ID (Damrosch & Perry, 1989;

Sloper *et al.*, 1991; Seltzer, Greenberg & Krauss, 1995; Hassall, Rose & McDonald, 2005), yet there is a dearth of knowledge regarding the parent's views of the personhood of their child. Greater focus in this area might contribute to the person-centred approach for this group, and go some way towards ensuring equal rights and respect for such children – an improvement which would surely encourage family members in a positive acceptance of the caring situation.

The concepts of person, personhood, and person-centred care are inextricably woven together (Kitwood, 1997). For this reason, equal attention must be given to the views and feelings of the cared-for person and carer on the issue of personhood. Cared-for persons are often so compromised by their condition that carers may feel they have lost their loved one. Such a feeling may not only make care seem meaningless, but may increase the chances that a carer becomes 'burnt out', delivering care in a monotonous and unreflective manner. The struggle to make care meaningful may begin with the search for an echo of such fondly remembered selves. In summary, a person should be recognized, respected and valued. The perceptions of others materially influence the concept of the person. The importance of understanding the carer's view of personhood could help to identify the meaning of caregiving.

### **2.3 Carer Resources**

Clair, Fitzpatrick and Gory (1995) identify three main types of carer resource: psychosocial resources, social support, and coping strategies. The level of available resource in the first two types influences carers' ability to adopt effective coping strategies (Lin, Dean & Ensel, 1986) or alters the stressful caregiving experience (Clair, Fitzpatrick & Gory, 1995). The issue of carer resources is complex; perception of support, and adoption of coping strategies may differ for every carer. The three types of resources will be separately discussed below.

### **2.3.1 Psychosocial resources**

There is considerable evidence that individual carers differ in their response to caregiving situation, such that some carers, who may have less psychosocial resources to deal with stressful events, are more vulnerable than others (Clair, Fitzpatrick & Gory, 1995). Psychosocial resources include appropriate attitudes, a sense of mastery, spirituality and religious beliefs, hope, and expectation. The degree of available psychosocial resource affects the individual's reactions to stressors, and influences the development and effectiveness of coping skills (Barnett & Gotlib, 1988).

#### **2.3.1.1 Attitudes**

Attitudes play a vital cognitive function in an individual's social psychology. Hogg and Vaughan (2005, p.150) define attitudes as,

“(a) a relatively enduring organisation of beliefs, feelings and behavioural tendencies towards socially significant objects, groups, events or symbols; (b) a general feeling or evaluation - positive or negative - about some person, object or issue”.

Attitude is one of the psychological resources for carers in dealing with the caregiving situation (Helmes, Green & Almeida, 2005). Franzoi's (2006) model of attitude structure identifies attitudes as comprising affective, cognitive and behavioural processes. Ajzen (1988) suggests that attitude may predict intended behaviour. This seems debatable, although further studies have replicated such findings (Armitage & Conner, 2000; Baron, Byrne & Branscombe, 2006).

Alternative terms have been suggested for carer attitude, such as, perception, perspective, view, viewpoint, or (broadly) feelings. Robinson and Yates (1994) found that carers who participated in caregiver-training programmes evolved a positive attitude toward asking for help and using day care services, and showed lowered levels of objective burden. It is possible that carers with a positive attitude to care may develop more effective ways of dealing with the caregiving situation, for example, acceptance, and openness to support. Sahar, Courtney and Edwards (2003)

reported that attitudes of family carers caring for elderly relatives at home included a sense of responsibility. Carers' attitudes to care play a part in leading to positive or negative caregiving experiences.

A longitudinal quantitative study by Vitaliano *et al.* (1991) investigated predictors of caregiver burden for carers of spouses with dementia over fifteen to eighteen months, and found that the carer's outlook on life was a potential contributory resource to the lessening of caregiver burden. Outlook, in this case, was defined as overall life satisfaction. Positive beliefs regarding life satisfaction, and the ability to 'count one's blessings' were also evaluated. These correlated to a sense of diminished burden.

'Is the wine glass half full or half empty?' The purpose of this question is to divide the latent sense of optimism or pessimism in the individual – the propensity of one person to see a problem where another sees opportunity. Hooker *et al.* (1992) identified optimism as a key contributory factor to the mental health of carers of spouses with dementia, reporting that it impacted significantly on their perceptions of caregiver burden. Robinson-Whelen and Kiecolt-Glaser (1997) reported that carers expressed less optimism than non-carers, and that latent pessimism predicated subsequent negative effects on psychological and physical health. These findings suggest that degree of life-stress plays an important part in the formulation of carer disposition.

### **2.3.1.2 Sense of mastery**

Mastery was described by Pearlin and Schooler (1978, p.5) as being "the extent to which one regards one's life chances as being under one's own control". This was the first study which focused on how a sense of mastery interacts with the caregiving experience. Haley *et al.* (1987) reported that carers who describe higher levels of perceived competence in managing care also report lower levels of depression. Bookwala and Schulz (1998) suggested that sense of mastery may contribute to overcoming perceived threat in the caregiving environment. In some literature an alternative term for mastery is, 'personal control', but it is important to recognise a distinction between the two notions; the locus of the sense of 'control' is specified as

internal in the former, whereas mastery does not discriminate between internal and external resources (Skaff, Pearlin & Mullan, 1996). Another term used - 'perceived control' - (Thompson & Spacapan, 1991) is closer in meaning to mastery. Ultimately, such ambivalence with regard to terminology is not useful.

Skaff, Pearlin and Mullan (1996) conducted a longitudinal study over a three year period, investigating the relationship between transitions and sense of mastery in the careers of Alzheimer's carers. The study found that high levels of mastery related to low levels of caregiver burden, but that sense of mastery alters across transitions. Yates, Tennstedt and Chang (1999) likewise suggested that carers with high levels of mastery were at lower risk of depression. Quantitative studies of parents of children with disabilities (Frey, Greenberg & Fewell, 1989; Wiggs & Stores, 2001) have also shown that low personal control is associated with higher caregiver burden. Krause (1990) identifies social support as an important contributory factor to this sense of control. A cross-sectional study conducted by Helmes, Green and Almeida (2005), exploring possible links between burden and sense of mastery, could identify no consistent relationship. Their findings, however, are based on a sample of only fifty-one participants, which may not readily yield significant differences in the data analysis.

### **2.3.1.3 Spirituality and religious belief**

Spirituality involves concepts of faith and meaning (Breitbart, 2005). Faith is defined by the Chambers 20th Century Dictionary (1983, p.453) as "trust or confidence; belief in the statement of another; belief in the truth of revealed religion". Spirituality was defined by Stuckey (2003, p.339) as focusing on "a relationship between what is human and that which transcends humanity, as well as on a search for meaning and purpose in life". Spirituality is an attitude or behaviour deriving in a sense of connection to others, self, and higher power (Reed, 1992). Acton and Miller (2003) further expanded on the notion of connectedness in relation to caregiving; connections with others means someone who knows the truth; one's self comprises feelings and thoughts related to personal beliefs and values; or a higher power implies relation to God. They reported that spirituality equipped carers of people with dementia with



both internal and external resources, enabling feelings of comfort, peace, acceptance and purpose in life. Breitbart (2005) points out that, although spirituality and religious belief are closely connected, spirituality is not necessarily concomitant with subscription to any specific religion, but may be manifest in trust or loyalty to a person or thing, as well as commitment to a relationship or family.

Religion plays an important role as both a social and a mental health resource in individuals (James & Wells, 2003). James (1958) suggests the notions of 'healthy soul' and 'sick soul' as two possible effects of religion in the individual. 'Healthy soul' implies a positive view of religious faith, whereas 'sick soul' relates to a negative view - for instance, the sense of being 'abandoned'. Matthews, Milano and Alerts (1998) argued that religious faith has a positive influence on overall health. There are certainly positive aspects of religious faith in relation to carers: the church or synagogue as a support network, the resorting to religion as a coping resource, the ability to grow spiritually in adversity, the ability to transcend loss and find meaning (Chang, Noonan & Tennstedt, 1998; Pargament, 1998; Stuke, 2001). Stuke (2001) conducted a qualitative study investigating how two groups of spouses of individuals with AD (ten carers, ten non-carers) integrated religion, spirituality and faith into their lives. The study reported that, for both groups, religion and/or spirituality were important in helping the subjects interviewed to cope with stressful situations. Beliefs and practices, especially, provide support, motivation and encouragement to carers during their caregiving experiences. In contrast, Hebert *et al.*'s (2006), reviewing eighty-three studies on the issue, could find no specific trend regarding the beneficial effects of spirituality and belief in family carers, but rather a range of positive, negative or non-significant results.

It should be noted that in the range of studies reviewed by Hebert *et al.* (2006), and earlier by Robinson and Kaye (1994), interchangeable terms are applied to denote spirituality and belief (i.e. spirituality, faith, religious belief). A further term 'pastoral care' cited by Taylor and Chatters (1988) is clearer in its designation, suggesting subscription to a recognised belief, and the correspondent benefit of church resources, including material, spiritual, emotional and informational support.

### 2.3.1.4 Hope

The Chambers 20th Century Dictionary (1983, p.604) uses ‘desire’ and ‘expect’ as synonyms for hope as a verb, and ‘desire’, ‘expectation’, ‘confidence’ and ‘anticipation’ in relation to hope as a noun. Clearly, hope is a complex and multidimensional emotion, and its significance as a caregiving resource, mediating between burden and well-being, is correspondingly broad and subtle (Irvin & Acton, 1997). It may be described as an emotion, an experience or a need (Kylma & Vehvilainen-Julkunen, 1997; Stoner, 1997); it consists in behaviour, feelings (affection), and as a way of thinking (cognition) (Herth, 1993). Ballard *et al.* (1997) suggest that hope is associated with goal-accomplishment, and the attendant degree of expectation.

Dufault and Martocchio (1985) explored the concept of hope in a two-year longitudinal study focusing on thirty-five elderly cancer patients. They identified two spheres (generalized and particularized hope) and six dimensions of hope (affective, cognitive, behavioural, affiliative, temporal, and contextual). ‘Generalized hope’ denotes a state of salutary orientation towards the future; ‘particularized hope’ is related to specific outcomes or states of being. The six dimensions of hope were applied in explaining the ‘hoping process’, which encompasses sensations and emotions, thoughts and perception, action and orientation, sense of relatedness or involvement, experience of time, and the forefront of awareness within the context of life. This model proposes that the entertainment of hope is a dynamic process, involving cognitive, behavioural and emotional factors. It implies a range of fluctuation (Gibson, 1999), such as hope-joy-enthusiasm or expectation-yearning-confidence-hope (Benzein & Saveman, 1998).

Farran, Herth and Popovitch (1995, p.16) refer to hope as constituting “...an essential experience of the human condition. It functions as a way of feeling, a way of thinking, a way of behaving, and a way of relating to oneself and one’s world”. In their study they developed instruments to measure hope in a palliative care setting, and emphasized that hope may be a spiritual process, thereby suggesting its importance in maintaining individual psychological well-being. Likewise, Farran and McCann (1989) suggested that an individual’s mental health and religious beliefs are nourished

by hope. Obayuwana *et al.* (1982) had previously suggested the association of hope with religion, positive self-concept, group support, economic success, and joyful anticipation; Bland and Darlington (2002) confirmed its importance to the psychological strength of carers, and its influence on carers' ability to adjust and cope in the caring situation.

Knorer (1970, p.134) characterised hope as a method of coping, adding, however, that it may be "a mixed blessing due to its potential for describing the individual's contact with reality". Bland and Darlington (2002), Kwon (2002) and Jones (2005) echo this reservation, suggesting that 'hope' is linked to psychological defence mechanisms. In other words, hope may be entertained as a shield against, or denial of, stressful situations. Yet in the study conducted by Kwon (2002) - in which one hundred and seventy-two undergraduates were assessed by the combined means of the Hope Scale, the Defence Style Questionnaire, and the Beck Depression Inventory - hope was seen to be related to levels of anxiety, dysphoria and depression.

It is important that most previous research has focused on hope in patient, terminal and palliative care settings. There are only two qualitative studies (Herth, 1993; Kausar, Javne & Sobsey, 2003) and two cross-sectional quantitative studies (Irvin & Acton, 1997; Bland & Darlington, 2002) which explore the concept of hope in family carers. Herth (1993, p.544) studied hope in twenty-five family carers of terminally ill relatives, defining hope as the "dynamic inner power that enables transcendence of present situation and fosters a positive new awareness of being". Kausar and colleagues (2003) studied hope in nineteen parents of children with developmental disabilities, identifying a dynamic positive transformation process that helped parents to reframe their lives. Although all these studies identified hope in positive terms, there is still a lack of understanding of how hope changes at the outset, and throughout the course of caring, and how it impacts on the individual's experience of caregiving. Irvin and Acton (1997) studied eighty-eight female carers of relatives with AD, identifying hope as a mediating agency between caregiver burden and well-being. Bland and Darlington (2002) investigated the significance of hope in eighteen carers of individuals with serious mental illness. They reported that hopefulness was a crucial part of the coping process in family carers.

To date, limited attention has been paid to the concept of hope in relation to those who care for individuals with dementia or adolescents with ID. Boland and Sims (1996) suggested that it was important to develop greater understanding in this area as a pragmatic means of identifying more effective nursing interventions and support for family carers. Kylma and Vehvilainen-Julkunen (1997) proposed that more qualitative longitudinal research is required to explore the concept of hope in context. However, it is perhaps artificial to suggest that the concept of hope can be investigated in isolation from the related fields of expectation and personal faith. The concept of hope must be recognised as an integral and interwoven element of the overall experience of caregiving. As such it will be explored in the current study.

### **2.3.1.5 Expectation**

The definitions of expectation are many and varied. The Oxford Advanced Learner's Dictionary (2000, p.483) states that expectation is "a belief that something will happen because it is likely, or a hope that something good will happen". Commonly, expectation refers to a thing looked forward to, or a prospect of future benefit. As such it shades into definitions of belief. Feather (1982) suggests that the terms expectation and expectancy are used interchangeably, implying a subjective probability that a response will give rise to a consequence. Expectation relates to a subjective value, employed by the incentive values, utilities, valences, and reinforcement values of the individual (Wigfield & Eccles, 1992; Wigfield, 1994). Wigfield and Eccles (1992) make the important point that subjective values determine the direct goal of behaviour – a notion previously suggested by Feather (1982), who identified personal value and expectancy as two major components in the individual decision-making process. Naturally, values, beliefs and expectations differ from person to person; the relative difference of these factors determines what specific actions will or will not be undertaken by one individual in any particular set of circumstances. Indeed, the same person may, in identical situations, choose to behave differently. Holzberg (1982) points out that expectations are strongly related to social and cultural contexts; Stewart-Williams (2004) emphasises their association with personal experience, and the extent to which they may be influenced by the observation of others, or by their suggestions.

Vroom (1964) refers to expectation as a motivation model, which elucidates the individual decision-making processes of membership and performance. Scheibe (1970) believes that a person's behaviour is a result of individual wants (values) and considerations of what is true about the world or oneself (belief). The extent to which individuals are motivated to perform in order to obtain a reward of value to themselves is based on their expectation of response or action and consequence. Thompson and Sunol (1995) define four types of expectation: ideal (desired or preferred outcome); predicted (realistic, practical actually expected outcome); normative (what should happen); and unformed expectations. It should be observed, however, that the ostensibly objective distinctions suggested in this model are to a certain extent artificial, inasmuch as all are ultimately the product of subjective experience. Also, as suggested above, it becomes difficult to draw a distinction between the concept of ideal expectation and that of hope.

Expectations contribute to an individual's psychological and physiological health (Evans, 1974) which means carers' expectations may maintain their well-being. However, there is no research primarily focusing on carers' expectations. Essentially, it should be considered that the perception of expectations plays an important role within the dynamic caregiving process. Carer's expectations about themselves, their relatives, other family members, and professionals are also an important issue. It can be assumed that different carers may have different expectations of their role and the role of others in various situations, which will lead to varying interpretations of the caregiving phenomenon. Importantly, the process of expectation is not static and it may have to change because of the changing role of carer. However, there is a dearth of knowledge regarding the process of expectation in the caregiving context. To develop a better understanding of the caregiving experience it is necessary to consider the way in which the process of expectation in carers variously contributes to their motivations and misgivings within that role.

### 2.3.2 Social support

Cohen, Gottlieb and Underwood (2000, p.4) define social support as “any process through which social relationships might promote health and well-being”. An efficient support may be categorized by indicators of social integration, functional aspects, and satisfaction with support (Pearlin *et al.*, 1996). Changes in social support, its increase or reduction, have been recognised in two longitudinal studies (Clipp & George, 1990; Hong, Seltzer & Krauss, 2001). Beresford (1994b) points out that need of support may vary across the lifespan.

Cohen and Wills (1985) suggest the notion of ‘perceived support’, defining the carer’s cognitive appraisal of contentment with support. The subjective perception of satisfaction with support is at least as important as the objectively measured level (White & Hasting, 2004). Roth and colleagues (2005) conducted a longitudinal intervention study over a year, reporting that increased carer satisfaction with the social support network reduced negative impact on carer depression.

It should be noted that in some literature on this issue, the terms social support, social network and social integration are used interchangeably. This suggests the lack of a clear theoretical framework, and a consequently broad range of definitions (Ell, 1996; Thompson *et al.*, 1993). Generally, social support can be subcategorised into emotional and instrumental types. Emotional support refers to the feeling of being loved and cared for, which derives in the act of sharing experiences and feelings with others; instrumental support refers to many types of tangible help, including information and advice help (Thoits, 1982; Finfgeld-Connett, 2005). Finfgeld-Connett (2005) subjected forty-four qualitative studies of social support (published from 1987-2003) to review and meta-analysis. Her review clarified a link between needs, types of social support, and outcomes. However, there remains a lack of understanding regarding the many and complex changes which comprise the dynamic process of social support. The following sections focus on types of support providers, discussing their consequences in terms of positive and negative impacts on carers.

### 2.3.2.1 Providers

Commonly, there are four major sources of social support for carers- namely, family, friends, religious and professional support. It is common that grandparents will provide support, helping parents to deal with the extra needs of cared-for children (Hastings, 1997). Support from marital partners may likewise lighten the burden of the parental carer (Beresford, 1994b; Herman & Thompson, 1995). Support from friends or neighbours is also a valuable resource for many carers, providing emotional and tangible aid (Krauss, 1993; Hastings & Johnson, 2001), although it is relatively unusual that friends or neighbours will offer to shoulder the burden of intimate physical care (Cant, 1992; Bamford *et al.*, 1998). A study of the role of friends in caregiving, conducted by Himes and Reidy (2000) reported that friend carers are more liable to provide care for persons with chronic mental illness than for those who suffer from physical problems. This study also suggested that friends are generally less likely than family to accept caring responsibilities, particularly when such responsibilities may conflict with their other roles.

Religious support refers to the possibility that carers may derive strength from their beliefs sufficient to confront the various challenges of caregiving. Fortier and Wanlass (1984) suggested that religious support is associated with reduced carer stress. A pilot study conducted by Kaye and Robinson (1994) compared the cases of seventeen wives who cared for husbands with dementia against twenty-three non-caregiving wives. They reported that the carers drew strength from religious symbolism and behaviours, including these practices and beliefs amongst the essential elements of their coping mechanisms. Rose (1997) describes professional support as providing affirmation, information, and reassurance, and the option (where necessary) of hospitalisation. Formal support services include support groups, education programmes, day care centres, home help, and a variety of types of respite care. The importance of these services to home-based carers in Britain is highlighted by Philp *et al.* (1995). Majerovitz (2001) identifies formal support as an important contributory factor to psychological well-being in carers of spouses with dementia.

### **2.3.2.2 Positive outcomes of social support**

Thoits (1986) identifies social support as a source of assistance in coping with the demands of care. It has been found to help carers develop efficient coping skills when dealing with their burden (Schilling, Schinke & Kirkham, 1985; Scott, Roberto & Hutton, 1986; Frey, Greenberg & Fewell, 1989; Aneshensel *et al.*, 1995; Atienza, Collins & King, 2001), it mediates between the responsibilities of care and carer burden (Pearlin *et al.*, 1990), and may thus be a positive influence at times of stress (Cohen & Wills, 1985). Similar findings are reported by McCubbin and Patterson (1983); Beckman (1991) and Hassall, Rose and McDonald (2005) which refer specifically to cases of parents of children with disability. Barakat and Linney (1992) found that social support is also related to higher maternal psychological adjustment in parents of children with disability. It is therefore unsurprising that, as Hobfoll and Lerman (1988) report, social support enhances parental well-being and decreases stress levels of parenting.

Numerous other cross-sectional studies (Montgomery, Gonyea & Hooyman, 1985; Pratt *et al.*, 1985; Scott, Roberto & Hutton, 1986; Hobfoll & Lerman, 1988; Vitaliano *et al.*, 1991; Krauss, 1993; Thompson *et al.*, 1993; Song, Biegel & Milligan, 1997; Choo *et al.*, 2003) report a positive correlation between social support and caregiver burden, both in carers of relatives with dementia, and carers of children with disability. The general tenor of these findings is that burden is inversely proportional to the level of support received - a notion consistent with a very early study of carers of persons with dementia (Zarit, Reever & Bach-Peterson, 1980). This study (the first to investigate this relationship) measured social support by numbers of visitors to the households of carers, and reported a concomitant lessening of caregiver burden. Conversely, diminished social networks are often associated with increased caregiver burden (Hauenstein, 1990) and carer depression (Pillemer & Suitor, 1996).

A direct relationship between depression and social support was found by Gallo (1990), Schulz and Williamson (1991). Pot, Deeg and Dyck (2000) and Pearlin and Aneshensel (1994) confirm that carers of persons with dementia who receive less social support are at risk of depression and self-loss. In addition, a number of



quantitative studies (Braithwaite, 1996; Pillemer & Sutor, 1996; Majerovitz, 2001; Ben-Zur, Duvdevany & Lury, 2005) have shown that the availability of social support plays an important role in maintaining the well-being of carers. In the study conducted by Ben-Zur, Duvdevany and Lury (2005) mothers of adult children with ID manifested high social support scores and enjoyed correspondingly high levels of mental health. On the other hand, studies by Fiore, Becker and Coppel (1983), Pruchno (1990), and Lawton *et al.* (1991) identify no such relationship. This disparity in findings may stem from a lack of further in-depth investigation (Pruchno, 1990; Lawton *et al.*, 1991). Coyne, Wortman and Lehman (1988) suggested that such intended support measures may fail because they are excessive, untimely, or inappropriate.

Interestingly, the study conducted by Hannappel, Calsyn and Allen (1993), which focused on sixty-six carers of older adults with dementia, suggested an inverted relationship between social support and carer well-being - i.e. the more support received the more depressed the carers became. It should be noted that this study measured the 'social support satisfaction' of its subjects by the frequency of visits, and levels of physical and other support. It is possible that the carers, in making their responses, were negatively affected by the realisation of their dependence upon the assistance of others. It is also possible that the negative responses recorded reflect the quality of carers' relationships with support providers.

Despite general consensus regarding the importance of social support, there continues to be a lack of consistency in the means by which it is measured. Pratt *et al.* (1985) used the Family Crisis-Oriented Personal Evaluation Scales (reliability coefficient .79); Vitaliano *et al.* (1991) used the Social Support Questionnaire (test-reliability .75 and .79); and Hannappel, Calsyn and Allen (1993) employed self-devised social support scales. The Family Crisis-Oriented Personal Evaluation Scales include informal support, spiritual support, and reframing coping. The Social Support Questionnaire focuses mainly on sources of informal support. Although the chief areas of social support are clearly being covered by these researchers, the coverage is expressed through different measures. It is important to emphasise that the levels of social support received inevitably differ from one case to another, as does the

subjective perception of, and satisfaction with, support. This must lead us to reflect that individual carers may have different views or expectations of their support, which may result in different findings across these studies.

Another quantitative study conducted by Thompson *et al.* (1993) assessed the relationships between six different types of social support (intimate interaction and confiding, material aid, advice, supportive feedback, physical assistance and social participation) and five measures of caregiver burden (Zarit's Burden Inventory, ADL Impairment Burden, Restricted Social Life, Negative Impact Caregiver/Elder Relationship, and Negative Interactions Friends/Family) in two hundred and seventeen carers of frail elders. The study identified social participation as the most important factor in diminishing caregiver burden. Importantly, this study reported that not all types of social support are helpful in lessening carer distress. Material aid and physical assistance were associated with negative interactions among carers, family and friends. Additionally, the researchers noted that levels of social support altered unpredictably in response to changes in the level of carer need and/or availability of resources. Correlational or cross-sectional studies have proven inadequate in their coverage to identify any pattern of change, due to the restricted research period. Likewise, quantitative studies elicit a significantly restricted view of social support from participants. All the above-mentioned studies have used cross-sectional design which precludes the possibility of assessing social support and caregiving processes over time.

### **2.3.2.3 Negative outcomes of social support**

Fudge, Neufeld and Harrison (1997), Merrill (1997), and Neufeld and Harrison (2003) all point to evidence of negative interactions in carer relationships, such as conflict and dissatisfaction with support. Families may be a source of certain types of carer stress, often the result misunderstanding or miscommunication (Ell, 1996) or unfulfilled expectations of support (Neufeld & Harrison, 2003). Rook and Pietromonaco (1987) identified four types of common unhelpful interactions in close relationships: ineffective help, excessive help, unwanted or unpleasant interactions,

and encouragement of unhealthy behaviour. Neufeld and Harrison (2003) identified further negative interactions, which included underestimating the value of carers' experience, and conflict over caregiving decisions.

Kinney and Stephens (1989) reported that carers of family member with dementia derived satisfaction from daily assistance, but also experienced emotional distress which stemmed from problems in their interpersonal networks. Semple (1992) reported that adult offspring carers experienced a higher incidence of conflict within their informal network than spousal carers. This may be a consequence of the greater number of competing demands associated with the multiple roles of the former group. It should be noted, however, that the cross-sectional design of Semple's study inevitably limits the relevance of his findings, restricting carer appraisal of well-being to a specific point in time. This might explain the fact that there are no other studies which support this finding.

Formal support services are not always regarded in a positive light. Wiles (2003) explored knowledge, perception and experiences of formal support in interviews with thirty carers of individuals with dementia. The majority of carers in her study described negative experiences of formal support, complaining of confusion, and the inflexibility or unavailability of services. Carer confusion was related to uncertainty about what services exist, where they were located, and who carers should talk to. Carers also described misgivings and a sense of vulnerability regarding the possibility of being visited by support professionals. A number of studies (Beresford, 1994a; Beresford, 1995; McGill, Papachristoforou & Cooper, 2006) have also reported negative reactions to formal support amongst parents of children with disability. Beresford (1994a) specified inadequacy of provision, and consequent conflict with service providers as particular source of stress for such carers. She also reported negative interactions (e.g. anger) in parents' dealings with medical professionals. In her 1995 study, she identifies three major sources of potential conflict between parents and service providers: difference of opinion, a confused relationship, and lack of coordination between services.

Findings with regard to the impact of social support in the caregiving process continue to be equivocal. Methodological limitations in previous studies (variance of

definition, variance of measurement criteria, and the lack of longitudinal studies) contribute to a general difficulty in establishing either consistently positive or negative relationships between social support or the caregiver. A qualitative longitudinal research approach may offer some solution of this difficulty, facilitating a clearer understanding of the carer's perception of social support over time.

### **2.3.3 Coping strategies**

Lazarus and Folkman (1984) define coping as a constant modulation of cognitive and behavioural effort in order to manage specific demands that tax or exceed an individual's resources. They add that coping is most often conceptualized as a response to the demands of specific stressful situations; for example, coping comprises the things people do in order to deal with stressful situations or events. Scott, Oberst and Dropkin (1980) identify coping as the formulation of goal-directed strategies, initiated and maintained over time and across encounters, by means of cognitive appraisal and regulation of emotion and physiological responses. The concept of coping will be further discussed under the following subheadings: coping resources; functions of coping; coping strategies and characteristic factors of carers.

#### **2.3.3.1 Coping resources**

Kramer (1993a) and Beresford (1994b) described two categories of coping resource: personal coping resources, and socio-ecological coping resources. Personal coping resources include physical health, morale, ideological beliefs, previous coping experiences, parenting skills, intelligence, and personality characteristics. Socio-ecological coping resources refer to the individual's environment or social context, which includes social support, social network, spousal support, and support from extended family, friends and formal agencies. It has been shown that there are many factors related to effective individual coping strategies, which must be taken into account when considering the complicated nature of the coping process.

O'Rourke and Wenaus (1998) examined the role of marital aggrandizement as a coping resource. Lustig and Akey (1999) focused on the importance of familial coherence, specifically in relation to parents and other family members of adults with ID. Their study suggested that family cohesion and enhanced levels of emotional bonding may be an important coping resource against the challenges of caring in such cases.

### **2.3.3.2 Functions of coping**

Lazarus and Folkman (1984) identified two functions of coping: problem-focused and emotion-focused. Problem-focused coping strategies are similar to problem-solving tactics, typically characterised by three stages: defining the problem, finding solutions, and carrying out the change (i.e. active and constructive alteration and management of the problematic situation). Problem-solving comprises an objective, analytical process, focused primarily on the problematical environment; problem-focused coping similarly includes internally directed strategies. On the other hand, emotion-focused coping strategies are aimed at reducing emotional distress (i.e. relieving the emotional impact of a stressful situation by means of expressions, thoughts and indirect actions). Such efforts involve a variety of tactics including: distancing, avoidance, selective attention, and wishful thinking.

#### **2.3.3.2.i Problem-focused coping strategies and caregiver burden**

Problem-focused coping strategies are more likely to be employed in situations under control (Lazarus & Folkman, 1984). A number of cross-sectional quantitative studies (Felton & Revenson, 1984; Haley *et al.*, 1987; Vitaliano *et al.*, 1987; Pruchno & Resch, 1989; Wright *et al.*, 1991; Miller, 1992; Kramer, 1997; O'Rourke & Wenaus, 1998) have focused on the effectiveness of coping strategies for carers of persons with dementia or children with disability. They report that the use of problem-focused coping can reduce psychological distress. A similar study conducted by Haley *et al.* (1996) adds that such strategies also lead to increased life satisfaction. In spite of the consistency of these findings, a reservation must be expressed concerning the variety

of measures employed within the studies mentioned; Borden and Berlin (1990) employ the Ways of Coping Questionnaire, Haley *et al.* (1996) the Coping Responses Inventory, Kramer (1997) the Ways of Coping Checklist, and Wright *et al.* (1991) the Jaloweic Coping Scale. It is possible that the use of such a range of measures may obscure some similarities as well as revealing differences.

### **2.3.3.2.ii Emotion-focused coping strategies and caregiver burden**

In contrast with problem-focused coping strategies, emotion-focused coping strategies are more likely to be employed in situations over which the individual exerts little control (Lazarus & Folkman, 1984; Beresford, 1994b). Quantitative cross-sectional studies by Stephens *et al.* (1988), Pruchno and Resch (1989), and Haley *et al.* (1996) found that resort to emotion-focused coping was related to an increased incidence of depression. Rose *et al.* (1997) and Knight *et al.* (2000) identify the use of such strategies with high levels of stress among carers of persons with dementia. Knight and colleagues (2000) compared African and non-African carers, finding a greater tendency in the former group to rely more heavily on emotion-focused coping, and a concomitantly higher level of caregiver burden. This finding suggests the value of considering carer ethnicity when exploring the process of coping. Frey, Greenberg and Fewell (1989), Sloper *et al.* (1991), Miller *et al.* (1992), Seltzer, Greenberg and Krauss (1995) and Patrick and Hayden (1999) reported that emotion-focused coping is also related to higher levels of stress in parents of children with disability. The only study which seems to express a contrary view is that published by Koch (1985), in which it is suggested that being able to express emotions is important in order to release the tension associated with stressful events.

‘Acceptance’ is recognised by some researchers as a discrete coping strategy, but is sometimes regarded as an element of emotion-focused coping (Almberg, Grafström & Winblad, 1997) or cognitive-focused coping strategies (Pratt *et al.*, 1985). Acceptance of a given situation implies a realisation that it cannot be altered, and indicates an ability to come to terms with one’s ‘powerlessness’ in this regard. Pruchno and Resch (1989) suggest that such acceptance enables carers to accommodate to the caregiving situation, and carry on. A study conducted by

Almberg, Grafström and Winblad (1997) and a review by Kneebone and Martin (2003) recommend a blend of problem-solving and acceptance as the optimum coping strategy amongst carers of individuals with dementia. The recommendation of acceptance seems a persuasive argument, but it is possible that the confusion of categorisation between acceptance and emotion-focused strategies might lead to misunderstanding of the functions of acceptance.

A separate but related area of investigation - expressed emotion (EE) in carers - has interested several researchers recently (Vitaliano *et al.*, 1993; Dossetor *et al.*, 1994; Beck *et al.*, 2004). EE relates particularly to issues of criticism and over-involvement, and their connection with behaviour problems both in people with dementia and children with disability. Wagner *et al.* (1997) and Dunkin and Anderson-Hanley (1998) have outlined some long-term consequences of high EE in carers of individuals with dementia, identifying increased depression and caregiver burden, and reduced social support. These findings agree with findings from earlier studies on the same subject (Dossetor *et al.*, 1994; Hinrichsen & Niederehe, 1994; Huckle, 1994).

### **2.3.3.3 Coping strategies and characteristic factors of carers**

The relation between characteristics of carers of individuals with dementia and their coping strategies have been widely researched. Quayhagen and Quayhagen (1988), Borden and Berlin (1990), Vingerhoets and van Heck (1990), Lutzky and Knight (1994), Ptacek, Smith and Dodge (1994), Almberg, Grafström and Winblad (1997), and O'Rourke and Wenaus (1998) have investigated gender differences; Parks and Pilisuk (1991) and Kramer (1993b) age. Kramer also focused on education in the above-mentioned study. The general tenor of findings suggests that female carers make more use of emotion-focused coping strategies than male carers, younger carers experience more depressive symptoms or burden than older carers, and carers with higher levels of education tend to rely on problem-focused coping strategies to a greater degree than carers with lower levels of education. It should be noted that the age range of carers in Kramer's study was between fifty-seven and eighty-two years – a fairly limited range, whose evidence may not accord with that of other age groups. Further, he did not mention the education range of his participants, which may lead us

to suspect a lack of clarity in his findings. A survey study conducted by McConaghy and Caltabiano (2005) failed to agree with his findings, but this could be due to the small sample ( $n=42$ ) in their study.

Frey, Fewell and Vadasy (1989), Rousey, Best and Blacher (1992), Heaman (1995) and Sullivan (2002) investigated the issue of gender in parent-carers of children with disability. Heaman's (1995) quantitative study identified different coping preferences between mothers and fathers. She reported, for example, that the majority of mothers in her study addressed the necessity of coping either by seeking to change something in themselves, or by suppressing knowledge of the difficulties they were facing. The fathers studied tended towards escapism – daydreaming, or imagining a better time. The cross-sectional study conducted by Sullivan (2002), using the COPE Inventory, suggested that mothers of children with DS demonstrated greater instrumental and emotional support than did the fathers. Overall, however, no consistent correlation between gender and coping styles is reported. A review by Beresford (1994b) suggested that mothers and fathers adopting different coping styles provide complementary mutual support, each enabling the other to face the demands of care more effectively.

The significance of personality in the development of coping strategies and maintenance of carer well-being has been recognised by many researchers (Aneshensel *et al.*, 1995; Bolger & Zuckerman, 1995; Patrick & Hayden, 1999). Hooker, Frazier and Monahan (1994), Reis *et al.* (1994) and Markiewicz, Reis and Gold (1997) have all conducted quantitative studies, exploring a range of specific personality traits in carers, and report that personality has an influence in determining coping mechanisms. Hooker and colleagues (1994) identified neuroticism, in particular, as a personality complex materially affecting the psychological well-being of carers. Welleford, Harkins and Taylor (1995) add that it is a predictor of caregiver burden. A cross-sectional quantitative study by Patrick and Hayden (1999) identified anxiety, anger-hostility, depression and vulnerability as common constituents of carer neuroticism. This study further reported that higher levels of neuroticism in female carers of adult offspring with chronic disability are associated with similarly high levels of wishful-escapism - leading in turn to higher levels of caregiver burden. A year-long quantitative longitudinal study conducted by Jang *et al.* (2004) confirmed



the link between carer neuroticism and depression. A possible limitation in these studies is their concern with exclusively negative personality traits – an emphasis which may lead to the ignorance of potentially positive outcomes.

To date, there is no categorical evidence as to which coping strategies are most effective. Clearly, whatever coping strategies are used, if they can ameliorate the stressful situation, they will tend to be favoured. Coping is a multidimensional and developmental process - responsive equally to intrinsic qualities in the carer, and to pragmatic factors, such as the availability of resources. The understanding of the coping strategies that are most effective in dealing with specific stresses in the caregiving context is still in development. Kneebone and Martin (2003) recommend a longitudinal approach to research in this area.

## **2.4 Carers' Autonomy**

Autonomy, as freedom of choice, is of fundamental significance in the caregiving situation, with regard both to the carer and the cared-for person. It is possible, for instance, that the demands of caring may constitute a serious infringement on the carer's liberty to choose how they live their life and use their time, from day to day, and in the long term. It is equally likely that the cared-for person, in consequence of their condition, is one for whom the exercise of autonomy is difficult or impossible – leading to a situation in which the carer feels obliged, or empowered, to 'step in', adopting a paternalistic role, and making choices and decisions by proxy. At its extreme, this attitude itself may amount to an infringement of the cared-for person's autonomy. Numerous studies discuss the concept of autonomy (Collopy, 1988; High, 1988; Horowitz, Silverstone & Reinhardt, 1991; Keenan, 1999), yet, as Aveyard (2000) has demonstrated, the meaning of the term 'autonomy' remains unclear. Little is known about the historical development of the concept. The aim of this section is to furnish an historical setting for the wider concept of autonomy, drawing on the ideas of three relevant philosophers - namely: David Hume, Immanuel Kant and John Stuart Mill, each of whom have related autonomy to self-determination. Relevant research papers are also discussed.

### 2.4.1 The definitions of autonomy

Autonomy is a multidimensional concept (Collopy, 1988). Meanings of autonomy fall within a range of terms such as liberty, self-rule, self-government, sovereignty, freedom of will, dignity, integrity, individuality, independence, self-assertion, and self-determination. Etymologically, autonomy is defined as *autos* (self) and *nomos* (rule of law or rule, governance) and was first used to refer to self-rule or self-governance in Greek city-states (Beauchamp and Childress, 2001).

Autonomy in this sense has three aspects. The first refers to the determination of one's own course of action in accordance with a plan. In this regard autonomy is linked to personal liberty of action (Abramson, 1985). The second aspect concerns the individual's awareness of his or her autonomy, for example, every person is autonomous to the extent to which they are consciously able to control their own lives (Dworkin, 1988; Aveyard, 2000). The third aspect refers to the ability of acting without external compulsion - "acting based on one's own mind or free will" (Wehmeyer, 2004, p.340), and includes consideration of the notion that, although an autonomous person has the freedom to think, that freedom is qualified by individual morality:

"... to regard himself as autonomous in the sense I have in mind, a person must see himself as sovereign in deciding what to believe and in weighing competing reasons for action" (Scanlon, 1974, p.215).

Autonomy is not only a theoretical right to self-determination, or to make choices based on one's personal attitudes, values, and preferences (Miller, 1981; Macmillan, 1986; Collopy, 1988; Atkinson, 1991; Keenan, 1999) but is the actual exercise of self-determination, established in practice as a human right. Respect for that right implies an obligation not to interfere with the choices of others, and to treat others as being capable of choosing (Miller, 1981).

Although the definitions of autonomy are somewhat diverse, freedom in a decision-making process seems to be the common element in every account of it. Macmillan (1986, p.95) indicates this clearly, stating that:

“The concept of autonomy concerns an individual’s ability to think about and decide on something freely, and to act in the light of such decision and thought. There is interdependence between the mental part of the process of self-determination and the physical outcome or response”.

For the purposes of this study, autonomy is defined as a concept ultimately concerned with right of self-determination, freedom of choice, and acceptance of the moral responsibility implied in the possession of that right.

Miller (1981) identifies four aspects of autonomy: freedom of action; authenticity; effective deliberation; and moral reflection. The sum of these ideas is an understanding that autonomous action is voluntary and consistent with one’s own mind: it involves an awareness of alternatives and of the consequences of alternative choices, and it implies acceptance of the moral values pertaining to those choices. Autonomy is thus an evaluative or reflective notion, and one that includes an ability to examine and alter one’s preferences (Dworkin, 1988). This multi-dimensional interpretation of autonomy is supported by Keenan (1999) who argues that autonomy consists of: independence in expressing one’s freedom of will, the capacity for decision making, the capacity for knowledge, and the capacity for self-determination.

#### **2.4.2 Theories of autonomy**

The concept of autonomy is a prerequisite for the construction of moral metaphysics – a notion supported by Ansell-Pearson (1991, p.273) who describes the necessity to “establish the grounds for a pure, *a priori* ethics in order to discover the supreme principle of morality, namely autonomy”. The relationship between autonomy and morality is based on the assumed existence of an autonomous and rational agent, capable of making choices and taking actions based on a sense of morality (Lee & Wringle, 1993). Three philosophers have contributed fundamentally to this body of thought: David Hume, Immanuel Kant, and John Stuart Mill. Their theories of autonomy display areas both of agreement and disagreement, which relate to their reflections on the significance of morality.

#### **2.4.2.1 Hume's theory**

David Hume (1711-1776) was a Scottish philosopher, historian, and essayist. Hume believed human experience is composed of reason and emotion (Tomm, 1987). In ethics, he argued that the genesis of a concept of morality cannot be restricted to the processes of objective reason. Hume also was an empiricist who believed that knowledge and ideas obtain in sensitive and reflective impressions. He draws a distinction between ideas and impressions, arguing that ideas are the secondary product of impressionability. The impression is clear, bright, vigorous, and active; the idea much vaguer, with less energy (Stanford Encyclopedia of Philosophy, 2007a). Hume was aware that the majority of empiricists believed in the causal relationship. However, there is a suggestion in his philosophy that the necessity of a relationship with experience is not absolute.

#### **2.4.2.2 Kant's theory**

Immanuel Kant (1724-1804) was a rule deontologist who suggested the importance of morality in the concept and operation of autonomy. Human nature is explained as comprising two essential aspects of value judgment: rational and desire-based. Kant believed that the 'autonomy of the will' is the highest principle of human nature, expressed through the self-determined pursuit of desires. Moral autonomy is defined as the legislation of the self by morally valid principles. Kant's view of moral relations requires that while the individual determines action by his or her own desires and emotions, he or she entertains, and is guided by respect for the autonomy of others (Kant, 2001). He thus describes the morally autonomous person as "one who is directed by personal interests shaped by a consciousness of the context of emerging interrelated conditions" (Tomm, 1987, p.459). Respect for another's autonomy is to imply that the individual is an end in him or herself, and advocates an autonomous nature for the individual in general (Lee & Wringe, 1993). In other words, belief in the truth of autonomy as a concept, and therefore of one's own autonomy, requires belief in, and respect of, the autonomy of others.

Kant's view is the opposite of heteronomy, which refers to the submission of the individual to rule by other persons or conditions. Central to the concept of moral autonomy is the concept of duty. Duty, in its simplest terms, implies knowledge and acceptance of the right way to behave. Kant defines two forms of duty: categorical and hypothetical. Categorical duty may also be referred to as laws of nature – for example, a man should not steal or lie. Hypothetical duty comprises a 'conditional-based' principle of action (Stanford Encyclopedia of Philosophy, 2004). Kant believed that categorical duty, or voluntary autonomous reason, is an absolute statement of moral action. A moral action is moral by virtue of reason, but reason is voluntary and autonomous, not heteronymous. This concept implies the existence of 'rational agents'- for example, persons whose actions are based on rational choice, namely 'autonomy of the will'. Self-legislation by means of reason must be independent of personal happiness; moral feeling and/or governance by God's are contained in each individual's principle of self-legislation.

#### **2.4.2.3 Mill's theory**

John Stuart Mill (1806-1873) was a British philosopher, economist, and moral and political theorist. He invoked the 'Utilitarianism' of Jeremy Bentham (1748-1832). The principle of utility is central to Utilitarianism, and is also called a consequence-based theory. He believed that people with true character possess genuine individuality, comprising qualities of firmness, self-control, and the facility for choosing a life plan. He alleged that freedom of thought and action will lead individuals to a moral way of life (Morse, 2001). Mill's theory of autonomy exceeds the simple notion of the individual's freedom from unwanted interference. Rather, the autonomous decisions of an individual reflect, not only their freedom, but their desires and happiness. Mill further suggests that morality is more than a necessary adjunct to autonomy – it is fundamental to one's right of self-determination. In Mill's view, autonomous individuals possess a right to freedom of action, whose only constraint is an obligation not to violate the freedom of others. He stops short of suggesting that the individual is responsible for the happiness of others; an individual may be 'self-regarding', but not 'other-regarding' (Stanford Encyclopedia of Philosophy, 2007b).

These three philosophers share some basic principles, but differ in their view of morality. Hume regards the natural virtue of the subjective human as the individual's feeling or sentiment. Kant adopts a more objective stance – proposing that morality is the product of individual reason and will. Mill gives greatest priority to individual desire and happiness as the basis for moral autonomy. These writers provide a theoretical concept of autonomy. In the next section research based around that concept will be discussed.

### **2.4.3 The dimensions, hierarchy and relationship of levels of autonomy**

Three types of autonomy are distinguished by Gillon (1985): autonomy of thought, autonomy of will, and autonomy of action. Autonomy of thought and autonomy of will are concerned with the mental aspect of the individual. Macmillan (1986) composed a PhD study exploring the concept of autonomy in the elderly, employing a life-history approach. She identified three hierarchically related aspects, or dimensions, of autonomy:

Autonomy of thought (Level one): is the fundamental freedom to think about, deliberate, and consider possible arguments, and decide or will action on the basis of such deliberation, without absolute intention. In the terms of this dimension, thought is the prerequisite of all autonomy; knowledge is among the fundamental aspects of the deliberative process.

Autonomy of will (Level two): is the ability to decide to do things on the basis of thought. This is the bridge between thought and action. The idea of will-power perhaps helps to elucidate the nuances of control of action.

Autonomy of action (Level three): is the physical ability required before autonomy of action can be facilitated. Freedom to act is based on the autonomy of will and thought.

There are, however, some problems with this model when it is viewed in the context of certain actual situations and conditions. Autonomy of thought is the fundamental

basis where attention to the exercise of the individual choice may be easiest to ignore – as, for instance, when an individual in care manifests a mental disorder which adversely affects his or her autonomy of thought. Personal decisions based on autonomy of will are more difficult to ignore, but this aspect of autonomy itself is perhaps most vulnerable overall – for example, in the case of a family carer, whose freedom of will is compromised by commitment to an ongoing long-term caring process. The individual's autonomy of action is hardest to deny, but easiest to override - for instance in the case of the cared-for individual who is physically and intellectually weakened by their condition. Such infringement of autonomy is easier to observe.

Numerous studies of autonomy in dependent elderly patients have concentrated on decisions with regard to medical treatment made in clinical situations (Dresen, 1978; High, 1988; Jameton, 1988; Pratt *et al.*, 1989; Horowitz, Silverstone & Reinhardt, 1991). Frequently, primary carers become the cared-for person's proxy and make decisions about, or for, the cared-for person, but this process often leads to infringement of autonomy. While one might accept that proxy decisions are necessary on occasion, such decisions must always be made with great caution. It is of course possible that a confused elderly cared-for person may make bizarre decisions, which everyone else is then obliged to accommodate. However, as has already been suggested, this study is also concerned to emphasise the autonomy of the carer, and the extent to which this may be compromised by the commitment to caregiving. In other words, the family carer is equally liable to experience restriction of his or her freedom of self-determination. This study seeks to address that aspect of the carer's experience.

Several studies have reported that the commitment to providing care affects the carer's freedom to work. This is seen particularly in research on carers of relatives with dementia (Scharlach, Sobel & Roberts, 1991; Kramer & Kipnis, 1995). Both of these studies focused on adult offspring or grandchild carers. It is possible, therefore, that their findings are different from those drawn from research into spousal carers. Carers of children with disability have also reported low rates of employment, or the necessity of reducing work hours (Shearn, 1998; Lewis *et al.*, 1999; Shearn & Todd, 2000; Seltzer *et al.*, 2001; Emerson, 2003; Gordon, Rosenman & Cuskelly, 2007).

Shearn and Todd (2000) conducted a qualitative study, exploring the impact of caring on employment in eighteen mothers. They reported feelings of isolation, lack of fulfilment and support, and low self-esteem in their subjects. Similar findings were reported in studies by Stephens, Franks and Townsend (1994) and Kagan, Lewis and Heaton (1998). Single mothers reported still lower levels of workforce participation than did mothers whose partners were co-resident (Gordon, Rosenman & Cuskelly, 2007). It is evident that the freedom to work is negatively affected by the commitment to caregiving.

Horowitz, Silverstone and Reinhardt (1991) focused on formulating an assessment criterion for the autonomy of frail older people. They identified four approaches for measurement of autonomy: (1) autonomy concerns relating to assistance with daily living tasks; (2) decision-making (for health care, housing, social activities, finances, daily diet, and vacation plans); (3) the respondent's attitudes toward autonomy, such as autonomy conflict, and autonomy dilemmas within the context of family relationships; (4) a series of questions touching on perceptions of independence, freedom of choice, and family attitude toward the elder's capabilities. Although the general concept of autonomy may seem equally applicable to carers, there is, as yet, no such empirical investigation focusing on this group. This needs to be addressed; understanding the impact of caregiving on the carer's autonomy is a fundamental aspect in our understanding of the caregiving journey.

#### **2.4.4 Paternalism**

As mentioned earlier, the necessity of making decisions for individuals whose decision-making faculties are in some way compromised or degenerated, may oblige the carer to adopt paternalistic attitudes. Paternalism is defined by the Oxford Advanced Learner's Dictionary (2000, p.928) as,

“...the system in which a government or employer protects the people who are governed or employed by providing them with what they need, but does not give them any responsibility or freedom of choice”.



Paternalism in the caregiving context often refers to decisions being made or actions taken on behalf of another person for that person's well-being (Stanford Encyclopedia of Philosophy, 2005). It is important that decision-making and action without consent is fully justified (Macmillan, 1986). Usually such situations pertain to persons whose mental competency is impaired or diminished.

It is generally the case that carers who act in this manner, particularly with regard to the matter of medical treatment, do so on the basis of serious discussion regarding the cared-for person's abilities to make decisions for themselves. It is also usual that the cared-for person is closely related - a spouse, parent, or child. Paternalism undoubtedly comprises interference with personal liberty, but this should be for reasons referring exclusively to the welfare, happiness, needs, interests or values of the person coerced (Dworkin, 1972). Dworkin (1988) identified two types of paternalism: 'hard' and 'soft'. Soft paternalism is defined as being self-evidently necessary and expedient; hard paternalism involves actions which must be specifically justified by the paternalistic agent.

It should be noted that the intention of paternalistic action is not the deprivation of the individual's freedom of choice. Such deprivation is seen as inevitable in the course of protecting and maintaining the well-being of the cared-for person. Undeniably, however, there are situations in which paternalistic attitudes and actions may be taken to excess – often leading to conflict between the cared-for person and the carer.

## **2.5 Summary**

Four sections of literature review have been discussed. Section 1, Context of Caring, focuses on the background of carers, and makes specific recognition of the dynamic process of caregiving. Section 2, Impact of Care, emphasises the consequences of undertaking the caring role, including both negative and positive aspects, as well as carer perspective on the personhood of the cared-for relative. Section 3, Carer Resources, discusses three types of carer resource: psychosocial resources, social support, and coping strategies. Finally, in section 4, Carers' Autonomy, the definitions and theoretical background of autonomy are discussed, with specific

reference to the work of three major philosophers - David Hume, Immanuel Kant and John Stuart Mill. Three dimensions of autonomy - autonomy of thought, autonomy of will, and autonomy of action – are identified by their differences, their hierarchical position, and their relationship, in relation to the caregiving situation.

As these four sections have been reviewed, the overall aim of the current study should now be addressed; its focus is an exploration by comparison over time of changes in the caregiving experience of family carers of individuals with dementia, and family carers of adolescents with ID. The research questions are:

- How do carers in both groups define their role?
- What are the caring experiences of carers?
- Do these experiences change over time?
- Does the caring experience affect carers' health over time?
- Does the caring role affect their autonomy?
- What expectations do carers have over time?

## **CHAPTER 3 RESEARCH DESIGN AND METHODS**

### **3. Introduction**

The review of literature in Chapter 2 identified the importance of understanding the experience of caring from the carer's point of view, and the lack of understanding of changes in this experience over time. The proposed comparison of these two groups - spouses of partners with dementia and parents of adolescents with ID - is new, with the aim of identifying the similarities and differences between their experiences. The purpose of this chapter is to present the rationale for the research design and methods chosen to answer the research questions and thus address these gaps in our knowledge. Various approaches to research are reviewed and practical issues of sampling and number of participants, data collection and analysis are discussed, as are ethical considerations and the trustworthiness of qualitative research.

#### **3.1 Overall aim**

The overall aim of the research is to identify, describe and explore the changes in carers' experiences of looking after a relative living with dementia or adolescents with ID, and the effect of caring on the carer's autonomy and health over time.

#### **3.2 Research questions**

In order to meet the aim of the research a number of research questions were identified:

- How do carers in both groups define their role?
- What are the caring experiences of carers?
- Do these experiences change over time?
- Does the caring experience affect carers' health over time?
- Does the caring role affect their autonomy?

- What expectations do carers have over time?

### **3.3 Paradigms**

A paradigm is a general conception of the nature of scientific endeavour within which a given enquiry is undertaken (Polit, Beck & Hungler, 2001). The term paradigm refers to a model or example of statements or principles about fundamental aspects of reality. Guba (1990, p.17) defined a paradigm as "...a basic set of beliefs that guides action, whether of the everyday garden variety or action taken in connection with disciplined inquiry".

The choice of methods in any research project presupposes a philosophy regarding fundamental aspects of reality. Such philosophies are often referred to as research paradigms and generally divided between positivism and naturalism, a division based on differences in ontology, epistemology and methodology. Ontology refers to the nature of reality and existence, and is also called realism, which alludes to the belief in the 'reality' of those external entities. Lincoln and Guba (1985) define ontology as the study of the nature of reality, hence the questioning of, or inquiry into, multiple realities, and discovery or exploration of phenomena. Epistemology is the theory of knowledge (Burns & Grove, 2005) and is described as the necessary truths relative to ways of knowing regarding a theory, or theories about how we know – for instance the relationship of knower to what is known (Lincoln & Guba, 1985).

#### **3.3.1 Positivism**

The positivist paradigm underpins the philosophy of scientific investigation. Positivism was introduced by Auguste Comte (1798-1875), who based the notion on the model of empirical sciences, described by Reese (1980, p.450) as "...an extremely positive evaluation of science and scientific method". As positivism focuses on the 'truth' of things and scientific method, it is regarded as being value-free and unaffected by social relevance and social context (Polit and Beck, 2004). Accordingly, the social world can be measured and verified by deductive research

logic and empirical evidence (Esterberg, 2002). Traditionally, positivism focuses on discovering the causal laws that can be used in social research to predict general patterns of human behaviour. Society can thus be investigated by objective rules of method that are largely independent of the content and context of the examination (Kvale, 1996).

Positivism thus regards knowledge as something integral to the natural world, waiting to be understood and discovered; there must be natural causes of this knowledge and these causes are discoverable by means of experimentation (Parahoo, 2006) - for example, the causes of sickness can be explained by scientific research. The scientist adopting a positivistic approach may conduct a research project, eliminating irrelevant variables, in order to understand cause-and-effect relationships. Ultimately, he or she might be able to draw factual conclusions, and so explain the general situations of the real world.

There are five axioms of the positivist paradigm (Lincoln & Guba, 1985, p.37):

- the nature of reality is single, tangible, and fragmentable;
- the relationship of the knower to the known is independent and dualistic;
- time and content-free generalizations are possible;
- causal linkages may represent real causes, temporally precedent to or simultaneous with their effects; and
- positivist inquiry is value-free.

It has been suggested that positivism is based on deductive analysis which, while leading to firm conclusions, might ignore other alternatives, rely excessively on operationalism, and lead to inappropriate judgements. It is further suggested that positivistic research with human respondents produces data which is potentially ignorant of their humanity, and is incapable of dealing with practical formulations in a variety of fields (Lincoln & Guba, 1985). The positivist paradigm was not suitable because the research focus in this study is linked to human values, interpretations and meanings relevant to a particular life context, and the role of the researcher as a tool to collect data.

### **3.3.1.1 Quantitative research**

The positivist paradigm is widely applied in quantitative research. Lincoln and Guba (1985) suggested that quantitative research emphasises the proof of objective concepts and causes in society, generating theories by which it is possible to predict and manipulate the future, and validate the result(s) of the research or project. Cohen and Manion (1985) argued that only ‘sensory experiences’ can form the basis of valid knowledge, and that accordingly knowledge can be advanced only by means of observation and experiment. The quantitative approach emphasises objectivity, pragmatism, and logic, embracing descriptive, correlational, quasi-experimental study designs (Burns & Grove, 2005). These approaches inevitably give rise to problems and controversy with regard to the means and criteria of measurement. However, when dealing with people’s life experiences, it is perhaps inappropriate to identify and to explore the nature of those experiences using this approach.

### **3.3.2 Naturalism**

The essence of the naturalistic paradigm is the notion that human beings are completely integrated in the natural world. Guba (1978) defines naturalistic inquiry as a discovery-oriented approach that minimises investigator-manipulation of the study setting, and imposes no prior constraints on what the outcomes of research may be. There are many elements in a naturalistic inquiry, including natural setting, human instrument, utilization of tacit knowledge, qualitative methods, purposive sampling, inductive data analysis, grounded theory, emergent design, negotiated outcomes, case study reporting mode, idiographic interpretation, tentative application, focus-determined boundaries, and special criteria for trustworthiness (Lincoln & Guba, 1985). Lincoln and Guba (1985, p.37) in addition suggest five axioms of the naturalistic paradigm:

- the nature of reality is multiple, constructed, and holistic;
- the relationship of knower (the inquirer) and known (or knowable) is

interactive and inseparable;

- generalization is only possible in time and context-bound working hypotheses;
- possible causal linkages prevail for entities in a state of mutual simultaneous shaping, so that it is impossible to distinguish causes from effects; and
- inquiry is value-bound.

The purpose of naturalistic inquiry is to present the lives and perspectives of those being studied, and to understand their social world as faithfully as possible. It is essential for researchers to be sympathetic with the world of their participants and to listen with equal care to the voice of every individual (Esterberg, 2002). Social context is thus crucial in naturalistic research. Naturalistic researchers immerse themselves in their field settings, often living among those being studied for long periods of time. It is important that the naturalistic researcher develops close, personal, and empathic relationships with those being studied, and becomes fully engaged with their world. The advantage of naturalism in the current study is that it will facilitate answers to those research questions which focus on the perception and experience of caring from carer's viewpoint.

### **3.3.2.1 Qualitative research**

The history and evolution of qualitative research, briefly, comprises five stages: the traditional age (1900-1950), the modernist or golden age (1950-1970), blurred genres (1970-1986), the crisis of representation (1986-1990), and the postmodern (1990-present day) (Hamilton, 1994). Lincoln and Guba (1985, p.40) suggest that naturalistic inquiry leads to qualitative methodology because

“...such methods expose more directly the nature of the transaction between investigator and respondent (or object), and hence make easier an assessment of the extent to which the phenomenon is described in terms of (is biased by) the investigator's own posture; and because qualitative methods are more sensitive to and adaptable to the many mutually shaping influences and value patterns that may be encountered...”

Definitions of qualitative research refer broadly to a holistic approach to questioning, a focus on the understanding of human experience, emphasis on the natural setting, and interpretation of phenomena. Human realities have a bearing on qualitative research. The concept of human realities is illuminated by Schutz (1973, p.207) in the following statement:

“...the origin of all reality is subjective; whatever excites and stimulates our interest is real; to call a thing real means that this thing stands in a certain relation to ourselves”.

Qualitative approaches have the potential to explore the individual person’s attitude to the meaning of human life or a life context (Munhall, 2007). They tend to describe life experiences and to give them meaning (Streubert & Carpenter, 1999), and have previously been employed in order to combine the scientific and artistic aspects of nursing. Qualitative research often relies upon inductive approaches in the exploration of phenomena, involving subjective human experiences, and the interaction of researchers’ perspectives, encouraging the art of interpretation through social process. The relation of qualitative research to grounded theory has been discussed by Strauss and Corbin (1998, p.11); they propose that it may,

“...refer to research about persons’ lives, lived experiences, behaviours, emotions, and feelings as well as organizational functioning, social movements, cultural phenomena, and interactions between nations....”

In the context of the current study, qualitative methods are most appropriate as a means of concentrating on the dynamic nature of the caregiving experience (Grant & Ramcharan, 2001). Broadly, in this research, the caring experience is considered as a whole phenomenon, involving complex relationships and interactions, and requiring specific focus on the individuality of all participants, their perceptions and responses.



### **3.4 Multiple approaches of qualitative research**

Having argued for the appropriateness of the naturalistic paradigm and qualitative methods, it is now necessary to identify, amongst the array of possible qualitative approaches, the methods most appropriate to the objectives of the current study.

#### **3.4.1 Phenomenology**

The phenomenological approach seeks to understand or describe the essence of the lived experience of humans. The term ‘phenomenology’ derives from the Greek word *phainomenon* - denoting both philosophy and methodology (Hallett, 1995). There are two major branches in phenomenology: the phenomenology of Edmund Husserl (1857-1938) and the hermeneutic phenomenology of Martin Heidegger (1889-1976), each based on a different epistemology and ontology (Holloway & Wheeler, 2002).

Husserl (1857-1938) was the leading light in the German phase of the phenomenological movement. Husserl espoused a rigorous scientific approach in relation to human life concerns, based on the fundamental tenet of the Cartesian tradition “that thinks of man’s relationship to the world in terms of subjects knowing objects” (Walter, 1995, p.792, cites Dreyfus, 1987). This type of phenomenology is referred to by various names including: descriptive phenomenology; transcendental phenomenology; and pure phenomenology. The aim of Husserlian phenomenology is to identify the essence of phenomena in an individual’s lived experiences (Sadala & Adorno, 2002). It comprises three main elements: essences, intuition and phenomenological reduction. The term essences refers to the true meaning and understanding of the phenomenon; intuition focuses on the subjective understanding of the phenomenon; phenomenological reduction is a process of approaching the natural phenomenon under investigation by excising extraneous influences, thereby enhancing the objectivity of data analysis. Sadala and Adorno (2002) suggest that the core of Husserlian phenomenology is ‘the intentionality of consciousness’ – i.e. the predisposition of human consciousness to understand the world.

Martin Heidegger (1889-1976) was Husserl's student. He developed the phenomenological approach, evolving what has become known as interpretive or hermeneutic phenomenology – a description of the real world which embraces subjective perception. He attempts to focus on *Dasein*, (which may be translated as understanding *being-in-the-world*). This is a new dimension, which relates to the understanding of human experience, in which interpretation is tentative rather than definitive (Heidegger, 1962). Heideggerian phenomenology is an approach to interpreting shared meanings and practices in the context of lived experience. Reed (1994) suggests that Heidegger believed researchers are part of the world and the experiences they investigate, and as such, are subject to expression in, and interaction with, that environment. Koch (1995, p.831) states that, “for Heidegger, understanding is no longer conceived of as a way of knowing but as a mode of being, as a fundamental characteristic of our being in the world”. Most importantly, Heidegger rejects the notion of excising, or ‘bracketing’ extraneous data. Heidegger's phenomenological view emphasises a concept of knowledge or phenomena embedded in our everyday life (Koch, 1995). In other words, humans (including researchers into human experience) interact with each other in the world. Lavery (2003) takes issue with the Heideggerian approach, suggesting that the inherent bias or prejudices of the researcher may not easily be bracketed or set aside, and are perhaps only mitigated by awareness of the bias.

The overall aim of phenomenology is a philosophy of thought and empirical perception – a philosophy which recognises the reality of individuals. Its aim is to provide a single effective approach to understanding the life of the individual, through assessment of his or her world, and respect for his or her beliefs and values, through empathic interpretation of subjective viewpoint. As such, it proposes a fundamental distinction between, on the one hand explaining phenomena, and on the other merely illuminating the essence of phenomena. As such, it is considered too restrictive an approach for the purposes of the current study.

### **3.4.2 Ethnography**

A second qualitative approach is ethnography. This has its roots in anthropology, and tends to focus on entire culture groups, providing an inside perspective on everyday life through the researcher's engagement with people (Spradley, 1980). Ethnography is guided by symbolic interactionism. Ethnographers believe that people are interpreters of events that experiences are constantly under revision and, in turn, help to shape action (Creswell, 2007). An understanding of culture, patterns of custom, values, and language is an essential requirement for this approach.

Two major types of ethnography are distinguished by Thomas (1993): descriptive ethnography and critical ethnography. Descriptive ethnography limits itself to the description of cultures or groups, whereas critical ethnography includes the study of macro-social factors such as power, control, and empowerment, and admits a wide range of data sources (Hammersley & Atkinson, 1983). Fieldwork and participant or non-participant observation, are necessary for the collection of data in natural settings. Ethnographers must become familiar with the group they intend to investigate (Holloway & Wheeler, 2002). Reflexivity is recommended as a means of maintaining the quality and rigour of the research and of providing a record of thought (for example, by writing a journal) (Pellatt, 2003).

The Ethnographical approach was considered inappropriate for the purposes of the current study, since the researcher did not intend to focus on the beliefs and practices of a defined culture group. In addition, it was realised that the process of formal observation might be a source of some stress to the participants – a level the researcher did not wish to add to by probing into unnecessary areas.

### 3.4.3 Grounded theory

Grounded theory was developed by the sociologists Barney Glaser and Anselm Strauss (1967). The term ‘grounded’ means that the theory or concept is derived from research data gained from those who experience the particular phenomenon. It also serves to initiate new theory and to reformulate, refocus, and clarify existing theory (Hutchinson, 1993; Backman & Kyngas, 1999). For example, the research work by Bowers (1987), by adapting a grounded theory approach, set out to generate a new theory of intergenerational caregiving - an area not previously extensively studied. Neufeld and Harrison (2003) also applied grounded theory to refocus on the relationships between female caregivers and social support. They found that unmet support needs, unfulfilled expectations and negative interactions exist among caregivers. Grounded theory is thus suited to the current study, since the study’s comparison of the two groups of carers under investigation comprises a previously unresearched area, and may give rise to new theory or perspectives on the basis of a familiar phenomenon.

The characteristics of grounded theory are: theoretical sampling; constant comparative analysis; the coding and categorising of data; the use of literature as a source of data; integration of theory; and theoretical memos. These are discussed separately in a later section describing the different processes applied in the course of undertaking such an approach. Constant comparative analysis is also separately discussed in the section on data analysis. Practically, in accordance with a grounded theory approach, interview questions are modified as the researcher enters into the field; questions are shaped in the process of analysis to provide more specific areas of focus (de la Cuesta, 2005; Sandgren *et al.*, 2006).

Since its inception, grounded theory has developed into two main streams: Glaserian and Straussian. Major differences between these two approaches include the use of literature in the initial stage of research and data analysis (Glaser, 1992, 2001; Strauss & Corbin, 1990, 1998; Stern, 1994; May, 1996; Cutcliffe, 2000; Hutchinson, 2000; McCann & Clark, 2003; Heath & Cowley, 2004; Walker & Myrick, 2006). Glaser (1978), and Strauss and Corbin (1990, 1998) have argued about the function of the literature review. Glaser (1978) claimed that undertaking a literature review prior to

the conduct of a study would taint the researcher's view when collecting data and analysing it. However, Strauss and Corbin (1990, 1998) argued that a preliminary literature review would enhance the theoretical sensitivity of the researcher since it draws attention to the meanings of other's concepts without obliging the researcher to have all the answers from the data (Strauss & Corbin, 1998). Hutchinson (1993) agrees with Strauss and Corbin and suggests that the review of the literature can identify the gaps in current knowledge. It may also provide a clearer rationale for the proposed research. This latter argument accords well with the employment of a literature review in PhD theses; the identification of gaps in knowledge facilitates the possibility of contributing to existing knowledge, which is a fundamental element in the rationale of such work.

Reflection on existing literature also contributes to the formulation of research questions at the initial stage of data collection (Strauss & Corbin, 1998). In the writing stage, literature may be used to confirm findings as well as explaining the inconsistency of results, as Hutchinson (1993, p.205) points out, analysis of literature

“...links extant research and theory with the concepts, constructs, and properties of the new theory... literature that illuminates, supports, or extends the proposed theory is interwoven with the empirical data”.

In procedures of data analysis, the Glaserian approach focuses on open, selective and theoretical coding; the Straussian approach identifies three phases of coding - open, axial, and selective - which are further discussed in a later section of Constant comparative analysis. A coding paradigm is applied in both approaches, but in different phases. The coding paradigm consists of causal conditions, phenomenon, context, intervening conditions, action or interaction strategies and consequences. In the Glaserian approach, the coding paradigm is to be completed in the open coding phase; in the Straussian approach the coding paradigm is developed in the axial coding phase.

Charmaz (2006) has built on Glaser and Strauss' work and has introduced another view of grounded theory which she terms 'constructivist grounded theory'. This approach focuses on a reciprocal relationship between a participant and a researcher growing from shared experiences. The generation of theory is dependent on only the

researcher's view though informed by the experience and explanation of the participants. This is at odds with the reality of some researchers who operate totally outside the participant's world. To make sure that the researcher is constantly in tune with the participant's view and understanding they are encouraged to make constant use of reflective diaries which challenge their own pre-conceived ideas. One of the most important tenets of Charmaz (2006) understanding is that the generation of theory can only be based on symbolic interactionism, and thus theorising is a practical activity rather than a 'blueprint for theoretical products'.

### **3.4.3.1 Symbolic Interactionism**

The theoretical foundation of grounded theory is symbolic interactionism. This was developed by George Herbert Mead (1934), a social psychologist. It focuses on the ways in which people define a relationship between the symbolic meaning of their perceptions and their actions in relation to society, thereby creating a social reality (Burns & Grove, 2001). It is important to understand that every symbolic meaning is unique to each individual; symbolic meanings interact to redefine or clarify conceptions. Mead (1934, p.xxv) states that

“...every action of the individual at either the non-linguistic or linguistic levels of communication changes the social structure to some degree, slightly for the most part, greatly in the case of the genius and the leader”.

Mead (1934) and Blumer (1966) identify a distinction between the behaviour of animals and that of humans. They suggest that animal behaviour is composed of 'non-significant gestures' or 'non-symbolic interaction'. In contrast, by virtue of possessing a mind and a self, the human becomes, through social interaction, a rational being (Mead, 1934). It is in role-taking and social interaction that the individual achieves a sense of self. In addition, humans develop 'significant symbols' and are characterised by co-operative responses to social stimuli and interaction.

There is a big difference between animal and human consciousness, which consists in the notion that humans have 'self' (Mead, 1934). The perception of 'self' is the

internal part of the human being which derives from the individual's experience and interaction with others. Self consists of two parts: 'I' and 'me' which are specifically defined by Mead (1934). 'I' refers to autonomic individuals who react to social stimuli. 'Me' alludes to the sum of group attitudes, which comprises the social part of the individual. In Mead's theory, human self is a social process occurring through communication. This is internalised, taking its place among the individual's behaviours, and human attitudes as part of social reaction (Benzies & Allen, 2001).

Blumer (1966) further suggests that 'self' is a reflexive process, for example, that human beings living in a world develop respect for the self as an object. According to symbolic interactionists, the concept of self is unique to humans. A human being possesses a concept of self, acting toward, and communicating with that self the same as toward others. The human ability to sustain a concept of self and for self-interaction is the basis for the formulation of meaning and experience in the world. Symbolic interactionists view human behaviour as the result of this process. Blumer (1969, p.132) summarises this viewpoint, proposing that all human behaviour is the result of "...a vast interpretative process in which people, singly and collectively, guide themselves by defining the objects, events and situations they encounter".

Symbolic interaction focuses on the meaning of events to people in natural or everyday settings. Meaning guides behaviour, or action, is preceded by a stage of deliberation, or definition of setting (Blumer, 1966). The reality or meaning of the situation is created by people, leading to action and the consequences of action. Deliberation and/or definition generates individual symbols; each individual has the ability to create and modify their interpretations of those symbols. Human history, culture, and forms of communication can be traced through symbols, and it is through symbols that meaning is conceived, through interpretation, action, and interaction. As such, symbolic interactionism is fundamentally relevant to qualitative research, facilitating exploration of phenomena in the human world. Blumer (1969, p.2) states there are three fundamental aspects of symbolic interactionism:

(firstly) "...human begins act toward things on the basis of the meanings that the things have for them... (secondly)...the meaning of such things is derived from, or arise out of, the social interaction that one has with one's fellows... (thirdly)...these meanings are handled in,

and modified through, an interpretative process used by the person in dealing with the things he encounters”.

Charon (1979) identifies three further fundamentals of symbolic interactionism: first, symbolic interactionism focuses on the individual as an active, thinking being; each individual has his or her background, experiences, perceptions, ideas, beliefs, attitudes, values and expectations, all of which influence action and the interpretation of meaning in actions. Second, symbolic interactionism prevails between an individual and other individuals or groups, and between the individual and his or her environment. Third, symbolic interactionism refers to the fact that individuals interact continually in their environment and engage in social interaction. We may thus refer to two levels in studies of symbolic interactionism: the behavioural or the interactional level, and the symbolic level. People create shared symbolic meanings through their interactions, and those meanings become their reality.

Esterberg (2002) indicates that researchers need to begin by examining the empirical world through an interpretative process of every symbol. He also suggests that researchers should begin by immersing themselves in the world inhabited by those they wish to study. This initial approach is similar to that adopted in the naturalistic approach, focusing on understanding how individuals construct their world; the main research task is to interpret those constructions. Klunkin and Greenwood (2006) explain how symbolic interactionism operates in grounded theory studies, throughout the whole process of research. They make specific reference to data analysis by the construction of categories, including the components of exploration (depiction) and inspection (analysis). The authors conclude that grounded theory is “usefully construable as the method of symbolic interactionism” (Klunkin & Greenwood, 2006, p.35).

Human beings actively participate in their natural situation, and generate actions. The overall aim of symbolic interactionism is to explain how individuals interact - fitting their lines of action to those of others, taking account of others' acts, interpreting them, and so and reorganising their own behaviour (Holloway & Wheeler, 2002). Actions or perceptions of individuals, and their intentions are the two major features of symbolic interactionism which lend themselves to qualitative inquiry. Symbolic



interactionism is the theory which proposes human interaction as a constantly enduring process, comprising dialogue and communication, during which individuals interact with each other, each attempting to understand the other's intentions, and reacting to them. Symbols used in social context stimulate in the individuals meanings that are likely to result in common actions. Moreover, thought and concrete situation have to be examined by the individual, and named in the corresponding meaning, which is created by their own experience.

### **3.4.3.2 Reflexivity**

Having described qualitative methods and the grounded theory approach, it is necessary to return to the issue of potential bias in the researcher, for the researcher and research cannot be significantly separated. Kvale (1996) agrees that it is not easy for the researcher to be a detached communicator within the interview. One way to address this is to cultivate reflexivity during the research process. Lamb and Huttlinger (1989) describe reflexivity as the reciprocal relationship between the researcher and 'researched' phenomenon. Reflexivity is an ability to acknowledge and examine one's own thoughts, actions, perceptions, beliefs, values, feelings and decisions, and to understand their impact (Horsburgh, 2003). Holloway and Wheeler (1996, p.263) state that reflexivity

“...means that researchers critically reflect on their own preconceptions and monitor their relationships with the participants and their own reactions to participants' accounts and action... researchers must reflect on their own actions, feelings and conflicts during the research”.

Given that it is almost impossible to monitor the impact of the views of the researcher within the interview, another vehicle needs to be found. Reflection after the event may increase the researcher's self-awareness and provide a clearer context of the phenomenon to audiences (Sword 1999; McGhee, Marland & Atkinson, 2007). Reflexivity can be applied to all stages of the research project (McGhee, Marland & Atkinson, 2007). In relation to sampling, reflexivity helps the researcher to reflect on the researcher-participant relationship, and consequently be aware of maintaining the

integrity of the data, avoiding biased or prejudicial judgements (Neill 2006). Particularly in the stage of constant comparative data collection and analysis, the researcher should be vigilant of his or her own assumptions in engaging with, and interpreting meanings from data (McGhee, Marland & Atkinson, 2007). However, it should be noted that the reflexive process is not straightforward (Finlay, 2002). The influence of personal preconceptions, values and beliefs is potentially problematic, especially for a novice researcher. Supervisory meetings provide an opportunity to redress potential imbalances, soliciting a range of different views from other individuals. Contrasting views in discussion may help the researcher clarify her or his thoughts, and view the topic or issue under discussion from a fresh perspective. In the current study, in addition to such meetings, a reflexive journal was maintained and reviewed, with the addition of new thoughts after each meeting.

Hall and Gallery (2001) further suggest that theoretical sensitivity is related to reflexivity in the grounded theory approach. The notion of ‘theoretical sensitivity’ is recognised by Glaser (1978) in reference to the process of sensitising concepts in relation to symbolic interactionism. Theoretical sensitivity focuses on the reflexive process by the inclusion of self in the research process. Reflexivity may enhance the researcher’s theoretical sensitivity in the field, guarding against the danger of making prejudicial or unreflected assumptions for granted, and may thus enhance a grounded theory study (Hall & Gallery, 2001; Neill, 2006). Continuing to keep a reflexive diary during the research process - with selective use of first person narrative, (as recommended by Horsburgh, 2003) has enhanced the credibility of this qualitative research project throughout.

#### The researcher’s personal reflexivity

In this section, I present some of my personal reflexivity notes:

An example of self-reflection in the initial stage of undertaking this study (03/10/2004)

I am an overseas student from Taiwan, currently pursuing a doctoral degree in Scotland. I am sensitive to the cultural differences between myself and the participants in this study. I bring personal values and beliefs developed throughout my childhood and adulthood, and influenced by the environments in which I have lived. My parents are Buddhists, and believe in the concepts of karma and causation, but, being of a younger generation, I do not share

their religious devotion. Undoubtedly, however, the pervasive influence of home has influenced me, perhaps in ways which I cannot articulate – although I am aware in myself of a tendency towards a fatalistic ideology.

Self-reflection during data analysis (05/06/2005)

Here is another example of the meeting of two cultures. I elicited data in an interview with Mrs. Macleod who cares for her daughter with DS.

Researcher: “Are you expecting to care for her forever?”

Mrs. Macleod: “I hope not! (laughs) I have... I mean I have thought about it. Yes. Yes. I have. I would hope that Elaine could be independent of Steven and I... I would hope that she could go into supported accommodation, something like that.”  
(Mrs. Macleod, Phase 1, p.20)

The major difference between my cultural expectations and those implied in this evidence contradicts in the notion of obligation or responsibility within Chinese family systems. Most Chinese families adhere to traditional notions of filial piety based on the Confucian ideology. Children accept responsibility for the care of their parents, and parents for the upbringing of children. Even unmarried children of thirty years or more will stay in the parental home before they marry. In other words, it is expected that different generations of the family stay together in the same house. They are obliged to care for each other and share the same environment. This is an expectation clearly not shared in the Scottish culture.

### **3.5 Longitudinal design**

Longitudinal design, according to Polit and Beck (2004), falls into three sorts namely trend, panel and follow-up studies. The trend study compares groups in a general population and selects different samples at repeated intervals. The panel study relies upon the same participants providing data at two or more times. Here the information revealed is better than in a trend study because it shows more detailed patterns of change and why it happened. The follow-up study employs data from the same set of participants to demonstrate the change in particular subjects in response to some treatment or other at different times.

In the current study, changes in the experience of caring were examined in a situation in which change over time was extremely probable. In the majority of previous quantitative studies, a cross-sectional approach was used, providing little or no information regarding the dynamic, changeable nature of their experience. For this

reason, a panel study seemed most appropriate, permitting the examination of the phenomenon at a series of points in time, while simultaneously demonstrating the process and nature of the changes (Polit and Beck, 2004). The design of this qualitative study involved three interviews over eighteen months. It was hoped that these would indicate the trend of change in the caring experience in relation to effects on carers' health and autonomy.

### **3.6 Data collection**

Various methods were applied in order to collect data in the current study, including interviews, and field notes reporting informal observations and memos.

#### **3.6.1 Interviews**

An interview is more than a conversation; it is purposely designed to gain a particular type of information from the participants. Interviews may be used in order to gain an understanding of the interviewee's perspective. It permits the interviewee to convey the meanings he or she attributes to his or her experiences in the social context (Silverman, 2006). The justification for employing an interview-based approach is the attainment of data, or privileged information, based in emotions, experiences, and the individual's reaction to sensitive issues (Denscombe, 2007). In the current study, interviews were chosen to obtain descriptions of the life-context of participants and their interpretations of the meanings of their experiences (Kvale, 1996). An in-depth interview is especially useful as a means of exploring important topics in detail, or as a basis for the construction of a theory (Esterberg, 2002).

Three types of interview are common in data collection: structured, semi-structured, and unstructured. For the purposes of the current study, the structured interview was considered too restrictive of the participants' freedom of expression, while unstructured interviews seemed to confront the novice researcher with too great a

degree of potential difficulty, at least in the initial stages of research. The semi-structured interview thus seemed the most conducive research vehicle, offering the reassurance of a framework of clarifying questions by which to encourage the participants' expression of the lived experience (Streubert & Carpenter, 1999). The basic approach comprised a standard opening question, followed by a series of related questions denoted by simple topic headings. This allowed the researcher to ensure that each interview commenced in a similar fashion, while providing an opportunity for the participant to drive the subsequent conversation. At the same time, the researcher was confident that all relevant topics were covered.

A semi-structured interview has the virtue of a clear structure, ensuring appropriate coverage of the relevant research areas. At the same time, it is flexible, allowing for changes to the wording and order of questions in response to the dynamic of the interview situation. Esterberg (2002) states that the semi-structured interview allows the investigator to explore a topic more openly and permits participants to express their opinions and ideas in their own words; each interview is tailored to the participant. Kvale (1996) also suggests that the researcher needs to listen carefully to the participant's responses and to follow his or her lead, respecting the participant's responses, and allowing sufficient time for them to be articulated. The further probing of those responses, through follow-up questions, enables the researcher to develop a clearer picture of the participant's perspective. Face-to-face interviews admit the possibility of clearer explanations, greater depth and accuracy of data, and the opportunity to observe the participant's material circumstances. However, a few disadvantages should be noted, including the difficulties of organisation, cost, and time (Hague, 1993).

In the current study, all interviews were conducted with participants in their own homes, ensuring that they felt, as far as possible, comfortable and at ease. Interview length varied from one to four hours. A two-hour interview was typical of Phase 1; Phase 2 and Phase 3 interviews were generally shorter (approximately one to one-and-a-half hours). Each interview was digitally recorded. Recording the interviews on digital recorder allowed me to maintain eye contact, observing facial expressions, while concentrating on the participant's responses. It also helped me maintain accuracy in the transcription of interviews, reducing the possibility of errors due to

lapses in memory. All the transcriptions were transcribed verbatim (see Appendix 2) by the same professional transcriber from a secretarial services company. A few inaudible segments (due to rapidity of speech, background noise, or the quality of recording) were indicated in some transcriptions. A professional transcriber was employed in order to ensure levels of accuracy. Every transcription was subsequently checked by me against the recording, before proceeding to data analysis.

### **3.6.1.1 Interview guide development**

To help prepare for the main study a series of pilot interviews were carried out. The purpose of the pilot interviews was to enhance my self-confidence and to develop my ability in maintaining or creating safe and stimulating interactions. I also practised developing the skill of transcribing interviews. At the same time, arrangements were made for an in-depth reflection session with a member of the supervisory team, in order to obtain feedback towards the improvement of my techniques and skills. The schedule of pilot interviews can be seen below.

The pilot interviews involved talking to five people.

- Pilot interview 1, a woman caring for her elderly mother
- Pilot interview 2, a man caring for his wife with breast cancer
- Pilot interview 3, a woman caring for her father with dementia
- Pilot interview 4, a mother caring for her child with profound physical disability
- Pilot interview 5, a mother caring for her adult child with cerebral palsy

A total of five pilot interviews was conducted (three before the intensive interview training). This training was recommended in light of my inexperience in conducting interviews. Short interviews were conducted with twelve University staff members. Permission to the digital file of the interview was given by every staff member. All of the practice interviews focused on the same topic: the interviewee's work and their working role. These interviews lasted between ten minutes and an hour, depending on the time available. I subsequently transcribed every interview, and evaluated my

performance in the role of interviewer. This increased my confidence in the application of multiple interviewing skills, while practice transcriptions improved my English. After two weeks training, I conducted two further interviews.

The findings of the pilot interviews helped to refine the interview guide in terms of clarity, content, and length. The differences of approach involved in interviewing two contrasting groups of participants were identified, enabling a more focused preparation for the main study. The early interview guide was also developed and modified in light of a review of relevant literature.

In the main study, participants were asked to talk broadly about their caregiving experiences, including both positive and negative aspects. The first question in the Phase 1 interview was, ‘As you know, I’m interested in your experience of being a carer. First, can you tell me who are you looking after? Could you tell me more about that?’ The Phase 2 and 3 interviews opened with the question, ‘How have things been since we last met?’ Subsequent questions and interviews were developed and/or modified on the basis of previous interviews, and in response to ongoing analysis of data. At the conclusion of every interview, I asked all participants ‘Is there anything else you want to add or talk about?’ providing each participant with the opportunity to make further spontaneous contributions. The three-phase interview guide can be seen in Appendix 3.

### **3.6.1.2 The development of serial interview guides**

A semi-structured interview guide was used in the initial stage of data collection. This ensured appropriate coverage of all relevant topics in the course of the interview. The transcript was analysed before the next interview, in accordance with the constant comparative method of analysis. Subsequent interview guides developed from the data analysis. A series of interviews was developed by means of interviewing the same participants on three occasions. In preparation for conducting follow-up interviews, I listened to digital files of previous interviews many times, and reviewed transcripts, field notes, memos and any other relevant information in order to refresh my memory and develop subsequent interview guides. This procedure enhanced my

sensitivity during subsequent interviews, demonstrating respect for participants by accurate recollection of their earlier responses. Probing and classifying questions were considered necessary in all cases, and followed issues previously raised by the interviewee. The issue of 'the perception of personhood', for example, was raised and developed in the three phase interviews with Mr. Brown. At the Phase 1 interview, he discussed his view of personhood:

"I feel, you know, upset, really, that she's not the person that she was. She was such a loving, caring, eh, person and now she's... she's... she doesn't have that side to her now, she's just a different person in a sense." (Mr. Brown, Phase 1, p.7)

I asked Mr. Brown to expand on this topic in the Phase 2 interview - had his perspective changed over time?

Researcher: "According to what you said last time, 'in a sense the person you married is not there any longer'. Could you explain that further?"

Mr. Brown: "I can see that she's not the same person, she doesn't... and obviously she can't do things that she used to do." (Mr. Brown, Phase 2, p.8-9)

Mr. Brown clarified his feelings on this issue still further in Phase 3:

Researcher: "But you were saying last time, you say to me, 'she's not the same person I married... Like she isn't the same person I loved'. What does that mean?"

Mr. Brown: "What does it mean? Um... She's the person that I loved, but she's not the same person. She can't respond in the same way about the children or about me or about or... anything really. She can't actively make conversation. You know, she can't respond in any way" (Mr. Brown, Phase 3, p.2-3)

The above examples demonstrate the typical pattern of inquiry into, and subsequent development of, issues, which was employed for each participant across all phases of the interview process.

One of the participants, however, was interviewed quite differently from others. In this instance the participant was caring for her husband, who had lived with dementia, for ten years. Her husband dramatically deteriorated and moved into a nursing home



before the Phase 2 interview. He died six months later. The flexible semi-structured interview guide allowed the participant to talk about whatever she wanted to talk about – an appropriate consideration, since she was in the grieving process – at the same time ensuring that all research topics was covered.

### **3.6.2 Field notes**

The ‘field’ is described by Atkinson (1992, p.5) as

“...something we construct both through the practical transactions and activities of data collection and through the literary activities of writing field notes, analytic memoranda and the like”.

Field notes are often used in conducting ethnographic observation studies. Note-taking is, however, being increasingly applied to other kinds of qualitative research such as the grounded theory approach. Montgomery and Bailey (2007) suggest that descriptive and interpretative field notes enhance the quality of understanding of the participants’ experiences. Patton (1990) further suggests that there are at least two purposes in taking notes in the tape-recording interview situation; doing so helps the researcher formulate new questions (following the participant’s train of thought), and also helps in later analysis. Taking field notes confirms understanding of the phenomenological situation under investigation, constructs a ‘trail’ assisting recollection of interview responses, and provides the researcher with an opportunity to append supplementary information and observations towards a clearer understanding of the field.

There are two strategies for writing field notes: the salience hierarchy and comprehensive note-taking (Wolfinger, 2002) – the former comprising the simpler approach. According to Spradley (1980), nine elements should be covered: space, actor, activity, objective, act, event, time, goal, and feeling. Clues about the intent behind statements, and comments on aspects of non-verbal communication should also be included (Denscombe, 2007).

Field notes can be influenced by researcher bias, particularly with regard to the interpretation of issues under discussion. For this reason, reflexive notes are also valuable for inclusion. The recording of field notes was undertaken at different times in the current study, such as after interview, during data analysis, and data coding – creating a foundation for the later development of an analysis. Patton (1990) suggests that field notes offer a context for the description of the setting, though a combination of what is said, and the researcher’s own feelings, reactions, and reflections.

In the current study, face-to-face interviews were supplemented by observations on the context and setting, plus a record of any relevant informal communication after the digital recorder was switched off. Field notes consisted of key words and themes, as well as records of participants’ facial expressions, gestures, and particular reactions and comments in the course of interview and self-reflection, which were written in the first person. For example:

Field notes for Mrs. Murray (Phase 2) 19/09/2005

When I ask her about the quality of support she has received, I say, “How did you get on with your General Practitioner (GP)?” she answers, “brilliant”. After a few seconds, however, when I ask her, “in what ways...?” she can not say anything, or give any further details, which suggests initial responses, like ‘brilliant’ may be somewhat of ‘an automatic reflection’.

Field notes for Mrs. Young (Phase 2) 20/10/2005

Mrs. Young has sore back and lies on the floor during the interview. As I want to keep eye-contact with her I decide to sit on the floor with her. When we discuss her health, she responds by describing it as “good”. I question this response, pointing out that she is lying on the floor. She laughs, and tells me “I have a bad back”. Interestingly, if I make no further mention of this fact, she seems to forget it.

Somewhat surprisingly, unsolicited documents were provided by the first participant (Mr. Brown, a husband who cared for his wife with dementia). These unsolicited documents were in two parts, one referring to a record of the progress of his wife’s disease. He offered them as a contribution to the history of her illness and medical treatment. The second document was a presentation handout entitled ‘The Family’ written when he was a member of a carers’ association.

### **3.6.3 Phases of data collection**

The main study was planned in three phases over eighteen months (each phase to be separated by a six-month interval). These intervals were based on the nature of the study (Polit and Beck 2004). Maternity leave interrupted the research process for six months. In light of this, all the participants agreed to postpone the Phase 3 interview for a year after the Phase 2 interview. I contacted all participants by letter as soon as I started the Phase 3 planning. This extra time added the strength to the longitudinal nature of this work.

A three phase structure was preferred to a two phase option, since the latter approach is restricted in that it can only demonstrate average change, ignores patterns of intra-individual change, and fails to capture the nature of change (Gaugler *et al.*, 2000). The matter of timescales was decided on a pragmatic basis; there was a need to analyse the issues thrown up by research over time, but since the nature or causes of intervening change could not be predicted, the precise length of appropriate time intervals seemed almost immaterial. Ultimately, a general interval of six months was deemed sufficient to allow for transcription and analysis prior to follow-up interviews.

### **3.7 Data management**

The NVivo software, a computer assisted qualitative data analysis package, was used. The benefits of using NVivo lay in establishing and maintaining the database for an efficient tracking of the analysis process. The software rendered interview transcripts, field notes, memos and other relevant documentation manageable by different categorisations, attributes, sets and cases. There were certain disadvantages encountered in the use of this software; it was more time-consuming than some other systems, and there was a danger of losing ideas in the independent coding procedures. To counter these shortcomings, manual analysis of ‘cutting and pasting’ was also applied in developing several drafts of theory.

### **3.8 Constant comparative analysis**

Constant comparative analysis was carried out. This is an essential element in the development of grounded theory (Hutchinson, 1993). While collecting data I also analysed it, developing and assigning particular categories simultaneously. In other words, data were analysed continuously during the process of the study. This process proved influential in deciding the tenor of subsequent interviews and at the same time facilitated the development of a fuller understanding regarding the relevance and likely direction of findings. The main purpose of data analysis in grounded theory is to reduce raw data into concepts or categories (Chenitz and Swanson, 1986). The constant comparative method of analysis includes coding, memos, and diagrams.

Four criteria are used to evaluate the development of grounded theory. These are; fit, work, relevance, and modifiability of concepts (Glaser and Strauss, 1967; Glaser, 1978). These criteria are concerned with the idea that collected data must fit the categories generated; theory must be practicable and readily acceptable to others to explain the phenomenon and relate to the research setting; and theory should be open to modification in the light of new information. This has the benefit of bringing a well defined structure to the analysis of transcripts, field notes and memos, as well as interweaving the analysis with the literature review.

#### **3.8.1 Levels of coding**

Coding is a first step in analysing data. It may be described as “the analytic process through which data is fractured, conceptualized, and integrated to form theory” (Strauss and Corbin, 1998, p.3). There are three levels of coding: open, axial, and selective (Strauss and Corbin, 1998). Open coding, consists in reading the raw data from the transcripts and field notes, keeping memos, and identifying, naming and categorising these in terms of their properties and dimensions. According to Strauss and Corbin (1998, p.101),

“Categories are the concepts that stand for phenomena; properties are characteristics of a category, the delineation of which defines and

gives it meaning; and dimensions are the range along which general properties of a category vary, giving specification to a category and variation to the theory”.

Line-by-line analysis was used during this stage. These properties and dimensions were then subjected to axial coding by which data was fixed data in categories. The properties are components of a category. Finally, these categories were selectively coded by integrating the concepts around a core category. The core category is the foundational concept for generating a theory (Strauss and Corbin, 1990; Streubert and Carpenter, 1999; Backman and Kyngas, 1999) which explains the basic social process of the phenomenon (Glaser, 1992), for example, what “this research is all about” (Strauss and Corbin, 1998, p.146). There are several essential characteristics of a core category: it must occur frequently in the data, it must accrete through the linking of various data, and it should explain variations in the data, permitting correspondent variation of analysis (Strauss, 1987).

Constant comparative analysis was used across all interviews, phases, cases and groups. Because of the longitudinal design of the study, analysis was conducted in complicated matrices, admitting comparison both within and across phases. Cases evolved in three phase interviews were compared repeatedly with other cases, while at the same time the two sets of groups were compared and contrasted. Every initial finding contributed to the development of subsequent interview guidelines. Growing evidence of various dimensions and properties of categories was sought and identified in the diversity of examples. Negative examples facilitated the confirmation and development of ‘thick’ categories.

As the coding moved through the various levels, memos were generated. This means that there are “written records of analysis” and diagrams as “visual devices that depict the relationships among concepts” (Strauss and Corbin, 1998, p.217). Writing memos helped me keep track of insights, thoughts, perceptions, and analytical ideas during data collection and analysis. Memos also helped in the development of categories into core categories, and ultimately theory. This practice is in accordance with recommendations made by Strauss (1987) and Denzin and Lincoln (2000), who point out that memo writing should be started at the beginning of data collection and analysis to link analytic interpretation with empirical reality. Memos were

additionally used to reflect on ideas, and to define and refine ideas and processes further. These stages in the process of coding analysis were useful in guiding me, as a novice researcher, in step-by-step analysis of data. At the same time I remained aware that the coding process does not yield a strict procedural flow, but is merely a guideline enabling assimilation and depiction of the general research field.

For example:

Memos for sorting thoughts (02/02/2006)

As categories emerged, various properties and dimensions were identified. Initially, the categories of Responsibility and Duty were viewed as identical. However, it became clear that Responsibility and Duty may be viewed as distinct but related concepts. As data analysis proceeds, the notion of Responsibility becomes more specifically connected with behaviour - orientation, Duty with moral obligation.

As a matter of course, I analysed data manually at the outset of each interview. At the conclusion of the Phase 1 interviews I developed life histories for each participant (see Chapter 4), which was further developed at the conclusion of Phases 2 and 3. Initial codes were derived from reviewing each transcript line by line and recording in the margin of the transcripts words and phrases that captured the meaning of the sentence or paragraph in the memos. Every transcript was read at least five times and individually analysed at least three times (this figure excludes case analyses and phase analyses throughout the study). Additionally, academic supervision meetings were set up at least one a month to evaluate and to reflect on the work.

### **3.8.2 The saturation of categories**

Theoretical saturation refers to a general rule in grounded theory, which is that data collection should continue until all the categories have been saturated with data (Strauss and Corbin, 1990; Bryman, 2001). Strauss and Corbin (1998, p.212) defined theoretical saturation as a state in which

“...(a) no new or relevant data seems to be emerging regarding a category, (b) the category is well developed in terms of its properties and dimensions demonstrating variation, and (c) the relationships among categories are well established and validated”.

Morse (1995) suggests the critique of saturation as ‘data adequacy’ and holds that it is independent of the sample size. The data should adequately focus on density, richness and integration in the categories.

However, there are problematic issues regarding the concept of saturation: by what criterion may researchers decide whether their procedures have explored all properties and dimensions of the category? In my own research, thirteen carers were chosen - six carers of spouses with dementia and seven carers of adolescents with ID. After the Phase 1 interview, initial categories emerged, but I found it was difficult to judge whether or not there would be any relevant new information from further interviews, suspecting that different participants might have different attitudes or views on their experiences. It seemed to me that subsequent interviews might well give rise to additional different dimensions, properties, and perhaps categories. This possibility seemed so real that the notion of calling a halt to the data-collection process quite frightened me – particularly in light of the limitations on time. Ultimately I decided to conclude data-collection after thirteen interviews in Phase 1, because in the last two interviews no new data emerged relevant to the categories identified. The longitudinal design enabled me to revisit participants, and to clarify their statements and explore any changes over time. Constant comparative analysis facilitated the development and confirmation of multi-levelled properties and dimensions within each identified category.

### **3.9 Sample**

The participants for this study were family carers who looked after either an elderly relative with dementia, or an adolescent with ID. The process of selecting participants proved difficult in consequence of their being, in some sense, hidden within the community. Since the work was qualitative in nature, purposive, as opposed to random, sampling seemed most appropriate, enabling the identification of participants whose experiences and demographic characteristics seemed most in accord with the overall aim of the study. A few carers’ organisations were approached as potential sources of participants (Appendix 4).

### **3.9.1 Sampling strategy**

Polit and Beck (2004) describe purposive sampling as involving participants who are deliberately selected on the assumption that they will yield data relevant to the research question set. However, on further reflection, and in response to communications with the carers' organisations I approached to obtain the sample, it became evident that I would have limited control over the nature of volunteers for the study. In accordance with the Data Protection Act 1998, the organisations made it clear that they would do no more than approach their members, leaving it up to potential participants to contact me independently. This meant I was faced with the possibility that the respondents might not satisfy the research criteria.

Theoretical sampling refers to "... sampling on the basis of concepts that have proven theoretical relevance to the evolving theory" (Strauss and Corbin, 1990, p.176). In other words, sampling contributes to the refinement of ideas, the identification of conceptual boundaries, and delineation of categories (Morse, 1995; Denzin and Lincoln, 2000). Theoretical sampling aims to maximise opportunities for the comparison of events and phenomena (Strauss and Corbin, 1998). This form of sampling presupposes that data is collected and analysed simultaneously after each interview, and that the findings of previous interviews influence forthcoming interviews. As such, the fundamental rationale of theoretical sampling is the location and identification of varying dimensions within populations, events, activities, and cultures. Consequently, sampling is not predetermined, but is directed by the emerging theory.

Sampling for the current study was not theoretical in a 'pure' sense, since it depended on participants voluntarily taking part. In other words, the sample of participants was random, within preconceived parameters formulated in relation to the purposes of the study; a phone call was made by the carers' organisations for family carers, either of relatives with dementia, or adolescents with ID, but beyond those parameters, no control over the nature of the respondents was possible. In consequence of this factor, application of the principle of theoretical sampling was expedient, inasmuch as it was



necessary to look for different dimensions, degrees and levels of data within the sample so assembled.

### **3.9.2 Sample size**

There are no guidelines as to how many participants are sufficient in a study of this nature (Patton, 1990). The question is a subject of debate amongst qualitative researchers (Sandelowski, 1995). In such research, it is clearly important that the researcher secures data sufficient to the emerging categories, and to ensure their saturation (Morse, 1995). This approach aims to guarantee a significant depth of knowledge within a natural (as opposed to experimental) setting. It should be noted, however, that sample size alone does not guarantee data sufficiency or the saturation of emergent categories; these requirements are also crucially affected by the projected number of interviews, and the constancy and thoroughness of observation.

Sandelowski (1995) seems to agree with this notion, suggesting that an adequate sample size in qualitative research is related to the depth and truth of the information collected. According to Chenitz and Swanson (1986), between twenty and fifty interviews are necessary to elicit major and repetitive themes in the topic being investigated. Morse (1995) recommends between thirty and fifty interviews for grounded theory studies. Lincoln and Guba (1985) suggest a sample size of between twelve and twenty participants, adding that researcher assessment of the appropriate number of interviews should be based on the interview process reaching a 'point of diminishing returns' – for example, sufficient interviews have been conducted when the researcher judges that no new relevant information is being obtained.

It also should be noted that the attainment of rich and meaningful information is an intense and time consuming exercise. In the current study, this requirement could only be satisfied by dint of several in-depth interviews. For the purposes of this study it was planned to recruit a minimum of six participants to each group of carers (Group 1, carers of older people with dementia and Group 2, carers of adolescents with ID), with participants being interviewed three times over eighteen months.

Among the younger group, an age range between eleven and eighteen years was chosen for the cared-for adolescents. This range was chosen with the understanding that the individuals in question would be dependent for the whole of their lives. The years of adolescence were selected with the intention of investigating the specific problems inherent in caring for young people who are almost, or in fact, as large as adults – a factor with implications concerning the level and degree of physical assistance required in moving and handling, as well as the levels of dependence in life activities. Concerns regarding transition from children’s services to adult services could also be specifically considered and explored within this sub-sample.

The criteria for selecting participants are shown below.

Group 1: Inclusion criteria for carers of people with dementia:

- The carer is the spouse looking after a person who is sixty years or over, and who has received a diagnosis of dementia.
- The carer is the primary source of help in his or her relative’s activities of everyday living.
- The carer is a native English speaker, and is able to understand and sign the Consent Form.
- The carer lives in the Edinburgh area.

All participants were recruited from within two carers’ organisations, and included six co-habiting married couples. There were three wives and three husbands. The age of the persons with dementia ranged from sixty-four to seventy-seven years (mean age 69.17) and the age of the carers from sixty-four to seventy-two (mean age 68.67) years. The length of caring period varied between six and ten years subsequent to formal medical diagnosis.

Group 2: Inclusion criteria for carers of adolescents with ID:

- The carer is the mother looking after an adolescent with ID who is between 11-18 years of age.
- The carer is the primary source of help with his or her relative’s activities of everyday living.

- The carer is a native English speaker, and is able to sign the Consent Form.
- The carer lives in the Edinburgh area.

Exclusion criteria for carers of adolescents with ID:

- The carer is excluded if his or her relative has physical disabilities only.

Seven mothers were recruited from a carers' organisation. One of them dropped out at the Phase 2 interview stage this was because no further contact could be made. However, the Phase 1 data from this interview set was retained for analysis and inclusion. The mothers' ages ranged between thirty-six and fifty years (mean age 42.71). The sample included one adoptive mother who assumed parenthood of her son when he was a few months old. The age of the adolescents ranged from eleven to seventeen years (mean age 13.86). Most mothers were married and lived with their husbands. One divorced mother co-habited with a common-law partner. One mother had two children with special needs (aged nine-and-a-half and fourteen). The majority of the interview focused on her fourteen-year-old daughter, who has ID.

### **3.10 Ethical considerations**

When undertaking qualitative research it is vital to spend time reflecting on the ethical issues involved in the research process. Polit and Hungler (1999, p.149) state, "...research that involves human beings requires a careful consideration of the procedures to be used to protect their rights". Talbot (1995) suggests there are three major ethical principles to be considered: beneficence, respect for human dignity, and justice. Beneficence refers to the notion that the benefits to be gained from participating in a research study should outweigh the risks. In accordance with this, although the participants were receiving no treatment, they were given opportunities to discuss with a knowledgeable outsider issues that were causing them concern. I remained sympathetic, and aware of the sensitive nature of some of the data which was revealed, and of the potentially distressing topics that were addressed. Planning was undertaken in conjunction with the carers' organisations concerning what

measures might be taken in the event that a participant should become overtly distressed at any point in the interview process.

Respect for human dignity refers to the importance of taking individuals seriously, particularly valuing their right of self-determination. Every measure was taken to ensure that participants had the freedom to control their own activities, including the voluntary nature of their participation in the study. Each participant was sent an Information Sheet (Appendix 5) and a Consent Form (Appendix 6). At the start of the initial interview, I made sure that the requirements of the study were understood and that the Consent Form had been signed. The opportunity of access to an independent advisor (an expert in the field who was not involved in the study team) was emphasised in the Information Sheet. In the process of planning subsequent interviews, I sought verification that each participant was willing to continue. Consent was requested of every participant, and further oral permission was secured at the outset of the Phase 2 and 3 interviews. In accordance with the belief that each individual's contribution was vital, whatever the respondent said in the course of interview was accepted at face value. All data were used, unless there was some clear indication that it was in some way invalid, (for example, if the respondent became obviously confused). In such cases, after discussion with the supervisory team, I contacted the carers' organisation. Participants were at liberty to withdraw at any time or refuse to allow particular data to be included.

Justice refers to the importance of treating all participants as equal, and honouring the rights of each individual. The right to privacy was guaranteed by maintaining anonymity by given all participants and their relatives pseudonyms. Confidentiality was assured by confirming to each participant that any information gathered was kept in a locked cupboard, and that no one had access to the names or addresses of the individuals involved in the study. Any data given, in the form of transcripts, was available to the supervisory team and the purpose of the thesis, and the interview digital files will be destroyed 5 years after completion of this study.

These ethical issues were considered and ethical approval was granted by the Faculty of Health, Life and Social Sciences Research Ethics and Governance Committee

Napier University (Appendix 7). Access to this permission was available to anyone connected with the project.

### **3.10.1 Access**

Approaches were made to five Carers' Organisations: Alzheimer Scotland, Profound and Multiple Learning Disability Network Scotland (PAMIS), Crossroads, Capability Scotland, and Down's Syndrome Scotland Association. Letters were written and followed up by email messages to the appropriate members of these bodies, requesting access to participants. The organisations would only permit approaches to come through them, leaving the matter of voluntary participation to the potential participants. The managers within the organisations sent out an Information Package which included Information Sheets and Consent Forms and pre-paid envelopes to potential participants. Interested participants completed and returned the Consent Form along with their contact details and arrangements were then made to meet.

### **3.11 Trustworthiness**

Rigour is an important consideration in research, referring to its reliability, validity, and generalisability (often referred to as 'the positivist trinity') – qualities deriving in openness, scrupulousness, philosophical coherence and thoroughness (Burns and Grove, 2005). Kvale (1996) suggests that there is no reason why qualitative data should not be assessed in such terms. If the qualitative researcher is to subject his or her work to scrutiny, notions such as reliability, validity, and generalisability must be conceived anew, in such a way that they can be applied to the authenticity of data regarding the dynamic issues of social interaction in the everyday human sphere of experience. In other words, the researcher must strive for reliability of observation, interview, and transcription, and coherence in generalisations made from one case to another.

Lincoln and Guba (1985) summarise this endeavour under the heading of trustworthiness – a virtue demonstrated by the researcher's attention to, and

confirmation of, information in qualitative research (Streubert and Carpenter, 1999). Lincoln and Guba (1985) state that the pursuit of trustworthiness obliges the researcher both in assessing and evaluating data, and considering the overall integrity and appropriateness of the qualitative approach to the phenomenon under investigation. They define four key aspects within this general concept: credibility, transferability, dependability, and confirmability (Lincoln and Guba, 1985; Sandelowski, 1986; Polit and Beck, 2004). Chiovitti and Piran (2003) have further modified the concept with specific regard to the procedures of grounded theory, identifying three prerequisites: credibility (true value), auditability (gauged through assessment of research process), and fittingness (assured in consultation with the supervisory team). Within the current study, these goals were pursued through repeated interactions with respondents, regular discussion with the supervisory team, and personal reflection. In addition, emerging themes and ideas were shared with each participant at the second and third interview as a means of ensuring clarity and validity. Silverman (1998) suggests that transcripts of audiotapes further contribute to the reliability qualitative research, while Lincoln and Guba (1985) and Lamb and Huttlinger (1989) confirm the usefulness of keeping a reflexive journal. Ultimately, the trustworthiness of this study will be in how believable the data and presentation is to those who read it.

### **3.12 Limitations**

There were two limitations to this study, one of them pragmatic, the other theoretical. The sample size was limited because the nature of qualitative research requires in-depth exploration and understanding of the phenomenon rather than quantification of statistics. Although my study time was extended by six months, which allowed the longitudinal nature of the work to be strengthened, it remains true that the investigation of both groups' experiences need to be looked at over a number of years. It was considered that, within these parameters, there was sufficient opportunity to observe and record changes in the caring experience. Despite the fact that I set out with limited experience of this sort of research, I am satisfied that, with the support of the supervisory team, sufficient appropriate measures were taken to ensure the

trustworthiness of the work – the use of pilot interviews, for instance, as a form of training in necessary interview skills.

### **3.13 Summary**

In this chapter I have identified the most appropriate research designs and methods to answer the research questions proposed for the current study. Other approaches were carefully considered, and the rationale for the selected approach approved on this basis. Naturalistic inquiry presents the lives and perspectives of participants through investigation and understanding of their social world – an endeavour requiring qualities of sympathy and meticulous observation in the researcher, as well as equal attention to the responses and sentiments of every participant. Qualitative research was selected as most suited to an exploration of individual experience in the social world. Grounded theory was chosen for its suitability in generating new perspectives from familiar phenomena. Longitudinal design was applied in order to investigate the nature and degree of changes over time.

The semi-structured interview was considered sufficiently flexible to allow the natural development of each participant's story. Purposive sampling was adapted to the practical limitations the researcher encountered in assembling the two groups of participants - thirteen participants being recruited from relevant carers' organisations. The sample included six spouses of partners with dementia and seven mothers of adolescents with ID. Data were collected by means of digital files of interviews, verbatim transcripts, field notes, memos and a reflective journal all of which were put into the context of existing literature which were also seen as being another source of data. Data analysis was conducted in accordance with the procedures of constant comparative analysis - through open, axial and selective coding - commenced at the outset of the study and continued throughout as an ongoing process. Regular supervisory meetings took place (at least once a month), establishing an audit trail in order to maintain the quality of research.

Categories, properties, and dimensions of caring experience were identified - categories as concepts of phenomena, properties as category types, and dimensions as

the range of variations within categories. In this way properties and dimensions were established as a means of enriching categories. A core category was identified by the recurrence and linking of key concepts and phenomena, providing the central aspect of the developing research story, and a foundational concept for the generation of theory (Strauss and Corbin, 1998). In accordance with recommendations proposed by Strauss and Corbin (1998) for the grounded theory approach, literature is presented as an element of data, and findings are interwoven with discussion.



## **CHAPTER 4 LIFE HISTORIES**

### **4. Introduction**

The following brief life histories help us to understand the circumstances pertaining to the participants and their experiences of caring. Each life history comprises an account of the age, home and family background and working status, together with a description of any significant life events. All names have been changed to protect confidentiality and all recognisable place names have been omitted. All ages are calculated and stated as at first interview in 2004.

### **4.1 Life histories of carers of older people**

#### **4.1.1 Mr. Brown**

Mr. Andrew Brown, aged 72, is the younger of two brothers. His father and brother both died of heart attacks around the age of 50. He has been married to Anne since 1956. They live in a large terraced house away from the city centre. They have four daughters - all married - and one son. The son is the second child; he has DS and stays independently in a satellite flat. In the early stages of their family life the couple devoted much of their time to caring for him, ensuring he received a good level of support from the formal services. Beyond the immediate concerns of caring at home, Mr. Brown has also been active in a range voluntary work, prompted by the experience of coping with his son's condition, and by his desire to improve the services available to others with similar difficulties and needs. Mr. Brown is well educated with a Law degree. He retired in 1992. Anne formerly worked as a librarian. Andrew and Anne are regular church-goers, and enjoyed playing bowls together. Around 1990, Anne's children noticed that she was becoming forgetful. However, Anne's deterioration did not really hit Andrew until 1995, when she suddenly became incapable of performing the domestic chores she had formerly taken such pride in. The family GP sent Anne to hospital for assessment. She was diagnosed with AD. Andrew's reaction was practical, taking upon himself the entire burden of managing their lives.

#### **4.1.2 Mrs. Miller**

Mrs. Mary Miller is 72. She is one of two children, and is now retired. For the last five years she has devoted her time to caring for her husband, Kevin, who has had dementia since 1999. They live in a semi-detached one-bedroomed house on the outskirts of the city. Mrs. Miller was formerly employed as a secretary, and enjoyed an efficient and organised lifestyle. Her first husband died from cancer when he was 38. Mary, was then only 35 (1968), and was left to bring up their two children, who were 11 and 12 years old when their father died. She married Kevin in 1976. Kevin, a divorcee, was raising three children from his first marriage. Mary had known Kevin for four years before marrying. They have always done everything together. However, they never had a child together. Around 2005, Kevin's health began to deteriorate rapidly. In May of that year, he was admitted to a nursing home, and died six months later.

#### **4.1.3 Mr. Owen**

Mr. John Owen is 66. He was an only child. He has been married to Iris for thirty-two years, and retired in 2002. The couple live in a semi-detached two-bedroomed house close to the city centre. They have two daughters who live in the same city. In 1996 Iris was diagnosed with Vascular Dementia. Since then John has devoted his time to caring for her. The severity of Iris's condition has obliged John to adapt to a whole range of domestic duties he was formerly unaccustomed to – such as cooking, washing and cleaning. He remarks that his expectations of life after retirement have been drastically altered by the necessity of coping with Iris's condition. Since 2006, the severity of her condition has increased. Recently she has been admitted to a formal institution for assessment, and offered a respite package.

#### **4.1.4 Mrs. Baird**

Mrs. Helen Baird is 64, one of four children. She married Neil when she was twenty years old. They live in a two-bedroomed semi-detached council house outside the city centre. They have three children - two daughters and one son. Most of the family live locally and they are often in contact with one other. Since 1997 Helen has cared for Neil who was diagnosed with AD. Helen retired in 1999. Her husband used to work all around the world as a welder. She raised their children alone which helped her to develop independent characteristics, enabling her to manage the home and attend to the full range of domestic tasks, including gardening and decorating the house, as well as overseeing the family finances. From the age of twenty Neil was a heavy drinker – a habit which worsened after he and Helen married. There were many family arguments in relation to his alcohol abuse, but he found it impossible to stop. Ironically, it was only with the onset of AD that his drinking ceased. Neil's mental faculties have deteriorated gradually. Currently, he is physically healthy, but increasingly forgetful, and has been incontinent since 2002.

#### **4.1.5 Mrs. Hope**

Mrs. Nancy Hope, a retired auxiliary nurse of 67, is the youngest of a family of three, and has two elder brothers. She and her husband, Mark, have been married for nearly fifty years. They live in a two-bedroomed flat in the city centre. They have two sons who are 41 and 39 years old. Nancy worked for nearly thirty years at the NHS Trust Hospital. For most of that time she did duty as a night staff nurse two nights a week. She is consequently very experienced in dealing with those who are confused. However, she confesses that when Mark was diagnosed with AD in 1999, her immediate response was shock, followed by denial. Two years after Mark's diagnosis she retired. Mark currently requires a high level of care and supervision.

#### **4.1.6 Mr. Tobin**

Mr. Jack Tobin, aged 71, is one of three children. His brother and sister died a few years ago. In 1952, Jack married Alison Cartwright. They have four children - two sons and two daughters. They live in a two-bedroomed semi-detached house near the city centre. Jack and Alison are members of the Church of Jesus Christ of Latter Day Saints – a faith they discovered as teenagers - and regularly attend services. In 1995, Alison began to display signs of weakness on the right side of her body, and was diagnosed with Vascular Dementia. As a result of the condition, her writing, speech, and general movement started to deteriorate. She now needs total care – including help with movement, toileting, eating, and bathing. Alison inevitably requires an increasing level of physical assistance. Jack has the benefit of certain facilities, such as a wheelchair and a hoist, and has received formal help from a day centre since 2000. The help he receives enables him to work part-time in researching his family tree.

### **4.2 Life histories of mothers**

#### **4.2.1 Mrs. Gill**

Mrs. Fiona Gill, aged 42, is the only daughter in a family of six. She was born in England, and married Neil in 1985. They have four children. Her parents still live in the south of England. Fiona, Neil and their family currently occupy a large detached house near the city centre. Neil has considerable professional commitments; he works between ten and thirteen hours a day and throughout the twenty years of their marriage has travelled widely. Consequently, the family has moved home many times. Fiona gave up work after the birth of her first child. Two years later, their second child, Alice, was born with DS. She is now seventeen. At the time of her birth the family were based abroad and received considerable support from the community and nursery. They moved back to Scotland when Alice was two and half years old. By this time it was apparent that the level of care Alice required would make it impossible for Fiona to return to work. Alice received her early education in a

mainstream primary school. She was then moved to a special secondary school, and is currently studying at college. Because the family have moved around so much they have few friends and relatives living locally. As a result of this Fiona has had to care for Alice with little aid or support from others. Neil's work commitments inevitably restrict the level of physical support he is able to offer.

#### **4.2.2 Mrs. Murray**

Mrs. Jenny Murray is 47. She married Fred when she was twenty-five, but divorced 10 years ago. At thirty-three Jenny gave birth to her first child, Lisa, and four years later to a son, Tom. Both children need special care; Lisa was diagnosed as DS when she was born, and Tom was diagnosed as being autistic at the age of three. Jenny, Lisa and Tom currently live in a detached three-bedroomed house outside the city centre. Fred left when Lisa was five, because he felt he could no longer cope with the caring situation. Jenny admits that, as a single parent, she found the burden of care very difficult and was frequently depressed and tearful. The situation was alleviated somewhat by the help and support she received from her parents, and by the availability of respite care, which started when Lisa was five. Since 2003, Jenny, Lisa and Tom have lived with Jenny's new partner, Mark Brown. Jenny says that, although Mark does not offer much in the way of hands-on help, he is a great source of emotional support to her. The children are fond of Mark, and Jenny is appreciative of the fact that he has involved himself willingly in their life.

#### **4.2.3 Mrs. Young**

Mrs. Kate Young is 50, one of three children. She married Kenny when she was twenty-two. They have four healthy children. The family lives in a large four-bedroomed detached house in the town centre. Kate and Kenny describe themselves as a warm-hearted couple. Evidence of this was the decision they took thirteen and a half years ago to adopt Stuart, a baby with DS. Stuart's maternal grandparents were initially reluctant about the idea - Stuart was only a few months old when the suggestion of his adoption was made - but Kate and Kenny argued that it would be

stimulating for him to be part of a large family, and to grow up among similar aged children. After much discussion, Stuart's grandparents agreed to let the adoption go ahead. Stuart, now fourteen, is happily settled in his adoptive family, and is coping well with his studies at a special secondary school. Kenny, who works as a researcher in a local College, provides the family's main income. Kate works part-time as a health specialist - a job she has kept for ten years. She is grateful to her employers and her colleagues for allowing her the flexibility to fit her work in around her commitment to Stuart.

#### **4.2.4 Mrs. Campbell**

Mrs. Maria Campbell is 36 years old, the eldest of four children. She married David at the age of nineteen. David works in the navy. The couple have three children - two daughters and one son. They lived for a while in navy accommodation, but have since purchased a four-bedroomed flat. It is situated in the area in which they have always lived, as Maria and David wish to retain contact with their extended family. Their oldest daughter, Claire, has DS. She is fourteen years old and currently studies in a special secondary school. Because David's work keeps him away from home for much of the time, the main responsibility for caring falls to Maria. Maria was a hairdresser by profession, but the demands of caring mean she was unable to pursue her chosen career. She supplemented the family income for several years by working part-time as a shop assistant. However, she has recently been forced to change jobs, as the grocery shop she worked in has closed down. It was at this time that she and David took the decision to buy their flat - a move financed through a mortgage from the bank. Realising that David's income alone would be insufficient to meet the monthly repayments, Maria took a job as a home care helper, working nights from Monday to Friday. At these times, responsibility for looking after Claire is divided between David, when he is at home, and Maria's parents.

#### **4.2.5 Mrs. Robinson**

Mrs. Joy Robinson is 45 years old, one of three children, and has been married to George for twenty-one years. They have two children, a boy and a girl. Their son, Harry, was diagnosed with DS when he was born. For the three years preceding Harry's birth, the family had lived in abroad, where both Joy and George worked. They moved back to England when Harry was seven. Joy says she was relieved by the move, having missed her home very much. Shortly after their return, George landed a job in Scotland, so the family moved again. They now live in a large detached four-bedroomed town house. Joy formerly worked full-time as a computer engineer, but gave up her job when Harry was born. Part of her reason for doing so, she says, was that she was tired of the job, and no longer wanted to work in the same field. A more important reason, however, was the need she felt to devote herself to the care of her son. She now works on an irregular part-time basis as a book-keeper in a small business - a commitment which involves her being out of the home for only a few hours every week. George's job is extremely demanding – sometimes requiring that he work up to twelve hours a day – so the burden of caring falls largely to Joy. Joy is nonetheless grateful for the emotional support her husband provides. Furthermore, since starting his job in Scotland, George has changed position. It was previously necessary for him to travel extensively, keeping him out of the home for long periods. His work is now more office-based. This means he is better able to share in the hands-on aspects of caring, as well as providing emotional support. Joy is comforted also, by the fact that Harry and his sister, Louise, are close, and is grateful that Louise accepts her brother's condition, and the level of care and attention he requires without complaint.

#### **4.2.6 Mrs. Cameron**

Mrs. Elaine Cameron is 36 years old. She is one of four children, and married her second husband, Ben, ten years ago. Her first husband, Alec, died in a car accident. Elaine has three children from her previous marriage. Since marrying Ben, she has given birth to a further son. All four children live together with Elaine and Ben in a three-bedroomed semi-detached house on the outskirts of the city. The children, says

Elaine, are friendly, and interact well together. Elaine's third child, Emma, was diagnosed at birth with DS. Emma is now eleven years old and preparing to go to a special secondary school. She requires a high level of care, involving regular medical treatment, as well as help with numerous aspects of her daily activities. Emma also displays elements of behavioural disorder, such as exhibitionism, and violence towards others. These aspects of Emma's condition, in particular, have increased Elaine's anxiety concerning her daughter's future. Elaine is a housewife and the income is provided by her husband who works full time as a businessman.

#### **4.2.7 Mrs. Macleod**

Mrs. Ruth Macleod is 43 years old. She is an only child and has been married to Ted for seventeen years. The couple have three children (two boys and a girl). The family lives in a large five-bedroomed detached town-house. Their eldest child, Rose, has DS. She is now thirteen, and attends a special secondary school. Ruth is a committed Christian. Since Rose's birth, she has devoted herself full-time to the care of her children. Ted is the sole provider. His job is extremely demanding. This places the onus of caring for Rose very much on Ruth's shoulders. She is helped in this by her father, who lives nearby, and is an experienced carer himself - having looked after Ruth's mother, who had Multiple Sclerosis, for thirty years.



## **CHAPTER 5 FINDINGS**

### **5. Introduction**

It has been recognised that in order to better understand the experience of home care, it is important to gain the views of carers themselves. This was a dynamic process, involving interviews with two groups of carers specifically chosen in order to compare and highlight the similarities and differences in their experiences, and so arrive at a more complete concept of caring.

Four categories have emerged in the data collected from both groups. These will be presented under separate category headings: My Life Changed, Commitment, Responsibility and Duty, and Support. These four categories have been defined and confirmed over time. Properties and dimensions of these categories will be identified in order to enhance the quality of the findings through the process of constant comparative analysis which included the development and use of theoretical memos. In this chapter, some illustrative examples of how theoretical memos helped in the development of categories and these will be presented figures in each section. It should be noted that, although the categories are presented as being discreet, there are inevitably interrelationships between them. To aid the understanding of these relationships within the categories the content of each of the properties and dimensions which make up the category has been included in the relevant figures. The synthesis of relevant literature and data is modelled after the grounded theory approach established by Strauss and Corbin (1998), whereby reference material is integrated and discussed within the findings. Sources of data collection, such as field notes, memos and a reflective diary are included in order to enrich the presentation of findings.

## 5.1 My Life Changed

The category My Life Changed broadly refers to alterations in the participants' lives subsequent to adopting the role of family carer. The changes discussed involve both negative and positive aspects. My Life Changed includes three properties from both groups: (1) Effects of change, (2) "...with a 16 stone man on my back", (3) Coping strategies. These properties will accordingly be enriched by reflection on a range of dimensions in regard to each.

It is important to confirm at the outset that changes in daily life were perceived by participants in the study as being closely linked to their coping strategies. The significance of this relationship is the connection implied between change and the ability to manage it. For example, one of the mothers, Mrs. Young, explained how the birth of her first child changed her life, referring to this transformation as part of a spiralling process of growth.

"You don't know... when your first baby's born - and I'm sure you must relate to this - the length of time it takes to look after a baby in the first few days, you don't realise how much time it takes, and how little else you can do. And that's something nobody can prepare you for. But then your life develops and your days get slightly easier and you suddenly realise gosh I can sit down and have a coffee. And then you get your baby into much more of a routine. So nobody can actually realise the impact that that wee baby will have on your life and your life forever, but then it's such a growing process isn't it? Because you grow with your baby, you grow and change as your baby grows and changes and demands...the different support that it needs. And you know, your baby starts walking, so therefore, your role has changed hugely because you're then running after it checking that it's safe all the time. It moves on, it learns to hop, skip, jump, go to school, and again your role as a parent then changes all the way along so it's been a very evolving process. And your needs change, and everything in your life is always evolving on a circular basis." (Mrs. Young, Phase 3, p.17)

The process of growth and change, as it is described above, is a reactive process for the first-time mother, unaware of the scale of the impending changes that motherhood and caring will bring. The ongoing reactive nature of this process is further emphasised in her description of the experience as an enduring and, to some extent, an unpredictable cycle. It became clear, however, in her further reflections on this issue,

that a beneficial product of the first-time experiences of childcare was a part of foresight and wisdom, which was subsequently and fruitfully applied in caring for subsequent children. It should be noted that, although Mrs. Young is an adoptive mother, her views in this regard are very much in accord with the other mothers in the study. All expressed the view that having a child brought significant and lasting change into their lives, regardless of whether or not the child has a disability. Mrs. Gill (mother of Alice) summarises this view:

“Your life’s changed by any child, yes. It’s changed. And I... yes, of course it’s changed since I’ve had her, uh-huh.” (Mrs. Gill, Phase 2, p.48)

A different, though clearly related view, expressed by participants in the older group, is represented by the description of caring as a learning process. For the objective onlooker, the pattern of this process is clearly observable. However, it is important to recognise that, for the carers themselves, confronted with unpredictable developments, and the necessity of accommodating to those changes, the experience is entirely ‘new’. The matter of adjusting to change is only with the luxury of hindsight that any learning may be recognised and acknowledged. Mr. Owen (husband of Iris) expresses the reality of this situation very clearly:

“Because you don’t realise you’re doing it. You do... It’s happening so slowly and you’re adapting to it. You adapt to it without realising it and you’re just doing things. You think that’s normal, everybody does and it’s not until you get to maybe the stage before Iris is at now, you know, there’s a problem there but by that time, you’re so far down the road that it’s easier. It’s not like something, somebody being struck down with something like that where you suddenly have to adapt your whole life to it. I’ve been learning this for the past ten years and growing as the, as the disease progresses, so has my caring progress, if you like, and the two are inseparable really.” (Mr. Owen, Phase 3, p.14)

In other words, it is quite possible that in the short term many carers in the situations described by these participants may perceive the changes they experience in a negative light. For example, Mrs. Miller stated that, with the advent of her husband’s dementia, and the unexpected and unpredictable burden this placed upon her, the happiness in her life was replaced by sadness and tears. Many carers, Mrs. Miller among them (see below) expressed the feeling that they were ‘on a treadmill’ - a

description which eloquently expresses the enduring sense of frustration and fatigue consonant with their burden:

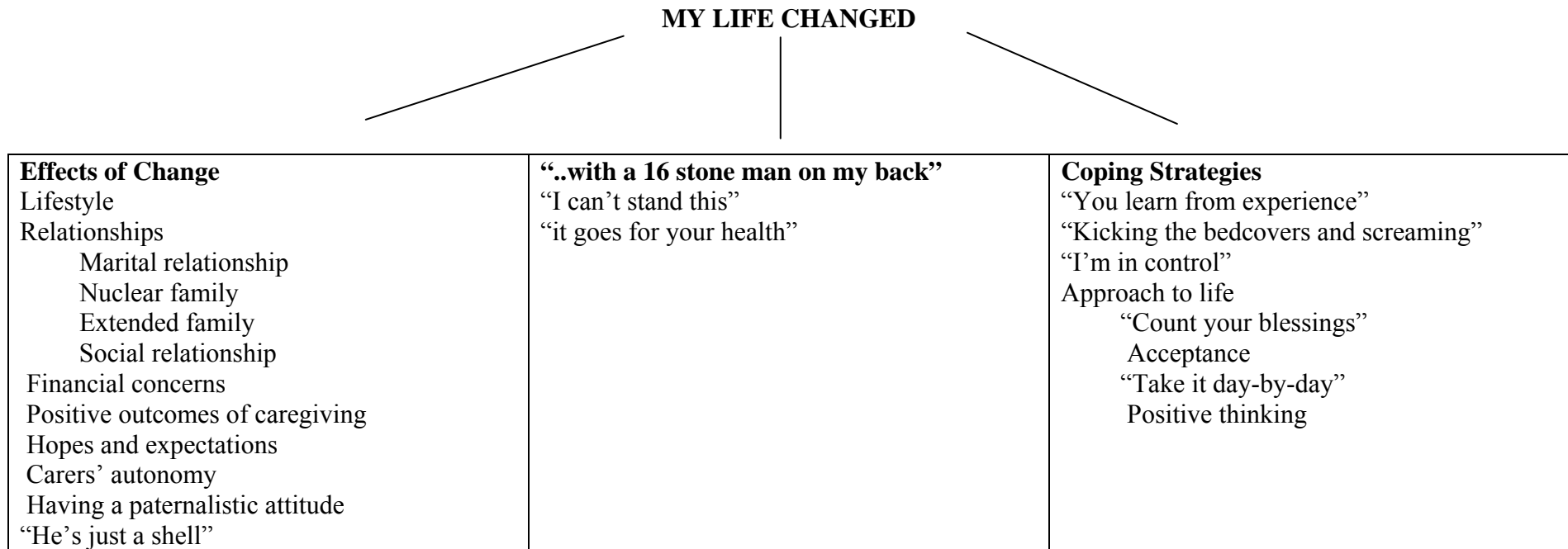
“...like being on a treadmill. It was like a hamster, run, run, run, run. And I mean I’m seventy-two. You can’t go on forever.” (Mrs. Miller, Phase 2, p.13)

Many carers in the older group expressed similarly negative sentiments. Mrs. Hope bleakly suggested that change is “for the worse” (Phase 1, p.64) and that life is “harder” (Phase 3, p.25), Mrs. Owen complained of feeling “stuck” (Phase 1, p.42). Yet even amongst participants in this group, who might be expected to express predominantly negative responses, the pattern is not consistent. Mrs. Baird, for instance, explained her feeling that life improved when she assumed the care of her husband. For her, the new situation was easier, the changes a source of relief, because her husband, Neil, used to work abroad and had for many years been addicted to alcohol, but found he forgot to drink as his dementia took hold. She explained that she quite enjoyed caring for her husband in the early years of his illness, and felt they became a couple again:

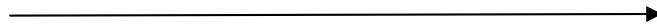
“When he first started, um, I was going out with him, you know, we were going to all these different things for, um, both of us... in that way it was kind of a happy time because for forty years... uh, thirty-odd years before that it was him being away, me bringing the kids up or when he was home he was just drinking. So, you know, it wasnae really a life...” (Mrs. Baird, Phase 1, p.6)

However, previous studies tend to suggest that changes in life are generally aspects of objective caregiver burden (Montgomery, Gonyea and Hooyman, 1985; Lim *et al.*, 1996; Borycki, 2001). The example of Mrs. Baird, although admittedly somewhat exceptional, contradicts the tenor of these findings - suggesting that change may contribute to a new and positive perspective on life change. However, to date there is no further literature to corroborate this finding.

Figure 2: Shows the properties of the core category, My Life Changed



This category starts with the diagnosis of dementia or the birth of a baby with ID



each property develops progressively

### **5.1.1 Effect of change**

The effects of change on participants' lives were many and various. Essentially, the effects of change under discussion are those directly related to, or resulting from, the participants' involvement in care, as opposed to the broader stratum of general and predictable changes from birth to death - parenting, school, marriage etc. The effects of change specific to this discussion will be presented in eight dimensions below.

#### **5.1.1.1 Lifestyle**

Lifestyle effect refers to alteration, enforced by change, in the way people live. These effects impinge upon a range of aspects, from daily routines to hobbies and recreation. Many in the younger group spoke of the alterations childbirth in general brought to their family lives; all admitted that the birth of a child with ID brought changes of an altogether more complex order. Mrs. Gill (mother of Alice), for example, in the excerpt below, explains the varying levels and degree of demand that caring for Alice involves - the necessity, dictated by her daughter's specialised needs, of co-operating with a range of services and professional individuals, and the influence that caring for her exercises on the choices available, for instance, in school and holiday time:

“Um... You have numerous, numerous doctors appointments, hospital appointments and when they go to school you have educational psychologists reports, you have to have carers in classes for them, you have to... work out whether they need special schools or normal schools, mainstream, will they need help with any carers when they move to the next school, you know, will they need help with any carers in the special school. Holidays are completely different because you have, you know there isn't the facilities to send them to after-school clubs so... or holiday play schemes, you can't send your child with a disability to a holiday play scheme whereas you can send a normal child along, can't you? It's totally different, totally different.” (Mrs. Gill, Phase 3, p.17)

What emerges very clearly from this quotation is the degree to which Mrs. Gill's life is dominated by consideration of her child's developmental needs. She clearly expresses her belief that much, which the parents of a 'normal' child might take for

granted in the way of activities for their child, is inaccessible to Alice, obliging her, as the mother and primary carer, to expend time and energy in the consideration of feasible alternatives. In the older group, several carers spoke of expedient practical changes they were obliged to make to the way they conducted their lives. For example, a number of participants mentioned the fact that, while out in public, they found it both necessary and convenient to make use of disabled toilet facilities, primarily as a means of accommodating their spouse's compromised mobility, but also for their own benefit (avoiding the inconvenience of using separate facilities themselves). A further example of such practical change was supplied by Mr. Tobin, who explained that he had developed the habit of feeding his wife her breakfast while she was on the toilet – thus avoiding the complication of having to disrupt her feeding. Mr. Tobin also pointed out that he was obliged to soften the consistency of his wife's food, as a result of her inability to chew. In the excerpt below he expands on this aspect of practical adaptation, describing how, rather than preparing separate meals, he has developed the habit of sharing the same food as his wife:

“Normally breakfast is like a mashed breakfast for me. The other... the other times, you know, I put aside something for Alison on the plate and mash it...because I'm conscious of the fact I don't want to eat mashed up all the time, you know, just for the digestion.” (Mr. Tobin, Phase 1, p.20)

It is worth noting that Mr. Tobin is consciously striking a balance between considerations of convenience, and his own particular tastes - admitting that while he is prepared to eat the same food as his wife, he sometimes finds it unappetising, and feels the need to make an exception.

A study exploring the management of changes imposed by the demands of caring for people with dementia was conducted by Norman *et al.* (2004). Through interviews and observation of twenty informal carers in domestic settings, the study confirmed a general trend of changes to daily routines and practice, and further reported that the reactions of carers and relatives to these changes were almost exclusively negative, resulting in increased levels of anxiety. Findings in the current study differ slightly from this view - identifying some positive reactions to change amongst participants.

Evidence of this has already been cited in the previous section above (see Mrs. Baird, Phase 1, p.6).

A common change experienced by many carers in the older group was the gradual and progressive diminution of adult interaction between themselves and their spouses, to the point where many reported that meaningful communication became impossible and/or exclusively one-way. Mr. Tobin speaks of the lack of any “interchange” (Phase 3, p.6) with his wife Alison, as a result of the fact that her condition has reached a stage where she is entirely unable to react or respond to him. ‘Normal interchange’ is an invaluable means of emotional and intellectual sharing between adults. The situation of being faced with exclusively one-way communication is highly likely to increase levels of stress in carers. A quantitative study conducted by Savundranayagam, Hummert and Montgomery (2005) confirms the link between reduced communication in cases of dementia and increased levels of burden and frustration in carers. However, it should be noted that the correlation identified by the above-mentioned study is perhaps more subtle and complex than might be suspected. Reduction or cessation of meaningful communication between carer and spouse not only leads to exacerbated practical problems for the carer, but may also give rise to a range of negative emotional effects. An example of such an effect may be seen in the quotation from Mr. Brown (below), who explains that the interest he formerly enjoyed in a recreational pursuit (in this case, bowling) has suffered on account of his inability any longer to discuss that interest with his wife:

“...if I do go bowling and I win... say I win the Championship... and I come back and I tell her, she doesn’t [respond]... there’s no interest, she doesn’t... and, I mean, whereas before she was always saying ‘How did you get on?’, and ‘What did you...’ ... in a sense it’s a disappointment in that you expect someone to respond, you know...”  
(Mr. Brown, Phase 1, p.48)

Not surprisingly, the predominant emotion in this excerpt is disappointment, but the example is also important in that it demonstrates how the independence of a family carer may be undermined by the effects of their partner’s condition, practically, emotionally, and psychologically. Mr. Brown’s wife (Anne) lives with AD; the cause of her reduced communicative facility is thus clearly the impairment of her memory. The result is a gradual and irrevocable shift in the balance of communication. Many



carers referred to this shift as an inevitable consequence of their partner's deterioration, explaining that the nature of interchange was so drastically altered they often felt as if they were talking to themselves. Mr. Brown, in the following quotation, expands on the nature of this experience:

“...it's rather a monologue when you're speaking. You don't... I mean, you can't discuss things, you can't say 'Should we do this?', 'Should we do that?', because she won't understand, she just doesn't react. So, all the time that I'm with her, I'm sort of speaking to myself...” (Mr. Brown, Phase 1, p.7)

Frustration and loneliness at the inability to share meaningful communication is frequently compounded by additional related effects. For instance, a number of carers in the older group complained of the way the changes in their partner's condition reduced, or effectively terminated, the possibility of enjoying shared activities - an aspect of their situation which often lead to feelings of loss. However, response to this aspect of the situation is not always exclusively negative; Hellström, Nolan and Lundh's (2005) study of carers of people with dementia, reports that some couples react to the projected pattern of deterioration by making a determined effort to do more together, as a way of maintaining quality of life, and strength in their relationship. On the other hand, it is entirely possible that the necessity of being always together, which is frequently expedient in such caring situations, may have an opposite effect. A quotation from Mrs. Hope (wife of Mark) makes this clear:

“We were going everywhere together, you know, and, well... you know, you're kinda... you were kinda stuck, you know...” (Mrs. Hope, Phase 1, p.5)

“...the worse thing that I find intolerable is he follows me all over the place. If... if... if we're in in the evening and he was sitting watching television, uh... he'll watch television and that, if I go to the toilet, the next thing he's... he's behind me at the toilet, you know?...” (Mrs. Hope, Phase 1, p.19)

Where togetherness should be mutually welcome, sought, appreciated and chosen, it may reinforce quality of life and the strength of the relationship. Where it is imposed - either by circumstances or one person - then this imposition may adversely impact on the relationship and the autonomy or health of the carer. Constant companionship,

for Mrs. Hope, is clearly an oppressive experience - a source of stress and frustration. However, an understanding of the context to these remarks is helpful: Mrs. Hope had previously explained that before Mark's illness the couple enjoyed a degree of independence from each other - having their own friends, doing things separately, and pursuing different interests. The evidence she has provided is therefore important in demonstrating the significance of prior lifestyles and subjective interpretation in defining the specific effects of change upon carers.

### **5.1.1.2 Relationships**

Relationships are inevitably affected by caregiving. The specific nature of effect is inextricably linked with the particular type of relationship under review. It is therefore necessary to analyse change and effect as they pertain to particular relationship-types. For the purposes of clarity, these are divided into four: marital relationship, nuclear family, extended family, and social relationship.

#### **5.1.1.2.i Marital relationship**

Changes in the condition of spouses had a fundamental impact on marital relationships within the older group. A predominant complaint was the loss of emotional closeness. This is consistent with findings reported in a cross-sectional quantitative study conducted by Morris, Morris and Britton (1988) investigating the relationship between marital intimacy and perceived strain in twenty carers of spouses with dementia. The study found a general reduction in marital intimacy. A qualitative study by Ingebretsen and Solem (1997) and quantitative studies by Cuijpers, Hosman and Munnichs (1997) and Townsend and Franks (1997), found emotional closeness between couples was diminished as a consequence of reduced mutual contact and meaningful sharing, connected to the gradual cognitive deterioration of spouses. Meuser and Marwit's (2001) mixed methods study, involving eighty-seven family carers of people with dementia, found that carers experienced a significant loss of companionship. Carers of both genders in the older group of the current study also describe a contiguous reduction in sexual contact. Mr.

Brown (husband of Anne) makes clear reference to this effect in the following quotation:

“And there’s no, shall I say... maybe I shouldn’t say this to you, no physical relationship between us. I mean, I give her a kiss every morning and every night but that’s it, you know? Our more physical loving relationship is nonexistent now. So I miss that...” (Mr. Brown, Phase 1, p.50)

Meston and Buss (2007), confirm that sexual activity is of major importance in sustaining intimacy between couples. It should be noted that the effect of changes with regard to sexual activity on couples within this category is not exclusively reductive. Baikie’s (2002) review concluded that there may be either a reduction or an increase of sexual interest in people with dementia, both of which have important effects on the status of the relationship. It should be pointed out that there is a paucity of studies which focus on this topic. This may be explained by the obvious sensitivity of the issue, and the consequent difficulty of creating reliable research methods for collecting the relevant data. An additional obstacle to the collection of salient data on this matter may be the age-group involved - a group which, for generational and social reasons, may feel inhibited in sharing intimate details of their relationships.

The magnitude of the effects, and the changes they may cause to the dynamic of the marital relationship were discussed by a number of carers of older people. Mrs. Hope, in the excerpt below, gives a vivid example of the alteration she perceives in her relationship with her husband (Mark):

“...I’m just like his mother, and I’ve got to say ‘Right, time to go to bed now’ and I’ll just get him ready and he’ll go to his bed and he’ll get up in the morning and I’ll get him dressed and he’ll go to his club, still goes to his club a couple of days a week. Um... So I am, I am like his mother and I think that’s how it, it turns out in the end, you know...” (Mrs. Hope, Phase 3, p.5)

For Mrs. Hope transformation in the orthodox pattern of married relations is perceived as an alteration to her role with regard to her husband - she becomes less like a wife, and more like a mother. Likewise, a male carer, Mr. Brown expressed a similar perception (i.e. of becoming more like a father). Surprisingly, to date there has been

no study which precisely identifies this change in the nature of relationship patterns. Perhaps the closest related field of investigation is that which features in a study conducted by Wuest, Ericson and Stern (1994), whose focus is the nature of relationship-change for carers of people with AD. The study identifies a dynamic process of estrangement - a more general and severe species of change than the intermediate transformation of the carer's role which is discussed above.

There is a largely predictable impact on marital relationships in the younger group. The effect is different than that described by carers of older people, tending to be dictated by the scale of caring demands faced by the mothers. The ways in which each mother reacts to and copes with those demands inevitably influences their marital relationship. Importantly, the impact of change on marital relationships reported amongst the mothers tends to emphasise psychological aspects, in contrast with the carers of older people who stress both physical and psychological effects. Mrs. Macleod recognised that her marital relationship had changed, largely as a result of time constraints, and the effects of caring on her energy levels, factors affecting both the amount and the quality of time she and her husband were able to spend together. She alludes to these factors in the excerpt below:

“I feel our relationship did change and yes, we did. Having said that, at the moment things are quite difficult for us but then I don't know if that's just because of the age that all the children are....” (Mrs. Macleod, Phase 1, p.8)

This situation was exacerbated by the comparatively low level of support she received in coping with the burden of care. Mrs. Macleod is not the only mother to describe the negative effects of change on marital relationships. Mrs. Murray's situation graphically demonstrates the deleterious effects; she is a single mother, divorced as a direct result of the pressure brought to bear on her relationship by the burden of care. Featherston (1980) suggested that parents of children with disabilities or chronic illness increased the chance of divorce. A study conducted by Hodapp and Krasner (1994) embellishes this statistic, reporting that, not only did families of children with disabilities show higher percentages of divorce, an above-average of the divorce sample also exist within the lower income bracket, and/or are single-parent families (common-law partners eschewing marriage, and eventually separating). However, the

tenor of these findings is contested by a recent quantitative study conducted by Urbano and Hodapp (2007) which found that parents of children with DS ( $n=647$ ) were slightly less likely to divorce than parents of children with other birth defects ( $n=10,283$ ) or parents of children without disabilities ( $n=361,154$ ). The study indicated that this result should be understood within the context of certain additional factors – namely, the maturity of the parents questioned, and their level of education, but it might also suggest that, to a certain extent, those concerns which are exclusively related to the health or otherwise of a marital relationship may perhaps be ‘put to one side’ in favour of the more immediate concern of coping with a child with special needs; the care of a child with special needs may, in some degree, actually unite marriage partners, giving them a reason to relegate concerns about their personal happiness.

Unsurprisingly, a number of participants in the current study described positive responses to the effects of care on their relationships. Several mothers did indeed express the belief that the responsibility of caring had brought them closer to their partners, explaining that the necessity of sharing problems and communicating more regularly has had a beneficial and strengthening effect on their marriages:

“We got stronger. I mean, we were just married but it did, it got... we were a lot closer. And I did... I’ll always remember, I did say to him, ‘If you don’t want this life, with a baby with Down’s syndrome...’, I mean, I knew straight away I was keeping him and there was no doubt about it, I wasn’t letting anybody else have him or anything because the nurses do say ‘Look, there’s other... you can do this, or this, there’s people that can...’ Yeah, things like that. And that really hurt me. But I did say to my husband, ‘Look, if you don’t want this life, bringing up a Down’s syndrome baby, just go now’, and he was like, ‘I can’t believe you said that, I’ll never, ever leave because of that’. So we did... we did... we did, we got a lot stronger.” (Mrs. Campbell, Phase 1, p.19)

The potential for positive impact on the marital relationship is confirmed by the findings of studies conducted by Heiman (2002) and Taanila, Kokkonen and Jarvelin (1996). Heiman (2002) investigated the effects of caring in thirty-two parents of children with disabilities, and found that 61.5% reported strengthened inter-parental relations. Taanila, Kokkonen and Jarvelin (1996) analysed the long-term impact of caring for a child with disability on marital relationships in eighty-nine families

(eighty-eight mothers and seventy-four fathers) using questionnaires and interviews. They identified both negative and positive effects: one fifth of their respondents described a strengthening of their relationship; 7% described a degree of estrangement, (although this did not necessarily result in divorce).

#### **5.1.1.2.ii Nuclear family**

The effects of caring are not restricted to the marital relationship, but may also exercise a great influence on other family members. A number of children with ID manifested behavioural problems. In the following excerpt, Mrs. Macleod from the younger group describes a typical outburst, and the effect it had upon the whole family:

“I was embarrassed on that occasion, because that was something that she had never really... never done it [spat out her food] before. I was really surprised. And of course, her dad was again, he was really angry with her. And ready to take her out and of course, it destroys it for everybody. And usually what happens is we're all quite chatty and the boys are maybe chatting about something, and then she'll start doing this and the whole thing is disrupted.” (Mrs. Macleod, Phase 1, p.14)

It is possible, of course, that the motive behind her daughter's behaviour was to draw attention to herself - perhaps in the only way she felt was liable to succeed - while the rest of the family were chatting and having their supper. Such negative attention-seeking is a common characteristic, particularly amongst children whose communicative abilities are compromised by their condition. Whatever the cause, the example furnishes a clear instance of the negative effect of the caring situation upon the nuclear family - a finding confirmed by Heiman's study (2002).

Behavioural problems are also evident amongst people with dementia; (a typical manifestation is the tendency of the cared-for people to wander). However, contrary, perhaps to expectation, evidence from within the current study shows that the effects of such behaviour upon the carer are not exclusively negative. For example, Mrs. Baird's husband, Neil, at a certain stage of his dementia, developed the habit of singing - not only at home, but in public situations. Mrs. Baird declared that she was

not troubled by this behaviour, but was happy to accept it. Statistically, this finding is somewhat exceptional. A number of studies (Schulz *et al.*, 1995; Shua-Haim *et al.*, 2001; Hooker *et al.*, 2002; Rymer *et al.*, 2002; Croog *et al.*, 2006) identify a range of behavioural excesses, including as aggression, destructiveness, paranoia, hallucination and agitation, which are generally associated with negative impact on the carer.

Many mothers stated that having a child with ID had affected the child's siblings, explaining that the necessity of understanding the limitations and accommodating the needs of the child in question severely restricted the range of activities the family as a whole was able to engage in. Mrs. Macleod, in the following statement, gives a typical example of such a situation:

“...there are some things that we just can't do together, you know um, like we couldn't decide we were going to go... like I really quite like hill walking and things like that and it's just not... we can't do that with Rose. I mean the boys are getting to a stage where, I'm not saying they would do it but probably it would be 'We don't want to do that', you know, but I definitely couldn't do it with Rose, you know.”  
(Mrs. Macleod, Phase 3, p.14)

Interestingly, Mrs. Macleod also made mention of an earlier experience of caring (for her mother, who lived with Multiple Sclerosis). Although, in that case, she was not in the position of primary carer, the experience had clearly impacted on her, influencing the approach she now adopts, as the following excerpt illustrates:

“I really, really try hard to give the boys time as well. Um, I don't know if that...my own background is...I've got...my mum is disabled. She's... she had multiple sclerosis for about thirty years. So a lot of the time when I was at home, you know she had that as well. And kind of... because of that experience and I felt that they were the... completely consumed by the illness and life really revolved around that. So I've been really conscious of just trying to keep a balance.”  
(Mrs. Macleod, Phase 1, p.5)

It is apparent from Mrs. Macleod's words that the effect of involvement in her mother's care has determined her to strike a more equal balance between the needs of her child with ID, and the needs of her other children without ID. Her declared intention is to maintain, as closely as possible, a 'normal' family life. A number of participants from the younger group adopted a contrasting attitude, relying

occasionally upon their normally able children to share in the burden of care, for instance by sitting with their brother or sister who had ID. Of course, this is not an unusual demand in many families. Nonetheless, it is reasonable to suppose that the demands of sitting with a sibling with ID may be somewhat more restrictive than is likely to be the case in more orthodox circumstances. Mrs. Young, for instance, described how her eldest son Luke, eighteen, while generally happy to help out in this way, occasionally grumbled about sitting with his brother Stuart, particularly at certain times of the week. Luke, it seems, found the unavoidable restriction on his time and freedom of choice a source of frustration. Mrs. Young explains her decision to include Luke in the burden of caring, and her response to his reaction, in the quotation below:

“I also think it’s a good thing for Luke to have the responsibility and I think he quite likes the responsibility. He and Stuart get on very well and although it’s restrictive to him for two hours in the week, he does have a lot of freedom for the rest of the week, and I think he sees that. And usually it’s not very often that... I’m trying to think. Occasionally Luke doesn’t like the restrictions, but most of the time he’s quite happy about it.” (Mrs. Young, Phase 1, p.17-18)

It is equally likely, however, that Luke, like many teenagers, has a range of other social interests, whose pursuit is compromised by his commitment to his brother. Luke’s mother seems to sympathise with him to a certain extent, but clearly believes that there is some benefit to him in maintaining this commitment.

As suggested, the perspectives of the two mothers quoted above (Mrs. Macleod and Mrs. Young) may seem to be opposed with regard to the issue of sibling involvement. However, certain militating factors must be taken into account when assessing their differing viewpoints: Mrs. Macleod’s daughter, Rose, who had ID, is also her eldest child. Her siblings are nine and eleven years old and possibly too young, in the judgement of their mother, to share in the burden of her care. In contrast, Stuart, who is fourteen, is the junior sibling in the Young family; it seems reasonable to suppose that his elder siblings should accept a portion of responsibility for his care.

Another more obviously negative effect confronted by siblings of children with ID is their likely exposure to discriminatory attitudes. This may be particularly divisive



when the source of these attitudes is located amongst the siblings' peer groups - even more so if such attitudes originate within the friendship group of the siblings in question. Mrs. Cameron (below) described such a situation:

“Her brothers have had quite a lot of crying... um, when they were in primary schools and things like that uh, they used to get horrible names like, like ‘Mongo’ and ‘Mongolian’ names used years and years ago and uh a few times ma sons have had a lot of fights over people being nasty towards their sister, so um, they’re very defensive towards their sister.” (Mrs. Cameron, Phase 1, p.8)

It is clear from this description that Emma's brothers were deeply affected by these occurrences. It is likely that such experiences may have a long-lasting and negative effect upon the siblings of a child with ID - quite possibly hindering emotional growth, and compromising their ability to form conventional friendships. Baxter (1989) and Malakpa (1993) suggest that people's attitudes toward disability are often negatively influenced by myths, misconceptions and stereotypes, and are frequently manifest in naive and prejudicial reactions to appearance and behaviour. Goffman's (1963) work on stigma suggests a framework for the formation of such attitudes: Goffman defines stigma as the severe and negative consequence of a situation in which an individual displaying deviance from social and behavioural norms is disqualified from social acceptance. It comes as little surprise that the burden of stigma may have a markedly negative effect upon the social and emotional development of both the child with ID and his or her family.

Rossiter and Sharpe (2001) quantitatively integrated twenty-five studies (1972-1999) of the siblings of children with disability, and suggested that the effects experienced by siblings were predominantly negative. These effects included impairment to psychological well-being and self concept, difficulties connected with physical involvement, and a tendency towards social isolation. However, certain methodological limitations within the body of studies assessed should be noted - most importantly: small sample size, self-reported measures, and parental survey. Nonetheless, the general tenor of Rossiter and Sharpe's findings regarding the negative potential of sibling involvement are of value. This is confirmed by the evidence of other researchers, who have reported additional contributory factors to these negative effects: Shulman (1988) identifies the incidence of reduced interaction

between siblings and parents, and maternal partiality; Bischoff and Tingstrom (1991) and Williams, Lorenzo and Borja (1993) refer to over-involvement in household activities and caregiving responsibilities.

However, evidence from the current study points to the fact that the effects of the caregiving situation on siblings are not exclusively negative. Evidence provided by Mrs. Gill (below), makes this clear:

“Uh, very helpful and, um, I think that’s why he’s... he’s doing medicine now, I think he wants to be a doctor because he wants to help other people but he’s... and he... I run a holiday club for... in the summer, a summer club, for three weeks at the school she used to go to, and he’s one of the workers and he’s always, you know, been very confident to work with special needs children because he’s got the confidence, I think, from... having a sister that’s... you know, got Down’s Syndrome. It’s been very beneficial, in that sense, for him...”  
(Mrs. Gill, Phase 1, p.25)

Studies conducted by Bagenholm and Gillberg (1991), Carr (1995), Seltzer *et al.* (1997), and Eisenberg and Baker (1998) confirm this finding. Seltzer *et al.* (1997), for example, studied three hundred and twenty-nine siblings of adults with ID, and found that siblings were more understanding and sympathetic towards their brothers or sisters. A significant number of the siblings studied by Eisenberg and Baker (1998) expressed the belief that they have developed a range of positive personal attributes, such as empathy, maturity, and family closeness, through their experience of caring.

For participants in the older group, the situation is inevitably different, since immediate and extended family members of all the couples lived away. Nonetheless, the majority of the carers of older group spoke positively of the support provided by family members, reporting a general willingness to understand and sympathise with their situations, and a readiness to offer practical help where possible. However, there was one exceptional case, that of Mr. Brown, who has care of their son with DS (Neil) as well as his wife Anne, who lives with AD. Neil’s understanding of his mother’s condition is compromised by his own disability; Mr. Brown reports that Neil found it difficult to understand the changes in his mother’s attitude towards him as she deteriorated. This situation was exacerbated by the fact that the additional burden of caring for Anne left Mr. Brown less time and energy for Neil. In the quote below, Mr.

Brown describes the gradual process of realisation in Neil, and its effect on his emotional attitude:

“And, of course, they... actually, one of the things that is really upsetting is that, for a short time, he was starting to say ‘I don’t want to come out [from his satellite flat]’ because he had problems communicating with Anne. He, you know, he was upset that she couldn’t answer him like she used to. He realised... he just suddenly realised that things were not right with his mum.” (Mr. Brown, Phase 1, p.26)

The consequence of this change in the Brown family was a shift in the onus of care for Neil from his father to his four siblings.

### **5.1.1.2.iii Extended family**

Extended family members are also liable to be affected by their proximity to a care situation. One of the mothers, Mrs. Young, described the varying attitudes of her parents and in-laws to her adoptive son Stuart:

“...Well, my mother always saw him as a child with Down’s syndrome. My dad was always a wee bit frightened I think, because they didn’t know how to take him, they didn’t know how to deal with his communications problems. Kenny’s mum was a lot more accepting I think.” (Mrs. Young, Phase 3, p.12)

She goes on describe the way in her father’s relationship with Stuart altered over time:

“...last time we were down with him [Mrs. Young’s father] he was much more accepting of Stuart, giving him a hug. And he doesn’t always understand what Stuart is saying, which becomes a problem because my father is a bit deaf, and he doesn’t understand what Stuart is saying, but he’s much much more accepting because Stuart is Stuart, and you know, much much more accepting. But I’ve never had problems with friends.” (Mrs. Young, Phase 3, p.21)

It is evident from the first quotation that simple lack of understanding with regard to a cared-for person’s condition may be a source of distance between extended family and the person who was looked after (and by implication, between extended family and the cared-for person’s immediate family). The second quotation illustrates how

one effect of change - namely the growth of understanding - may alter that situation in a positive way. There is a certain amount of research which has studied grandparents as main carers of a grandchild with disability (Force *et al.*, 2000; Janicki *et al.*, 2000; McCallion *et al.*, 2000). However, to date there is little research concerning the issue of grandparents as a secondary resource within the caregiving context.

As suggested in the introduction to this section, there is an equal likelihood that younger extended family members - grandchildren for instance - may also be affected by secondary involvement in caregiving situations. In many families, the relationship between grandparents and grandchildren is close, and plays an important part in the emotional growth of the grandchildren. Evidence from participants in the older group illustrates the potential for negative impact on this relationship as a consequence of either the grandmother or grandfather living with dementia. A quotation from Mrs. Hope (wife of Mark) illuminates some specific disadvantages arising from her own situation:

“We had a good life. We used to... we had a nice, nice family, caring family and we had a little grandson and that was lovely um... but yeah I’ll tell you how I feel... I feel a bit unfulfilled with regards to my grandchildren, because I feel I would like to see much more of my grandchildren than I do, because I have to sort of... the first grandchild I looked after Monday’s and Tuesday’s that’s the wee boy, he’s nine now, he’s at school and so for the three years that Mark had Alzheimer’s, I still looked after my wee... my grandson. And that was lovely, but now ah, I’ve got a granddaughter and Mark’s not very good with her, no. I’m trying to think... um... I’m trying to think... he’s just not very good with her, you know.” (Mrs. Hope, Phase 3, p.7)

Mrs. Hope’s words point particularly to the lack of time she now has to spend with her grandchildren, and the barrier to communication between Mark and his granddaughter caused by his condition. Consequences for the reduction in quality time between grandparents and grandchildren are included in the findings of a study conducted by White-Means and Chang (1994). They reported that family carers in general have less time for participation in extended family activities. However, as the evidence from Mrs. Hope above suggests, the negative effects of the caregiving situation are not confined to issues of time. The possibility of meaningful contact between grandparent and grandchild may also be significantly compromised by the

nature of the cared-for person's condition itself. This is confirmed by further evidence provided by Mrs. Hope, in which she explained how her grandchildren decreased the frequency of their visits as a result of Mark's agitation. It is understandable that grandchildren may be upset by such manifestations of demented behaviour, and likewise, that the presence of visitors may exacerbate those symptoms. It also seems likely that such negative impacts on the grandparent and grandchild relationship may have further ramifications within the extended family in general, becoming a source of conflict and distance. A quotation from Mr. Owen (husband of Iris) illuminates the possibility of such complex and difficult developments:

“It impacts in the way that she treated the grandchildren. That was the biggest impact. She went through a stage where she became unreasonable, you know, and she took a dislike to my granddaughter quite unreasonably, you know, it's just the disease now. I know that and my daughters know that, but my granddaughter, while she says, you know, she's only twelve, so while she says 'Oh yes, I understand' it must hurt her, and the other side, my grandson, the same time that Iris was going through the difficult stage with my granddaughter, she was praising my grandson to the high heavens. He was the best thing since... so that was a creating a conflict between, between them, you know.” (Mr. Owen, Phase 3, p.6)

While it is entirely possible that the tendency towards favouritism within grandparents may occur in conventional family situations, the tone, as well as the detail of Mr. Owen's description suggests that this situation was particularly painful and difficult for him; he is compromised, on the one hand by his loyalty to Iris, and his responsibility for her care, and on the other, by the sense of responsibility he feels for the wider family conflict.

#### **5.1.1.2.iv Social relationship**

This dimension refers to changes, of both a positive and negative nature, in the social lives or activities of participants from both groups. A common negative development was the loss of friends. Mrs. Campbell, for instance, referred to the fact that some of her social acquaintances ceased contact with her after the birth of her daughter, Claire - a change which she attributes to lack of understanding in her friends regarding the issue of disablement. Her experience in this matter accords with findings in a

quantitative study conducted by Heiman (2002) which likewise reported the loss or impairment of friendships among mothers of children with disability. Similarly, a carer of older people, Mrs. Baird (wife of Neil) believed her friends found it difficult to deal with her husband's behavioural problems. Her demeanour, as she recalled their attitude, made it clear that this was a source of disappointment to her- something which is also obvious in the tone of her words:

“When I think about, you know, they could spend a couple of hours here and I've asked them, you know, for tea or Sunday dinner or something like that, and, oh, they've always got something else to do. They can't... I don't think they can handle the fact of how he is.” (Mrs. Baird, Phase 3, p.4-5)

An inevitable consequence of such developments is the feeling of isolation the carer suffers - a feeling enhanced by the fact that, at the same time as losing friends, it becomes increasingly difficult for the carer to go out and engage in the social interactions they formerly enjoyed. This accords with findings reported in a study conducted by Tebb and Jivanjee (2000) which identifies isolation as a predominant effect of changes in social activity. A quotation from Mr. Tobin amply demonstrates the reality of this effect amongst carers of older people:

“You lose a bit of your social life in as much as, as I said to you before, you don't... you don't holiday so much, you know, by that you don't... you don't... so you lose the companionship you get, you know, whenever you go anywhere you usually meet people and things like that, so you lose out there. Um, I suppose where you lose out is that... there's probably times where people would maybe want to invite you but they would have to question 'Well, how would they get there?', or 'Could they cope with the wheelchair?', you know?...” (Mr. Tobin, Phase 1, p.34)

A further negative aspect of the changes brought about in the dimension of social activities is a reduction in the time many carers feel they can set aside for themselves - a reduction which affects their freedom to pursue both routine and leisure activities. A conversation with Mrs. Miller (below), illustrates this point:

Mrs. Miller: “I have been untrue to myself up to now because...”  
Researcher: “What does 'untrue' mean?”

Mrs. Miller: “Well, I’ve been... I mean, my... every hour of my day is spent looking after Kevin and if we go somewhere I see that he’s all nicely dressed and then five minutes, you know... um, I don’t spend any time on myself and people’ll say ‘You should go and get your hair done regularly’, but I haven’t got the time... you know, I don’t have the time to spend on my own self”. (Mrs. Miller, Phase 1, p.14-15)

This finding is supported by quantitative studies conducted by White-Means and Chang (1994), Heiman (2002) and Van Riper (2007). All report that caregiving impacts significantly on the carer’s personal time. White-Means and Chang (1994), particularly, refer to the likelihood that reduced leisure time may lead to emotional stress and a general sense of diminished life-satisfaction amongst carers. Heiman (2002) and Van Riper (2007) reinforce the point, reporting that parents of children with disability rarely spend time with their friends or participate in social events.

In addition to the emotional and psychological barriers to social contact, there are also inevitable practical obstacles, such as the issue of wheelchair access, or inappropriate provision in public transport - factors which add to the difficulty of maintaining contact with the outside world. An important aspect of the way such obstacles may affect carers is the attitude they adopt in responding to them. Mr. Tobin, for instance, adopted a positive attitude, seeking to address the problem of maintaining social contact, both for himself and for his wife, by inviting people into his home (a solution made possible by the co-operation of his daughter):

“I invite our missionaries to dinner, you see? And I used to do it two nights, two dinners. And then when Michelle [his daughter] was here, I said, ‘We always invited the missionaries to dinner Thursday night, a Wednesday and a Thursday.’ She said, ‘Could you not get them to come together, instead of the two coming... two Wednesdays and two Thursdays, get them to come together. It’s just as easy for me to make a big meal’, you see? They love it. They love just all being together so that’s become the thing now. That just brings a little bit into the house.” (Mr. Tobin, Phase 2, p.20)

Mr. Tobin’s evidence suggests the possibility that involvement in the caregiving situation is not always damaging to social life (a possibility which is not referred to in any previous studies). In the younger group, Mrs. Young, for example, explained that her network of friends expanded as a result of meeting similarly placed parents. She

also took a leading role in promoting her son's sporting activities, and found that this, too, led to the growth of her social life.

“Our social life was very much tied in with the our kids, and it was very much tied in with... we met a lot of people through going to swimming competitions, watching the children swimming, and Stuart was there anyhow... And I met other people; people contacted me because I was an adoptive parent so they contacted me. People contacted me because I had a disabled child and, you know... so the social life is... is maybe... maybe you can see it growing more...”  
(Mrs. Young, Phase 1, p.26)

Sadly, there is little evidence of similar positive developments for members of the older group. While Mr. Tobin's evidence suggests a positive attitude, it is related to the maintenance of existing social outlets (made possible by the good-will of his daughter), rather than an extension of social opportunities. It may be that this disparity is explained by the difference in age between the mothers and the carers of older people, and the greater vitality and energy the mothers are likely to bring in addressing the changes which affect them. It seems reasonable also to suggest that the natural behavioural pattern of any mother in caring for her family is more likely to lead to positive outcomes with regard to maintaining and developing social contact. In the older group, on the other hand, may become progressively less gregarious; their mobility and general health are naturally diminishing, and so too, correspondingly, their circle of friends. Holmen and (2002) have conducted a ten year follow-up longitudinal study of loneliness, health, and social networking among the elderly; their findings broadly support this suggestion.

### **5.1.1.3 Financial concerns**

This dimension deals with the impact of the financial burden of providing care among participants in the current study. It was found to be a major area of concern for carers in the older group, less so for those in the younger. One mother in the younger group, Mrs. Murray, is a divorcee. She received financial support, through maintenance, adequate to allow her to own a property, and provide appropriately for the additional



demands of childcare, without the necessity of going out to work. (However, she is fortunate in also having a partner with whom she shares living expenses). Other mothers were also able to eschew the necessity of employment, enabling them to perform as full-time carers. An important factor facilitating this freedom for the carers in the younger group was the reduced likelihood of deterioration in their child's condition, as compared with carers of older people, who can anticipate a worsening in their partner's condition, and a correspondingly increased level of necessary expenditure in terms of additional care provision and resources.

Carers in the older group expressed particular concern regarding this increasing necessity for additional formal assistance, and were particularly exercised by the prospect that their partner would eventually be obliged to go into a permanent nursing home. For one participant, Mrs. Miller, this prospect became a reality in the course of the current study; by the time of the Phase 2 interview (July 2005), her husband, Kevin, had moved into full-time nursing accommodation. Her case provides an example of a symptomatic dilemma for having adjusted to the initial difficulties of caring for her husband, she found herself obliged to deploy the majority of their life savings in order to cover the cost of the move. Several carers complained that this is 'a very bad system'. Mr. Owen and Mrs. Miller, in the following excerpts express such an opinion, explaining the details of the obstacles they, and many others in their situation, have encountered:

“And if you get a full old age pension, you earn too much for a Carer's Allowance. It's a very bad system, the Carer's Allowance... That's been brought up at the various courses we've been at... and lots of people think, 'Oh well, we should qualify for that.' But it's so stringent.” (Mr. Owen, Phase 2, p.20)

“...in Britain, if you save hard for your old age and you buy your house, at the end of the day you're penalised because you have to pay for everything. But if you don't save and don't worry about money, at the end of the day you don't pay anything, they just take your pension.” (Mrs. Miller, Phase 1, p.38)

It is important to note that Mrs. Miller employs the term 'penalty' in the above excerpt, demonstrating her perception that she considers this to be an unfair system. It is worth noting, too, that the fear of being penalised by this system played a part in

many of the carers' decision to keep their partners at home as long as possible. Mrs. Hope, in the following quotation, seems to be expressing such a feeling:

“So that’s another thing, I don’t want him...ah, ah, to go into a... into a nursing home because they take away all, all the savings that he’s got and you’re left with nothing, you know.” (Mrs. Hope, Phase 3, p.16)

While the intention of keeping care within the home is not negative *per se*, it is surely wrong, not to say potentially dangerous, that a carer’s decisions on important matters of this kind should be influenced so fundamentally by material considerations. It is little wonder that this aspect of caring is such an area of concern – reportedly by Mr. Brown the cause of poor sleep, and correspondingly diminished levels of health and energy among elderly carers.

The unfairness of this system is widely recognised. In response to growing awareness of the issue, the pressure group Age Concern conducted a study in 2006, involving six qualitative focus groups. The study (entitled ‘Who Should Pay for Care?’) reports that the majority of its participants are strongly resentful regarding the use of private pensions in payment for care. It further reports a feeling that the current charging system is inherently unfair, and in contravention of the basic tenets of the welfare state. The participants questioned argued that the state has a responsibility to citizens, and that private property should not be seen as a means of subsidising the unavoidable expenses of proper care. This study concludes that the current system discriminates unfairly against those who have accumulated savings, and thus offers little incentive to others to follow their example and save for the future.

#### **5.1.1.4 Positive outcomes of caregiving**

This dimension refers to positive outcomes carers derive from the experience of providing care for their relatives. Outcomes included a sense of reward, happiness, enjoyment and pleasure associated with the caregiving situation. In the younger group, many mothers described the happiness and pleasure they experienced in watching their child progress, as well as a sense of admiration and pride at how much

they were able to achieve. Mrs. Robinson (mother of Harry) describes her perceptions of Harry's improvement in the excerpt below:

“...he's being supervised by a woman who has... she's got four children of her own, she doesn't take any nonsense but she doesn't have... how shall I say it? She doesn't um, put barriers on what he can do. She just lets him try... so you know I'm not really brave enough sometimes - I mean she sent him to the supermarket that's near the store with a shopping list and a telephone, her mobile phone, and she waited outside and she said 'Now you go on in...'...oh no... she wrote down her phone number - that's right - on the shopping list and she sent him in with some money and said 'Right you go and get the things' and she waited outside and she said to him you know, 'If you have a problem, get somebody to phone me' but he got everything and paid for it. You see I would never even have dreamt he could do that, but he did it and he will do perhaps things for her more willingly than he would for me, because that was work, and he's very motivated so... um, you know it was really good for him from that point of view...”  
(Mrs. Robinson, Phase 3, p.5)

In the older group, the possibility of material progress of this type is, inevitably, highly unlikely. Nonetheless, a number of carers expressed positive feelings about the effects of their care upon their spouses. The element of pleasure and satisfaction in these cases tends to be associated with a sense that their partner is as happy as possible:

“Well, the reward I get is seeing Anne [wife of Mr. Brown] happy. You know, that is a reward. And that's the same as you do with children, bringing up children. You're rewarded when you see them responding to your care and love by loving and caring for you. So it's rewarding and that's why it's enjoyable. It's not enjoying in the sense that, oh, it's like having a thousand pounds given to you. It's... but it's rewarding in a fulfilling sense that you enjoy it.” (Mr. Brown, Phase 3, p.7)

It is important that Mr. Brown, in the above quotation, draws a comparison between the way he perceives his responsibilities, and the role of the mother regarding her children. This tends to reinforce the notion that there is a valid parallel between the positive sentiments reported by mothers of children with ID, and the satisfaction experienced by elderly carers.

The foregoing examples illustrate a further, more general parallel between the experiences of mothers and spouses in conventional situations, and those of family carers: like any parent, or any spouse, participants in both groups derive a sense of fulfilment and purpose in improving the happiness of their loved ones. However, it is important to reflect that success in their endeavours is achieved in the face of specific and unusual difficulties; this perhaps serves to make the sense of fulfilment greater, and motivates them to continue. A review conducted by Hastings *et al.* (2002) and a quantitative study conducted by Greer, Gret and McClean (2006) focused on the positive perceptions of mothers of children with ID, and identified a range of beneficial outcomes, including happiness, personal growth, a sense of fulfilment and increased emotional and psychological strength. The simple necessity of acquiring new knowledge and skills in the process of caring has also been shown in the course of this study to be an additional benefit, linked to a significant growth in personal confidence. Mrs. Gill (mother of Alice) confirms this finding in the following quotation:

“My understanding of um... people with disabilities is huge. My knowledge of Down’s syndrome is quite good and I’m actually caring for a little girl now who’s two and who’s got Downs syndrome um... so my, my... my confidence to work with her and to look after her is probably much greater than it would be if I hadn’t had Alice and um... I’ve done things with disab... disabled children that I wouldn’t otherwise have done, just because I’ve had Alice and, yeah, I think they’re the most positive outcomes.” (Mrs. Gill, Phase 3, p.25)

It is clear from Mrs. Gill’s words that the knowledge she has acquired in caring for her daughter has not only increased her empathy with similarly children with ID, but has enabled her to develop a deeper understanding of herself.

#### **5.1.1.5 Hopes and expectations**

The terms ‘hope’ and ‘expectation’ were used by different mothers in reference to the possibility of their children establishing independent lives. The use of these terms is related to the mothers’ perceptions of their child’s present capabilities and potential for future progress. For certain mothers - those whose confidence in their child’s

potential was greatest - the emphasis was on expectation; for those who were more ambivalent in this regard, the focus was rather hope. The two emotions are clearly related, but for many mothers the 'safer option' is more likely to be hope. Mrs. Young, in the quotation below, succinctly articulates this point:

“And... expectation is a level you want to reach. And an expectation is actually, in some ways, asking for disappointment if you don't get it.” (Mrs. Young, Phase 3, p.19)

However, it should be noted that some less realistic hopes can also be found in some mothers' thoughts. For example, Mrs. Murray (mother of Lisa) talks about her daughter who may become 'normal' one day and Mrs. Cameron (mother of Emma) had a wish for her daughter, as she said:

“I just hope one day that she's going to be this perfect girl and she's... I dream that she's going to have a future...” (Mrs. Cameron, Phase 1, p.18)

The drastic change to those conventional expectations which are associated with the birth of a perfect baby, and the difficulty of adjusting to that change, was recognised by all the mothers. Many referred to the fact that this adjustment was particularly hard because of the fact that they had never entertained the possibility of giving birth to a child with ID. Mrs. Robinson, in the following quotation, vividly summarises the nature of her own emotions on the matter:

“But I suppose it... I felt it more, I think, when he was a baby, you know it was more... because you have to... you go through a process of grieving for the child that wasn't... that wasn't. You know, it's almost like a child's... not died, but your expectations died, and you have to grow new ones.” (Mrs. Robinson, Phase 2, p.16)

Mrs. Robinson's allusion to the feeling of grief is particularly resonant. It is an emotion commonly identified in mothers in her situation, and is specifically mentioned in a study conducted by Bruce, Schultz and Smyrniotis (1996) as a significant element in many mothers' reactions to the birth of a child with ID. It is interesting to compare this reaction to the reaction of Mrs. Young. As an adoptive mother, she freely accepted the responsibility of caring for a child with ID, and was

therefore more likely to have entered the situation ‘with open eyes’ – foreseeing the possible effects for herself and her family. In the following excerpt she describes the process by which the decision was made:

“...we knew, I suppose in some ways we’re in a slightly different situation, if it were the fact that we had Stuart, we had given birth to Stuart, but because it was a choice we made, we made the choice and we went looking for a child with special needs. We... so therefore, with the preparation we had in terms of looking towards adopting a child, the Adoption Society made us and any other couples do a lot of thinking about what we were taking on, you know, about the history of the child we were taking on, and the potential of the impact that history might have on our child in the future. So we had a lot of discussion, a lot of planning, we had to do a lot of thinking. And when they phoned us and said to us about Stuart, we then found out about Down’s syndrome and we went and visited a family who had a child, a teenage child with Down’s syndrome, because they wanted to make sure we knew exactly what we were taking on. So that we wouldn’t turn round when he hit teenage years and says we can’t cope with it.”  
(Mrs. Young, Phase 3, p.7)

The role of the adoption agency in preparing Mrs. Young and her family was of key significance. As a result, her expectations of her son were different to those of birth mothers who had not foreseen that their children would have special needs, and the process of adjustment less problematic. Mrs. Young was therefore able to enter into the situation with a more positive and pragmatic attitude, and was consequently far less likely to suffer the negative emotions experienced by the other mothers in the study. This particular area of concern formed the focus of a quantitative study conducted by Flaherty and Glidden (2000) which compared levels of depression between birth and adoptive mothers of children with DS over a five to six year period. They found that birth mothers displayed higher levels of depression at diagnosis, and decreased levels of depression over time; adoptive mothers manifested lower levels of depression from the outset, and throughout the period of the study.

However, it is important to note that the level of maternal expectation from individual to individual is variable, depending upon perceptions of the particular child’s capabilities. These are factors which cannot be predicted with any certainty, and mirror the factors which parents in general must consider. It is perhaps only safe to state that the single constant factor in the experience of the mothers in the current

study is a degree of aspiration towards expectations for their child – for example, to a great extent, all of the mothers studied were looking forward, with hope. A study conducted by Vroom (1964) emphasises the importance of this mindset, suggesting that parental expectation plays a key role in the day-to-day decision-making processes of the parent, and their assessment of their child's performance. As such it acts as a source of motivation for mothers of children with ID. A quotation from Mrs. Young (below), illustrates the progressive growth of expectation, and its effect upon her emotional disposition regarding her son's attitude and achievements:

“...our expectations increased as he became a teenager. Our expectations of what he should be doing for himself increased so therefore if he wasn't doing it then maybe yes we would get more frustrated. Um... You know, when they're little and they don't go and get a coat you make allowances for that because they're little. And when he's fourteen and you tell him to go and get his coat and he doesn't then obviously you're going to get more cross because you know he's able.” (Mrs. Young, Phase 1, p.13)

Unlike the mothers, the carers in the older group experienced changes in their expectations which differ considerably from couples of similar age in conventional circumstances. All of these carers referred to the likely disappointment of various hopes and ideas, and more specifically, described their acceptance of the continued deterioration of their spouses' cognitive abilities. This perhaps, is the clearest point of difference between the attitudes of carers in both groups. All of the mothers, to a greater or lesser degree, while remaining pragmatic about their situations, felt able to entertain the possibility of progress for their children in this regard, and were thus motivated to address their caregiving responsibilities with energy and hope. For the carers of older group, pragmatism is closer to a sense of resignation, as Mr. Owen, in the following excerpt, suggests:

“The future if it continues like this, I would think will mean that Iris will have to go into a residential home if she continues to deteriorate, because I just won't be able to look after her. I need... and of course, I'm getting older as well. So you know, that's the way it will have to go.” (Mr. Owen, Phase 2, p.24)

It is important that Mr. Owen, in adopting this realistic attitude, is obliged to consider not only the decline in his wife's capabilities, but his own increasing limitations. He

seems calm and accepting in his assessment of the situation, and in his anticipation of future developments, but it is worth reflecting that, for many individuals in his situation, such realism might just as easily lead to feelings of hopelessness or apathy.

The divergence in expectations of the mothers and the carers of older people is further illustrated by the fact that a few of the mothers actually looked forward to a time when the burden of care might be left behind altogether. Mrs. Macleod, in the following excerpt, explains her hopes in this regard:

“I would like to think I would have a job either paid or otherwise. It’s something that I could be interested in for me - just being more involved in, um...the community and just seeing the family grow up and, you know, hopefully...and what I would like to think is that, you know, I’m going to have raised... independent, you know, children, independent people that are able to go out there and you know, live their own life to the best of their ability. I would like to think they are leaving here, you know, having grown as far as they can in the confines of the family. And then they are ready to go out and do their own thing and... and the same for Rose, yeah, and then hopefully, you know, God willing that Ted and I will have some time together because Ted has got the kind of job where, you know, he maybe could work, you know, if he’s in Europe or the States or something. And then he would be in a position where just the two of us could go and do that.” (Mrs. Macleod, Phase 3, p.13)

Importantly, it demonstrates the multidimensional nature of hope – for example, in this case, the fact that Mrs. Macleod is expressing hope not only for Rose, but also for herself. Irvin and Acton (1997) drew attention to this multidimensional aspect, identifying hope as an essential mediating factor between caregiver burden and well-being.

#### **5.1.1.6 Carers’ autonomy**

Beauchamp and Childress (2001, p.63) defined the principle of respect for autonomy as the acknowledgement of “...a person’s right to hold views, to make choices, and to take actions based on personal values and beliefs”. With regard to the family carer, autonomy is a relevant issue insofar as caregiving responsibility may be perceived to infringe the individual’s freedom of choice. A number of mothers in the current study



expressed the belief that the burden of responsibility for their children was not an infringement of their freedom, but a natural and acceptable element of their role. Mrs. Gill, for example, in the following quotation, makes it clear that she regards the care of her daughter with ID as a choice she has made, not as burden which has been thrust upon her:

“... That’s not a conflict that’s a... that’s the way you decide you’re going to do it. And then you’re not going to do the other things because they don’t work for you.” (Mrs. Gill, Phase 3, p.22)

It seems reasonable to suggest that this is a pattern accepted by mothers in general - in short, that all adults who enter willingly into parenthood are choosing an existence which will require them to perform certain predictable duties, to be in a certain place at a certain time, and to furnish the material resources necessary to bring up children. This implies an acceptance of constraint on freedoms they formerly enjoyed. This understanding of the nature of human autonomy accords with the ethical theories of Immanuel Kant, who proposed the notion that every human individual is an autonomous being, but must be possessed of a capability and willingness to bear responsibility, which is based on respect for moral actions. Moral actions are actions guided by a sense - in part innate and in part learned - of what is the right thing to do. From the mother’s point of view, the care of her children clearly falls into this category.

Acceptance of the caregiving burden as a conscious moral choice was expressed also by many carers in the older group. The basis of their belief, in this case, seemed to be that caring is an extension of the loyalty and devotion inherent in the spousal relationship. As such it may be seen again to be a choice motivated by the combination of innate (i.e. emotional) intuitions, and culturally received ideas about the nature of relationships between couples.

It should be pointed out, however, that caring for a spouse with dementia, or a child with ID, is an enduring dedication, whose impact on the freedom of the carer cannot be confidently predicted. Consequently, the effects on the carer’s autonomy are likely also to be a lifelong issue. Adolescents with ID will eventually become adults; their needs, and the demands they represent, will necessarily alter, and so too will the way

in which they affect the freedom of the parents. In the same way, the situation regarding older couples will be dominated by the inevitable deterioration of one, and the continuing sense of restriction experienced by the other. It is perhaps in consequence of this reality that many carers in both groups were keenly aware of the constraints they faced in the present, and expressed anxiety about their ability to manage the burden of care as time went on. In the following excerpts, carers from both groups give voice to these concerns:

“Caring for her [her daughter] can be a burden sometimes because you can’t go out sometimes... you can’t see to your own needs...” (Mrs. Cameron, Phase 1, p.24)

“Well, I mean, obviously, I mean, I think we said that earlier, it restricts what I am able to do, both in my sort of voluntary work and in my sporting things and activities and things like that...” (Mr. Brown, Phase 1, p.57)

The specific nature of the limitations the carers allude to is various. It includes predominantly a realisation that the ability to act spontaneously is compromised. The necessity of forward planning - for instance, arranging sitters prior to going out - was mentioned by many. It is true to say that mothers in general may be obliged to make similar considerations, but for older couples, the necessity of thinking in this way is more obviously an imposition, and perhaps therefore more likely to provoke negative emotions. A quotation from Mr. Brown is suggestive of this possibility:

“I mean, I can’t take Anne... the carer’s group which meet at The Tower, that’s where she goes on a Monday, they don’t like the... cared for person going so I’ve got to arrange one of my daughters to look after Anne. So it’s... it’s always a wee bit awkward. I’ve got to get my life organised to drop Anne off and then pick her up and that kind of thing...” (Mr. Brown, Phase 2, p.13)

The tenor of Mr. Brown’s comments in the above quotation suggests that he is struggling to be sanguine about the inconvenience of making alternative arrangements in order to accommodate the difficulties imposed by his wife’s condition. The phrase “a wee bit awkward” seems to play down the inconvenience. Yet he is clearly put to a good deal of effort, and cannot hide the fact that this is hard for him.

Opportunities for paid employment or career advancement were inevitably restricted for both groups. In the younger group, the ages of the mothers range from thirty-six to fifty a figure which explains the higher incidence of career ambitions amongst this group. Mrs. Robinson was one of the mothers who managed to combine part-time employment (in a small business) with the demands of caring, although, as she points out in the excerpt below, she had to cope with a certain amount of guilt regarding the necessary division of her time that this entailed:

“... It tends to go in... seem to get a lot at once and then nothing for a while and then... so I do feel responsible sometimes because I work for a small business and if I'm away, it's detrimental to them. There's nobody else who can take over what I do....” (Mrs. Robinson, Phase 2, p.23)

She went on to explain that on occasions she is obliged to go home early, or miss work altogether, when her son is sick - an eventuality whose frequency is highlighted in a study by Shearn and Todd (2000). It should be pointed out, however, that this is a situation commonly encountered by mothers in general, not necessarily restricted to mothers of children with ID.

In the older group, one carer in particular, Mrs. Baird, pointed out that caring interfered with her ability to continue work, to the extent that she was eventually obliged to give it up:

“I retired because... no because... partly because of him [her husband], partly because I was sixty but I did have the chance to work on until I was sixty-five... ..” (Mrs. Baird, Phase 1, p.15)

It is perhaps unsurprising that, to date, there has been no study investigating the issue of restricted employment in senior carers - probably in consequence of the fact that the majority of viable participants have already passed retirement age. This situation is likely to alter in the next few years, following recent changes in legislation regarding equal employment opportunities for senior citizens; a situation now exists which allows older people who have reached retirement age to continue work, provided the employer is happy to allow it (The Employment Equality (Age) Regulations 2006).

The majority of mothers questioned saw themselves returning to work when their children were older, but were unable to predict with any certainty when this might become possible. The attitudes of the mothers in these cases provide an example of 'autonomy of will' (see page 69) - a typical form of response in individuals whose long-term goals and ambitions are interrupted by the demands of care. The circumstances of the carers in the caring role would be much affected on autonomy of their will. Carers had freedom of thought as they were capable to think, but their freedom of will was curtailed by caring demands. Once autonomy of will of carers was intervened and consequent their autonomy of action was impeded. It is interesting to understand the position of carer and the extent of effects on their autonomy. An inevitable consequence in such situations may be sentiments of frustration and disappointment. Mrs. Gill, in the following excerpt, describes a situation of this type, and describes her struggle with these emotions:

“[Sighing]...I suppose it's more difficult at this point in time because the others [children] have become independent to some extent. One of mine has left home and the other two are pretty self reliant although I like to be here for them and I obviously cook meals and wash and all that sort of thing. Um... So presumably at this time of my life if I didn't have Alice I would definitely, definitely be doing something else from what I'm doing now.” (Mrs. Gill, Phase 3, p.24)

It should be pointed out, however, that over time, the possibility and/or necessity of returning to work may alter. A case in point is provided by the example of Mrs. Campbell (mother of Claire) who between the Phase 1 and Phase 2 interview, secured a part-time job, working eighteen hours a week. As the excerpts below illustrate, this major life-change was prompted by a combination of expedience and conscious choice: the purchase of a house necessitated that she supplement her husband's income in order to cover the mortgage repayments; at the same time, her assessment of Claire's progress in self-care enabled her to take this important step with confidence.

“Obviously because we need more money now as well with having a mortgage and this is quite a bit mortgage and we've spent a lot of money doing the house and things like that, so I do have to go out to work....” (Mrs. Campbell, Phase 2, p.4)

“...She’s older, uh. She’s a lot bigger and as I say, more independent.”  
(Mrs. Campbell, Phase 2, p.6)

For carers in the older group, of course, the demands of care are liable to increase, rather than diminish over time. As a result, it is highly improbable that any of the carers will experience similar opportunities. Any increase in autonomy in this group is most likely to be possible in the event of their partner being taken into care. Mr. Owen, for example, referred to the “huge” (Phase 3, p.3) difference it made to his life when the hospital provided safe care for his wife Iris. The sense of relief and liberation he experienced in the aftermath of this change comes through very clearly in the quotation below:

“You’re free. You’re free. You can do what you want, when you want. That’s the difference, whereas before it was controlled by Iris’s... um... the care of Iris if you like. You couldn’t always do what you wanted to do, but of course now you can - that’s the difference.”  
(Mr. Owen, Phase 3, p.11)

Mr. Owen went on to explain how his circumstances had altered, from the responsibilities of full-time carer, to a situation in which he was visiting Iris every day, and spending the remainder of his time meeting friends and watching football. He described the happiness he felt at being able to take time for himself, while knowing that his wife was safely looked after. Some of the other carers of older people, however, found their experience of similar changes difficult to cope with, primarily because the transference of their partner into care intimated that the end of their relationship was coming near. This is perhaps suggestive of situations in which the demands of caring for a spouse become so all-consuming that the routines and customs they entail become identical with the emotional attachment formed between the couple. Mrs. Miller, who underwent an experience similar to Mr. Owen when her husband Kevin was taken into a formal care by professionals, eloquently describes emotions of this kind in the following excerpt:

“... I feel now as if there’s no substance to my life, I feel I have my freedom, I can do what I want but I feel I should be looking after somebody because I had all these years of looking after him. I feel that my life’s not worthwhile....” (Mrs. Miller, Phase 3, p.5)

This finding demonstrates the fact that the achievement of new freedom may be a negative as well as a positive experience, and highlights the potential difficulties of moving on from a long-established situation. A sudden access of autonomy is not necessarily accompanied by the will or desire to exercise it. It seems reasonable to suggest that part of the reason for this is that, while the carer's freedom to make choices is in many ways enhanced, one fundamental choice is denied them and the choice of keeping things as they were. By this interpretation, Mrs. Miller may be seen to experience a simultaneous increase and reduction of autonomy. This suggestion accords with findings from a qualitative study of chronic sorrow in caregiving spouses of partners with AD, which was conducted by Mayer (2001). The study confirms that carers who were in the grieving process manifested diminished levels of motivation in the exercise of their autonomy.

It is possible that this disparity in the reactions of Mr. Owen and Mrs. Miller, as their partners moved to formal settings, may be connected to the issue of gender. It seems reasonable to suggest that female carers are typically more emotional, both in their attachments, and in their response to change, while a male carer is perhaps more likely to manage change by seeking opportunities for detachment from the situation.

#### **5.1.1.7 Having a paternalistic attitude**

Paternalism is an attitude in the carer which tends to overlook the autonomy of the cared-for person - a tendency to make decisions which, while they are directed towards the good of the dependent, are largely ignorant of their wishes. As such, it is perhaps based in the assumption that impaired cognitive abilities are necessarily attended by unreliability of judgement. The development of this tendency seems to be an inevitable consequence in the caring situation - most obviously perhaps, in the disposition of parents towards children with ID, but nonetheless also prevalent amongst carers of older group.

Figure 3: The theoretical memos for developing the concept of Paternalism

<p><u>22<sup>nd</sup> of Oct, 2006</u></p> <p>The dimension of ethical issues is found in relation to the property of Paternalism. Ethical issues are identified in this study: Power of Attorney, and Informed Consent. These two topics are found in both groups.</p>
<p><u>27<sup>th</sup> of Nov, 2006</u></p> <p>The concept of Paternalism is identified as being an attitude from the hierarchical pattern of a family based on patriarchy, (the man making the decisions for the family) which means that carers make decisions on behalf of their cared-for relatives for that person's own good or wishes, as well as being based on the perception of their likes and dislikes or interests as explained by the participants. For example, Mrs. Gill talks about restricting her daughter's food to help prevent her from being overweight (Phase 1, p.5). Mrs. Campbell decides the types of school for her daughter because she wants her to mix with normally able children (Phase 1, p.8). Furthermore, these two ethical issues closely relate to carers' thinking about what is best for their relatives. Thus these ideas should be categorised as being under the property of Paternalism.</p>
<p><u>16<sup>th</sup> of Feb, 2007</u></p> <p>Paternalism is part of the category Responsibility and Duty because I believe carers developed a paternalistic attitude towards their cared-for relatives based on their sense of responsibility.</p>
<p><u>6<sup>th</sup> of March, 2007</u></p> <p>Responsibility or Duty</p> <ol style="list-style-type: none"><li>1. My role = My job<ol style="list-style-type: none"><li>1.1 A typical day</li><li>1.2 Taking him into account</li></ol></li><li>2. Paternalism<ol style="list-style-type: none"><li>2.1 Sense of control and confident</li><li>2.2 Protective or overprotective care</li><li>2.3 Hard to let go</li></ol></li><li>3. She's a person</li><li>4. Decision making</li><li>5. Autonomy restriction</li></ol> <p>At this point, paternalism seemed to be about the nature of the carers' developing a sense of responsibility towards their relatives.</p>
<p><u>10<sup>th</sup> of March, 2007</u></p> <p>Carers have developed a paternalistic attitude which resulted from their life changes. Carers became more involved in the decision making for their cared-for relatives. This Paternalistic attitude of carers helped prevent their spouses from hurt or danger but it was dominated by the carers' own thoughts or interests. Importantly, the paternalistic role increased as their spouse's health deteriorated because as Mr. Brown explained, that they were not equal partners any more (refers to the quotation of Mr. Brown, Phase 2, p.8-14).</p>

It was found in the older group that paternalism became increasingly evident in the carers' attitudes and behaviour as their partners' health deteriorated. Predictably, mothers displayed paternalism to differing degrees, dependent upon their child's progress through different stages of learning, and in response to their assessment of the child's ability to make decisions and manage practical necessities. Mrs. Gill (mother of Alice) displayed a similar attitude in connection with the management of her daughter's diet:

“...She doesn't say 'I've had...', she never says 'Oh, I've had enough', or, 'Oh, I'm full', she just eats, so I'm always being very strict with her, um, not to eat too much because I don't want her too large....”  
(Mrs. Gill, Phase 1, p.5)

An important aspect of the paternalistic attitude is protective care. This describes initiatives and behaviour intended to prevent the cared-for individual from meeting with physical harm. Many carers in the older group confirmed that the exercise of protective care formed an essential element of their responsibilities, referring to the fact that the diminished cognitive faculties of their partners often resulted in reduced awareness of the dangers of fire, or an increased likelihood of getting lost. Mrs. Baird, for example explained that it was sometimes necessary to lock her husband in the house to prevent him from wandering. Several of the carers added that they were at pains to keep close watch over their partner whenever they were out. Likewise, all the mothers referred to the necessity of close observation of their children as an essential aspect of maintaining a protective atmosphere at home. Mrs. Cameron (mother of Emma aged eleven), describes the precautions she felt bound to take in the following quotation:

“... I'm very protective of my daughter, my daughter doesn't even get outside, she only gets out the back green and I've got a fence that's like twelve feet high and she's got all her toys in there, she's got a wee house to play with and, to me, I feel I... You can say I probably isolate her from children outside, but if she's out and we go to a swing park then yeah, I'll let her play with other children, but I don't think I can...” (Mrs. Cameron, Phase 1, p.22)



It is interesting that Mrs. Cameron refers to the term ‘isolation’, and further, that she appears to be defending herself from perceived accusations in this regard. This seems to imply that she is aware that her attitude may appear excessive. It is perhaps reasonable to suggest that this may be so; over-protectiveness is likely to hinder the development of the child - particularly the child’s potential for developing an independent awareness of what is safe and unsafe. The fact that a number of the mothers went so far as to admit that they were over-protective reinforces the suggestion that protective care tends towards an excessive extreme. Their attitude is nonetheless understandable; letting go is difficult for mothers of all children in general to some extent. It should be noted, however, that it is a more complex and problematic issue for mothers of children with ID. Mrs. Gill’s words in the following excerpt clearly articulate the dilemma such mothers may face:

“... I think I’m too protective, I agree with that, but I’m not prepared to not be protective because of what might happen if I don’t care for her and be protective. I know I’m over protective, I won’t let her go on the bus on her own, I’m absolutely adamant I’m not going to let her go on a bus on her own.” (Mrs. Gill, Phase 3, p.10)

It is inevitable that the autonomy of people who are cared for is infringed to a certain extent. The frequent unpredictability of the symptoms of their condition (particularly with regard to deterioration in dementia), and the relative ignorance of family carers in comparison with trained professionals, are perhaps the factors which most contribute to the development of over-protective paternalistic behaviour. Given that this is the case, it is valuable to consider the consequences of paternalism. Evidence from the younger group suggests that it may lead to a degree of conflict between mother and child, stemming from the child’s natural desire to be independent.

“Because that is a source of conflict between her and me, she wants to be independent but I have to care for her because she hasn’t got the ability to be independent...” (Mrs, Gill, Phase 1, p.11)

At the time of this interview Mrs. Gill’s daughter (Alice) was seventeen - an age at which the urge towards independence is particularly strong. Adolescents in general tend to be resentful of their parents’ paternalism, and will often engage in conflict in defence of their autonomy. A number of child education and psychology studies have

focused on this area (Sliverberg and Steinberg, 1987; Small, Eastman and Cornelius, 1988). These studies recognised that the adolescent years bring changes within families, which may frequently lead to paternal stress, regardless of whether the children with or without disability. A study conducted by van Hooren *et al.* (2002) suggested that there is an inevitable conflict between the provision of high quality care and respect for the autonomy of young adults with ID. Murtaugh and Zetlin (1988) shed further light on the issue; they investigated the achievement of autonomy by adolescents with and without ID, and found that adolescents with ID generally lag behind their normally able counterparts. Perhaps surprisingly, they found that the teenagers with disability were generally satisfied with their limited freedom, and so displayed a lesser tendency to become involved in conflicts with their parents. An explanation for this finding might be that the group of adolescents had developmental delay - a factor which may have affected their confidence, hindering the full achievement of autonomy, and necessarily affecting the reliability of their statements.

Cicirelli (2003), using a quantitative study, identified conflict between adult daughters (average age 54.9 years) and elderly mothers (average age 82.6 years) over the issue of selecting nursing home care. The root of the conflict is clearly the paternalistic attitude of the daughters. However, it should be pointed out that the mothers in Cicerelli's study (unlike the elderly spouses in the current study) were neither physically nor intellectually impaired. It is perhaps natural, therefore, that their resentment of their daughter's paternalism - and thus the degree of conflict - was exacerbated, since they felt that they were able, and should be permitted, to decide the matter autonomously. The findings are nonetheless significant, since they highlight the conflicting perceptions of need which may exist between the carer and the cared-for individual. Tuckett (2006) reinforces this notion. He provided a review of literature on paternalism and autonomy, as preparation for a qualitative study on truth-telling amongst carers and elderly residents in the environment of the nursing home. He suggested that the conflict between paternalism and autonomy is a common dilemma, but a lack of attention has been paid to it.

There are two common ethical scenarios in relation to the dimension of paternalism, which are relevant to both groups of carers in the current study: power of attorney, and informed consent. In the younger group, Mrs. Gill explained that she felt it was

important to obtain power of attorney for her daughter, because she believed she was incapable of making decisions:

“Well, I... every time you... that something happens or you need something everyone [social workers] asks you, uh, why I’m ringing and not her and, um, do I have her authority to ask things... Yes, she said ‘Does your daughter know you’re ringing?’, and I said, ‘Yes’, which actually wasn’t true because I hadn’t even thought to tell Alice... because Alice wouldn’t understand what I was talking about. So I was thinking that I would... I would like to officially be her power of attorney...” (Mrs. Gill, Phase 1, p.72)

It is possible to assert that Mrs. Gill diminished her daughter’s personhood by depriving her of the right to make independent decisions regarding her well-being. However, when viewed from the mother’s perspective, it might equally be claimed that she was simply looking after her daughter’s best interests. Although, from this point of view, it may seem that paternalism is a necessary adjunct of proper care, it should be added that this attitude must not be allowed to develop in such a way that it diminishes the carer’s respect for the child or spouse’s autonomy. The fact that Mrs. Gill, as she freely admitted, lied in pursuance of her intentions suggests that, in this case, a certain lack of respect for the cared-for person is evident.

Power of attorney is also a problematic issue in the older group. The necessity of obtaining power of attorney is perhaps clearer, since in the older group the conditions of the cared-for individual are generally characterised by progressively diminishing responsibility. The problem with regard to power of attorney is more commonly associated with the carer’s decision as to when it should be obtained. Mr. Tobin describes his experience of this problem:

“What I got caught out on is I didn’t take out power of attorney, you see... and that’s something you should do, take out power of attorney.” (Mr. Tobin, Phase 1, p.37)

The consequence for Mr. Tobin, and others in his position, is the necessity of enduring a lengthy and complex legal process, whereby the potential recipient shall be subjected to a judgement based on an assessment of the cared-for person’s future ‘expected’ incapacity (section 15 (1), Adults with Incapacity (Scotland) Act 2000). In

Britain, ‘incapacity’ is decided on the basis of a legal definition (Scottish Executive 2005). It is defined as a state in which a person is incapable of acting, making, communicating, or understanding decisions, or retaining the memory of decisions (Section 1 (6), Adults with Incapacity (Scotland) Act 2000). However, people with dementia may lose the capacity and competence to manage their affairs gradually; the carer’s decision to take authority for their relatives in smaller matters is often spontaneous, rather than premeditated. Since the progression of dementia is very individual, it is frequently impossible to identify or project a specific point at which the transference of power of attorney becomes expedient. This was clearly the problem for Mr. Tobin.

Another scenario relates to informed consent. This is perhaps best demonstrated by specific example: in the younger group, a particular case was described by Mrs. Macleod, whose daughter, Rose (fourteen), would not agree to have a minor ear operation. In spite of her Rose’s objections, Mrs. Macleod took her daughter to the hospital and gave consent for the operation to go ahead. This resulted in conflict between the mother and daughter. As it turned out, the doctor could not persuade Rose to submit to treatment, and they left without the procedure being carried out. In the following excerpt, Mrs. Macleod graphically describes these events, and her reaction to them:

“...We’re in the ward, in the bed, you know, the trolley’s there to take her down. And she wouldn’t budge. And I was so surprised that nobody would help... nobody was helping me. I thought, they’re not going to let her away with this surely? I was expecting somebody to manhandle her onto the trolley and take her, kicking and screaming. You know? I thought that’s what they would do.” (Mrs. Macleod, Phase 1, p.13)

The sort of situation described above, and the ensuing conflict, is a common occurrence for many mothers in the current study. The conflict, in particular, may be explained by the fact that, although the children of these mothers have ID, they nonetheless have a certain level of understanding, and possess a degree of self-awareness. The Age of Legal Capacity (Scotland) Act (section 2 (4), 1991) stipulates that children are entitled to make their own health care decisions if, in the opinion of the medical professional(s) concerned, the child understands what is at stake. Further

to this, it is stated that if children are unable to make a fully informed rational decision, they still have a right of involvement in any discussion concerning their healthcare (NHS Scotland, 2006). Parental consent by proxy does not permit the parent to take control over the child's consent.

Three key aspects are defined regarding the ability to make valid consent: capacity to take a particular decision, capacity to act voluntarily, and the provision of appropriate information to form the basis of a decision (Department of Health, 2001b; Keywood and Flynn, 2003). In relation to the above example (Mrs. Macleod), as long as Rose understood how the operation would affect her health, the doctor and her parents were bound to take account of her wishes, regardless of her age and condition. This is a statutory obligation, based on the Rights of Consent for Children and Young People under Sixteen (Scottish Executive, 2004; NHS Scotland, 2006).

The question of informed consent was also found to be relevant amongst participants in the older group. In these cases, the relevance of the issue often centred on carers' decisions to disclose or withhold information regarding their partner's medical condition. Mrs. Hope (wife of Mark) explains her handling of the issue in the statement below:

“I don't think he really knew what Alzheimer's was, you know, and then that's when I say to him, 'This Alzheimer's...' I say, '... it's a, it's a, you know people that sort of lose their memories', you know. I wasn't going to go into everything, like you lose your memory, you'll not know people, in years to come you'll might not even know... not know who I am, who your children are, you might not even know that... you know. Well I would never say that to him.” (Mrs. Hope, Phase 1, p.72)

The question to be considered in this case is the basis of Mrs. Hope's decision to withhold information from Mark regarding his condition: one explanation might be that she believes he is incapable of fully understanding such information; on the other hand it may simply be the case that she wishes to spare her husband the distress of understanding the severity and terminal nature of his affliction.

A number of studies have focused on the dimension of consent among people with dementia. Resau (1995), Agarwal *et al.* (1996) and Baskin *et al.* (1998) chose to investigate the issue of obtaining consent for participation in research; Emanuel *et al.* (1994) investigated the problem of obtaining consent for medical treatment. People with dementia are recognised as retaining sufficient capacity in the early stages of the progressive condition to continue making valid decision for themselves. Inevitably, levels of capacity change as the illness develops, and judgements regarding the cared-for person's inclusion in the decision-making process become increasingly problematic. In practice, it is recognised that carers always play a key role in making decisions by proxy for their relatives' best interest - as identified in provisions of the Mental Health (Care and Treatment) (Scotland) Act 2003. However, it should be further averred that while, for people with dementia, the capacity to make decisions may become fundamentally compromised, relevant health information concerning themselves must continue to be disclosed. Such a stipulation is based upon the key notion of respect within relationships. Although the carer's tendency towards paternalism is both inevitable and understandable, it is important that in developing this attitude, the carer continues to respect and support the cared-for person's right of disclosure, rather than opposing it.

#### **5.1.1.8 "He's just a shell"**

"He's just a shell" (Mrs. Miller, Phase 1, p.14) eloquently sums up how many carers in the older group came to view their partners. It is a phrase which refers an attention to the key aspect of personhood. Two essential elements by which, for this purpose, carers from both groups identified the quality of being a person were the capacity to make decisions, and the ability to engage in meaningful verbal and non-verbal communication. It is important to point out, however, that participants from the younger group more often alluded to these qualities positively, as characteristics they were either confident of defining in their children, or whose development they anticipated. All members of the younger group, at the least, were secure in their child's ability to communicate.

Figure 4: The theoretical memos of the development of the concept of Personhood

<p><u>15<sup>th</sup> of July, 2006</u></p> <p>The concept of personhood is identified as a category which does not show a clearly a link with other categories at this time. The purpose of understanding the concept of personhood is trying to explain what the carers are doing, their relationships and actions toward their relatives.</p>
<p><u>12<sup>th</sup> of Oct, 2006</u></p> <p>This concept seems to be closely related to a deeper understanding of the carer's paternalistic role. Also, this topic can be enlarged to explore the symbolic interactionism which can identify the symbols of being a person, respecting and values. This property fits with the category of My Life Changed as it only became an issue since they became carers. This is seen, in the older group when Mrs. Miller describes her perception of how her husband's personhood changed (he became like a shadow) as his health condition deteriorated (refers to the quotation of her Phase 2, p.9).</p>
<p><u>6<sup>th</sup> of March, 2007</u></p> <p>Responsibility or Duty</p> <ol style="list-style-type: none"><li>1. My role = My job<ol style="list-style-type: none"><li>1.1 A typical day</li><li>1.2 Taking him into account</li></ol></li><li>2. Paternalism<ol style="list-style-type: none"><li>2.1 Sense of control and confident</li><li>2.2 Protective or overprotective care</li><li>2.3 Hard to let go</li></ol></li><li>3. She's a person</li><li>4. Decision making</li><li>5. Autonomy restriction</li></ol> <p>Concepts of decision making versus autonomy-restriction presented a dilemma in relation to making choices for carers. In other words, the cared-for-person's inability to make decisions for themselves and the carers' sense of responsibility and, therefore, putting themselves and their choices on hold. Making decisions for the cared-for person is recognised as being based on the carer's sense of responsibility. However, the carers' autonomy-restriction is a consequence of accepting the role of being a responsible person. These ideas or notions came from participants. For examples most mothers felt a strong sense of paternalism toward their children, especially those with special needs. They expressed the reality of how their children wanted to be independent but they still needed to be looked after. Mr. Brown described how he wanted to care for his wife, Anne (refers to the quotation of his Phase 2, p.14). However, this was so time-consuming that he could not in consequence pursue his own choices.</p>

Such was not the case amongst the carers of older people. In the majority of cases in this group, the carers observed a steady deterioration in their partner's ability to make

their thoughts and feelings understood, and progressively harboured increasing doubts as to the cared-for person's capacity to form intelligent thought, or understand their own emotions. Not surprisingly, in consequence of this, the issue of communication was a prime concern amongst those carers. Mr. Owen, for example, explained his conviction that "if you don't have communication, you have nothing" (Phase 2, p.8). Interestingly, both of the male carers in the older group expressed the belief that their wives still loved them, in spite of the fact that neither spouse was capable of communicating the feeling in words. Mr. Brown explained his belief:

"...it's the dementia. It's not because Anne doesn't love me anymore. It's because the dementia has put a barrier in her communication and in her intellectual skills...." (Mr. Brown, Phase 3, p.19)

Mr. Brown's attitude here suggests some indication of the importance for carers of understanding and accepting the nature and progress of their partner's disease. The ability to make this adjustment has clearly helped some carers in the older group to re-think their perspective on personhood, in specific relation to the changes they perceive in their relatives, and so retain a concept of their personal value, both to themselves, and perhaps also in general social terms.

In the younger group, the mothers' views on personhood are exclusively positive. In light of the reasons suggested above (paragraph one), this should not be a surprise. All the mothers asserted that their children were people. Mrs. Gill, for instance, gives this description of her daughter Alice, (she is) "...a person with feelings and understanding, but it's just a different sort of understanding....." (Phase 3, p.18). This positive attitude was accompanied by a similarly general acceptance and understanding of the children's incapability. When questioned, all of the mothers confirmed their recognition of incapability in four main areas: communication, management of money, cognitive understanding, and physical activity. In response to this recognition, mothers modified their approach to the children in question, adjusting their own behaviour and communications to accommodate the child's levels of function and understanding. Mrs. Young, in the following excerpt, explains her reasoning in this regard:



“...although Stuart is fifteen he’s still working as... functioning like he was a seven or eight year old. So he still needs that different care, the extra care, the extra support that any seven or eight year old would need....” (Mrs. Young, Phase 2, p.8)

Several mothers stated a belief in the importance of regarding the child with ID as being the same as other children. This is known as normalisation. Those mothers who felt capable of adopting this approach explained that their role as mothers of children with ID is, in all important respects, identical with the role of mothers in general, adding that they felt it was important to respond to their child as they would to any adolescent. Mrs. Robinson, for example, described her son’s teenage behaviour as being identical with what she would expect from any adolescent:

“...you know, like teenagers do, he’s very much a teenager so trying to get him to do something else is quite difficult...” (Mrs. Robinson, Phase 3, p.7)

The concept of normalisation features prominently in a number of studies (Deatrick, Knafl and Walsh, 1988; Knafl *et al.*, 1996; Gallo and Knafl, 1998; Morse, Wilson and Penrod, 2000) addressing the conduct of family life in the context of chronic illness. It is described as a means of minimising the impact of the illness. Morse and colleagues (2000) studied seventeen mothers of children with chronic disabilities, using participant observation; the study identified normalisation as a constant process of identification. This study further defined three components of identification: mind and body functioning, behavioural responses by others, and recognising ability and inability. These components relate fundamentally to the way in which parents see the personhood of their children. Importantly, none of the mothers in the current study expressed the feeling that their child was a different person or ‘a shell’. As suggested above, this may be explained by the fact that the mothers are starting from a radically different viewpoint than the carers of older people. Babies are commonly regarded in terms of their potential; it is thus entirely reasonable that these mothers should consider their children in terms of development, rather than deterioration and loss.

It has been shown that normalisation involves an adjustment of attitude on the part of the carer to the difference, or changes, in the cared-for person’s condition. As such, normalisation for the carer of older people is likely to be more difficult and

problematic, because, in these cases, it particularly relates to changes in the nature of a long-standing adult relationship (which can be related to the earlier section on Relationship, see section 5.1.1.2). There is, however, some evidence of normalisation amongst this group of participants. Mr. Tobin, for example displayed a determinedly positive attitude to his wife Alison, saying “this is the person I married” (Phase 2, p.22). In making this statement it is clear that he is consciously endeavouring to adhere to a belief in his wife’s continuing personhood. This reflects the fact that her personhood remains important to him. It may also signify his appreciation that she retains an equable disposition. It perhaps also helps him to remain strong, providing a continued rationale for caring. Predominantly, however, carers in the older group were confronted with the challenge of accepting the progressive diminution of personhood in their partner. Mrs. Baird, for example, in reference to her husband Neil, states the belief that “his mind’s gone” (Phase 2, p.12); Mrs. Miller gives a similar description of the feelings she experienced after her husband Kevin was moved into formal care:

“I’ve had a death of my husband but his body’s still there.” (Mrs. Miller, Phase 2, p.19)

The difficulty of admitting the extent of degeneration for these carers is often considerable. Mrs. Miller, for instance, wept throughout the course of the interview from which the above statement is taken. However, it is worth reflecting that the carers’ ability to recognise and describe the changes in their partners - effectively, their willingness to relinquish attachment to the personhood of their partner - although painful, may nonetheless be an important means of accepting and coping with the reality of their situation. Mrs. Hope, in the quotation below, clearly demonstrates this process of adjustment:

“He’s this other person that’s ill now and he doesn’t know what’s wrong with him and he can’t... what he does like being incontinent... he can’t help that. It’s, it’s his illness. That’s how he’s a different person, that’s how he’s a different person and that’s how I can, I can cope with him ah, because I know that he’s not that, he’s not that... he’s a different person because he’s ill, that’s it.” (Mrs. Hope, Phase 3, p.25-26)

This suggestion is consistent with a study conducted by Davis (2004), which challenges the biomedical view of dementia from perspectives of sociology and philosophy. He pointed out that deliberate preservation of the personhood of people with dementia may increase the burden for family carers, because they face a progressive condition; the effort of cultivating and sustaining a concept of personhood in the face of progressive deterioration is more likely to result in a negative outcome, increasing rather than lightening the caring demand. In addition, it might be noted that changes in the cared-for person do not always have a negative impact. In the progress of a condition such as Alzheimer's, for instance, the early stages of the disease may often be considerably more distressing, both for the cared-for person and the carer. A quotation from Mrs. Hope, whose husband Mark lived with this condition, confirms the possibility of positive personality change:

“...I would say his personality's a bit... he's more... he's more, uh... he's more, um, he seems to be happier.” (Mrs. Hope, Phase 1, p.30)

### **5.1.2 “...doing it with a sixteen stone man on my back...”**

The above quote, drawn from a longer quote by Mrs. Murray, a single mother, who cared for two children with special needs, expresses her perception of the caregiver burden “...so everything's just heavier, longer and harder” (Phase 1, p.53). Caregiver burden refers to the onus of stress and demands on the carer's time - both in terms of hours per day, and the long-term period of care duration. It is inevitably compounded by an attendant range of general household chores, and issues of health and ability with regard to the carers themselves. As such, it might be summarised as representing the negative consequences of change in the carer's life. Mrs. Murray's perception of the weight of this burden is illuminated in the following excerpt, in which she extends the descriptive metaphor cited above:

“You just try doing something, say somebody says to you go and run up and down there, okay, but you have to carry me on your back. So how... You would be tired, you would be really puggled but if you were just doing it on your own you'd be fine, but that's what it feels like half the time. You've got this big man on your back, you are

just... not a man... it could be anybody, you've just got this big twenty pound package on your back." (Mrs. Murray, Phase 3, p.4)

Physical confirmation of the effect of this burden on Mrs. Murray is perhaps provided by the fact that, between the Phase 1 and Phase 3 interviews, her weight had visibly increased. This may of course be put down to the natural effects of ageing, but equally might reflect the attritional effects of caring - a 'slowing' effect, the palpable signs of which are often increased body fat and loss of muscle tone. It should be noted that the majority of past research has sought to demonstrate levels of caregiver burden quantitatively, and/or by relating it to subsidiary variables, such as caregiver gender (Rousey, Best and Blacher, 1992; Bruce, Schultz and Smyrnios, 1996; Winslow and Carter, 1999) and levels of education (Haveman *et al.*, 1997; Scharlach, Li and Dalvi, 2006). The relevance of such characteristics is inevitably restricted to the specific relationship in which they are observed. Other studies have focused on relation between effects (Hinrichsen and Niederehe, 1994; Meshefedjian *et al.*, 1998), which tend to produce inconsistent results. Within this body of research there is little in the way of qualitative evidence, (such as is offered above by Mrs. Murray). Importantly, such qualitative evidence offers a better understanding of the nature of the caregiver burden, and is many ways more powerful.

On the evidence elicited from both groups in the current study, it is possible to define five types of care demand, which may be regarded as comprising the weight of the caregiver burden: personal care, supervision, domestic chores, encouragement, and nursing tasks. These tasks comprise an objective response to assessment of caring demand. It is important to add, however, that the responsibility of care also includes a range of subjective demands.

Figure 5: The theoretical memos for developing the concept of Caregiver Burden

20<sup>th</sup> of Nov, 2006

‘A typical day is giving her medicines, changing her nappy, dressing her, making sure that she does not em, talk to strangers, go away with strangers. Making sure she doesn’t hurt herself in anyway of... outside or inside the house. Making sure that you’re in the same room with her or if you’re not in the same room that you’re in the next room and you’re monitoring her by listening to her. You’ve got to have very good ears eh, and you’ve got to have eyes in the back of your head quite a lot with Emma so.’ (C6-1, p.13)

‘A typical day’ describes the daily demands of care. I included this concept in the property of My Role because I believe that, if I understand their role as carers, this then introduces some clarity into what they do for their relatives and begins to draw attention to the caregiver burden.

28<sup>th</sup> of Jan, 2007

The concept of caregiver burden is identified as being both objective and subjective burden and which come from the literature (Montgomery, Gonyea & Hooyman, 1985; Platt, 1985; Braithwaite, 1992; Vitaliano *et al.*, 1991; Reinhard & Horwitz, 1995; Borycki, 2001; Brannan & Heflinger, 2001). Objective burden refers to the negative effects resulting from household chores, such as: loads (amounts) of care. For example, Mrs. Murray points out that she is “shadowing” (Phase 3, p.3) to supervise what her daughter is doing on a daily basis; Mrs. Hope also stated that “it’s not just day care, it’s being there when they want you there and time it takes” (Phase 3, p.21). Subjective burden refers to emotional stress resulting from the role of caring, such as the feelings of guilt and frustration. Noticeably, care demands are categorised as a part of the load of care (objective burden).

The property of care demands started off by being placed in the category of Responsibility and Duty but was then moved to being a dimension of the property of Caregiver Burden because it presents a different level of the view of the diversity of the load of work.

12<sup>th</sup> of July, 2007

The diagram of this dimension can be seen below:

Category: My Life Changed

- Property 1: Effects of Change
- Property 2: “...doing it with a sixteen stone man on my back...”- the nature of burden and the load of work
  - Dimension 1: “I can’t stand this...”- psychological burden
  - Dimension 2: “It goes for your health...”- physical burden
- Property 3: Coping Strategies

Personal care involves maintaining personal hygiene, and meeting the private needs of the cared-for person. All carers in the older group assisted their partners in the

disposal of various tasks within this category, such as bathing, toileting and dressing. Supervision involves monitoring the behaviour of the cared-for person, ensuring that they do things correctly, and are generally physically safe. Mrs. Murray gives a typical description of this element of her responsibilities in the following quotation:

“...I’ve just always had to be one step ahead, I’ve always had three eyes, or four because I’ve got one at the back of my head as well because I seem to have rotating eyes, and then I always know what's happening behind...” (Mrs. Murray, Phase 1, p.25)

Domestic chores typically include such activities as washing, cleaning, cooking and general household maintenance. All participants confirmed their involvement in such chores. In addition, many spoke of their efforts to persuade the cared-for person to co-operate, and, where practicable, contribute in the general range of caregiving activities. In the older group, Mr. Brown encouraged his wife to maintain some involvement in self-care, for instance, by helping to bathe, herself. Inevitably, however, in cases such as Mr. Brown’s, which involve his wife with dementia, the degree of success in persuading the cared-for person to sustain such efforts decreases over time.

Nursing tasks involve the administration of medication, and making judgements with regard to the need for additional assistance (from relatives, for instance). Responsibility in this area was common to both groups of participants. Many carers reported that the organisational effort of categorising care demands proved useful, enabling them to maximise use of time and energy, and making the tasks themselves seem less onerous. It should be added, however, that inevitably, at certain points in the day, a number of caregiving tasks may require simultaneous attention. Even when this is not the case, it must be remembered that every task involves the expenditure of time and energy - a fact which must always be taken into account in any assessment of caregiver burden.

The demands of care discussed above are consistent with those identified in a number of previous studies (Beresford, 1994a; Twigg and Atkin, 1994; Nolan, Grant and Keady, 1996; Padeliaadu, 1998; Read, 2000). Padeliaadu’s (1998) study focused on the caring experience in eighty-two mothers of children with and without DS. It

identified levels of demand on time which were generally higher, and tended to increase, for mothers of children with DS, as compared with the total time expenditure for mothers of children without DS. These levels of demand were related to time spent on recreational and educational activities.

Longitudinally, major changes in caring demand were found in both groups. For most of the mothers, this change comprised a reduction of physical caring demand as their children got older. Evidence from Mrs. Gill (below) confirms this tendency:

“Well when they are very young they need such a lot of physical cares all day, every day, don’t they? So it’s much easier when they are older....” (Mrs. Gill, Phase 2, p.48)

This finding is consistent with a quantitative survey conducted by Haveman *et al.* (1997) of 2,573 parents of children with ID across the life cycle. The survey revealed that time demand reduced from early childhood (average thirty-one to sixty hours per week) to adulthood (average thirteen to thirty hours per week). Although the mothers in the current study confirm this trend, the general weight of opinion amongst them was that, in comparison with mothers of similar-aged children without disability, their workload is obviously higher. Mrs. Young, in the following excerpt, articulates this feeling:

“Well... a fifteen year old... a fifteen year old boy would be a lot more independent about going out. He would be able to communicate better than Stuart does. I would feel a fifteen year old boy...it would be safe for him to go to the shops on his own, to take a bus on his own, um... to be left in the house on his own, and to be able to make their own decisions about where they went and what they did. Whereas, for Stuart, he’s not able to do that so he needs extra support from us.” (Mrs. Young, Phase 2, p.5)

For carers in the older group, longitudinal change of care demand was consistently described as an increase in caregiver burden. Mr. Owen referred to a process of “caring and more caring and more caring” (Phase 1, p.3) which, for him, had extended over eight years. However, although the levels of demand clearly differ for both groups (for the younger tending towards reduction, for the older increase), in both

groups, caregiver burden is associated with a long-term caring commitment - a commitment which, for some (particularly mothers) is likely to be lifelong.

“I think as time’s gone on I’ve realised that I will have to spend my life caring for her. She was eighteen this year. That was very hard because, you know, at eighteen you become independent, you are an adult and you leave, and I realised that... that wasn’t going to be the case. It kind of hit me that ‘Oh dear, she’s eighteen, she’s an adult and she needs as much care as a six-year old’ and that’s always going to be the case. So that was quite hard. I found that really... more hard than having her in a way, more hard than when I had her...” (Mrs. Gill, Phase 3, p.4)

It is fair to suggest that, at least for some mothers of children without disability, there is the prospect of an end to their responsibilities. This is unlikely to be the case for the majority of mothers in the current study. The realisation of this fact is clearly difficult for Mrs. Gill. She is faced with an inevitable comparison between the expectations she might have of an ‘ideal’ daughter, and the reality of her own daughter’s limitations - and specifically of what this will mean to her as a mother. She must envisage a state of permanent childhood in her daughter, and consequently a life of permanent motherly responsibility for herself. It is clear that although Mrs. Gill has no illusions in this matter, she is nonetheless struggling to accept the implications. The emotional drain of such a struggle is, in this case, and most likely for many mothers in Mrs. Gill’s position, an important element of the caregiver burden.

#### **5.1.2.1 “I can’t stand this...”**

The phrase “I can’t stand this” vividly conveys the reality of emotional stress which carers in both groups experience. It is an outburst, clearly subjective, connected with the carer’s perceptions of an intolerable situation, and is self-evidently a negative emotional response to the burden of care. It is drawn from a longer statement delivered by Mrs. Miller, which is given below:

“I get frustrated and... He’s not got the concentration and if I tell him things I have to tell him... If I say to him ‘Get the brush and brush



your hair... get the brush and brush your hair'. I have to say it about ten times and then I go in to the bathroom and I go 'Oh! I can't stand this', you know." (Mrs. Miller, Phase 1, p.5)

Mrs. Miller's statement is in many ways typical, in that it confirms the connection of emotional stress with the frustration many carers expressed at having to do and say the same thing repeatedly.

However, although emotional stress was a common complaint amongst many carers, other forms of negative emotional experience were confirmed. A number of carers, for instance (particularly amongst the older group) described feelings of guilt. For the carers of older people, this feeling often accompanied a realisation of the decline in their own health and capacities - an eventuality which, in tandem with the increasing demands incumbent on them as their partner's condition deteriorated, necessitated a greater level of assistance from other family members, or from external sources. Acceptance of the inability to manage alone, and the frequently difficult prospect of asking for help are both productive of guilt, as Mrs. Hope confirms in the statement below:

"Well you feel that you're sort of handing your... your... your... your husband, or your child, over to somebody else and you don't know how they're going... if they're going to be well treated as well as you can treat them, you know, as well as you could look after them. You... you just feel guilty, you think... you feel that you should be here, you should be... you're... you're the one that should be doing everything and looking after your husband and you do feel guilty..." (Mrs. Hope, Phase 1, p.46-47)

It is often also the case that carers may accuse themselves of accelerating their partner's deterioration, and hastening their death by committing them to formal care. Mrs. Miller, in a moving statement, expresses these emotions:

"... I felt it was because I put him into the nursing home, and I felt if I had [crying] kept him here it would never have happened... Anyway, he's at peace now. But it's very difficult to come to terms with, because I blame myself." (Mrs. Miller, Phase 3, p.3)

A study conducted by Nolan and Dellasega (2000) reports that such feelings of guilt may last for several years following the transition from community-based to

institutional care. To the objective observer it will seem obvious that, in the majority of cases, such self-accusations are false and unnecessary, tending to be based upon unrealistic self-expectation in the carer, or an overly optimistic assessment of the extent to which they can affect their situation. It is important, however, to recognise the reality of these emotions for the carers in question, if one is to understand fully the nature of the caregiver's burden.

Participants in both groups described experiencing feelings of loss. Mrs. Miller displayed visible signs of grief when she referred to her husband's move into a nursing home:

“I've lost him completely, but he's still there - and it's worse than a death....” (Mrs. Miller, Phase 2, p.22)

Mrs. Miller provides an example both of transitional loss (when her husband was moved), and actual loss (he died six months after the move). However, it was evident that her feelings of loss were greater and more debilitating in reaction to the move than they were to his eventual passing. It is possible that this was because acceptance of the transitional loss presented her with the greater and more complex emotional challenge. This is suggested by the specific detail in which she recalls the experience of visiting him - the fact that he did not recognise her while she held his hand. The exactness of the memory tends to suggest that it represented an important emotional turning point for Mrs. Miller, one which, in some ways perhaps initiated in her the process of adjustment to the prospect of actual loss, thus making that eventuality ultimately easier for her to deal with. While her husband's move into formal care may have provided her with a form of physical relief (from the burden of caring), his death provided her with an emotional relief. However, the longitudinal impact of her husband's death should not be overlooked. After six months of visiting him, she was, she explained “...utterly exhausted, and... but I couldn't settle myself...” (Phase 3, p.7). She went on to describe the changes which her husband's death wrought in her:

“I became bitter and I became bolshy and arguing with everybody and I just felt... I don't know what I felt but my daughter said ‘Mum, you've changed, I want my mum back’. She says, ‘You have changed’, I says, ‘I haven't!’ [laughs] But I had. I realised I had... I felt... I was arguing with everybody, you know.... Because I felt so bitter

about life, the fact that my... the person I loved most had been taken away.” (Mrs. Miller, Phase 3, p.9)

Adams and Sanders (2004) posed open-ended questions regarding experience of loss in ninety-nine family carers of relatives with dementia. In the resultant findings they identified three categories of loss in relation to the stages of disease: loss of sharing in the early stage; loss of personal time and activities in the middle stage; and loss of interpersonal relationships at the final stage. However, it is reasonable to suggest that in the day-to-day and long-term course of the illness, the divisions between the feelings of loss thus identified will not be so clear cut, but (certainly for the carer in question) will present as a very mixed emotional state.

A distinct, yet related emotional response is that of simple sadness. In the younger group, Mrs. Murray described the sadness she felt when reflecting on her own state as someone caring for two children with special educational needs (SEN) alone. Mrs. Macleod also described feelings of sadness for herself, although in this case her sadness was identified with reflections on how things might have been different (for example, if Rose had been born ‘normal’):

“...it’s at times like that I’ll catch myself thinking, ‘Oh you know, if only she’d been okay we wouldn’t have this hassle.’...” (Mrs. Macleod, Phase 2, p.3)

But she further described the sadness she felt for her daughter, lacking similar aged friends with whom she could communicate and socialise.

Many participants in both groups also spoke of worry and anxiety. A common source of such feelings among carers from both groups alike was the prospect of facing an uncertain future. Mrs. Robinson was one of several mothers who admitted to anxiety about a possible future in which she was no longer able to care for her son Harry:

“You know, they’re living with ageing parents and it must be a terrible worry to the... what happens to them after the parents... well, not to them but the parents must worry about what will happen to them if they can’t care for them any longer....” (Mrs. Robinson, Phase 1, p.32)

The concerns expressed by Mrs. Robinson in this excerpt are in many ways consonant with findings in a number of extant studies. A qualitative study conducted by Llewellyn *et al.* (2003) explored the caregiving biographies of sixty-four mature parents of adult children with ID. The study suggested that ageing parents are often fearful of the future, as in all likelihood, they will die before their children. Such concerns may lead to feelings of persistent anxiety through middle-age into old age - feelings which are likely to increase as the effects of ageing (tiredness, decreased mobility) become more evident.

Worries of a similar nature afflicted many carers in the older group. All were confronted with a negative prognosis with regard to their partner's condition, and at the same time with the signs and symptoms of ageing in themselves. It was therefore natural for many of them to worry about the difficulties of managing in the immediate future.

“I didn't used to bother about it, but now I think how far is it going to go? How bad is it going to get? Before I could handle it, now it really bites, just how... how far is it going to go?” (Mr. Owen, Phase 1, p.22)

The difficulty of projecting and anticipating future developments in cases of dementia is an inevitable source of anxiety for the spouses of people with dementia. For Mr. Owen, it is clear that his uncertainty as to what the future may hold is the core of his worry. He is obviously pragmatic about his wife's condition and likely deterioration, but this pragmatism does not bring him any comfort. Rather, it seems to cause feelings of helplessness, which could well lead to emotions of frustration and anger at his inability to alter the course of events. The day-to-day attrition of dealing with such an emotional burden cannot be overestimated, both in terms of its psychological and physiological effects. Mr. Brown's development of insomnia and symptoms of stress reinforce this point.

A number of carers in both groups also reported feelings of depression. One of the carers of older people, Mrs. Baird, was faced with the dual burden of managing her husband's care and coping with the physical and emotional distress of breast cancer. Depression in such a situation is unsurprising. Furthermore, while many carers in the both groups described symptoms of depression, there was no evidence that any had

been clinically diagnosed. However, a number of cross-sectional studies (Stommel, Given and Given, 1990; Tennstedt, Cafferata and Sullivan, 1992; Gallant and Connell, 1997; Olsson and Hwang, 2001) have found depression to be significantly associated with caregiver burden. Olsson and Hwang (2001) investigated levels of depression in two hundred and sixteen parents of children with ID, and a control group of two hundred and fourteen parents of normally able children. They found that parents in the former group manifested significantly higher depression scores than the control. A series of longitudinal studies, lasting between one and six years (Pruchno *et al.*, 1990; Schulz and Williamson, 1991; Shaw *et al.*, 1997; Goode *et al.*, 1998; Alspaugh, Zarit and Greene, 1999; Li, Seltzer and Greenberg, 1999) confirm the association of depression with caregiver burden, and report that depressive symptoms and general negative health effects increase over time.

#### **5.1.2.2 “It goes for your health...”**

As suggested above, the psychological and physical health of family carers may be profoundly affected by the emotional burden of their responsibilities. Examples of such effects were found in both groups, but tended to show up more clearly in the older group - quite possibly because the vitiating effects of fatigue and stress may exacerbate the natural process of ageing. A common complaint, exemplified by Mr. Brown’s experience, is sleep disturbance.

“...I think... oh, she’s only had about two or three nights at most that she’s actually wakened up... It’s usually me that wakens up because I’m sort of lying on edge, waiting on her, and I think... I think it’s possibly the... the sort of... the stress of looking after her, I don’t sleep as well as I used to.” (Mr. Brown, Phase 1, p.17)

Mr. Brown went on to reflect upon the possible causes of his insomnia, identifying a general sense of anxiety, and worries in particular about his wife’s tendency to wander at night. A study conducted by McCurry and Teri (1995) found 68% ( $n=136$ ) of family carers reported sleep disturbance on three or more nights per week.

General fatigue was a feature of the experience of both groups. A number of the carers reported feeling physically tired throughout the day, putting this down to the combined effects of age and care demand. These findings are broadly consonant with findings published by Pinguart and Sorensen (2007). In a review of one hundred and seventy-six papers, they found that elderly carers and their spouses displayed significantly worse physical health than carers and the cared-for persons in other types of relationship. Mrs. Hope (whose words provide the heading to this section) gives evidence of this possibility below:

“I think it does go for your health, yes. Because I... I never used to have high blood pressure but I've got high blood pressure now...”  
(Mrs. Hope, Phase 1, p.42)

Mrs. Hope's experience accords with findings reported in two studies published within the last fifteen years. A study conducted by Shaw *et al.* (2003) established a relation between raised diastolic blood pressure in carers (over 90 mmHg) and behavioural problems of the cared-for people. The study further established a correlation between carer hostility and short-term fluctuations in blood pressure. A clinical trial study conducted by King, Oka and Young (1994) compared instances of raised systolic blood pressure in carers of people with dementia, as against non-carers, and found that the incidence was significantly higher in the former group.

Some of the more mature mothers in the younger group of participants felt that the effects of menopause negatively impacted upon their abilities as effective carers, causing a shortening of temper, and increased incidence of physical and mental fatigue. Mrs. Robinson (mother of Harry) talks about such experience.

Mrs. Robinson: “Well you know menopause and all that sort of thing...”  
Researcher: “Does that affect you caring for Harry?”  
Mrs. Robinson: “You know there's more moods now which is hard sometimes. Sometimes depression, you know, which I think is part of it; I get very tired sometimes.” (Mrs. Robinson, Phase 3, p.16)

This evidence accords with findings published in a study conducted by Todd and Jones (2005). The authors investigated caring experiences in thirty mothers of children with ID, using qualitative interviews. In their results they sought to

emphasise the importance of interactions and relationships between mid-life mothers and adolescent children, and reported that the mothers studied described decreased levels of energy, and general debilitation in their physical health. To date, however, there is no evidence that the burden of providing care in any way impacts on the natural course or effects of the menopausal change.

### **5.1.3 Coping strategies**

Coping strategies are physical and mental mechanisms which enable the carer successfully to consider, manage, resolve and reflect upon the various difficulties and challenges of the caregiving situation. Numerous strategies were applied differently by every participant; it is clear in the evidence from both groups that there is no single optimum approach to the variety of problems and difficulties they must encounter.

#### **5.1.3.1 “You learn from experience...”**

“You learn from experience” (Mrs. Gill, Phase 2, p.47), is a phrase which epitomises one of the commonest coping strategies amongst both groups of carers. It refers to a fundamentally practical long-term attitude to the development and acquisition of necessary caring skills. At its root seems to be the belief that the only way to learn how to care successfully is by doing it – because only in that way can you understand the nature of the physical, psychological and emotional demands that will be made upon you, and develop the necessary skills and resilience to meet them. The way of linking learning and coping strategies was suggested by many participants. The following example (below) is Mrs. Hope (wife of Mark) and she talks about her learning experience in dealing with her practical situation.

“...he’s quite possessive. I don’t mean with me. Like supposing we’re in a café or a bar, and we’re having maybe a drink or a cup of coffee or something, and he’s finished his glass of juice, right? And he’s finished it. And it’s empty, and he’ll put his glass down and maybe the waiter will come and just goes like this. And he’ll go, ‘That’s mine.’ He thinks it’s his glass. He’s lost that social skill, that the glass belongs to the café, to the restaurant, to the bar, you know?”

And wee things like that. So how we handle that is, we put him right in the middle of us all, so instead of him being at the end where the waiter's walking past, and he goes like that and goes like this, to the waiters you know? We'll put him in the middle so that that never happens. But these wee things you learn as you go along." (Mrs. Hope, Phase 2, p.5)

Many participants confirmed that they had developed broader outlooks, and acquired new skills as a direct result of finding themselves in situations which required them. This basically pragmatic attitude to coping is summed up by Mrs. Murray:

"Life doesn't come with a guarantee and unfortunately I had to learn in a bit of a big bump but, no, I mean, it's sad because, even though, they are a lot of hard work..." (Mrs. Murray, Phase 1, p.42)

Amongst the older group, Mrs. Miller felt that she developed a stronger personality as time went on, which helped her to be firm in the face of her problems. Mr. Tobin, whose wife's vascular dementia severely restricted her movement, gives a detailed account below of the practical process of learning to cope with the attendant difficulties in dressing her:

"Sometimes, it's a bit trial and error, for instance, you learn that if the movement is bad on the right side then when you put something on, clothes, you put the right side on first and then you put the left side because there's more flexibility on the left side for getting, for instance, into a sleeve. Um, because then you learn, when you're taking the garment off, it's the opposite, you take the left side off because there's movement there and when you've got the left side off she can slip the right one off." (Mr. Tobin, Phase 1, p.3)

The concept of learning was not thought to be important at the beginning of data collection and analysis period, rather, it was viewed at this time as being a matter of common sense (Memo of 26<sup>th</sup> of February, 2005). However, during subsequent interviews, some participants, especially the carers of older group, expressed the view that they found their lives were more manageable as they went along in relation to the process of learning. It was at this time the concept of learning from experience began to emerge as an important element of their experience (Memo of 7<sup>th</sup> of July, 2006).

"I don't know because I've never cared for anybody before. I've always been cared for. So this has been a learning experience, a



learning curve for me and I take it as it comes.” (Mr. Owen, Phase 3, p.15)

Researcher: “How can you describe your caring experience for 10 years?”

Mr. Owen: “Because you don’t realise you’re doing it. You do... It’s happening so slowly and you’re adapting to it. You adapt to it without realising it and you’re just doing things. You think that’s normal, everybody does it and it’s not until you get to maybe the stage before Iris is at now, you know, there’s a problem there but by that time, you’re so far down the road that it’s easier. It’s not like something, somebody being struck down with something like that where you suddenly have to adapt your whole life to it. I’ve been learning this for the past ten years and growing as the, as the disease progresses, so as my caring progressed, if you like, and the two are inseparable really.” (Mr. Owen, Phase 3, p.14)

The foregoing quotations shows that caring is a learning process which accompanies a growing experience. Learning also requires understanding, recognition, realisation and reflection which enhance the quality and effective of learning strategy which were reflected through writing memos (Memo of 8<sup>th</sup> of April, 2007). The process of learning provides a realisation reason for accepting things. As Mrs. Hope talks about it:

“... And getting angry, before I would maybe get angry because he was still okay and I was saying, ‘Why, why are you doing that? Why are you breaking that pen?’ or whatever he was doing. But now, I don’t... I still get annoyed but I understand that he can’t help it, you know? And angry, getting angry does not work so why put your blood pressure sky high? (Mrs. Hope, Phase 2, p.15)

Moreover, further analysis of learning is influenced by the purpose of the activity engaged in, sources and outcomes of their experience and through the gleaned thought the researcher’s theoretical memos (Memo of 16<sup>th</sup> of April, 2007). In this latter sense, further reflection revealed that of the process of learning from the experience of caring helped the participants to manage their lives more effectively (Memo of 27<sup>th</sup> of April, 2007). For example, Mrs. Hope, wife of Mark, illuminates that learning gives her a strategy to deal with her emotional stress.

Mrs. Hope: “I’m anxious you know? I’m uptight.”  
Researcher: “But how did you manage?”

Mrs. Hope: "Well, just experience."

Researcher: "Uh-huh."

Mrs. Hope: "You just learn just as you go along. You think, 'What's the point of getting uptight about something, getting flustered about something when it can't be helped and he's not doing anybody any harm?' But I don't get... I don't really get uptight now. I'll just maybe say to him, if we meet somebody in the street, or he's sitting in the bus and he's talking away to somebody, I'll say to him, 'Mark, look at that.' You know? Like a child I'll distract his attention. So I learn, you learn to do things like that, to distract their attention." (Mrs. Hope, Phase 2, p.7)

The sources of learning are many, such as friends, support groups and personal experiences. Learning from other people provides an example of dealing with certain things or situations but there is still an uncertainty and a potentially unhelpful risk in applying it to practice as the effective strategy may differ from person to person in different circumstances. On the other hand, and importantly, learning about one's self offers a uniquely useful approach to a deep understanding and realisation about one's situation (Memo of 15<sup>th</sup> of September, 2007). For example, Mrs. Gill and Mrs. Hope talk their experience of learning:

Mrs. Gill: "I was very stressed then, because I had Dan, who was 22 months old and was a little two year old rushing around like a two year old and having two year old tantrums and not sleeping and pulling the baby this way, that way and the other way and was ill and special needs. Yes. That was very stressful, yes. Hugely stressful."

Researcher: "Yes? How about now?"

Mrs. Gill: "Less stress."

Researcher: "Oh, so she doesn't need any health... No. She don't need any appointments?"

Mrs. Gill: "Oh yes, she has a lot of appointments, but you don't get into the same level of stress, because you've done it all hundreds of times before so it's not stressful."

Researcher: "Yes?"

Mrs. Gill: "Do you see what I mean? If you've done something loads of times you know where you're going and you know where you're going to see and..."

Researcher: "Uh-huh."

Mrs. Gill: "You learn from experience." (Mrs. Gill, Phase 2, p.47)

"Well I feel, I feel since I've become a carer I'm more understanding ah... as regards people that are ill. I mean I've always been like... like understanding of people that are ill but I... I just feel I'm more understanding with Mark and I've got more, I've got more patience, more patience and it's not because I've got patience it's because I've

had to learn to have patience because you have to have patience in this job. It is like a job I tell you.” (Mrs. Hope, Phase 3, p.20)

The dimension of you learn from experience fits into the category of Coping strategies as I believe that this type of learning can be activated by life changes as experienced by the participants. Since carer’s lives changed, they wanted to cope with these differences using their developing knowledge. ‘You learn from experience’ represents one of the fundamental coping strategies (Memos of 8th of August, 2007).

A study conducted by Rapp et al. (1998) confirms the general view that gaining knowledge is a fundamentally important coping strategy. Several other studies (Haley et al., 1987; Wright, 1994; Almberg, Grafström and Winblad, 1997; Grant and Whittell, 2000; Kim et al., 2003) reiterate this point, and emphasise the particular importance of learning as a means of altering difficult situations. Such ‘learning’ strategies may be grouped with problem-focused coping strategies identified in Lazarus and Folkman’s Stress and Coping Model (1984). Kneebone and Martin (2003) reviewed sixteen studies of carers of relatives with dementia in relation to this model, and reported that problem-focused coping strategies were recognised as being advantageous. On the other hand, Pruchno and Kleban (1993) could identify no relationship between problem-focused coping and improved mental health, stating that the existence of such a relationship could only be advanced on the basis of further investigation. However, reflecting on the disparity between these findings, it may be worthwhile to notice that Pruchno and Kleban’s research sample involved 424 adult carers. However, their parents were in institutions and so their experiences could not be said to be the same or as a comparable group. From this limitation, the contention in this thesis is that learning from experience, has been identified as being qualitatively different and therefore could be seen to constitute new knowledge in our understanding of these carers perspectives and experiences of caring.

### **5.1.3.2 “Kicking the bed covers and screaming...”**

“Kicking the bed covers and screaming” (Phase 1, p.26) is Mrs. Miller’s succinct summary of her response to the frustrations of caring - a way of venting the pent up

emotions which may accumulate in the course of a 'normal' day. The detail of how she found herself at this point of frustration is added below:

“...he had wet everything on the bed, I had to strip the whole bed, I had to even take the underblanket, everything off, and it was all lying on the bedroom floor and he's standing in a mess and, um, I just couldn't cope and I'm kicking the bed covers and screaming...” (Mrs. Miller, Phase 1, p.26)

Mrs. Miller's account demonstrates a very necessary form of coping strategy - the need to regulate the tension which can mount up inside a carer, by finding some means of expressing it. Carers in both groups referred to various means by which they achieved this release, including crying, shouting, and walking away from the source or trigger of the outburst. Although such outbursts are clearly spontaneous, not in any way premeditated, their value as a coping strategy should not be underestimated. A number of mothers and elderly female carers admitted to crying. This is not uncommon, particularly in female carers. Several previous studies (Borden and Berlin, 1990; Miller, 1990; Vingerhoets and van Heck, 1990; Baum and Grunberg, 1991; Ptacek, Smith and Dodge, 1994) point out that crying is more usual among female than male carers. This finding can be linked more generally with the understanding of the differences in emotional expression between genders - differences which may be due both to innate expressive tendencies as well as the effects of social and cultural conditioning.

Strategies of emotional release may also be specific to the individual carer. Mrs. Murray, for instance, admitted she often found relief through shouting, as she explains:

“Actually the shouting quite often helps me. It does, it's just like the pressure cooker or the... you know, just a steaming pot and you just let the lid go where you just... and then you come down and you think 'oh right, right' ....” (Mrs. Murray, Phase 1, p.34)

The frequency of such outbursts also varies considerably from individual to individual, so too the specific triggers which provoke them, although these tend to be characterised by some species of 'crisis', such as the incident of the bed-wetting referred to by Mrs. Miller's earlier quotation. It may also be that a carer will resort to differing release strategies, often depending upon the specific nature of the crisis

which provokes them. Mrs. Murray explained that she sometimes found relief in simply withdrawing from the scene of a provocative crisis, or ‘putting her thoughts away for the day’ as a way of coping with emotional fatigue:

“I’ve got quite a good filing cabinet up there that we just, put it away for another day. Because you can’t... I mean sometimes it gets on top of you and you could have a big bubble and say, “Why me?” But then you just have to...” (Mrs. Murray, Phase 2, p.9)

There are perhaps some similarities between the approach Mrs. Murray describes and escape-avoidance coping strategies, and it might be tempting to ascribe her behaviour to a form of denial. But there may be a danger of over-simplification in making such a judgement. Rather, it should be perhaps asked whether the particular dilemma she is addressing – namely the question ‘why me?’ is soluble in any other way. It is not, for the simple reason that this carer is responding, in this instance, to the reality of a situation which has been thrust upon her, whose progress she cannot materially alter. Therefore, in this case, the act of putting her troubles to one side represents an expedient and effective coping strategy. To put the matter in its simplest terms, ‘why me?’ for Mrs. Murray represents a question to which there is no rational or valuable answer. To desist from trying to answer it is more useful than allowing her inability to do so to exacerbate her frustration.

Perhaps a more conventional and less controversial release strategy, which was mentioned by a number of carers, is the development or cultivation of a harmless diversion - a means of ‘switching off’. Mr. Brown, in the following quotation, gives an example:

“If I’m thinking about a crossword... I’m not thinking about something else... It’s relaxation, but I’m concentrating... I’m not thinking about ‘What’s Anne doing?’, or ‘What am I doing?’, and that kind of thing, I’m thinking about a crossword!” (Mr. Brown, Phase 1, p.30)

This type of release tended to be more prevalent amongst carers in the older group. A possible explanation for this might be the fact that mothers in the younger group tended to have a wider circle of friends, and so more opportunities to go out, as well

as the money and the energy to do so. Their home situations also made it more likely that they could rely upon someone to fill their shoes while they relaxed in this way.

The above-mentioned group of coping strategies bears close resemblance to certain emotion-focused coping strategies identified by Lazarus and Folkman (1984). Several previous studies (Haley *et al.*, 1987; Frey, Greenberg and Fewell, 1989; Miller and Cafasso, 1992; Seltzer, Greenberg and Krauss, 1995; Haley *et al.*, 1996; Patrick and Hayden, 1999; Knight *et al.*, 2000; Powers, Gallagher-Thompson and Kraemer, 2002) have reported negative affects associated with emotion-focused strategies (for example, caregiver burden or carer depression). On the other hand, some qualitative studies (Brown and Hepple, 1989; Beresford, 1994b) have suggested that certain emotion-focused coping strategies, such as watching a comedy programme, having a hot bath, or even, as in the current study, doing a crossword were helpful. On the basis of the evidence in the current study, it certainly seems to be the case that emotion-focused strategies may bring the benefit of diminishing psychological distress. The broad view might be that the effectiveness of such strategies is very much dependent upon the individuality of the carer.

### **5.1.3.3 ‘I’m in control...’**

In an interview conducted during Phase 3 of the current research (p.21), Mrs. Macleod used the above phrase, referring to the sense that she is ‘on top’ of the caring situation. A number of participants were like her in expressing the importance to them of a sense of control, and the ability to manage their lives. This sense of control may derive from a variety of sources, and apply not only to the carer’s confidence in their control of the cared-for individual, but also to those bodies or individuals connected to the case. Mrs. Murray, mother of Lisa (DS) and Tom (Autistic Spectrum Disorder), for instance, refers to the importance of routine in providing her with this confidence:

“...I’m the boss so I know when she [Lisa] is away to Respite, I know when she’s doing all those different things. That means that I know for a fact that she’s away from Monday to Friday next week, so that’s a big bonus. So I don’t know, Tom’s at Respite next Thursday, I’m away to Aberdeen with my mum for the day next Thursday, and I’m

trying to think because I always have everything worked out well in advance.” (Mrs. Murray, Phase 3, p.21-22)

This sense of mastery clearly has to a positive effect on her life. This accords with the findings of two previous quantitative studies (Haley *et al.*, 1987; Helmes, Green and Almeida, 2005) which suggested that a measurable sense of control is associated with reduced levels of psychological distress and caregiver burden, positively affecting carers’ ability to manage their situations. It is interesting that this sense of mastery was more predominantly reported amongst mothers in the younger group, and where it was referred to amongst the carers of older people, it was more often in relation to its diminishment over time, as the health of their partners deteriorated. Mr. Brown expresses his feelings on this issue in the excerpt below:

‘Well, there’s lot of things you can control but there’s lot of things beyond your control. Like the future, what Alzheimer’s is going to do to Anne, whether she’s going to get some other illness which may mean that she has to go into care. Or whether I get an illness that means I’ve got to go into care. And then what happens to Anne? All that kind of thing, these could be beyond my control. But so far as I can control them, in other words, keep myself fit, keep Anne happy, clean, well fed and enjoying life, I’ll do the best I can.’ (Mr. Brown, Phase 3, p.16)

In the younger group, levels of mastery are generally reported to be constant - neither increasing nor decreasing. This tends to suggest that the sense of mastery is in some way fundamentally linked to the relative stability of the cared-for person’s condition. A predominant distinction between the older and younger groups is the likelihood, in the former, of deterioration in the cared-for person. The comparative stability, or potential improvement of condition among children of carers in the younger group is reflected in the range of structured care situations – play-groups, respite, friendship networks, schools – into which they may be integrated, providing the opportunity (as suggested by Mrs. Murray in the above quotation) for the mother to attain a greater sense of mastery over her life.

#### **5.1.3.4 Approach to life**

People with an upbeat and positive perspective tend to be healthier and enjoy longer lives than those who are generally gloomy and cynical about the future (Hogg and Vaughn, 2005; Franzoi, 2006). This observation might be summed up as representing the importance of positive thinking, and epitomises a simplistic, but nonetheless important and successful coping strategy, exemplified by those participants in the current study who seem to cope most successfully with the difficulties they face. It is an attitude which persuades the carer, as far as possible, to accept with equanimity, cheerfulness, and good grace the inevitable vicissitudes of caring in the home.

##### **5.1.3.4.i “Count your blessings”**

The ways in which various carers in both groups attained a positive attitude were various. In the older group, Mr. Tobin, for instance, explained that it was important to “count your blessings” (Phase 1, p.27) - an outlook which enabled him to be thankful for the positive aspects of his life, and motivated him to continue in his efforts, accepting, and dispatching to the best of his ability, the responsibilities he faced. A study conducted by Vitaliano *et al.* (1991) reinforces the benefit of this attitude, reporting that the simple act of ‘comparing oneself to others who were less fortunate’ may have the effect of mollifying the sense of burden experienced by carers. It is worthwhile observing that the adoption of this positive attitude is often a conscious decision taken by the carer. This is illustrated by a quotation from Mr. Tobin, in which he describes the effort he makes to remain positive:

“...I’m trying to take that aspect that, you know, count your blessings because it could be a lot worse....” (Mr. Tobin, Phase 1, p.27)

This is important, in that it indicates that the adoption of a positive attitude represents a deliberate strategic initiative on the part of this carer, rather than simply indicating an accidental and fortuitous element of his disposition. Mr. Tobin is here resorting to



one of a number of recognisable cognitive coping strategies, characterised by thoughts and attitudes aimed at managing and finding meaning in life-burdens.

#### **5.1.3.4.ii Acceptance**

A further cognitive coping strategy is represented by the ability to accept inevitable situations, rather than objecting to, avoiding, or attempting to deny them. The importance of acceptance was mentioned by many participants from both groups, as being synonymous with knowledge and understanding of their role in providing care. Mrs. Young, an adoptive mother, pointed out that it was her choice to have a child with ID, indicating her awareness of the fact that she, unlike her fellow participants, had knowingly accepted the demands of care:

“I think we both really accept the situation we’re in, we really accept... we're lucky we have a nice home, we have five fabulous kids, and we accept our lifestyle, we’re not looking for anything more....” (Mrs. Young, Phase 1, p.19)

Her expression (smiling) and tone of voice (light and cheerful), as she explained her outlook clearly indicated an equable acceptance of her situation. A three-year longitudinal quantitative study conducted by Glidden and Pursley (1989) investigated the situations of forty-one mothers in adoptive families, and reported that they attained a more stable adjustment than birth mothers. The evidence provided by Mrs. Young, in tandem with these findings, simultaneously confirms the value of acceptance, and the greater ease of acceptance amongst adoptive mothers, identifying the process of acceptance with the premeditated decision to adopt. The experience for birth mothers of children with ID is obviously different, and more likely to be problematic, since they are confronted at one and the same time with the practical burden of care, and the emotional burden of adjustment to an unforeseen, and often emotionally charged situation.

There is a distinct species of acceptance which may be described as resigned acceptance coping. This is characterised by a form of resignation to a situation over which carers have little real control, and acceptance of responsibilities they feel

obliged to discharge. The attitude is summed up by a quotation from Mr. Owen, in which he describes the care of his wife, Iris, in the following terms:

“[Sighing] ...nobody else is going to come along and do it.” (Mr. Owen, Phase 1, p.12).

A study conducted by Norman *et al.* (2004) explored perceptions and the management of change in carers of people with dementia, using interviews and observations ( $n=20$  pairs). The study confirmed that the quality of resignation is a common coping strategy.

#### **5.1.3.4.iii “Take it day-by-day”**

With these words (above), Mrs. Campbell (Phase 3, p.5) referred to an important element of her coping strategy - describing a deliberate and pragmatic decision not to dwell on future possibilities, or look any further ahead than the immediate concerns of the day in front of her. The attitude is based in a realisation that attempting to anticipate the course of future events within the care situation is largely pointless, and liable to lead to additional unnecessary anxiety. This strategy was of benefit to a number of participants, who explained that the management of their lives was made easier by a conscious resolution to ‘make the best of their lot’ by focusing on events in the short-term, rather than worrying needlessly about the future. Beresford (1994a) reported that, particularly amongst the parents of children with disability, this philosophical approach was found to be of benefit. The reason given by the carers questioned was that the prospects for the future were distressing, and the temptation to consider them too closely a source of debilitating stress.

#### **5.1.3.4.iv Positive thinking**

This dimension is different from ‘count your blessing’ in that this indicates a comparison between themselves and others, while the present one relates to contemplation of their own situation. Mr. Owen described his endeavour to think positively, explaining “You think of what you can do” (Phase 1, p.34). Again, this strategy, like so many adopted by participants in the study, is characterised by a

conscious decision on the part of the carer, in this case to concentrate on the extent to which the carer can affect their situation for the better, rather than dwelling upon aspects they cannot change. This was an attitude adopted by a number of participants - Mrs. Young, for instance, who explains her outlook in the following excerpt:

“...I think we’ve had a much better life because we’ve had all the kids and because we’ve got Stuart. And so therefore, we’ve never, never kind of mourned a life that we haven’t got, because we think it’s greener on the other side. We’ve always had a really positive attitude and loved it...” (Mrs. Young, Phase 3, p.17)

Individuals with a positive attitude tend to entertain positive ideas, and manifest similarly positive behaviour. They are likely to look for positive and meanings and optimistic interpretations in the situations they encounter. For example, in the older group, Mr. Tobin interpreted the responsibility of caring for his wife as a series of challenges. Such determined positively may frequently take the form of positive comparison - a strategy found amongst both groups of carers, which is illustrated in the following quotation from Mrs. Murray:

“...it’s sad because even though they are a lot of hard work, but they’re not really when you compare other families as well, you know, they’re not in wheelchairs, they’re not tube fed, you know, and, you know, they’ve not got epilepsy, they’re not on medication...” (Mrs. Murray, Phase 1, p.42)

A study conducted by Nolan, Grant and Keady (1996) investigating family carers of elderly people with dementia, and a study by Grant and Whittell (2000) of families of children with ID, identified the strategy of positive comparison as a common and beneficial resort amongst both groups. Borden and Berlin (1990) have also focused on the issue of positive comparison. They suggest that this appraisal of circumstances amongst carers increases the ability to cope, and contributes to carer well-being by bolstering self-esteem and morale.

Such approaches to life bear major similarities to cognitive-focused and reframing coping strategies. Pratt *et al.* (1985) describes reframing coping as “the ability to redefine stressful experiences in a way that makes them more understandable and manageable” (p.28). Pruchno and Resch (1989) reported that the use of cognitive

coping strategies among family carers of people with dementia relates to lower levels of depression, higher levels of positive affect, and reduced incidence of negative physical symptoms.

## 5.2 Commitment

The second category to be discussed is entitled Commitment. This is an aggregate of data collected in all three phases. Commitment is defined as the desire of participants to care for their relatives, and the happiness and willingness derived from their participation in that care. The category is enriched by reference to qualitative non-verbal data such as body language, which contributes to the perspective of emotional involvement, and will be presented later on in the text. Commitment comprises three properties, one of which (1) I love her, is drawn from reference to data in both groups. The other two - (2) She'd have done the same for me and (3) He's been my left arm represent analysis and reflection on data from the older group.

Figure 6: Shows the properties of the category, Commitment

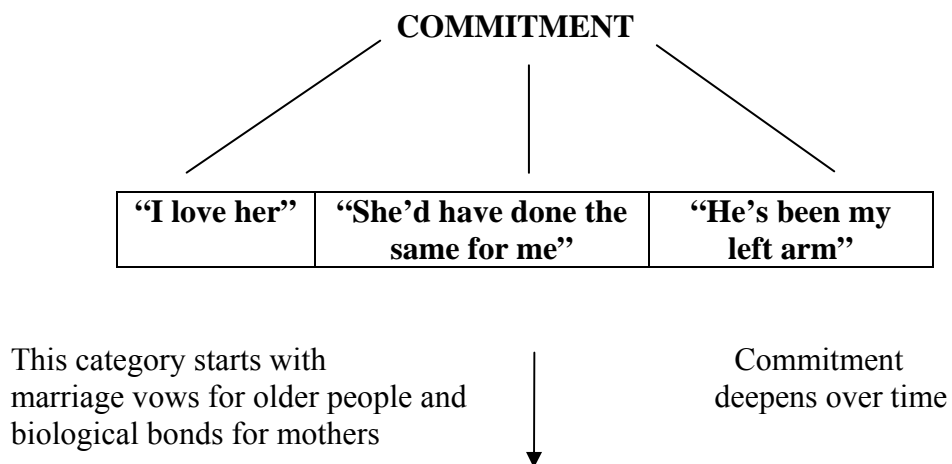


Figure 7: The theoretical memos for developing the concept of Commitment

10<sup>th</sup> of Nov, 2005

Commitment is an important factor in maintaining the carer's motivation to continue caring.

15<sup>th</sup> of July, 2006

The concept of Commitment is composed of a sense of responsibility and reciprocity. The idea for this comes from a textbook on social psychology (Franzoi, 2006) which includes the notion or idea of reciprocity. The sense of responsibility is a component that makes up Commitment. The sense of reciprocity is the extent to which the 'give and take' was possible within the relationships.

11<sup>th</sup> of Dec, 2006

Two core categories- Commitment and Responsibility or Duty are recognised through several discussions at supervision meetings. I now understand that they are in fact different concepts. Their relationship is equally important because I believe these elements maintain the security of providing care. I believe that carers have commitment and responsibility to their relatives which provides a strong reason for their caring role or position. However, I am not sure what or how different the characteristics of these two concepts are.

4<sup>th</sup> of Feb, 2006

Two concepts, Commitment and Responsibility, are certainly divided. While they might be closely related to each other, they are independent concepts in relationship to caring. Commitment refers to married couples who undertake their marriage vows, to love and care for their spouses. Commitment also involves the emotions, feelings and interests of doing things for each other. On the other hand, the sense of responsibility, I think, refers to the carers' sense of duty and obligation brought about by their role or position. The notion of responsibility comes from what the participants said. For example, Mrs. Young expresses her responsibility in caring for her son for a longer period of time as he has special needs (Phase 2, p.8). Mrs. Hope, wife of Mark, describes her strong sense of duty in providing support for her husband based on their relationship. However, I am not really sure yet what these differences between responsibility and duty are.

16<sup>th</sup> of Feb, 2007

Further synthesis (advanced) of the concept of commitment is that Commitment involves emotions and reciprocity. Emotions come from how the carers feel toward their relatives and include a sense of love, attachment, or being there for someone. Interestingly, the change of love is found in some participants over time. However, I was not able to find a link between these particular carers who did not love their cared-for relatives. However, clearly, the nature or quality of love is altered by the carers' satisfaction with their relationship and the intimacy between the couple.

23<sup>rd</sup> of Feb, 2007

Furthermore, the concepts of reciprocity and mutuality are recognised as being different properties of category Commitment. Reciprocity refers to involving two or more people who agree to help each other or to behave in the same way towards one another, for example, Mr. Owen (husband of Iris) suggests, “I know that if the situation had been reversed, she would have been looking after me” (Phase 2, p.13). On the other hand, Mutuality focuses on the feelings of mutual understanding which took the form of a feeling experienced equally by both the people involved, for example, Mrs. Miller expresses “I’ve been his right hand and he’s been my left arm” (Phase 2, p.14). The diagram of this category is presented below:

Category: Commitment

Property 1: Emotions

Property 2: Reciprocity

Property 3: Mutuality

### 5.2.1 “I love her”

“I love her” (Mr. Brown, Phase 1, p.52) is the simple declaration made by Mr. Brown for his wife Anne, in which he sums up the commitment which motivates him to care for her. Further on he expands on the nature of the commitment, confirming his awareness of the challenge it represents:

“...in a fact it’s a burden but it’s not a burden that I would willingly pass on to anyone else while I can do it. You understand what I mean? I want to care.” (Mr. Brown, Phase 1, p.57)

What comes across very clearly in Mr. Brown’s statement is the fact that he is entering into the commitment ‘with open eyes’, and yet is confident that the strength of the attachment he feels to Anne is sufficient to support his commitment. What is interesting also is that he is explicitly rejecting the idea that he might pass the burden of his wife’s care into other hands. This seems to suggest that he has considered this possibility, and is rejecting it on the basis that his commitment derives in an emotional, rather than a professional obligation. Implicit in this notion is the idea that Mr. Brown regards the emotional bond he is describing as being an essential element in the proper care of his wife. It is possible to suggest that all the participants in the current study share this understanding, because, although their individual cases are in many ways unique, the single characteristic which unites them is the fact that they are family carers - related to the cared-for person, either as spouses or as parents. Such

expressions of emotional commitment are frequently difficult to articulate; the invisible and unspoken bonds which unite husband to wife and parent to child should not be ignored.

In the younger group, Mrs. Murray expressed a similar sense of commitment to the care of her children Lisa and Tom, both have special needs (Tom's age disqualifies him from explicit inclusion in the current study):

“...I'll always be there for them, and I'll do as much as I can just to help them and make them independent, make them anything. And I've just... I'm happy doing it, I want to do it. I mean I have to do it and I'm happy with my life...” (Mrs. Murray, Phase 3, p.18)

Mrs. Murray's use of the phrase “I want to do it” shed further light on the complex nature of such a commitment; ‘want’ implies a sense that, in accepting her responsibility, this mother is fulfilling an innate desire. As such, it might be conjectured that love is perhaps the more important element of the carer's motivation, since, rather than infringing his or her basic freedom to choose, it proceeds from it.

The sense of love is the factor which compels spontaneous and voluntary acceptance which is confirmed by the evidence provided in both groups of participants. All of the mothers stated that they loved their children with and without ID equally, and not surprisingly, the carer of older groups also made similar declarations with regard to their partners. Mrs. Miller, for instance asserted that love was the fundamental concept which arose from the marriage bond, and felt that caring for her husband, Kevin, was “a labour of love” (Phase 2, p.21). Mr. Brown went further, suggesting that love is the basis of a bond which is capable of transcending, or surviving, the physical and emotional changes caused by age and sickness:

“I still want to care for her, yes. [laugh] That's part of the... That's part of the deal, as they say... Well, it's when you marry, you marry for better or worse and in sickness and in health and, you know, because I mean although she's not the same person I married, she's the same person I love, so we just carry on.” (Mr. Brown, Phase 2, p.14)

It is interesting that in this quotation, Mr. Brown seems to be drawing an implicit distinction between the ties of loyalty into which he entered in marrying Anne, and

the emotion which unites them, effectively suggesting that the fundamental emotion is more important than the social institution that the institution underpins the emotion. Were this not the case, it might be possible to suggest that the bonds which unite the mothers and their children are in some way stronger than those between marriage partners – since the former (except in the case of adoptive parents) are biological (in the truest sense of the word, innate), whereas the commitment which obtains between marriage partners may, at least hypothetically, be entirely the sum of a social contract – as for instance in arranged marriages. It cannot be denied that the social contract is a major factor affecting the context and nature of the caring relationship in the older group, and has an important influence on the degree of obligation and responsibility. A study conducted by Wuest, Ericson and Stern (1994) reinforces this notion, identifying the social contract as an underpinning factor of spousal commitment in caregiving situations. However, this study offers no exploration of the role of married love in the caregiving commitment, simply defining it as one of a number of transcendent variables in the process of estrangement between carer and spouse.

As suggested above, a fundamental distinction between “love” as referred to by the carer of older people, as opposed to the mothers, is that the latter (apart from Mrs. Young, who is an adoptive parent) are not bound by any social contract to their children. For this reason, it is interesting to analyse the ways in which the mothers speak of their commitment, since this provides an opportunity to investigate what might be described as a ‘pure’ emotional bond, untrammelled by any legal consideration. There is evidence given by Mrs. Murray (Phase 3, p.18), it would be an over-simplification to propose that the nature of the maternal commitment to care is entirely the result of an innate compulsion. Here is Mrs. Cameron discussing her emotions towards her daughter, Emma:

“I love her and I want to care for her... I want to spend time to help her.” (Mrs. Cameron, Phase 1, p.19)

It is reasonable to suggest that there is an aspect of Mrs. Cameron’s statement which is unusual, in comparison, for instance, with the description a mother of a normally able child might give of her maternal love; she speaks of her desire to “help” Emma.



While it is entirely possible that mothers in general might feel a similarly powerful compulsion to help their children, it is clear that the special nature of Emma's needs compels Mrs. Cameron to consider consciously this particular element of her commitment. It is also obvious that the nature and level of help Emma is likely to need is different and greater. It is interesting that Mrs. Cameron's demeanour as she made this statement displayed signs of zeal and happiness which might be considered uncommon in a more conventional situation; her eyes sparkled as she spoke, and she sat leaning forward, nodding her head with smile. This sort of qualitative evidence tends to suggest that the extra challenge of caring for a child with ID not only obliges the mother to consider more closely the complexities of maternal commitment, but may also reward the mother with a more intense and complete experience of the emotion upon which the commitment is founded.

It is possible also that part of the excitement which a mother such as Mrs. Cameron may experience in reflecting upon her commitment is connected with the pleasure that any parent may feel when they consider the challenge of parenthood – the sense that they are at the start of an exciting and potentially rewarding project. It might, of course, be argued that for the mother of a child with ID, the experience of this excitement may be compromised by their understanding of the additional, potentially daunting obstacles they will face in consequence of their child's condition. By the same token, however, precisely the opposite view might be ventured; that the special obstacles and specific challenges faced by the mother of a child with ID will have the effect of intensifying their focus upon the possibility of progress for their child, and the sense of parental success. This is certainly one point on which the nature of the emotional commitment for the mothers and carers of older group differs radically. While, for the mothers, there is the anticipation of progress, a sense of looking forward, for the carer of older groups, there is the inevitable prospect of deterioration in their partner's condition, and with it, the possibility of estrangement over time. This brings with it the likelihood that the nature of the love which obtains between the couple will change, and an equal likelihood of alteration or diminution in emotional communication – for the partners with dementia because the ability to understand and communicate is progressively lost, and for the carer because the act of offering expressions of feeling becomes correspondingly futile. At its most drastic, this is a process of estrangement which may lead to the transgression of feeling between the

couple altogether. In the following excerpt, Mrs. Hope (wife of Mark) gives us an insight into the complexities of this process of change:

“I still loved Mark because he was still Mark, he was still this nice person but um... as the time goes on, I can't say I love him, I mean I do, but in a different way... I love him as a child now...” (Mrs. Hope, Phase 3, p.26)

Here shows how both the nature of the love she feels for her husband, and the way in which she can express her love, are altered as a result of the change in Mark. Moreover, Mrs. Miller (wife of Kevin) went on to explain that she cared for her husband, despite, the fact that she did not take pleasure in her responsibilities, because she loved him:

“...I don't think I enjoyed it but that's where love came into it again. You did it because you loved him. But I didn't enjoy doing it. I mean, I would get him all changed and I would take him out in the car and... oh! I had to take him back home again, start again, bath him, change him. No, I don't... I don't think I can honestly say I enjoyed it...” (Mrs. Miller, Phase 3, p.17)

There could hardly be a clearer contrast between the nature of the love which motivates the carers of older group and that which motivates the younger. In Mrs. Miller, there is none of the zeal and enthusiasm (different from Mrs. Cameron earlier), no pleasure or sense of anticipation in dispatching her duties.

In fact Mrs. Miller seems to be questioning whether the love she feels for her husband is adequate to the challenge of sustaining her caring role, asking, further on her saying “how far does love go?” (Phase 1, p.15). The impression conveyed by her statement, is reinforced by qualitative non-verbal evidence: she wept as she spoke these words. This example suggests that she was perhaps entering on the threshold of the grieving process - a type of self protective emotional economy against the final estrangement of her husband's passing.

It has been seen already, and it is evident in Mrs. Miller's words above, that the concept of love is an important element in enhancing the motivation to provide care.

Another carer from the older group, Mr. Owen reaffirms this connection in the excerpt below:

“...nobody’s going to care for her like I will, or be as interested as I will. There will be people who will be interested, but not as interested as I am. So I ensure that Iris gets the best care that’s possible and so help her in this difficult time for her in the journey in which she’s... she’s embarked upon.” (Mr. Owen, Phase 3, p.9)

However, Mr. Owen went on to say that the level and degree of love alters as the effects of his partner’s dementia become more problematic and challenging:

“The love tends to... the love is there. You feel so very sorry at times, but then she can be so bitter towards you, that it’s difficult to maintain it. I suppose deep down, yes.” (Mr. Owen, Phase 2, p.13)

The process of love is dynamic - both influenced by, and influencing the quality of relationship and the interaction between couples. To this extent, it is possible to say that the carer’s degree of commitment to the cared-for person is changeable depending on their perception of love and satisfaction with the relationship. This is confirmed by the findings of two previous studies (Murray, Holmes and Griffin, 1996; Rusbult, Martz and Agnew, 1998). An understanding of this concept may help explain the way in which a changing perception of love in the carers of older people influences the nature and level of commitment to their spouses. In the younger group, there is little evidence of the intervention of change in the conception or operation of love *per se*, although a number of the mothers did describe a feeling of detachment over time between the day-to-day disposal of caregiving tasks, and the emotional foundation of their commitment – a feeling that their maternal love, while remaining intact and unaltered, is no longer a conscious presence in the momentary fulfilment of quotidian responsibilities. Mrs. Murray, for instance, suggests the idea that caring for her children was becoming like “a shift” (Phase 2, p.5) which will be further discussed in the category of Responsibility and Duty – for example, not so much an intense emotional expression of maternal devotion as something which is ‘all in a day’s work’.

Interestingly, I can find no study in the nursing literature which offers any significant exploration of commitment in relation to carers of individuals with dementia or children with ID. This may well be because nurses tend not to focus on relatives or carers, nor do they see themselves as being in any committed individual relationship with their patients. That a commitment exists is evinced by the fact that the majority of nurses will unquestioningly go on duty even if they are not feeling well (Kroposki *et al.*, 1999; Kuokkanen, Leino-Kilpi and Katajisto, 2003), but possibly, the commitment they feel is to the whole group of patients on the ward, rather than specific individuals. Some might claim a commitment to their colleagues or to their profession; this area of interest falls outside the parameters of the current study, but has been explored in sociological and psychological literature.

In social psychology, commitment is viewed as a process (Wieselquist *et al.*, 1999) and involves dealing with the development and continued stability of close relationships (Adams and Jones, 1997). There are two major reviews in psychological literature which have investigated the concepts of commitment or love (Rusbult, 1980; Sternberg 1986), but these researchers tend towards opposing views: Sternberg (1986) suggested that commitment is one of components which make up love; while Rusbult (1980) proposed a model of commitment in which love is a component.

Sternberg (1986) suggested a triangular model of love in which commitment comprises one of three components, along with intimacy and passion. He suggested that the element of commitment includes a short-term decision that one loves another, as well as a long-term decision to maintain that love. Rusbult (1980) developed a model based on his analysis of a questionnaire and a four-page essay given to eighty-nine undergraduate students on his psychology course. He asked these students to envisage imaginary situations, feelings, and attitudes. Obviously, this study did not explore the real life experiences of carers, which is a strength of the present study. Rusbult's (1980) investment model proposed an association of commitment and satisfaction in relationships between couples, which suggests that every individual is committed to a relationship to a different degree. Like Sternberg, his model is triangular: the three elements of commitment, he suggests, are satisfaction, alternatives and investments. This model proposes that a greater level of commitment to a relationship is attended by a correspondingly higher level of satisfaction, and

greater investment (for example, devotion of time and energy to the relationship, and the prevalence of shared experiences and emotional involvement); in such a relationship, the significance of available alternatives (e.g. of dating other partners) is accordingly diminished. Rusbult's study is only of relevance to the carer of older people in the current study, since its concern is with sexual relationships, rather than mother-child relationships. Fehr (1988) suggested that Rusbult's (1980) notion that satisfaction is interchangeable with the experience of being in love with an individual, or feeling affection for them - is subsumed in the general concept of commitment. To this degree, the current work is consistent with Fehr's ideas.

It should be noted, that almost none of these sociological and psychological studies based their findings in practical caregiving settings, although there was a single sociological study by Russell (2001) which explored a concept of commitment in fourteen elderly husbands who cared for wives with dementia using a qualitative approach. However, his analysis of the data was of insufficient depth and clarity to furnish a full concept of commitment.

The current study contains similarities as well as differences to these studies, in that love is conceived as a component of commitment, further suggesting that the context within which love is so defined may determine the degree and level of commitment made by the respective carer. This is an important consideration, unmentioned in previous literature. For example, in this study mothers describe a sense of vocational fulfilment in discussing their commitment, whereas data from the carer of older people seems to suggest an outcome more akin to the meeting of a contractual obligation. This is clearly an important distinction within the findings. The identification of this distinction is a direct consequence of investigating the emotional context in which commitment is made.

In many ways, the nature of the carers' commitment in both groups might be summarised by a statement made by one of the mothers, Mrs. Macleod, "I am here for her" (Phase 1, p.26). This statement refers to the degree in which participants are prepared to devote their time and energy to care for another. The specific origins and manifestation of this sentiment are various among the participants. For example, in the older group, Mrs. Baird explained that her husband was part of her life which was

why she wanted to keep helping him. This explanation suggests a degree of interdependence within their relationship – or to put the matter simply, a sense that neither is complete without the other. Viewed in this light, Mrs. Baird’s statement may be seen as representing her need to retain a conception of her own identity. Likewise, the majority of mothers in the current study expressed a similar willingness to ‘be there’ for their children. Mrs. Campbell expresses the sentiment in the following terms:

“...as soon as I seen her I knew that she was mine...” (Mrs. Campbell, Phase 1, p.20)

It conveys an element of unpremeditated emotional compulsion which is conspicuously absent from the carer of older people’s words - a sense reinforced by the fact that Mrs. Campbell smiled as she spoke. It implies that, for this carer, there is a degree of intrinsic pleasure in the connection she experiences between herself and her daughter, and that, in her willingness to commit to her daughter’s care; she feels an increased sense of herself and her purpose.

It might be argued that, in this element of the carer’s commitment, there is, for the carer of older group, a greater degree of pragmatic deliberation; that if any aspect of their commitment should come into question, it is likely to be the continuing strength of the emotional bond between carer and spouse. This is not to say that, for the mother, there is no element of conscious consideration or premeditation. A statement from one of the mothers, Mrs. Cameron (below), provides evidence of the necessary pragmatism a mother must possess in committing to the care of a child with ID:

“I’m going to have her for the rest of my life... and you do care for her.” (Mrs. Cameron, Phase 1, p.22).

These are not the words of a mother in the grip of an overwhelming maternal emotion, but seem altogether more measured, representing a clear-sighted awareness and acceptance of the fact that, in committing herself to be there for her daughter, she is undertaking a lifelong commitment – ‘being there’ means being there for the rest of her days. The outlook she exemplifies emphasises the importance not so much of the emotional intensity of commitment, as its durability.

Mrs. Cameron's statement above mentions the truism 'a child is for life', and applies it the special circumstance of becoming the parent of a child with ID. In doing so, it make a very particular and detailed assessment of the nature of the maternal commitment. It also partakes of a sentiment voiced by several mothers in the current study, who explained their readiness to 'be there' by reference to the simple fact that this was a child as they had brought into the world. The exception to this is Mrs. Young, an adoptive mother of a son with ID. She nonetheless predicted that the present happiness she experienced in caring for her son would not change in her lifetime, and that there would always be satisfaction and fulfilment for her in meeting her son's needs:

“...that's something we want to do, because we want to be involved with his life...” (Mrs. Young, Phase 3, p.9)

Not only Mrs. Young, but all of the mothers, have made a lucid decision to fulfil the lifelong commitment of caring for their child. This finding suggests that qualities of powerful emotional attachment and durability which must characterise the carer's commitment and which are applicable to both groups in this study.

Attachment is an important concept in both parental and spousal relationships. It has been discussed in literature on psychology and sociology (Bowlby, 1988; Feeney and Noller, 1990; Bersheid, 1994; Taylor, Peplau and Sears, 2006). In the study conducted by Taylor, Peplau and Sears (2006, p.237), attachment is defined as “a strong emotional bond to a significant other person”. Recently, Feeney and Hohaus (2001) conducted a survey-based study amongst their married students, investigating the issues of attachment between spouses, and the relation of caregiving to marital satisfaction. Through questionnaires, they found that spousal caregiving was related to the marital bond and to marital satisfaction for couples considered 'securely attached'. This finding is supported by the data in the present study, which is based on the real-life experiences of carers.

Again this is a concept which has not previously been researched and so it is unique to this study. Thus, in the current work, 'being there' for someone is recognised as both an emotional and practical expression of commitment. It should be noted that the

issue of commitment is immensely complex. It is not susceptible to generalism or simplification, but differs significantly from participant to participant.

### **5.2.2 “She’d have done the same for me...”**

“She’d have done the same for me” is a statement made by Mr. Tobin (below), in which he expresses his confidence in the strength of the mutual commitment he and his wife, Alison, have shared throughout the course of their marriage. He expands on this sentiment in the excerpt below:

“...I just say ‘she’d have done the same for me’. If it was me that had had the illness, you know, she’d have done the same for me. So I think the very fact that you’ve a partner and you’ve lived together for so long, and your lives, you know, are entwined in that way...” (Mr. Tobin, Phase 3, p.16)

He seems to be suggesting that the commitment in some way continues – they remain “entwined” – in spite of the deterioration in his wife’s cognitive faculties – a state of affairs which renders her progressively incapable of participating in or, ultimately, understanding their relationship. This suggests that Mr. Tobin’s continuing belief in the validity of their relationship is an implicit expression of his decision to stay true to that commitment, through the act of caring. In order to rationalise this decision to him it is necessary for Mr. Tobin to resort to a hypothetical premise – namely how Alison would have responded if the situation were reversed. This enables him to rely upon his memory of a previous stage in their relationship – a time when his confidence in the strength of their mutual commitment was not, as it must be now, based upon a continuing act of faith in the face of militating factors, but the material confirmation of Alison’s reactions to him. The conclusion he draws, that “She would have done the same for me” refers to the notion of reciprocity. Reciprocity, in this context, may be defined as an implicit or explicit agreement between two people, indicated through words and or gestures, that each is prepared to help or support the other in the same way, and to an equal degree.



Reciprocity is a concept of relevance only to the carers of older people – it cannot be applied to the relationship between mothers and their children, because the mother-child relationship is not a relationship of equals. The carers of older group who refer to this notion are drawing on the key notion of trust – a belief, in the absence of continuing evidence, regarding the value and integrity of their marital relationship. The importance of this notion is confirmed in work published by Hogg and Vaughan (2005).

The close similarity between the concept of reciprocity, as it is expressed by Mr. Tobin, and the sort of relationship which prevails between a mother and her child, is that both refer to the idea of unconditional love. Mr. Tobin is alluding to his continued devotion and loyalty, in spite of the fact that it cannot any longer be reciprocated. Similarly, a mother, particularly a mother of a child with ID, makes a gesture of devotion in spite of the fact that she cannot expect her child to reciprocate the level of support, comfort and protection she provides. What the mother may receive is a sense of happiness, fulfilment and pride from the relationship with her child. This is evident in the findings of the current study, and was discussed in relation to the property ‘Positive Outcome of Caregiving’ which is under the category of My Life Changed (see section 5.1.1.4).

It should be noted that the concept of reciprocity is frequently discussed in connection with relationships between elderly parents and adult children. A quantitative study conducted by Walker, Pratt and Oppy (1992) investigated perceived reciprocity in one hundred and seventy-four adult daughters of elderly mothers with AD, and found that both mother and daughter experienced a strong sense of reciprocity, which was manifest in the daughter’s willingness to return and help her mother. However, this type of relationship falls outside the parameters of the current study. Nonetheless, it is worth reflecting that spousal reciprocity is a key component on which the later caregiving relationship may be built.

### 5.2.3 “He’s been my left arm...”

The previous section dealt with the confidence carers of older people felt in the strength and continuing validity of their relationships, focusing particularly upon the notion of reciprocity, as an expression of that strength. This section begins to investigate the source of that strength in more detail “He’s been my left arm” is a statement made by Mrs. Miller (below), and represents a sense of mutual involvement and understanding with her husband. It refers to an intuitive level of sympathy, or communion, which is the sum of many years spent together (within the current study, the period of married co-existence amongst the carer of older people ranged from thirty-seven to fifty years). All of the participants from the older group expressed confidence that, before the process of dementia intervened, their partner could understand and anticipate their interests, feelings and needs. This sense of shared understanding is described as the concept of mutuality. Mrs. Miller expands on this concept in the following excerpt:

“I’ve been his right hand and he’s been my left arm.... [.] You know, we’ve been together for so many years and we’ve done every... we thought alike, if we’re sitting quiet, and he would say something and I would say, ‘Oh I was just thinking that same thing’.” (Mrs. Miller, Phase 2, p.14)

Non-verbal qualitative signs noted during the course of this interview, confirm the sense of confidence and communion she alludes to; while she spoke she maintained eye-contact with her husband, at the same time nodding and smiling, with a look of brightness in her eyes.

A phenomenological study conducted by Chesla, Martinson and Muwaswes (1994) investigating thirty families of people with AD, confirms the importance of mutuality, reporting that the concept contributes significantly to explanations of the carer’s involvement in caring. Their study identifies three dimensions of mutuality: the carer’s capacity to derive gratification in the relationship with the cared-for person, the carer’s positive interpretation of the meaning and purpose of caregiving, and the carer’s sense of reciprocity. This suggests a slightly different take on the concept of mutuality than the current study, in which mutuality is more exclusively related to the

existence of sympathy and shared understanding between carer and cared-for person. It is worth reflecting that the concepts of reciprocity and mutuality are closely interrelated, married carers have a reciprocal relationship. However, a number of carers clearly regarded mutuality as representing a more profound and inclusive level of intimacy, of which reciprocity is a component.

The importance of the basic concept of mutuality is clear – its significance perhaps suggested by the fact that a number of key aspects in the carer and cared-for person relationship are related to it. A study conducted by Baldwin (2006), investigating the cases of sixty-two family carers, using a grounded theory approach, found the sense of mutuality to be one of the moral principles of caring. Again, however, as with reciprocity, mutuality is chiefly of relevance to the relationship between carers of older people and their partners, less so to mothers and their children. Mutuality, like reciprocity, alludes to a degree of equality in the relationship (a situation which is ultimately, of course, altered as a consequence of the cared-for person's deterioration, but which nonetheless forms the basis of the carer's commitment to them). The relationship between mother and child is, by its nature, unequal; none of the mothers described themselves as being 'intertwined', although of course, most did speak in terms of the child being 'part of them', in the way that all natural mothers and their children are biologically connected. While mothers and their children are close when they are young, an important aspect of the parent's ambition is for the child to develop and become an independent individual, ultimately capable of forming their own unique relationships outside the mother-child bond. Although the mothers in the current study were inevitably faced with greater obstacles than those which confront the mothers of normally able children, all expressed a similar aspiration for their child.

### **5.3 Responsibility and Duty**

In this analysis, the third category is entitled 'Responsibility and Duty' – a title drawn from references in the evidence from both groups. Most participants alluded to a sense of responsibility and duty in terms describing the degree in which they 'have to' or 'need to' perform tasks for their child or partner, in consequence of the child or partner's inability to perform those tasks for themselves. The phrases 'have to' or

‘need to’ presents a feeling of obligation – a belief in the moral rightness of the commitment, and thus perhaps a conviction which is influenced less by innate compulsion and more by societal expectations, connected with concepts of duty. A particularly high level of non-verbal communication from participants was observed by the researcher when this topic was discussed, and will be further described, together with supporting quotations in the later text. It is also worthy of note that, in the course of those interviews in which this topic was raised, the responses of the participants tended towards curtness, or were interspersed with statements emphasising the quality of the relationship in question. This phenomenon may be interpreted in two ways: either the sense of responsibility is regarded by the carer as being a ‘given’ – something which requires little or no elucidation; or it may be that the pragmatic acceptance and articulation of those wearisome and often repetitive tasks is simply less ‘inspiring’, and the participants, in speaking of them, seek to leaven their statements by referring back to the emotional bonds which are the basis of the responsibilities they have undertaken.

Figure 8: The theoretical memos for the development of the concept of Responsibility and Duty

<p><u>6<sup>th</sup> of March, 2007</u>  The concept of Responsibility and Duty has caused me difficulty because I see them as being the same but others have been trying to point out that they have different bases. So I think currently that they are similar and express the same meaning at this time.</p> <p><u>4<sup>th</sup> of April, 2006</u>  After one month’s discussion and clarification, I’m beginning to better understand the difference between the concepts of Responsibility and Duty. For example, Mrs. Hope points out that she is responsible for her husband’s behaviour (refers to the quotation of Mrs. Hope, Phase 1, p.44). On the contrary, the concept of duty refers to the sense of obligation in the role of spouse or parent relating to providing food, care, and a safe place.</p> <p><u>10<sup>th</sup> of April, 2006</u>  I’ve now decided to put these two concepts together because they seem to me to be so close but the dimensions help to indicate what the differences are.  Category: Responsibility or Duty  Property 1. My role = My job  Dimension 1. A typical day  Dimension 2. Taking him into account</p>
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Property 2: Paternalism

Dimension 1. Sense of control and confident

Dimension 2. Protective or overprotective care

Dimension 3. Hard to let go

It is interesting that only the term ‘responsibility’ was mentioned by carers in the younger group, while both terms ‘responsibility’ and ‘duty’ were current in the older group. This is perhaps explained by the fact, that for the mothers, as already mentioned, the sense of responsibility is attended by a degree of aspiration and optimism for their child. This sentiment is conspicuously absent in the evidence from the carer of older groups, for whom the future holds only the prospect of terminal deterioration in their partner, and the hope of maintaining them as far as possible in safety and comfort. For this reason, the concept of duty may come to be of far greater importance as an element in their continuing commitment to care. Having said this, a sense of duty is nonetheless implicit in many mothers’ descriptions of the responsibilities of their role. A quotation from Mrs. Macleod demonstrates this fact:

“...I have to just to be a mother like I am to my other children. I’ve got to be here for her, I’ve got to do the washing, you know, do all these things for her.” (Mrs. Macleod, Phase 3, p.7)

It may be valid to suggest that the term ‘duty’ is not mentioned in name by the mothers, precisely because it comprises those daily tasks – washing, cooking, cleaning, clothing – which are assumed for parenthood in general. Duty, for the carer of older group, is perhaps a broader concept, representing a greater part of the specialised commitment of care, where so much of what their relationship once was has changed and diminished.

Nevertheless, it is important that a distinction between the concepts of responsibility and duty is observed. Although both derive in a sense of moral, rather than emotional compulsion, for the purposes of the current study, responsibility is defined as moral accountability, and is therefore, to a certain extent, attended by an element of freedom of choice - the individuals to whom one is accountable are oneself (primarily), and, to a lesser degree, the cared-for person. Duty is more consonant with the notion of

obligation – born of a sense of societal expectation, and thus involves a more important infringement, and conscious sacrifice of the carer's autonomy.

This definition of duty has much in common with the deontological model proposed by Kant (1724-1804), a model he describes as duty-based ethics (referred to in Seawell's critique of 1998). Under this model, Kant defined duty as comprising two distinct aspects: hypothetical duties, and categorical duties. Hypothetical duties, (also called hypothetical imperatives) are described as actions only required to be carried out under certain practical circumstances - the duty to help or care, for example, when someone falls down in the street while you are there. Categorical duties, (also called categorical imperatives), are universal obligations, required to be enacted in all situations, for example, a duty not to lie. Kant suggests that every individual is subject to categorical duties, under which his or her actions are governed by three formulations: universal law, respect for others, or moral values (Stanford Encyclopedia of Philosophy, 2004).

In a study of spousal caregiving conducted by Boeije and Dooene-Huiskes (2003) it is suggested that duty of care is related to the security derived in the social relationship of marriage. In longstanding spousal relationships, it is, of course, unlikely that either partner will allude to their sense of duty. However, in cases where one partner lives with dementia, the notion of duty becomes foregrounded for the other partner in the various caring tasks they find themselves obliged to perform. At the same time the balance of reciprocal security shifts; emphasis is placed increasingly upon providing a sense of security for the cared-for person. This emphasis upon the recognition of duty for the carer does not, however, preclude a simultaneous awareness of personal responsibility. This is confirmed by evidence in the current study; like the mothers, a number of the carer of older people made specific mention of the sense of responsibility they felt. But there is a distinction between what is understood by the concept of responsibility in the two groups. Most obviously, in the older group, carers' concept of responsibility is based upon the fundamental idea that, within a marriage, both partners are equally responsible for their own behaviour. However, as their partners condition degenerate, that balance shifts, so that the carer comes to feel increasingly responsible for the conduct of his or her spouse to - in much the same way that a mother feels responsible for the conduct of her child. For example, the

symptomatic tendency of the people with dementia to wander, or to disregard potentially hazardous situations, may be source of danger both to themselves and others. Responsibility for avoiding the possibly harmful outcomes in such situations falls to the carer.

Even when those partners with dementia were no longer being cared for directly by their spouses, because they had gone into long-term care units, the overarching and enduring feeling of the need to care is still present in the carer. For example, Mrs. Miller and Mr. Owen had similar experiences when their spouses were taken into a formal care environment. They both continued to feel an abiding sense of duty sufficient to want to go to the nursing home or hospital nearly every day to visit their spouse, and make sure they were being looked after. Mrs. Miller explains her feelings in the following excerpt:

“Well my life will consist of going to see him, and making sure that he’s okay. And then the rest of my life I work round that.” (Mrs. Miller, Phase 2, p.18)

The continuation of her emotional involvement is evinced by the fact that she admitted weeping because she felt so sorry for her husband. The extent of the responsibility she continued to feel may be gauged from the fact that visiting him was clearly a source of physical, as well as emotional stress for her, requiring a long journey involving two or three bus rides. She explained that she liked to take her husband out of the nursing home to a garden to enjoy sunshine and fresh air when it was dry – an undertaking which also involved considerable mental and physical exertion, arranging transport, and moving her husband (his mobility at this stage was seriously compromised). Further, if the weather was inclement, she would set to tidying his room. It became increasingly obvious as she described these customs, that, in extending herself in this way, she was fulfilling some emotional need in herself – a sense of duty and responsibility formed over the years of their married life together, and brought into sharp focus in the period of her time as a carer in the home. This was clearly suggested by a comment she made in connection with this behaviour: “You’ve got to be needed in life” (Mrs. Miller, Phase 2, p.13). It seems plain that there was an element of comfort for her in continuing to dispatch duties which, to the objective observer, might seem an unnecessary burden. A combined qualitative and

quantitative longitudinal study conducted over a nine month period by Ross, Rosenthal and Dawson (1997) confirms this suggestion, identifying a number of motivational factors behind the desire of spouses to visit their partners in care homes, which included a continuing sense of responsibility, obligation to monitor their partner's welfare, and a need to perpetuate their own sense of usefulness and emotional well-being.

Amongst all carers from both groups, priority in the matter of comfort and well-being was accorded to the cared-for person. Many carers would often dress or feed their relatives before themselves. Of course, this is often the case amongst mothers in general. Mrs. Campbell seems to register her recognition of this fact in the following statement:

“I just think it's children... it's your children and you just... they, they come before anything else really ah, I think anyway personally.” (Mrs. Campbell, Phase 3, p.11)

This example demonstrates the way in which Mrs. Campbell rationalises the tendency to prioritise her responsibility as carer to her child over and above her own needs. Another mother, Mrs. Murray, similarly remarked that her responsibility of care was subsumed within a general sense of maternal solicitude such as any mother might feel which is a sentiment reinforced by findings in Read's study (2000). Mrs. Young (below) contributes usefully to our reflections on this issue, explicitly comparing the responsibility of care towards her adoptive son with ID, Stuart, with the responsibility she feels towards her other children:

“But that's what I take on with any of the children. When... when the other children were younger and needed my care and my support I did the same. It's just Stuart needs that for longer because he is not as able as the others were at the same age.” (Mrs. Young, Phase 2, p.8)

She seems to suggest that the sense of responsibility is identical for all her children, simply adding that for Stuart, practically, a greater period of intensive care was required as a result of his condition. She had also spoken earlier of the “extra support” (Phase 2, p.5) which was necessary in order to fulfil this responsibility for her son.



For the carer of older people, however, the care situation originates from a different standpoint – a situation, prior to their spouse’s affliction, in which both partners are equally capable of looking after themselves. Inevitably, as their partner’s condition deteriorates, there is an increased need of support in the accomplishment of daily activities, both from their spouses, and from external sources. Perhaps due to the sense of responsibility and duty felt by the carer, there is frequently an uneasy relationship in his or her, estimation of how far he or she is obliged to contribute to this additional level of support, and how far it can be committed into the hands of others. Mrs. Miller, again, illustrates this dilemma, describing a situation her home when her husband had soiled the floor and, in spite of the presence of other people, she felt obliged to clean up the mess herself:

“...because I didn’t want anybody else... to deal with it, it was my husband that had done it and I just wanted to do it myself.” (Mrs. Miller, Phase 3, p.14)

This is clearly an example of a situation in which the carer accepts the onus of responsibility for their partner’s conduct, on the basis of the fact that the partner is no longer capable of meeting that responsibility himself. It is also likely that Mrs. Miller was motivated by a feeling of embarrassment, and a fear that the involvement of external helpers might cause her husband to be devalued. It might also be possible to suggest that, in a way, Mrs. Miller was attempting to ‘conceal the evidence’ of her husband’s accident, and therefore of his behaviour. Mr. Tobin describes this process succinctly in the excerpt below:

“I woke and found that life was duty. When you analyse duty, it goes right through the whole structure of life.” (Mr. Tobin, Phase 2, p.21)

He went on to make specific reference to the relationship he perceived between responsibility and duty:

“If you have been a responsible person in any way, being responsible, you can’t be responsible without having some form of duty.” (Mr. Tobin, Phase 2, p.21)

It is clear that he is referring here to both responsibility and duty in general terms – not merely confining their relevance to the responsibilities and duties of care, but suggesting that a general sense of responsibility for one’s actions necessarily leads to the acceptance of dutiful activities – concepts which he is relating implicitly to the responsibility he has accepted late in life of caring for his wife. It was evident, however, during the course of this interview, that there was a great deal more in Mr. Tobin’s commitment to his wife than adherence to moral principles; he held her hand and looked into her eyes as he spoke these words, with a smile on his face. This shows the emotional foundation on which the fulfilment of duty to his wife is based. However, this emotional involvement in the carer’s acceptance of responsibility and duty can also accompany with emotionally charged. Evidence of this is given by Mrs. Macleod, one of the mothers, as she describes the impact on her family of the duty of caring for her daughter Rose, and importantly, the sense of responsibility she felt for minimising that impact:

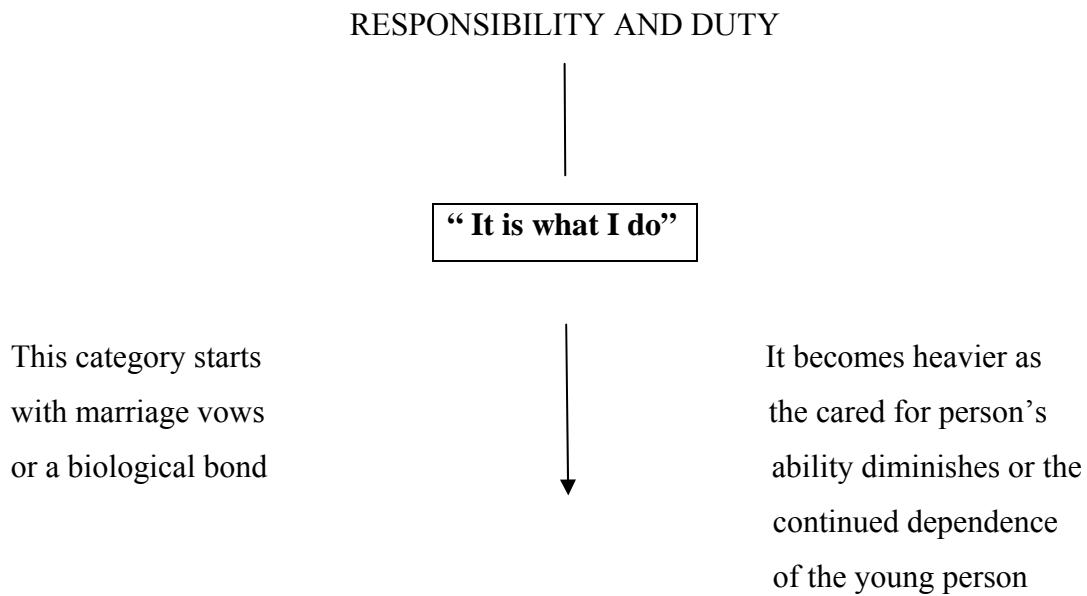
“I have to do extra for Rose there’s no doubt about it, but it’s just, it’s just our life, it’s just what our life is so, you know, the way I look at it, you know, I want to get the best out of it, you know, I want to get the best out of it, you know, have it running smoothly as well as I possibly can, you know, so I try to do that as much as I can, yeah and some days yeah I feel ‘Gosh I want to give up, if only my life were different’, you know, sort of thing but it’s not so there’s no point in saying that, you know, because of the situation and I have to do it and I want to do it....” (Mrs. Macleod, Phase 3, p.10)

This demonstrates the extent to which a sense of responsibility, particularly amongst the mothers in the study, is not confined to the matter of caring for the child with ID, but spreads from that point of focus to embrace all who are affected by it in the immediate and extended family.

Consciousness of emotionally charged in the responsibility and duty to care varied from carer to carer. Mrs. Gill explained her attitude to the care of her daughter in these terms: “I see her as a responsibility but not as a problem” (Phase 2, p.39). This demonstrates a calm acceptance of responsibility, and a degree of optimism in relation to the positive aspects and effects of care which was common to a number of mothers.

On the other hand, another mother, Mrs. Robinson, is candid in admitting the sometimes onerous and difficult nature of her role: “I would say it’s a heavy responsibility at times. So it is... it is like a burden sometimes...” (Phase 2, p.33). It is possible that this disparity in the statements of these two mothers may be due to the fact that Mrs. Robinson’s response is narrower – less a representation of her general disposition and outlook, and more specifically concerned with the practical duties of caring.

Figure 9: Shows the property of the category, Responsibility and Duty.



### 5.3.1 “It is what I do...”

“It is what I do” (Phase 2, p.32) is a statement given by one of the mothers, Mrs. Campbell, which summarises the degree to which she identifies with her role as carer. This form of self-identification is perhaps more clear cut for the mothers in the study, since so much of what they do in the specific case of caring is consonant with the responsibilities of mothers in general. All the mothers referred to their role as simply ‘being mum’. In a fuller quotation from Mrs. Campbell, she goes on to describe this sentiment:

“... Your kids are your responsibility. I don’t mind like people coming in and looking after them and things like that. It’s very... it’s very rarely it happens, but you just prefer... you’re their mum...” (Mrs. Campbell, Phase 2, p.32)

However, many of the mothers distinguished their role from that of mothers in general, explaining their view that, as mothers of children with ID, this role is necessarily indefinitely extended - not something they could shirk or change when their children got older. This echoes the notion of ‘perpetual parenthood’ identified in Shearn and Todd’s study (1997). It also accords with quantitative findings reported in a study conducted by Smith (1996) which investigated the cases of elderly mothers of children with ID ( $n=235$ , average age 70.3 years), and found that they fulfilled their caregiving responsibilities on a long-term basis.

It is also worth considering that, not only in terms of long-time commitment, but on a daily basis, the responsibilities of a mother of a child with ID will differ significantly from those of mothers in general. Well into adolescence, and possibly beyond, offspring with ID are likely to require a level of physical input from their mothers in the conduct of daily activities which is commonly associated with the care of infants. Although both adolescents with or without ID may have similar emotional needs, the disparity in necessary levels of physical involvement between the two sets of parents might lead to a quite different sense of parental responsibility from the mothers of children with ID.

Nonetheless, in common with most mothers, the mothers in the current study displayed an unquestioning acceptance of their role. Mrs. Murray sums this up: “You do things automatically without having to question it” (Phase 1, p.4). This points to an element of intrinsic or unconscious understanding of the responsibility to provide care. She illuminates this instinctual element in the following quotation:

“Just it’s human need. It’s something that you would do. Just can’t say. Don’t know why. It’s one of those things. You’re the mum, just automatically...” (Mrs. Murray, Phase 2, p.7)

The use of the term ‘automatic’ is interesting here. Although what Mrs. Murray describes is a common maternal experience, it is perhaps unlikely that mothers in general would either use such a term, or necessarily recognise the extent to which they are responding to unconscious suggestion. It is possible that in the case of such a mother as Mrs. Murray, the unusual and special nature of the tasks she must perform as a mother draws attention to the unquestioning manner in which she addresses them. She elucidates this point further in the following excerpt:

“You just... you’ve got, you’ve become a mum. You’ve got certain... you have to look after the three so... and I think once you become a mum, it doesn’t matter if she was a regular person. She was doing things and away from home etc. etc., you would still always be a mum, like thinking about her, worried about her, etc. etc. And just my role is just like I’ve maybe had ten kids you know, because they’re still like three and four years old. Like you just... you automatically, you just get on with it...” (Mrs. Murray, Phase 2, p.10)

Two important points emerge from this quotation. The first is represented in Mrs. Murray’s repetition of the word “got”. This clearly denotes a sense of obligation, reviving Kant’s notion of the awareness of moral duty which arises from the acceptance of personal responsibility. It is possible that this sense of obligation is more present to Mrs. Murray than some of the other mothers, since she is a single mother. Her husband Fred no longer lives with the family; therefore, for her, the awareness of her practical and emotional burden is greater, perhaps prompting her to focus on the societal preconceptions and personal qualities within her which compel her to fulfil the responsibilities inherent in that burden. At the same time, her

husband's conduct presents her with an example of the possible denial of one's parental obligations – a fact which is also likely to increase her awareness of them.

The second point which emerges in this statement is her realisation that, with regard to Lisa (her daughter), she believes she will “still always be a mum”; in common with many of the mothers in this study, she recognises that caring is a lifelong commitment. However she predicates this statement with the qualifier, “it doesn't matter if she was a regular person...” This seems to suggest that Mrs. Murray regards the notion of ‘perpetual parenthood’ (see above, Shearn and Todd, 1997) as equally applicable in the case of normally able children, a notion reinforced by her suggestion that if she had brought up ten normally able children they would be “still like three and four year-olds”. This sets Mrs. Murray apart from the other mothers in general.

It may be that this difference in Mrs. Murray's beliefs is partly due to the fact that her other child, Tom (who was diagnosed with autism), meaning that she has no benchmark of ‘normality’ against which to measure the level of responsibility she faces. It is possible also that her situation as a single mother, has some part to play in shaping this element of her outlook; her situation is perhaps more extreme and stressful than the other mothers, a fact which might prompt her unconsciously to reject the idea that, even for mothers of normally able children, there is a foreseeable end to their responsibilities, since to dwell on this possibility which is unavailable to her might lead her into feelings of frustration and hopelessness.

By the same token, the likely loneliness of single parenthood may cause her to cling to the role and purpose which continue to define her, and give her a sense of being useful. These reflections emphasise what a very complex issue the carer's obligation is - an aggregate of various distinct yet overlapping influences, including the carer's perceptions of societal expectations, their reactions to the view of others, and their own sense of personal responsibility, which is perhaps closer to the innate instinctive promptings of emotions.

It is interesting to observe how the carers' understanding of responsibility and duty, and of the societal expectations which underlie them, not only plays a part in forming their own sense of obligation, but also influences their beliefs regarding the priorities

of care. An example of how this may affect a mother is provided by a statement from Mrs. Young:

“...I think we’ve had a responsibility as parents to try and bring him up to be a nice person as well, and to behave properly and things....”  
(Mrs. Young, Phase 3, p.21)

This shows that acting in accordance with the concepts of responsibility and duty, the mother simultaneously becomes the agent of these, seeking to teach her child a similar awareness of social and moral proprieties. Interestingly, it is also possible to see that in some ways the strength of a sense of obligation may, conversely, lead them to consider and accept changes to their socially orthodox roles. Mr. Brown expresses his own perception of this process very bluntly: “...you’re doing all the things that your wife used to do...” (Phase 1, p.49). However, as he continues in this statement, he seeks to qualify the perception:

“...but it’s not role reversal, it’s role additional, because I’m still doing the car, the garden, the accounts and all the other things, you know?”  
(Mr. Brown, Phase 1, p.49)

While there is no cause to doubt the truth of this additional statement, the fact that Mr. Brown is at pains to point these matters out may lead one to reflect that he is perhaps uncomfortable with the notion of assuming what are regarded as female responsibilities, or at least, that he is overtly aware of the possibility that, in doing so, he may seem to be adopting a contradictory role, and feels the need to mollify the impression this conveys.

Mr. Brown was certainly not alone in discovering the necessity of accepting changes to his habitual role. Two other husband carers referred to the fact that they had never cooked before their wives became ill. Similarly, three wife carers admitted to the necessity of accepting responsibilities formerly discharged by their husbands. Mrs. Miller provides an example of her experience in the following excerpt:

“...as before he did such a lot in the house, you know, but, well, I have to... he can’t drive, he used to drive the car, I do the driving and, um, well, he used to take care of the bills... household bills but I have to do

that now. I have to do everything that he did before.” (Mrs. Miller, Phase 1, p.11)

A sociological study conducted by Calasanti and Bowen (2006) suggests that this is a common phenomenon. They made a qualitative investigation of twenty-two spousal carers of partners with dementia, and reported that the caring role necessitated taking on responsibilities formerly carried by the cared-for person, pointing to the specific necessity of crossing gender boundaries.

Another carer from the older group, Mr. Owen, provides a further example of this necessity, explaining the fact that, since the deterioration in his wife’s health, he has been obliged to take on housework duties. In the course of this statement he made specific reference to the chore of Hoovering, a task he clearly dislikes and finds physically uncomfortable in consequence of a dust allergy. In the context of the cultural and emotional challenge of caregiving, this may seem a fairly minor objection, but it nonetheless serves to highlight the various and complex impact of role change on the carer. Mr. Owen’s demeanour as he described the situation suggested a degree of anxiety and distaste which illuminates the degree to which such apparently small changes may negatively affect the carer’s physical and psychological well-being.

In the younger group, Mrs. Gill (mother of Alice) also spoke of the changes she perceived in her role, making an implicit distinction between her responsibilities as a mother, and her responsibilities as a carer. She explains this in the following statement:

“...I see myself more as her carer now than I did when I was younger, when she was younger I would definitely see myself as her mother but now I see myself as more trying to help her to reach her potential, whatever that’s going to be....” (Mrs. Gill, Phase 1, p.29)

It is obvious that, from the moment Alice was born, Mrs. Gill was aware of being both a mother and a carer. It is interesting, therefore, that she regards herself as having been less a carer in Alice’s infancy than at present. This seems to suggest that, for Mrs. Gill, there was initially a degree of conflict or competition between the general responsibilities associated with the role of conventional motherhood, and the special responsibilities of caring. It is possible that this was caused either by an



element of resentment or denial of her daughter' condition in infancy, or perhaps by a sense of social isolation and stigma attached to the fact of being the mother of a child with ID, which, with the passage of time, she seems to have resolved.

Further examples provide evidence of similarly fundamental role changes – the necessity of wholesale psychological and emotional adjustments for participants in both groups. In the following excerpt, one of the carers of older people, Mrs. Miller, describes how the responsibility of caring has come to dominate her life, and altered her perceptions of her own identity:

“...just like a nurse. I feel that they're all that I had in life, say fifteen years ago, ten years ago, where we were husband and wife and we had a good life and we had things to look forward to and I feel now I'm really just a carer and that is my role in life, a carer.” (Mrs. Miller, Phase 1, p.21)

Mrs. Miller's statement is reminiscent in some ways of the statement given by Mrs. Gill (above), in which she describes the change from being a mother to being a carer. However, as has already been suggested, Mrs. Gill's description of her role change is very much connected with a subjective perception of herself; while Alice was young, she regarded herself as a mother, even though she was clearly responsible for her as a carer as well. In Mrs. Miller's case, although, in describing herself as “a nurse”, like Mrs. Gill she is giving us a subjective description of how she perceives herself, the actual deterioration in her husband's condition provides an objective framework which reinforces the perception. The significance of actual change (as opposed to subjectively conceived change) is confirmed by a phenomenological study conducted by Karlin, Bell and Noah (2001) in which changes in relationship, intimacy, and life situation are identified as factors contributing to role re-identification. Certainly, all three factors are detectable in the evidence provided by Mrs. Miller, although it is perhaps possible to suggest that the alteration in levels of intimacy Karlin identifies is, at least in this case, the result of a reaction on the part of Mrs. Gill to her altered position, rather than a factor contributing to that change.

It is generally recognised that the caregiving role changes with time – a process which begins with initial adjustment to the diagnosis, and develops with the carer's

responsibility to help in the carrying out the essential activities of daily life, and toleration of behavioural problems (Burns and Rabins, 2000). However, it should be noted that the identification of additional roles in the current study is different to the roles identified by Karlin, Bell and Noah (2001) who was concerned chiefly to investigate role reversal in adult carers of elderly parents with AD. This particular disparity in findings between the current study and that conducted by Karlin and colleagues may be accounted for by the different types of relations between carer and cared-for person covered by the current study. Although the carer of older people in the current study did describe the necessity of assuming responsibilities formerly the preserve of their partners, all confirmed the belief that, as the care situation developed, their roles developed beyond this point, and were supplemented, rather than simply reversed. As Mr. Brown comments above: "...it's not role reversal, it's role additional..." (Phase 1, p.50).

A number of participants in both groups referred to the business of caring as being like a job – an obligation requiring the pragmatic disposal of routine tasks, attended by a degree of emotional detachment. Mrs. Murray, for instance, described caring for her two children with SEN as resembling something close to shift-work:

“... I’m trying to think off the top of my head...sixteen and a half or seventeen hour day shifts that we actually do for both of them, by the time we get them up and put them to bed.” (Mrs. Murray, Phase 3, p.2)

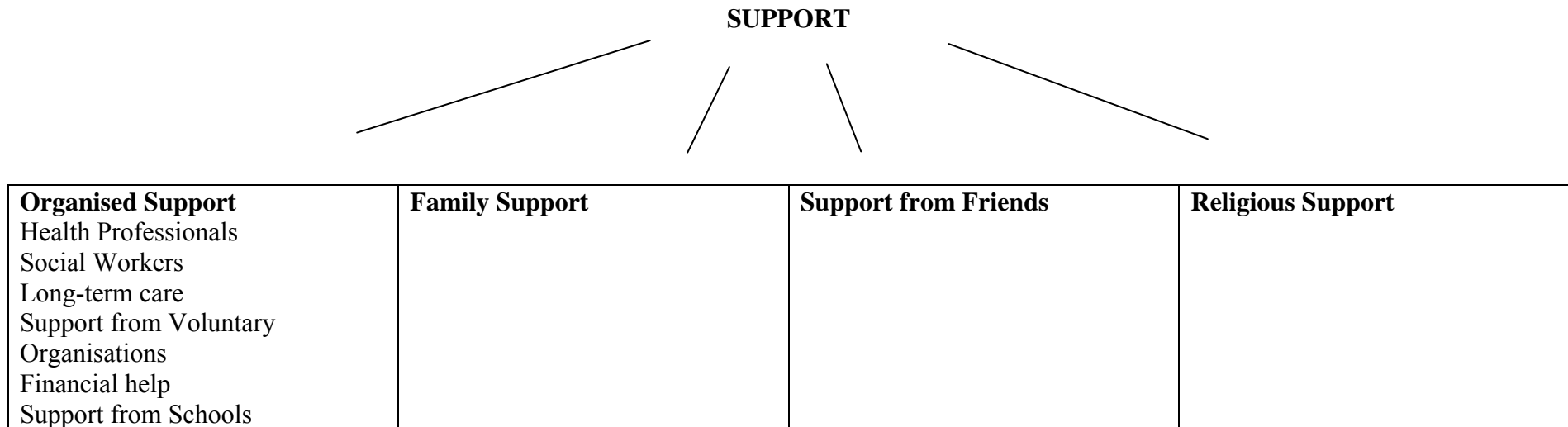
In this respect, the responsibility of the family carer certainly seems to differ from the experience of spouses and parents in general. The degree of emotional detachment implied in this description should be noted, since it affects our understanding of how the carer’s role relates to caregiver burden and other negative impacts on carers. To date, there is no literature related to this specific aspect of the caregiving role. There are, however, a number of studies (Wilson, 1989; Lindgren, 1993; Aneshensel *et al.*, 1995; Nolan, Grant and Keady, 1996) which identify important parallels between the role of the carer and that of a paid employee. The identification of a career-like pattern in the role of the carer is touched upon in a study conducted by Aneshensel *et al.* (1995). The authors of this study carried out a six-phase survey of the transition from home to nursing home in five hundred and fifty-five family carers of persons with AD or related dementias. Three ‘career’ stages were identified, which closely

paralleled the course of the dementia: (1) role acquisition, (2) role enactment, and (3) role disengagement. Role acquisition and enactment occur in the home care setting. Role acquisition refers to the relative's acceptance of a caring role; role enactment describes the carer's gradual recognition and adaptation to the increasing demands of care; role disengagement marks the point at which the cared-for person moves into institutional care. The study thus proposes a one-directional pattern, or 'career' in relation to the care of individuals with dementia. Evidence from the current study, however, suggests that, even beyond the point of institutionalisation, the carer continues to feel a sense of emotional involvement, responsibility and duty towards their relative. To the best of my knowledge, there is no published investigation or discussion of a 'career pattern' with regard to parents of children with ID. A possible explanation of this may be a scarcity of evidence, resulting from the difficulty for parents of cultivating or maintaining emotional detachment from their children. For the carer of older group, emotional detachment is very often a necessity, since, as a result of the deterioration in their partner's communicative and cognitive faculties, the sentimental feedback necessary to the continuation of an emotional attachment ceases to be offered. Under such conditions, the assumption of a pragmatic or business-like attitude is more or less expedient.

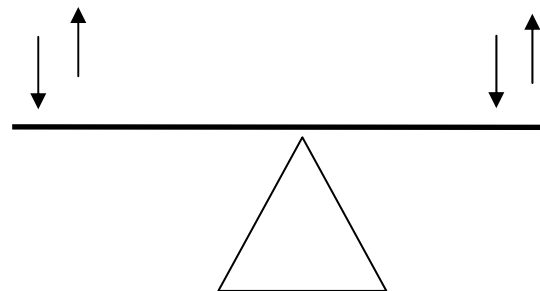
#### **5.4 Support**

The fourth category is called Support which refers to the perception and the level of satisfaction of help received by participants. Not surprisingly, different participants' perceptions of support are influenced by the specific and unique nature of their individual situations. Support is defined by various sources, types, and functions of help. The term 'support' was chosen by participants who talked about it, rather than the term 'social support' which is often used in earlier literature. The category of Support covers four properties, each referring to a different characteristic of the category: (1) Organised support, (2) Family support, (3) Support from friends, and (4) Religious support. A range of subsidiary dimensions will be discussed under each of the above properties, in accordance with the specific sort of that aspect of support.

Figure 10: Shows the properties of the category, Support



This category starts when the carer's Life Changed



This dimension increases and decreases according to the health status of the cared-for person or the availability of those providing support

### **5.4.1 Organised support**

Organised support refers to the help provided by appropriately trained professionals, or the provision of welfare assistance from statutory social care services. Many different organisations help in sharing care demands with participants in both groups - for example health professionals, social workers, and voluntary support organisations. A subsidiary dimension of organised support - support from schools - is only found in the younger group.

#### **5.4.1.1 Health professionals**

Health professionals offer a range of interventions for participants whose relatives have medical problems. They are also a source of relevant information on appropriate caring practice in such cases, or are able to refer carers to relevant sources of information and assistance, such as GPs, District Nurses, or other therapists. In the younger group, many children with ID have heart, hearing or bowel problems. Mrs. Young's son, Stuart, for example, is obliged to attend hospital frequently as an in-patient for his bowel problem. Recently, Mrs. Robinson's son, Harry, was diagnosed with rheumatoid arthritis, and required medical intervention to control the condition. Similarly, in the older group, many carers maintain beneficial relationships with their GPs, enabling them to cope better with the demands of care, while receiving, at the same time, a significant degree of emotional support. Mrs. Hope, whose husband Mark lives with AD, describes this situation:

“And any time I have to go up to the GP for anything he's so nice and he'll say now, 'Are you getting all the help that you ... you need, are you ... how are you? Eh, how are you?' ... You know.” (Mrs. Hope, Phase 1, p.55)

An excerpt from interviews with Mr. Tobin, also from the older group, illustrates how he benefits by the provision of equipment from occupational therapists, such as wheelchairs, commodes, and hoists (making it possible for him to deal with the difficulties of his wife's immobility, and thus keep her at home):

“That’s from the social services yes. And then they had, eh... we also had a new... that’s a different wheelchair, and we also have a different commode now, and again with the support.” (Mr. Tobin, Phase 2, p.3)

This example suggests how the equipment provided by the social services is updated at different stages, to accommodate the progression of the cared-for person’s condition, indicating the importance of ongoing assessment of carer need (Scottish Executive, 1999; Community Care and Health (Scotland) Act 2002).

Also, in the younger group, a number of mothers talked about various types of intervention from health specialists. A statement from Mrs. Gill (mother of Alice) refers to such an arrangement:

“Um, when she was a baby she was very easy to look after because she was... she didn’t cry or make a fuss or... she was very easy, but she needed lots of help and therapy, and speech therapy, and physiotherapy, and occupational therapy and so I had to work with her doing exercises and lots and lots of different things...” (Mrs. Gill, Phase 1, p.3)

However, in the case of Mrs. Gill, the consistency of this support was inevitably compromised by the fact that the family moved frequently – a pattern which may be observed in several of the families studied. Importantly, this example emphasises the fact that time, energy and patience are required on the part of the family if the maximum benefit is to be derived from the professional help available.

Most mothers confirmed that they were satisfied with the help they received from the medical services. However, one particular mother, Mrs. Cameron, expressed some uncertainty as to whether those who dealt with her were fully able to understand and empathise with the particular circumstances of her case:

“...when you go to a doctor, it’s normal for them to tell you things that you don’t want to hear and it’s quite hurting. Then you can see this doctor saying things to you and you say, ‘they’ve not got any feeling in how they’re explaining it to you’ and you...you get quite upset... Because they deal with that every day in life and you don’t understand how they can be so emotionless in the things that they tell you, so it can really upset you towards people being very straight forward with you.” (Mrs. Cameron, Phase 1, p.11)

This quote clearly shows Mrs. Cameron's unhappiness with what she considers to be a somewhat casual attitude towards her feelings. However, where medical staff demonstrate due understanding and consideration, the outcome of a consultation in which parents are given uncomfortable information can, in fact, be quite positive; this explanation from Mrs. Cameron again:

“...doctors can be quite hard but they tell me sometimes the truth as well and I feel that they understand you more than a lot of... uh... a normal mother... uh... a mother that's got a normal child that doesn't understand about disablement... but you feel that you...you're more supportive towards a doctor explaining things to you, because they understand.” (Mrs. Cameron, Phase 1, p.17)

Mrs. Cameron seems to be saying that dealing with someone who takes time to understand her situation (caring for a child with ID) makes it easier to accept the uncomfortable truths they have to tell her. Her ambivalence regarding professional support perhaps results from the discomfort she experiences in learning the hard facts of her daughter's condition – pragmatic realities which, albeit that they are expressed in a detached, or 'unemotional' manner, are nonetheless vital to the consideration of further intervention.

Further dissatisfactions with the support of health professionals are found in both groups. Here Mrs. Young, adoptive mother of Stuart, talks about her experience:

“Only once a doc... a couple of doctors have said comments that... one doctor looked at him and told me I'd got... he said 'Oh, you've got a good one there', and I was thinking that was a bit... I felt a bit hurt because that was unfair and another doctor had said 'Oh they probably won't do anything about his ears because he's got Downs syndrome', and I felt that was... but it was the medical profession, it's not been people...” (Mrs. Young, Phase 1, p.7)

There are several elements of this excerpt which are worth noting: at the beginning of Mrs. Young's quotation, her dissatisfaction regarding specific instances of insensitivity towards her son (in this case, demeaning comments from two doctors about his condition and his appearance, which suggest, in the first instance, an ignorance of her son's feelings, and in the second, a somewhat belittling attitude toward him); she then makes a comment, indicating her disappointment with members

of the medical profession in general, drawing a negative comparison between the attitude she has come to expect from them, and the attitude of individuals outside the profession. This implies a degree of disappointment – as if she expects better from members of the medical fraternity. It is worth reflecting that the outcome of such negative interactions is likely to be detrimental to the relationship between the mother and the medical profession – a relationship which is, and should continue to be, essential to her son's well-being. Mrs. Young's sentiments in this excerpt in many ways echo those expressed by Mrs. Cameron (previous quotation above) regarding her 'mixed feelings' about certain health professionals who were seen to be detached or even prejudicial in their attitude towards people with disability. This finding is consistent with Read's (2000) study, which she reports that many mothers of children with disability find clinical professionals in some way biased against their child, tending to regard children with disability as being less important than those without, and giving priority to the latter in terms of treatment.

Beresford, in her (1994a) study of the caring experience, interviewed twenty mothers of children with severe disabilities, and found a number reporting negative feelings in response to clinic visits and consultations with medical professionals. One of her participants complains specifically about doctors' reluctance or inability to understand the experience of caring for a child with disability, and about the low level of respect accorded to her child – suggesting a tendency amongst medical professionals to view the child more as a specimen than a human being. Read's (2000) qualitative study also reports that most mothers experience difficulty in dealing with the medical services, particularly finding “going to hospitals and clinics a great trauma in itself rather than a help” (p.34-35). Recently, McGill, Papachristoforou and Cooper (2006) conducted quantitative research investigating the levels of satisfaction with support for sixty-six family carers of children with developmental disabilities, and found the majority of carers dissatisfied with the services they received. It should be pointed out, however, their study is limited by its small sample size and the nature of the quantitative approach, which tends towards collection and enumeration of data, rather than exploration of the issue.

Nonetheless it seems fair to assert that, in many respects, participants are reporting a very mixed response to their experience of help and support from various health



professions. It seems that having a child with ID may lead to interactions in which unsympathetic and insensitive judgements are expressed, and this naturally provokes concerns amongst carers regarding the nature and quality of support likely to be offered in such cases. It is slightly ironic, given that situations, such as those described amongst both groups in the current study, in which families' needs are met by a range of agencies and professional individuals, could, and perhaps should, be regarded as a positive scenario – alleviating a stressful situation for the family in question. Conversely, evidence from this, and other studies, seems to indicate that, in a number of cases, the opposite is true. The following quotation from Mrs. Miller, one of the participants in the older group, certainly seems to illustrate this point:

“I felt for a wee while that there was too many people coming, you know, and it was causing more stress...” (Mrs. Miller, Phase 1, p.12)

Mrs. Miller may be referring here to the necessity of having to repeat the same information for the benefit of various individuals from different support services – an activity which is likely to divert her time and energy from the duties of care, and could quite conceivably be a source of considerable frustration and stress. Mrs. Hope, another carer from the same group who expressed similar sentiments, goes further, identifying particularly the discomfiture she experiences in relation to the invasion of her privacy:

“...Um... It's like there's people coming to your house like nurses, people from clubs and um... things like that um... coming to collect Mark [her husband] and take him away for the day although they're lovely people... but I could have... I didn't really want people... I felt they were... it was an intrusion into my privacy. You ask people to come to your house that you want to come, like your friends, your neighbours, your relations, these are all strangers to me and it was, it was... they were strangers and I didn't... I found that a wee bit difficult to handle...” (Mrs. Hope, Phase 3, p.6)

Whitlatch, Feinberg and Sebesta (1997) and Wiles (2003) report that most carers are reluctant to seek outside help, feeling similarly uncomfortable, and fearing disruption to their daily routine. It is possible, of course, that the carers featured in those studies were not, at that point, fully cognisant of their support needs – perhaps being at an early stage of the caring experience – or that the anticipatory offers of support from

the professionals in these cases may have had the effect of adding to the carers' distress, forcing them to consider the reality of what lies ahead.

#### **5.4.1.2 Social workers**

A number of participants in the current study have received support from social workers, which was either independently sought, or recommended in response to medical referral. Such support is often a useful source of relevant information. Several mothers in the younger group, for example, have found contact with social workers helpful in providing information about certain benefits to which they or their children are entitled. Some of the mothers mentioned the fact that they discovered their entitlement to transport allowance – a form of assistance available to parents who are obliged to make numerous journeys in the course of conveying their children to appointments, care centres or special schools – through contact with social workers.

Support from social workers is equally important for the carers of older people. All participants in this group confirmed that they have received help from social workers in arranging sitters or respite care, allowing them either to pursue other aspects of their lives, or simply to enjoy a break from the demands of care. Mr. Tobin, in the excerpt below, alludes to this fact:

“...they're looking at it from the point of view of supplying help to enable me to still carry on part-time; I'm working about eighteen hours a week.” (Mr. Tobin, Phase 1, p.6)

Mrs. Baird also confirms the general level of support she received, and the confidence she felt that the social workers connected with her case were there for her and her husband Neil:

“Well the social workers are there on hand. The person as I say, Mary, who works in the hospital, if I want anything for me or Neil I just have to say to her and she gets it activated.” (Mrs. Baird, Phase 2, p.26)

The latter example highlights two important issues: Mrs. Baird is not only confident of the availability of support, but also of her ability to access it. In other words, Mrs.

Baird feels in control of the situation; if a circumstance arises where she feels she needs the input or assistance of social workers, (“if I want anything...”) she can request what she needs.

On the other hand, interactions with social workers are not always so positive. A number of mothers expressed frustration regarding the contributions of social workers. Mrs. Gill (mother of Alice) described the individuals who dealt with her case as “hopeless” (Phase 1, p.17) in their efforts to secure the support and information she felt needed:

“I rang social work, after about... that was probably January 2004, eventually after a long... lot of phone calls, a lot of this hassle, a social worker came to visit us in July, did an assessment, and I said what I want is something for her to do in the holidays and, um, I’m also thinking of her long-term care. And she said ‘do you want respite?’ I said, ‘no I don’t want respite, I don’t want respite, I just want something for her to do’. So I was thinking of these Wednesdays where she has the whole day [her day off school]... because it is very isolating for her. ‘Oh, something maybe for a Wednesday and something for the holidays, and maybe something at a weekend where she can go out and be independent of us’, because otherwise you all go out together, or I take her out or she stays in or... And I got this letter back and the only piece of information in there was for respite, you know weekends and weeks, and a letter saying that this lady was leaving the department and if I needed any further help to ring emergency. By which point I was so despondent that I’d spent eight or nine months and got absolutely nowhere that I kind of gave up...”  
(Mrs. Gill, Phase 1, p.44-45)

This quotation clearly conveys Mrs. Gill’s frustration that her needs were not met. It is possible these feelings may lead to mistrust in future dealings with the department.

One area in which the support of social workers seems to have elicited a more generally favourable response, across both groups of participants, is in the arrangement of respite care. Such a service was provided on a regular basis for two mothers from the younger group, and one carer of the older group. The two mothers, Mrs. Murray, who has two children with SEN (Tom and Lisa) and Mrs. Cameron, whose third child Emma, received respite care for their children when they were aged between two and four. Both mothers declared themselves satisfied with the provision, describing the benefit they derived from the time it gave them to focus on other

aspects of their lives, or as Mrs. Cameron explains in this quotation, from the simple chance of a break from the routine of caring:

“She goes there once a month and she goes to Share-a-Care six days a month. I feel the Share-a-Care side gives you the rest of not having to... give your the attention to other children, because that day, I mean you’ve not got Emma... you can put your attention to your other children. So I feel that that’s really good for me because it charges my batteries.” (Mrs. Cameron, Phase 1, p.4-5)

Mrs. Murray decided to get help from respite service because she found that she was unable to provide sufficient care for two children, both of whom have special needs. Having separated from her husband, she was forced to accept that the burden of caring for them alone was too great. The following quotation makes it clear how much she appreciated the help of social workers in resolving this problem:

“And then there could be a light at the end of the tunnel ‘Oh good Tom’s away this weekend [for respite], so that means I’ve only got Lisa’. So it’s half, half the burden. So that’s just how you sort of think about things.” (Mrs. Murray, Phase 3, p.5)

Respite support helps this single mother to run her life smoothly. She feels that the provision has given her a greater degree of control over her situation as she identifies her appreciation in connection with a particular service (respite care), describing the time and space it gives her to plan ahead. It should be noted, however, that although both Tom and Lisa (Lisa is Mrs. Murray’s elder child) have access to regular respite care, they have always attended on different days. As a result, there is never an occasion when Mrs. Murray is fully relieved of the duty of care. In spite of this fact, she remains appreciative of the service, explaining that the care of one child is a great deal easier than the care of both simultaneously. Nevertheless, Mrs. Murray’s is not an ideal situation. As a consequence of her somewhat unique position, unlike the majority of mothers, she is unable to benefit fully from this resource. In general the virtue of respite care is that it allows the family carer a complete break from burden of their responsibilities - a notion supported in a recent study conducted by Douma, Dekker and Koot (2006), which reports the view of a cross-section of parents of children with ID ( $n=289$ ), that respite care is amongst the most helpful of the services available to them.

In the older group, Mrs. Baird, has had two weeks respite for her husband, every month for over two years. The provision, in this instance, was furnished by the hospital. In another case, Mrs. Iris Owen, who is cared for by her husband Mr. John Owen, underwent such drastic deterioration between Phase 1 and Phase 3 of the interviews that she was assessed by the hospital in the interim, and a respite plan formulated and offered to Mr. Owen. This allowed him to continue caring for Iris at home – his declared wish. His excitement at this development is clear in the following excerpt, in which he describes his thoughts at the prospect:

“The first time they were... what they normally offer apparently is four weeks in one or six weeks in two, but they’re offering me four in two because they think that’s what I’ll be able to... that’s the most I’ll be able to handle. That was their suggestion, not mine so we’ll go along with that, and until it happens I can’t comment on it but, from... from the plan that they’re offering, that, plus the back up from the social services... I think I can handle it. And only time will tell if I can’t and then we’ll go back to the drawing board and see where we go from there.” (Mr. Owen, Phase 3, p.16)

The generally positive tenor of these findings on the issue of respite care seems to accord with those reported by a number of earlier studies related to this area of carer support (Strang *et al.*, 1999; Chan and Sigafos, 2001; Cowen and Reed, 2002; Jeon, Brodaty and Chesterson, 2005). All affirm the benefits of respite care, and emphasise the connection between respite care and reduced depression amongst carers. A review (Chan and Sigafos, 2001), evaluating the effects of respite care among families who have children with developmental disabilities, suggests that respite care is associated with major reductions in caregiver burden for the majority of parents who accept it. A descriptive quantitative study, conducted by Cowen and Reed (2002), which involved one hundred and forty-eight families of children with developmental disabilities, reports similarly beneficial outcomes similar to Chan and Sigafos’s study and a reduced risk of the development of dysfunctional parental behaviours. More recently, Jeon, Brodaty and Chesterson (2005) have reviewed research literature on respite care for carers of people with dementia. They suggest that the predominant practical benefit of the service is the freedom carers enjoy pursuing other activities. However, they make the point in their review that, on the issues of reduced caregiver burden and enhanced life satisfaction, the findings are less clear.

It should be noted that the decision to accept respite care was hard for some of participants. The chief reason seems to be a sense of guilt – a feeling that they are, in some way, ‘palming off’ responsibility for their loved one. Most however, came to terms with this emotion in time, as the positive benefits of the service became clear. Mrs. Hope, from the older group, wife of Mark, sums up this process of acceptance:

“...He still goes to respite, they get respite in the hospital and I find that’s really a big help to me. Eh... he’s, he’s home for a month and then he has two weeks’ respite in the hospital. And, that is really good and I feel now that as the time’s going on and he’s getting that wee bit worse, that I really need, ah, I really need the respite and I really look forward to having it. At first I didn’t want to do it at all, in fact I felt terrible. I didn’t want it at all. I was so upset...but as the time goes on you realise that you can’t do everything yourself and if you don’t get respite, it just means that I would go under, I would be ill and if I’m ill well that’s... who’s going to look after Mark? So I’ve got to look after myself and this respite really helps me ah... but other than that he’s, he’s alright, he’s not too bad at all.” (Mrs. Hope, Phase 3, p.2)

The emotional conflict described by Mrs. Hope, is in many ways similar to that defined in a phenomenological study conducted by Hartrey and Wells (2003), which investigated the impact of respite care on mothers of children with ID. The study identifies a clear relationship between the strength of attachment the subjects feel for their children, and a range of conflicting and ambiguous emotions connected with the acceptance of respite care.

Another cause of negative or ambivalent reactions amongst some of the participants in regard of respite, or temporary formal service, is the perception of discontinuity or disparity between care at home, and that provided in the formal setting. Several participants in the older group expressed a fear that the care supplied in the formal setting simply did not match up with what they provided themselves. Mr. Brown (husband of Anne), for example, described how he used a nursing home service while he was on holiday. Within the space of a week, his wife’s toilet routine was mixed up. Having left a note detailing Anne’s daily routine, he returned to find that nursing staff had not followed it. He also criticized the nursing home for not providing one-to-one care. He summarised short term care as being ‘a mixed blessing’ - a notion clarified in the following quotation:

“...it gives me a break but I worry about how she’s being dealt with and then, when she comes back, getting back into the routine and all things, it’s quite a problem.” (Mr. Brown, Phase 2, p.5)

This example confirms the benefit, but also points out the difficulties, of using nursing home support for this particular participant. He added that the experience will cause him to think twice before using the same service again.

#### **5.4.1.3 Long-term care**

A further element of support available from organised services is long-term care. Consideration of this possibility is recorded only among participants in the older group. Although the majority of carers in this group made no explicit plans regarding this form of support, a number found themselves entertaining the thought as the situation at home developed. Inevitably, the realization and acceptance of deterioration in the health of their partners is a major concern to some of the carers. Realistic consideration of the necessity of long-term care is an understandable reaction to this concern. Further to this, however, some carers realised that the issue of their own health, and its possible deterioration in relation to the growing demands of care, might force them to consider this option. Mrs. Hope (wife of Mark) expresses this view very clearly in the following excerpt:

“... I can see Mark ...ah, within the next maybe two years or maybe longer, having to go in to long term care because I’m sixty-eight just now and I’m quite fit but if I wasn’t, I wasn’t fit, I’d feel it really difficult to look after him, because he’s hard work to get dressed, showered, things like that, take him on the bus, off the bus...” (Mrs. Hope, Phase 3, p.14)

Long-term care can be costly – certainly it is generally a greater financial strain than caring in the home; some carers, while conceding the potential benefit, or necessity, of this option, expressed reservations regarding this issue.

“...Oh yes well we couldn’t afford that anyway, you know, but I... I want to keep Mark at home as long as he’s..., he’s able to stay here

and as long as I'm able to look after him... but if I... if I felt he was getting too much for me and my health was beginning to deteriorate, I would have, I have to call it a day, he would have to go into care, you know." (Mrs. Hope, Phase 3, p.16)

The issues connected with the resort to long-term care, as demonstrated by these findings, are broadly consistent with those highlighted by a number of previous studies (Penrod and Dellasega, 1998; Park, Butcher and Maas, 2004; Buhr, Kuchubhatla and Clipp, 2006; Strang *et al.*, 2006). Buhr and colleagues (2006) conducted a three year longitudinal quantitative study, in which over two thousand carers of relatives with dementia ( $n=2,200$ ), were questioned as to the reasons behind their decision to opt for institutionalisation. The study identified a range of motivational factors. This included: the need of more skilled care (65%); the carer's health (49%); the patients' dementia-related behaviours (46%); the need for more assistance (23%). A qualitative study conducted by Park, Butcher and Maas (2004), involving interviews with nineteen family carers, reports a similar number of factors: the interviewees in this study cited exhaustion, deep sorrow, the fear of damage to their relationship, and apprehension over the growing demands of care among the emotional considerations behind their decision. A recent study of twenty-nine family carers (Strang *et al.*, 2006) focuses on the transition to long-term care, using an exploratory descriptive qualitative approach (interpretive phenomenology). This identifies the importance of progressive deterioration, availability of placement, loss of control, and changes in the reciprocal relationship as the aspects most closely considered by carers. Surprisingly, there is no study in which financial issues are mentioned in connection with decisions over long-term care.

No study has yet investigated the issue of long-term care for mothers of children with ID. Interestingly, when questioned, mothers in the current study generally expressed confidence in their ability to provide extended care for their children. This is perhaps connected with the fact that the possible deterioration of their health or of their child's condition is less immediate concerns.



#### **5.4.1.4 Support from voluntary organisations**

A number of participants in both groups had contacted voluntary organisations, and received information, advice and practical support. A mother described a video she received from one such organisation, whose purpose is to teach young girls who, like her daughter, are on the threshold of puberty, about the management of their personal hygiene. Carers in the older group acquired similarly relevant information packs designed to enhance understanding of the particular condition, symptoms and needs of their partners, and advising on the management of care demands. It should be noted, however, that, perhaps because such organisations are voluntary, the range of information and support available is not necessarily comprehensive. In other words, a single organisation is unlikely to offer the same level of relevant advice and/or practical assistance to every carer. There are two aspects to be considered in this connection: on the one hand, although there is now a wide range of voluntary organisations and support groups who cater to the needs of family carers, it is still, to a certain extent, a matter of luck whether an organisation can be found whose specific area of concern accords with the needs of a particular cared-for person; on the other hand, even when such organisations do become involved, they are unlikely to offer the same level of help to carers of widely different characters, or likewise to carers whose levels of ability to manage independently are unequal. Such organisations are more likely to differentiate the amount of assistance they offer depending upon the specific needs of each case.

Many participants in both groups also received support from paid carers, arranged in the main by voluntary organisations, or, in a few instances, by the social workers attached to their case. Such services must be distinguished from those provided by health professionals, because a large number of the paid carers have received no professional training. The sort of support provided by such carers includes sitting, or perhaps taking the carer's relative out for a few hours. A number of carers in the older group were happy to pay for these services, in return for the opportunity to enjoy a little time to themselves. Mr. Brown (husband of Anne) declared that it was "money well-spent" (Phase 1, p.33). All the carers in the older group take advantage of day-clubs, and are satisfied with the service they receive. Mr. Owen summed up the positive response to this provision, describing it as a "win-win situation" (Phase 1,

p.8), allowing him a spell away from the burdens of care, with the reassurance that his wife is in a safe place.

There are also a number of voluntary services available to mothers of children with ID. These include special clubs, offering the option of outdoor activities in a safe and controlled environment. Such clubs differ slightly from the day-clubs used by carers in the older group, supplying a more specialised level of support from tutors trained in appropriate care and educational approaches. Again, the general response from the mothers who made use of these clubs was positive - a fact suggested by their willingness to provide the necessary transport to and from the clubs. All seemed to feel that the opportunity these clubs offered their children to broaden the range of activity and social interaction was of great benefit. Another service used by several mothers in the younger group is the 'Befriending Network'. This employs youths of a similar age to the carer's child, whose function is to act as a 'special friend', accompanying their partner in a variety of outdoor activities, while providing an opportunity for the child to enjoy a social life outside the home. In the following excerpt, Mrs. Robinson (mother of Harry) describes the benefit that both he and she have derived from this service:

“...he does have two girls who act as what they call ‘befrienders’ who... they take it in turns at the weekend, so one comes one weekend, one comes the other weekend, and they’ll take him out somewhere and do something that he wants to do like going bowling or going to the cinema, something like that. So that’s a couple of hours of... of respite for the weekend. And it means he gets a social life too with somebody close to his own age.” (Mrs. Robinson, Phase 2, p.12)

This quotation suggests one benefit of such organisations - encouraging the mother to believe that her child is capable of enjoying a social life with his peers. Heslop's study (2005) confirms this benefit, reporting high levels of satisfaction with the service, and the general opinion of parents that befriending services are 'a good thing'. There are parallels between the befriending network and the use of paid carers among the older group. However, it is important to understand a distinction between them: in the older group, paid-carers are employed as a means of alleviating the burden of carer responsibility, rather than expanding the social circle of the partner.

Another important form of voluntary organisation is the support group. These provide opportunities for family carers to meet and talk - sharing their experiences and problems. All of the participants in both groups were offered the opportunity to attend such meetings. However, their views on the virtues and demerits of these gatherings varied greatly. Mrs. Cameron, one of the mothers, expressed her appreciation for the sympathetic environment of the support group, and the opportunity to meet with others who understand from first hand experience the difficulties of caring for a child with special needs:

“I had a lot of friends that had normal children, and I had this child that... eh...was Down’s syndrome and had medical problems. I don’t feel they could understand me about the needs that she needed and I needed somebody I could sit in and have a cup a tea with in a group that made me feel that they knew what I was talking about, because they probably went through it themselves and they could give advice. So to me I feel that every bit of advice you get from a mother that’s special needs helps in lots of ways. It might not help you then, but you still... it could help somebody else’s child, but it makes you very aware of things and it... the advice you get from people does help, does help you a really lot, and when you’re having a bad day and mothers are around knowing you’re having a bad day, they’re very supportive around you as well, so to me I believe in being around groups that eh, support you so.” (Mrs. Cameron, Phase 1, p.20)

The sentiments expressed by Mrs. Cameron in the above excerpt are consistent with findings reported in a quantitative study conducted by Heller, Hsieh and Rowitz (1997). This study identifies three most frequently cited reasons for regular attendance at meetings of support groups: emotional support, information, and the reassurance of feeling less isolated. However, a number of mothers in the current study stated that they simply did not have the time to attend carer meetings. Again, this is consistent with Heller and colleagues (1997) who list time issues amongst the reasons for non-attendance, along with transport problems, and the feeling that such meetings are unlikely to be helpful.

Mrs. Murray, who has two children with SEN – Lisa and Tom, is one of several mothers who attended only a single meeting, before deciding against going again. In the following quotation, her description of the experience makes it clear that she found it both alarming and depressing:

“And I thought ‘oh, I dinnae ken if I can be bothered with this’, I thought... we went into a room and there was maybe like eight Down’s syndrome babies and toddlers and running about, and snottery noses and everything, and I thought... and they like... pounced on you because you were new, and they wanted to know everything about you. And I thought ‘that’s why I’ve waited nearly two years to come! I can’t be bothered with this’. And Penny [another mother in the meeting] said to me... Lisa wasn’t walking - Lisa started to walk just before I... just... she was two when she started, really started to walk - and Penny says ‘Oh don’t worry, Joyce [Penny’s daughter] was four before she started to walk’, and I thought ‘you’re depressing me here’...” (Mrs. Murray, Phase 1, p.48)

It is perhaps important to emphasise the source of Mrs. Murray’s depression in this excerpt; a specific piece of information shared with her by another mother in the group, regarding the development of her child’s mobility, seems to upset her. Her reaction implies that she does not want to hear about, or understand, the long-term problems she is likely to face. This suggests, at least in Mrs. Murray’s case, that there may be a certain element of denial in her reluctance to join, or take advantage of the support group. It is interesting that she had, on another occasion, enjoyed meeting and talking informally with a group of mothers with special needs children, at a gathering arranged under the aegis of the Sleep Scotland Project. Her enjoyment of the occasion, she admitted, was such that she kept in touch with three of the mothers on a regular monthly basis after the project closed. It seems likely that her positive response to this event is connected with the fact that, although the mothers originally met to address a common problem (the sleep difficulties their children share) the children themselves were not all DS – as was the case at the meeting of the support group – but lived with a variety of conditions. Mrs. Murray’s reaction to a later gathering with the three mothers she met on that occasion certainly suggests that this aspect of the experience was important to her. The following quotation illustrates this:

“...when I meet the three Scotland girls [friends from Sleep Scotland Project] and that’s, that’s great, that’s just like a pressure cooker and you just walk in there, and it doesn’t matter how you feel, what you look like or what you say we’re all in the same boat, and all our kids are similar but different. We’ve all got different problems, you know, which is quite good. And we can make it funny as well because it helps us, um... which is quite good. I am quite... I come in and said ‘Can I kick her until she died...?’ I mean, they’re all fine I love her to

bits, but that, you know, kind of morning that you've had, or I'm thinking of one of my friends...in particular her wee boy has just started secondary school, and he's tried to kill himself about five times now. And we're all different but we've got the main thing in common, and we can come away. Anybody listening to us or hearing us talk, you'd think we were completely sick or off our heads or whatever, but we don't really give a damn, it really just depends where we're meeting." (Mrs. Murray, Phase 3, p.12)

It is possible that the environment of a mixed-carer group allows Mrs. Murray to compare her position with other mothers, and perhaps gain some sense of reassurance that her situation is not the worst. This gives her a different perspective on her own situation, and allows her to feel more upbeat and optimistic. It is also likely that the fact that the other mothers were not mothers of children with DS meant that, in choosing to cultivate the relationship she developed with them, Mrs. Murray felt that she was exercising an element of choice – choosing friendship, rather than responding to expedience.

A number of other mothers from the younger group spoke of such informal networks. All agreed that an important aspect of their meetings is the fact that they organise them for themselves. This emphasises again the importance to carers in the current study of feeling that they have some measure of control in their lives. Mrs. Gill expresses this feeling clearly:

"...if you want to know something, you ring them up [other mothers who also had children with ID], you know, if you think they might be able to help you, you ring them up or if you want to just have a little moan about something, you ring them up whereas if you go to an organised meeting, you end up on the committees and things and I don't want that." (Mrs. Gill, Phase 3, p.14)

Mrs. Gill chose not to attend further meetings of the support group because she did not want to "...be part of the Down's syndrome world, because then it sort of dominates your life..." (Phase 1, p.26). She nonetheless understood the benefit mixing with other mothers, and therefore decided to seek group support on her own initiative.

The attitude to organised carer meetings in the older group is markedly different to that of mothers in the younger group, (illustrated by the evidence from Mrs. Murray given above). Whereas Mrs. Murray, and a number of the other mothers, eschewed the organised meetings, preferring to arrange informal friendship-based social gatherings, the carers in the older group seemed altogether more ready to attend the organised meetings, and cognisant of their advantages. This difference in attitude seems, at least in part, to be based upon a willingness to put up with any initial negative feelings about the meetings. This is suggested in the following quote from Mr. Owen, who cares for his wife, Iris:

“I go to the carers’ meeting that’s once a month. I go there and meet other carers and over the years I’ve seen the difference. At first it’s Oh these people, you know, they’re very far advanced - in fact when I first went I thought ‘what am I doing here? Iris is not anything like that’... but of course over the years I’m at that end now and the people who are going, everybody is a lot less worse than Iris. So you go from one end of the scale to the other end of the scale but it’s good to meet other people. You don’t feel so alone.” (Mr. Owen, Phase 3, p.8)

It seems that Mr. Owen’s willingness to give the meetings a chance results in a gradual realisation and appreciation of their benefits. Mr. Owen’s attitude seems more typical of the attitude generally reported regarding support groups. A qualitative study conducted by Ainbinder *et al.* (1998) explored the experiences and responses to such groups amongst a group of parents with children living with ID, and reported that many responded positively to the sense of being amongst others with similar issues and problems. Other benefits recorded by this study included the potential for learning and growth, the sense of mutual support, and the fact that support is available round the clock. A mixed methods study conducted by Solomon, Pistrang and Barker (2001) reinforces this finding, confirming that the majority of participants were satisfied with the support they received from organised carer meetings - adding to the list of benefits the participants’ appreciation of the sense of control, and the reassurance of belonging to a group. It should be noted, however, that the latter study recruited its participants largely from parents who regularly attended such meetings, and that the range of responses recorded are therefore more likely to be positive. Also, in contrast with the mothers in the current study, the participants questioned by Solomon, Pistrang and Barker (2001) refer only to the sense of control they

experience within the parameters of the organised carer meetings, and make no mention of arranging informal friendly gatherings independent of the group. Where continued contact outside the support group is confirmed, it is in the context of training courses, day clubs and respite care.

It is worth considering the possible explanation for the difference in attitude to organised meetings between the younger and older groups in the current study - specifically, the mothers' preference for meeting informally, or maintaining friendships outside meetings. It is possible that the mothers may not have the benefit of a fixed circle of friends, and are therefore more likely to pursue the possibility of creating friendships. In addition, as Macmillan's study (1986) points out, carers of older people tend to be less decisive, or find the issue of making independent decisions more stressful. They often also have fewer people at home to fill in for them; people with dementia are frequently hard to manage - if the group of people attending to their needs is too great, the difficulties of care for the main carer (spouse) are liable to be compounded. Consequently, carers of older group are less likely to feel that they can afford to be out of the house for any longer than is absolutely necessary, and are therefore less likely to feel they can afford the luxury of informal gatherings.

Having said this, not all the carers in the older group shared Mr. Owen's positive sentiments. A quotation from Mrs. Miller illustrates this:

“... That doesn't do anything for me, because for me to go and sit at a meeting and listen to everybody else's problems, that doesn't help me. If I had time off I'd like to go to a theatre show, or something that would uplift me a bit. Or go to dancing or something happy. But to sit and listen to everybody else that's a downer for me.” (Mrs. Miller, Phase 2, p.20)

Mrs. Miller's feelings here are closer to those expressed by the mothers in the younger group.

Interestingly, Mr. Tobin took the view that the organised carer meetings had both good and bad points. He explained that there were many positive aspects of the carer meetings, such as emotional support, but confessed that he felt it detrimental to listen

to others. Specifically, he seemed troubled by the possibility of subscribing to a group mentality. He explains this idea by analogy to a simple story:

“I think part of that... ah... we can all be brainwashed, brainwashed, ah... sorry... years ago in a small town, right, the main street into the town where the King had his palace, right, had a hole, right. There was a hole in the road, and the King noticed [right] that the people complained, you see. And they were complaining it would be filled with water and they’d go by and they would complain because they didn’t want to get their wheels in it and buckled, you see. So one night the King went out, right and he put some diamonds in the hole, and he put a big rock on top of the hole, you see. And his... his citizens, his people ‘ah who put that hole’ see, they went by they cursed, they went by they passed, you see. After a while he got them altogether and he says ‘now you’ve gone by this hole, right, when it was a hole, and you’ve gone by it when there’s rocks on top, and none of you have ever thought of saying ‘let’s move the rock’ you see, and you know what you’ve missed?’ And he moved the rock and they saw the diamonds, you see.” (Mr. Tobin, Phase 3, p.19)

It is possible that the idea of being ‘brainwashed’ might have occurred to other carers who felt negatively about organised meetings. However, there were many who seemed quite confident of their thoughts, and were prepared to agree or disagree with the views of others.

Nonetheless, for many participants, attendance at organised meetings does seem initially to have been a difficult or unpleasant experience. In the following excerpt Mrs. Hope (wife of Mark) describes how she found the first few meetings she attended disturbing, but goes on to explain how her feelings changed over time:

“I remember at one of the first carer’s meetings I ever went to and I’m thinking ‘Oh my goodness me, is this what I’m coming to?’ and it’s kind of scary, quite scary and I must say I didn’t really like it, but I went back a couple of times and there was other people the same level as Mark and we made friends and we all went through the same emotions, emotions like being sad and upset together, but it’s when you hear somebody that’s much further down the line, it’s scary, you know, but since I went to the carer’s meetings, I’ve met quite a few women and a few men whose husbands or wives have got Alzheimer’s and we’re all quite friendly and we can all understand what we’re all going through, you know, but that’s on the same level as you but when you first... when it first happens to you and you hear somebody saying



that they're sort of seven years down the line, it's scary, that's what I didn't like at the beginning." (Mrs. Hope, Phase 3, p.18)

This example illustrates a distinct process, or pattern of emotions, many carers seem to go through when attending support groups; this pattern is defined by a period of initial ambivalence, followed by gradual progressive acceptance and appreciation. The ambivalence may be associated with a sense of discomfort at finding oneself amongst a group of unknown individuals - people whose only common bond may be the nature of their loved one's condition. The discomfort, to this extent is an understandable reaction against an inevitably artificial social gathering. This is clearly how Mrs. Hope felt in her early experiences amongst the group. Her description of the comfort she increasingly derived from the empathy and support of others who shared her experiences also demonstrates the benefits of persevering, in spite of the early discomfort. This finding is consistent with the qualitative study conducted by Sutor, Pillemer and Keeton (1995), which reported that experiential similarity (for example, having experienced a similar status transition) is associated with emotional reassurance.

#### **5.4.1.5 Financial help**

Information about financial help is often either gained by carers themselves, by social workers or by voluntary organizations. Children with ID are entitled to Disability Living Allowance (DLA) (Department for Work and Pensions, 2006a). All the mothers felt it was a very helpful provision, enabling them to cover some of the living expenses associated with childcare. Carers in the older group, whose partners were over sixty-five, received Attendance Allowance (AA) as their main disability-related support payment (Department for Work and Pensions, 2006b). Those whose partners were under sixty-five received DLA. This threshold is a stipulation of the Department for Work and Pensions. Mrs. Hope, who receives the former payment to help with the care of her husband Mark, commented that it was more or less sufficient to finance a certain amount of supplementary paid care.

A common complaint amongst the majority of participants in both groups was that the process of securing these benefits was by no means a particularly pleasant or easy one. In the younger group, a number of mothers were clearly irritated by this fact, referring to the application process as a 'fight'. The following quote from Mrs. Campbell is typical:

“You have to fight for the money. They're Down 's syndrome and they're born with Down's syndrome and they'll die with Down's syndrome, so I... I think it's really unfair that you have to fight for what they're entitled to.” (Mrs. Campbell, Phase 1, p.17)

Mrs. Hope (wife of Mark), from the older group, reports a similar struggle:

“...when Mark first took Alzheimer's we had to apply for Attendance Allowance - now that was dreadful, it was terrible and everybody I think is in the same boat. You get this...it was only a form...that thick [indicated by hand gesture], not that thick, THAT thick...and you've got to fill all this form in. You've got to put everything about Alzheimer's and it's horrible filling the form in, sometimes you don't even understand what the form is about. You know, and you fill it in, you send it away to get this attendance allowance, and they knock you back, you get knocked back now at the very beginning. I think it's hard enough um... having, having the person with Alzheimer's being diagnosed and then you get this form and they knock you back. They say 'No, no you can't get it, you've not got enough points or the person's not bad enough' and the person is bad enough, and sometimes on the form, you're trying to understate they're not that bad - it's you that doesn't want them to be that bad...” (Mrs. Hope, Phase 3, p.22)

The negative sentiments felt by both groups of participants towards this complex application procedure are vividly exemplified by these quotations. Beresford's study (1994a) makes it clear that such reactions are common amongst carers. It is certainly worth considering how unsettled such individuals are likely to feel in their new and unaccustomed role, and the extent to which the additional burden of applying for financial assistance is liable to increase the stress they are already feeling. This may be the case not only because the process itself is so involved, but because, as Mrs. Hope's statement suggests, it forces the carer, rather brutally, to consider the severity of their relative's condition. The fact that a specific degree of severity is required in order to qualify for assistance, may conceivably tempt some applicants to deny the seriousness of the condition - effectively depriving themselves of benefits to which

they are entitled. It seems that, in the legislation connected with this issue, little or no consideration has been given to the problems many carers face in accepting the disabilities of their loved ones, or in dealing with the guilt of seeking assistance. Unfortunately, to date, there has been no relevant study regarding this area of concern.

#### **5.4.1.6 Support from schools**

A certain amount of specifically devised support is available in both mainstream and special schools, to children with ID. This includes the provision of personal tutors and classroom assistants, as well as specialised resources and accommodation (although the level of provision may vary from school to school). Most schools hold annual reviews, at which the individual child's progress is discussed and assessed, and their statement of need, if appropriate, modified. These reviews are attended by relevant managers and teachers from within the school, by educational psychologists, and by parents. They provide an opportunity for both school and parents to evaluate the child's progress and for the parent to air any concerns they may have. Mrs. Robinson (mother of Harry) supported his inclusion in mainstream educational establishments throughout his primary and secondary years. Despite this, she freely admitted that she is not fully satisfied with the provision. The following excerpt illustrates the sort of issues which, typically, a parent in her position may need to consider:

“Things are changing a lot at school in terms of we have to plan for his future, whether he stays at school or goes to college... maybe a mixture of the two for next year. Yes, we have to plan ahead for that.”  
(Mrs. Robinson, Phase 2, p.2)

Her specific area of concern here is the management of Harry's transition from conventional schooling. However, a study by Heslop *et al.* (2002) makes it clear that support from schools in this important matter is by no means guaranteed. The study reports that a fifth of young people ( $n=272$ ) with statements of SEN left school without any transition planning, or any that their parents were aware of.

Another mother, Mrs. Murray, who has two children with SEN (Lisa and Tom), unlike Mrs. Murray, sent her daughter to a special school. She described how Lisa's teachers communicated with her via a notebook which was regularly sent home. She explained that she found this a very useful means of keeping up to date with her daughter's progress and needs. It is clear, however, from the comments made by other mothers, that such considerations are not necessarily consistent from school to school. A number complained that information was not always offered, but had to be sought instead. A quotation from Mrs. Gill (mother of Alice) illustrates this point:

“The school would give... would have given as much help as you require I would say. They gave a lot of help for moving her from... school to college... You don't get anything unless you make a noise...” (Mrs. Gill, Phase 1, p.51)

The experience Mrs. Gill describes here suggests a certain passivity on the part of the school - a sense that support from the school is conditional on the parent's request - and implies a degree of irritation that the school is not proactive in communication. The possible conclusion to be drawn from this evidence is that some schools may be guilty of ignoring their duty to parents of children with special needs.

The dangers of passivity or recalcitrance on the part of schools - indeed the whole issue of communication between school and parent - should be seriously considered. The experience described by another mother, Mrs. Macleod (mother of Rose) illustrates the possible consequences of ignoring this matter. Mrs. Macleod had for some time cherished the hope of sending Rose to mainstream school. The following quotation from her describes how the process of negotiating with the school over this matter, eventually persuaded her to relinquish this hope:

“... I would have liked her to have some time at mainstream secondary but it didn't happen. It was just... too difficult and at some point, I will probably regret that I didn't fight it a bit harder at the time.” (Mrs. Macleod, Phase 3, p.17)

What is noticeable about Mrs. Macleod's account is the clear reluctance and regret she felt in arriving at her decision, and the fact that she feels compelled to seek some explanation for the disappointment of her hopes. This tends to suggest that she can

see no obvious reason why Rose should have been denied this opportunity. Also noticeable is the fact that she seems to be blaming herself, for not ‘fighting’ a bit harder; yet the fact that she felt obliged to fight might lead one to wonder whether the school in question was merely passive in its response, or actively resistant.

Mrs. Macleod is not alone in feeling that schools are not always balanced or realistic in their attitude towards children with special needs. Mrs. Gill recounts an experience in which she felt that the school, rather than being merely passive or negative, were overly ambitious in their assessment and treatment of her daughter Alice, potentially exposing her to situations she was unable to cope with:

“...some of the young adults on the course may be one day able to be independent but she... I mean, she will get better, but she will not be able to, I don’t think, do everything she has to do in the time frame. She may, but I don’t think so...but that’s their goal - to make them as independent as possible....” (Mrs. Gill, Phase 1, p.12)

The important question here is whether the school were, in actuality, unrealistic in their judgement, or whether Mrs. Gill’s response is the product of over-protectiveness. It suggests the possibility that, in some cases, it may be that parent, not the school, who stands in the way of their child’s progress - that, in fact, there may be an element of unconscious resistance in certain parents to the development of independence and autonomy in their children.

In the case described above, it is perhaps less easy to make an accurate assessment of the true source of conflict between parent and school. But in the majority of instances, both in the evidence of the current study, and in previous studies, the issue of bias or inconsistency is more clear cut. There is, it seems an element of discrimination in schools against children with special needs. In the passage below, Mrs. Campbell, describes a situation in which her daughter Claire, was excluded from school Drama classes:

“... You do get a lot of nasty people still that discriminate people with disabilities, and it is discrimination. Um, like I’ll give you a for instance... I don’t know if I spoke to you but she done a Drama class um, and she’s done it for two years - the Drama class - and this, this year she never got into the Drama class so I thought that was the

teacher's... that was quite a discrimination against people with disabilities, because when she was younger people thought she was cute, and she was this and she was that, but now that she's older people see her as she has got a disability, but she looks more clumsy and things like that in Drama class - or whatever... that's what I think they thought. So I had to go and fight, I had to appeal to get her into this Drama class, and what my fight was, was how can you let her in a Drama class for two years but not let her in now when she's in her...like, she's quite confident with herself...? and, whereas if they said to her 'You're not getting into this Drama class' it's going to knock her confidence and things like that, so I had to appeal, and I did get her in it - but um... and she was quite happy with that, but I thought that was discrimination." (Mrs. Campbell, Phase 3, p.13-14)

Sadly, Mrs. Campbell's experience is not unusual. A study conducted by Read (2000), confirms that discrimination in schools against children with disabilities is commonly reported.

Prejudice against children with special needs in schools is not always so obvious as in the situation described above. Often, it is less a case of personal bias on the part of teachers, as institutional discrimination. This often takes the form of a lack of appropriate resources and accommodation, suggesting that the needs of such children are less important to the school, or less rigorously considered than the needs of their more able peers. In the statement below, Mrs. Robinson, whose son Harry attended a mainstream primary school, describes her feelings about the provision of teaching materials in Harry's class. Her words clearly illustrate the problem of inadequate resourcing:

"He keeps on asking me when he can get married because there's a girl he likes at school! [laughs] It's quite hard to deal with that and there's not very much material available for... you know, the stuff that they give out at school, which they've sent me home, just isn't appropriate. It's too... you know, a lot of it's little booklets written in very small type, which he wouldn't be able to read anyway, and it's too much information." (Mrs. Robinson, Phase 1, p.16)

This tends to confirm that there is a paucity of appropriate teaching materials for children with special needs in mainstream schools. It also incidentally points to Mrs. Robinson's personal difficulties in explaining sexual matters to her son. Of course, she is not alone in this; parents of both children with and without disability may be

similarly ambivalent. This area of difficulty for parents has been recognised by the educational establishment; responsibility for sex education has, for several decades, been a key element of the school curriculum. The important point illustrated by the case of Mrs. Robinson, and many other parents in similar situations, is that sex education in schools seems to be chiefly aimed at normally able children, with insufficient consideration for the additional difficulties specific to students with special needs.

It is perhaps no surprise, then, that the issue of selecting a suitable school is generally more problematic for mothers of children with special needs than for mothers of children without disability. The levels of parental involvement in either case may be broadly similar, but there will clearly be differences in degree, since the obstacles likely to confront the mother of a child with special needs, may be greater, more numerous, and more diverse. Read's study (2000), confirms this, reporting an increased prevalence of 'problematic battles' for mothers of children with disability in dealing with education issues. A questionnaire survey ( $n=1380$ ) of parents conducted by the Down's Syndrome Association in 2004, resulted in a report which found that the majority of parents experienced difficulty in making a choice between inclusion in mainstream and special education for their child. In the following excerpt, Mrs. Young, whose adoptive son Stuart attends a special secondary school, rehearses some of the issues she and her husband considered in choosing the right school for Stuart:

“...a mainstream primary school and the primary school did have... had no experience of working with children with disabilities, and certainly not a child with a learning disability. And I think the teacher in the primary one had thought that Stuart would learn in the same way as all the other children, but maybe six weeks behind. So for her it was really difficult, she had a large class of children, all with different problems, and one child in the class that needed help because he wasn't learning in the same way. And there were times the school lost confidence in their ability to be able to teach Stuart... [.] But as parents we could see he was socialising, he was, sort of, fitting in, he was enjoying school, and that was really important...” (Mrs. Young, Phase 1, p.8)

The key aspect for Stuart's parents seems to have been the question of finding a balance between the academic and social aspects of his education. It appears that during his pre-secondary years, they were initially happy to persist with mainstream

schooling, on the strength of his social progress. The fact that he has since transferred to special education perhaps suggests that their early optimism in this regard was replaced by a more pragmatic acceptance of his inability to cope with the academic curriculum. Several parents in the current study arrived at a similar decision. Interestingly, however, these findings are not in accord with findings from earlier reports. Buckley *et al.* (2006) conducted a comparison study of mainstream and special education for adolescents with DS, and found students in the mainstream displayed greater improvement in expressive language and literacy skills, and fewer behavioural difficulties than those in special education. It should be noted, however, that progress in life skills and socialisation was found to be equal between the two groups. It is perhaps worth reflecting on the implications of this particular finding; it suggests that there is little relationship between improved communication and progress in social skills. This might be due to the fact that, in mainstream schools, the area of language and literacy is regarded as a separate discipline, whereas in special schools there is greater emphasis on the acquisition of these skills as an element of social learning.

In general, it seems that mothers and carers of children with special needs want to be involved in their child's education, and feel that schools are open to this involvement. This is confirmed by a survey study of parents and carers of children aged between five and sixteen ( $n=2021$ ) attending maintained schools conducted by the Department for Education and Skills (Moon and Ivins, 2004). A few mothers in the current study reported receiving some help and guidance from teachers and educational psychologists in making these decisions. However, as the following excerpt demonstrates, Mrs. Robinson expressed negative feelings about the guidance she received:

“...it was very confusing for me I didn't know whether to trust my instinct which was that college was the best place, or whether - you know... it's difficult...” (Mrs. Robinson, Phase 3, p.10)

In Mrs. Robinson's case, it seems that the involvement of professional 'experts' was a source of stress and confusion, leading her to doubt her own judgement and intuition as to what was best for her son. A study conducted by Smart (2004) illuminates this danger, reporting that, in a number of cases, reliance on the advice of experts may



actually be detrimental in making the appropriate educational choices for children with special needs, and so be a source of anxiety to the parents. Conversely, however, a number of parents in the current study complained of inconsistent or inadequate communication between themselves and their children's schools - particularly as the children progressed from primary to secondary education.

“...I mean, I can phone up and say ‘How’s she got on today?’ and at the beginning of the year, they phoned up, she wisnae... she took a long while to settle, in fact she’s still settling in. She’s settled in a lot but she’s still settling in now. And they will phone and say ‘look, she’s done this, this week, she’s done that this week, she’s been fine’, things like that. And they’ll write wee notes in her book and things like that. So, yeah, we do communicate but just not as much as the primary school.” (Mrs. Campbell, Phase 1, p.32)

A Scottish Executive report by Russell and Granville (2005) suggests that this is a common problem for parents of children with SEN, confirming that communication between home and school tends to decrease in line with the child's age. According to the Scottish Executive's study, the causes of this falling-off all relate to a reduction in opportunities for informal contact between home and school, connected with greater school size, and necessarily more formalised systems of home-school communication.

#### **5.4.1.7 Changes in organised support over time**

Evidence from the current study suggests that the degree of organised support received by carers altered over time. However, there seems to be no consistent pattern to this variation in either group of participants: in some instances the level of organised support rose, while in others it fell. In the younger group, one particular mother - Mrs. Robinson - spoke positively in this regard, indicating that the level of professional input increased as her son reached transition from childhood to adulthood:

“...they are coming round in a couple of weeks to start the process and I think it will be very good for him and for us and it's the company that supplies the support workers also do something called person-centred planning which is long term looking at what, what goals people have, what they want to do with their lives, you know, their living as they get older their um, living situation, you know, where

they live and so on because they have... the company has several... not branches, but sections that deal with one; they have a job section and an independent living section and then the support workers, but they also do this planning which covers all those things really and can help people with... not help them with decision making, but help them practise decision making, so that they know what options are open to them and can help them through that process and try to determine what they want from their life, which is...and what I said to them was it's nice to know there's somebody out there to help with that, because we are not very well equipped to deal with it and it's quite reassuring that there is someone else who can help with that process as he gets older.” (Mrs. Robinson, Phase 3, p.8)

Experienced supporters may provide useful information, and suggest practical strategies for dealing with future problems and issues. In Mrs. Robinson's case, transitional planning provides her with a formal structure for anticipating and providing against her son's needs, and is clearly a source of reassurance to her. However, another mother, Mrs. Gill feels no such confidence. Her daughter, Alice, was seventeen at the time of these interviews, and, as the following quotation shows, Mrs. Gill worried about the level of support decreasing:

“Um, I think that it's more difficult, in the sense now that you've got to think about the future. Whereas when they go to school, school kind of takes care of them, but there's not a lot to do once you've left school.” (Mrs. Gill, Phase 2, p.47)

It is natural that parents should worry when their child leaves school, as the support structures they have become accustomed to are left behind, and they find themselves having to search for new sources of advice and assistance. A qualitative study conducted by Knox *et al.* (2000) suggests that the difficulties at this stage are exacerbated, reporting that the involvement of organised support services actually decrease as the child gets older.

The notion of transition is relevant not only to the child's experience of school, but must be considered in connection with their movement between different elements of the health and welfare service. Consistency of support is likely to be greater for adults requiring care than for children, because, quite apart from their conditions, these children, like their more able peers, are constantly developing. Between the ages of five and sixteen they will pass through a number of transitional phases, the

significance of which is greater than is the case for their able contemporaries, on account of the additional complications of their condition, and their needs will correspondingly alter. Such frequent change in the necessary level and nature of support is likely to be unsettling for parents. The following quotation from Mrs. Young illustrates the point:

“At the moment he’s under the Sick Children’s Hospital and the service for children at the Sick Children’s Hospital is very different from the way the service is organised in the adult service. And at the moment, if he’s taken sick I can phone his Consultant or the Hospital and the Hospital know him really well and they just bring him in and they know how to make him better again and then he comes home. In the adult service we won’t have that facility. We would have to go to the Casualty Department. We would have to then be, I don’t know, admitted. I don’t know quite how they would do it. But the personal side of somebody who knows Stuart really well will be gone. So that’s a concern because I know when he’s sick, I do know how it should be dealt with, and it’s very difficult when you have to tell a doctor ‘This is how I want it dealt with’, because a doctor wouldn’t accept that. And that will be different for him.” (Mrs. Young, Phase 2, p.19)

The specific cause of Mrs. Young’s anxiety in the above excerpt is that, with the inevitable movement from child to adult health provision, both she and her son will be obliged, as it were, to ‘start over’ - building new relationships with professionals whose familiarity with her son’s condition and circumstances will be based, at best, on information and records transferred between different arms of the service at the point of transition. Security and confidence, both for the child and the parent may be negatively affected by this process. This is clearly true for Mrs. Young.

Transition, and therefore the importance of continued organised support, is of course relevant amongst carers of older people. The condition of the cared-for individuals in this group is, in many cases, equally likely to be changeable, and the degree and nature of necessary support consequently subject to alteration. An important difference, however, is that change, amongst the cared-for individuals in this group, will nearly always be deterioration. This may account for a marked difference in the experiences reported by carers of older people, with regard to the issue of continuing support - the difference being that most of the older carers felt positively, reporting increased levels of care. Although changes in organised support were also found in

the older group, many carers actually reported receiving increasing levels of care for their partners. In the following excerpt, Mr. Owen, whose wife Iris lives with Vascular Dementia (a degenerative condition resulting in diminishing levels of mobility), explains how the care package changed as her condition worsened:

“[District nurses would come] Four times a day because she’ll be immobile and needing that amount of nursing care because she’s immobile you see? Even to lift her out the chair it needs two people at this stage so that’s why that... and then they’re going to also offer a respite plan whereby I’ll have Iris home for four weeks and then she goes back to hospital for two weeks and that will continue on. So I’ve always got a bit of respite, two weeks in six respite. So that’s the plan when she comes out of hospital.” (Mr. Owen, Phase 3, p.3)

Some of the carers in the older group did, however, express negative sentiments in connection with continuing support. In the following excerpt, Mrs. Baird (wife of Neil) describes how, as a result of the deterioration in his condition, Neil’s continued attendance at a day-club was no longer feasible, due to deterioration of his health condition:

“I would like to get him back to his day, but, but that’s not going to be so, um... there’s no anywhere else like, you know, the Royal Ed. for these day things. And it so happens Mondays and Fridays are days for people at his stage. Tuesday, Wednesday, Thursday is for people which are starting.” (Mrs. Baird, Phase 2, p.15)

It is important to note, however, that the experience described by Mrs. Baird, in common with many of the carers of older people who voiced anxieties on this issue, is not concerned with the withdrawal or unavailability of services, but reduced opportunity to take advantage of them, as a consequence of the cognitive and behavioural deterioration of their spouses. Her complaint is valid, inasmuch as there is no appropriate alternative available to her, and what she thus, subjectively, perceives, is a decreased level of organised support.

The most important aspect in connection to the issue of ongoing organised support is that the needs, both of older spouses, and children with ID, are dynamic, not static - they change over time, and therefore levels of care need to change to accommodate them. There are two issues of importance to be considered here: objectively,

provision of adequate support is inevitably influenced by the actual availability of services; subjectively, while services remain in place, the individual perception for specific carers may be that levels of support decrease, because the extant services no longer satisfy the altered needs of their dependents. The dynamics of this complex relationship between altered need and altered levels of support are, to date, insufficiently understood which is suggested by Finfgeld-Connett's review (2005).

#### **5.4.2 Family support**

Family support is recognised as being the fundamental help by most carers from both groups, which gives carers the opportunity to release their feelings, to express and share emotions with other family members, as well as providing a break from the demands of care, and help with carrying out some of the tasks involved in caring. The sources of family support are not only immediate family members, but also the extended family. In the younger group, mothers identified their husbands as the most common direct providers of support, because the couple were living together.

“I think... [pause 3 sec.] we, like I said, with the kids we've always worked together as a team because it wasn't possible for me to have five children and not have him help me out. And he would come home from his work and deal with whatever situation we were in, if it was bath time then he would dive in and help with the bathing, if it was getting them into bed he would help get them all into bed, if I was tidying up the kitchen he would do the ironing. We worked together and it always has been that we worked together, and we knew that we could only have five children if we worked together, doing it all the time....” (Mrs. Young, Phase 1, p.21)

Such teamwork is recognised as a useful resource. Sharing the burden of care enables the carer to cope better. Other studies confirm that spousal support in caring for children with disability can be further linked with positive effects among parents (Sloper *et al.*, 1991; Beresford, 1994b) and lower levels of caregiver burden (Herman and Thompson, 1995). Quine and Pahl (1985) conducted a survey interviewing two hundred families of children with ID, and found fathers' participation in caring tasks an important resource. It should be noted, in the current study, that although all husbands or partners were working during the week, most were nonetheless happy to

participate in helping with care demands or sharing with housework, as was Mrs. Young's husband in the quotation above. Another illustration explains that both Mrs. Robinson and her husband were in a position to support each other:

“...usually it's not both of us feeling low at the same time so one of us can cheer the other one up.” (Mrs. Robinson, Phase 2, p.32)

A further form of support, exemplified by husbands or partners in the younger group, is financial backup.

“...I've been really fortunate having a you know, good husband who has been very supportive and we have worked through it together and I think that's been really important and we've always been, you know, quite financially secure and that's been a big plus...” (Mrs. Macleod, Phase 3, p.22)

In the older group, the main source of financial support was provided by the carers themselves. However, since none of the offspring of the older group lived with their parents, such practical support was not always directly available. Mrs. Hope (wife of Mark) often spoke to her sons on the phone, in order either to seek advice, or simply as a means of relieving tension. She felt that her sons were supportive as they were prepared to listen to what she wanted to say, or discussed her issues and problems.

“...if I feel uptight about something, you know, or something's really bothering me I... I get on the phone to my sons, or if they're down here, because they're good sons and they're always phoning or they're down here, I feel when I speak to them or that when I put the phone down I feel a lot better. I feel I've got things in perspective, they'll say 'you're getting yourself a bit, um, anxious and just try and calm down'. And they'll... they'll... they'll come up with another side of what... say whatever's bothering me, they'll say 'but listen, you know, it's... it's no worth getting worried about', you know, that sort of thing, you know.” (Mrs. Hope, Phase 1, p.43)

The above quotation suggests that emotional support, although invisible, is a powerful and important source of strength for the carer. A quantitative study conducted by Scott, Roberto and Hutton (1986) confirms that such support is an effective resource, positively associated with the carer's ability to deal better with the demands of caring.

Further to this, some participants in the current study explained that, in addition to emotional support, they also receive a certain amount of hands-on help from family members other than their spouses. In offering such assistance, other family members may volunteer to ‘fill in’ for the primary carer, by taking over some of the caring tasks, for example, by agreeing to act as a sitter. On the other hand, they may offer help with jobs - such as housework - which, although not directly connected with caring, are nonetheless contributory factors in the overall burden of stress upon the carer. In the younger group, siblings of children with ID often supervised their activities. In the following quotation, Mrs. Gill (mother of Alice) explains how oldest son, who is nineteen years old, will act as a sitter if his mother needs him:

“He was here from June until September the 17th. So he’s been here, a lot of... help, yes, because he was here for the summer. I could leave Alice here for a few hours with him if I need to get my shopping done.” (Mrs. Gill, Phase 2, p.24)

Similarly, in the older group, Mr. Tobin mentioned that his son would come to his home to do gardening for him, and Mrs. Hope (below) referred to the fact that when the family went away together for a holiday, other family members would take it in turns to relieve her of the burden of caring, giving her the freedom to do other things:

“Like when you... when we’re all together, like, they’ll maybe be walking and they’ll be talking to him and then the next one will talk... Then I’ll talk to him, it’s instead of me being there all the time, you know...” (Mrs. Hope, Phase 1, p.31)

These examples of family support in the older group show how, for family carers, such support may make the difference between being able to maintain their spouse at home, or being split up, with one partner going into a care facility and the other remaining behind.

#### **5.4.2.1 Barriers to family support**

There are however, barriers to family support found in both groups. These relate to aspects of the home and family life of the participants which hinder, obstruct or

compromise the provision of help to the carer. In the younger group, husbands or partners of the mother of a child with ID often felt compromised in their ability to offer support, because of the gender of the child. A quotation from Mrs. Campbell (mother of Claire aged fourteen) illustrates a typical aspect of this problem:

“Well on that point, like, my husband will not go in and bath her now. Whereas when he... she was younger he would go in and wash her hair and things like that, but she’s getting a big girl. She’s getting all the different things....” (Mrs. Campbell, Phase 2, p.9)

Mrs. Campbell’s statement suggests that the gender of child may have a negative influence on the nature or degree of support available from other family members. This is particularly an issue, as shown in this example, when such children reach puberty and begin to develop. However, it is also relevant in situations where the cared-for individual is an elderly person - if, for instance, that person’s spouse is unused to providing intimate care to their partner, or in cases where the offspring of the cared-for person feel embarrassed about offering such help to their parent.

In the older group, carers also reported a reluctance or inability to give support amongst offspring who were married or cohabitating, or who were supporting children of their own. Mr. Brown describes a situation of this type:

“They’re always on the phone, finding how I’m doing and, um... I mean, unfortunate... well, it’s not unfortunate. I mean, I understand they’ve got their own family... I mean, obviously, if they... they were single, um, they would be more here to help with me but they can’t because they’ve got their own children....” (Mr. Brown, Phase 1, p.41)

It is evident from the tone of this quote that Mr. Brown is prepared to understand and accept the legitimacy of his offspring’s alternative commitments. It suggests that such alternative family commitments, although common, may be regarded as a tolerable barrier.

On the other hand, there are some cases in which help from the other family members is unavailable for the simple reason that they are reluctant to become involved. In the following quotation from interviews conducted with the older group, Mr. Owen seems



to be suggesting that his daughters' input amounts to little more than a "cosmetic" (Phase 1, p.54) level of support:

"But they're not here. They're not here daily. They're not here first thing in the morning and they're not here late at night. They accept that she's a problem. They can't help in that respect. If they're here obviously, they support me, but it's at... the times when they're not here." (Mr. Owen, Phase 2, p.6)

It seems evident from this statement that Mr. Owen was dissatisfied with the level of family support he received; but the source of his daughters' reluctance is unclear. It may be that they are not fully aware of the strength of his feeling on the matter, or, perhaps more likely, that they simply do not feel it is their role to participate more fully.

Support from the extended family, including grandparents of cared-for children, or grandchildren of elderly individuals, was mentioned by several participants. Grandparents and grandchildren often provided emotional support through their willingness to listen and offer advice, and a certain amount of practical support, for instance, by offering to act as a sitter. The following quotation from Mrs. Campbell provides evidence of this type of support:

"... My mother-in-law, she had actually worked with people with Down's syndrome so she sort of knew a lot about it as well, which was a big, big help. So, as I say, I think I would not have been able to do it by myself, but having that support there constantly from the day she was born to today, that's a big help... It's a big weight off your shoulders having that as well." (Mrs. Campbell, Phase 1, p.21)

These sorts of findings are reinforced by evidence gathered in a number of questionnaire survey studies (Hornby and Ashworth, 1994; Hastings, 1997; Hastings *et al.*, 2002) and a research review (Mitchell, 2007) which investigated the importance of grandparent support among families of children with disability.

Evidence from some of the mothers interviewed in the study also confirms that geographical location may provide an obstacle to the possibility of consistent practical support. They referred to the fact that, although members of the extended family

might maintain contact via telephone, thus providing emotional support, their distance from the family home made any level of regular hands-on help difficult or impracticable. The specific nature of the problem in these cases seems to be the lack of any commitment to help from extended family members. As a consequence of this, the carer becomes reluctant to ask for help, or felt he or she could only do so if considerable notice of the request was given. Mrs. Macleod's sentiments in the excerpt below are demonstrating this particular aspect of the problem:

“Well my mother-in-law lives locally, but she... I mean, she does now and again, if we ask her, yes, she will do. But it's not... she's, she's... she's a widow and she really has her own life and it's not... we don't like to... or she hasn't said to us, she hasn't come to us and said, 'look, I wouldn't mind. If you want to go and have a night out have it.' You know? It's always like we have to ask like weeks in advance!” (Mrs. Macleod, Phase 1, p.8)

Another obvious obstacle to the possibility of support from grandparents is age. Advancing frailty inevitably compromises the grandparent's ability to offer practical help, and consciousness of this fact may increasingly deter carers from seeking such help. Mrs. Robinson sheds light on this aspect:

“I can talk to my mother-in-law and she's quite supportive, but they're all getting older now. And you... it's almost like the roles are starting to reverse, and you end up as a... having to help them with things because the physical frailty that it's... with them.” (Mrs. Robinson, Phase 2, p.17)

Multi-generational caring is becoming a reality for an increasing number of people. The two quotations above highlight an important aspect of the problems associated with it; for example, it may be the carer's perception of the grandparent's unwillingness or inability to help which is the source of the barrier. This perception might not necessarily reflect the truth of the situation.

#### 5.4.2.2 Changes in degree of family support over time

Change in degree may refer either to the increase or lessening of family support over time. Most participants in the study report no such variations. A few cases, however, should be noted. Mrs. Hope, a carer in the older group reported an enhanced level of support from her sons as her husband's condition deteriorated:

“...my family are really very understanding. Right from day one they were supportive and they still are supportive but it's a different kind of support now, you know, because at first he was okay. I mean we didn't really need a lot of help at the beginning because he was still... it was just a memory thing he had, but now that he's needing more attention, my sons treat him in a different way, you know.” (Mrs. Hope, Phase 3, p.4)

Similarly, in the younger group, Mrs. Robinson received more support from her husband because he could not accept the offer of doing his job abroad. This meant that the level of practical support he could offer was greater, although the level of financial support was likely to decrease:

“... George is home more this year, which helps. He's not away so much and that makes a difference. And then I'm not on my own with him a lot....” (Mrs. Robinson, Phase 2, p.6)

Some of the mothers, however, reported a lessening of support from their offspring, who formerly provided help in the form of supervision and sitting for their siblings. In the excerpt below, Mrs. Robinson, whose eldest child, Louise, had been a source of assistance in caring for her son Harry, expresses her fears in this regard:

“I think it will get more difficult next year because Louise won't be at home any more. And she's... we don't ask her to do a lot of, sort of, evenings in or anything but just now and again... and we have had sitters [from befriending network] in the past, it's just that, you know, some of them, they're mostly teenagers so they leave and then...” (Mrs. Robinson, Phase 1, p.15)

This pattern is similar to that recorded in Todd and Jones's qualitative study (2005) on the caring experiences of thirty middle-aged mothers of children with ID. They report that structural change within the family leads to a lessening of family support.

### 5.4.3 Support from friends

Input from friends is one of the most important sources of informal support for participants in both groups. Carers reported receiving varying degrees of emotional support from their friends, providing opportunities to talk, either on the phone or by meeting together. All carers who received this type of support described the sympathetic company of friends as a source of strength and reassurance. Mr. Owen is one of several carers in the older group who benefited in this way, as the following quotation demonstrates:

“I can... when we... when we go out we have a... we chat about all things. And... it's maybe what you'd maybe chat with your partner with normally, and, um, we all chat about it...” (Mr. Owen, Phase 1, p.53)

It is obvious that Mr. Owen, who, in earlier interviews, had specifically complained of the sense of isolation he suffers, directly relates the benefit of talking to friends with the sort of communication he formerly enjoyed with his wife. It seems that the social release of being amongst friends goes some way towards filling the gap created by the effects of his wife's condition. Several mothers from the younger group were similarly positive in their description of the benefits of friendship support. The quotation from Mrs. Campbell below exemplifies this reaction:

“I've got two really good friends, don't really usually go out on a having night with them. I've got two friends actually they've got Downs syndrome children as well. One's got a daughter that is actually in Claire's class at school and they're really good friends and ones got a wee boy that's just started mainstream secondary school as well and um. We usually go for a meal, we'll go for a meal and have a bottle of wine there um, and we usually sit and chat about the kids and how they're getting on and things like that....” (Mrs. Campbell, Phase 3, p.8)

There is a clear difference, however, between the quality of the experience described by the carer of older people and the mother (Mr. Owen and Mrs. Campbell); whereas Mr. Owen finds a degree of consolation for something which is missing from his life, Mrs. Campbell, while clearly enjoying the opportunity of emotional release to the

same extent, identifies an additional benefit, referring to the opportunity of sharing problems and difficulties she has in common with her friends – namely the fact that all three are mothers of children with DS. In the brief excerpt which follows, another mother, Mrs. Gill, refers to a similar advantage – in this case, the opportunity to share useful information:

“Usually about um, um, what’s around that they can go to? And I have had a lot of phone calls with a lot of people about this direct payment thing.” (Mrs. Gill, Phase 2, p.30)

Although the distinction between Mr. Owen’s appreciation of friendship support, and Mrs. Gill is relatively minor, it is nonetheless worth reflecting that there is some significance to the difference in specific benefits described by two groups of carers: while it is entirely possible that an carer of older people might also derive the advantage of sharing information or common problems through the company of adult friends, it is unlikely that the mother of a child with ID will seek consolation for any void in intimacy between herself and her child from the same source. This perhaps accounts for the slightly more pragmatic, practical attitude to friendship support which is displayed by the mothers in the current study. The fact that the advantages of friendship support are thus diverse, rather than singular, perhaps further explains the general benefit which is associated with it. This benefit is confirmed by a number of earlier studies (Krauss, 1993; Hastings and Johnson, 2001; Saloviita, Italinna and Leinonen, 2003). A qualitative research study conducted by Lilly, Richards and Buckwalter (2003), involving interviews with sixty carers, summarised the positive aspects, reporting that the company of friends provides emotional support and facilitates social integration. This study identified a further unique aspect of friendship support – for example, that its level varies little, if at all, over time. Since friendships amongst adults tend to be stable relationships, this is perhaps not surprising.

#### 5.4.4 Religious support

Religious belief is a source of support for several participants from both groups. Those who espoused a faith explained that belief in God helped them in overcoming some of the frustrations and stresses which attend the responsibilities of care. Typical among many faith systems is the encouragement of forbearance and acceptance of one's lot. Many admitted that adopting this outlook enabled them better to accept their situations, and the prospect of future trials. In the following quote, Mrs. Macleod, from the younger group, exemplifies this benefit, making a specific connection between her faith and the ability to remain positive about her situation:

“I mean religion does, as well, it plays a part because it's what sustains me. You know, and um... just to be positive and you know get strength from it and just to go on from day to day.” (Mrs. Macleod, Phase 3, p.16)

Another mother, Mrs. Gill expressed similar sentiments. This quote is characteristic of her attitude:

“I think God gave her to me for a reason... to look after her.” (Mrs. Gill, Phase 1, p.62)

A further statement from the same mother highlights an additional benefit:

“Oh yes lots of strength. I also get quite a lot of support from them in terms of people... they see Alice and I can now sort of leave her in church and go out and do the Sunday School and people will keep an eye on her for me and people know her a bit and she's kind of latched on to a couple of people who can handle... really supportive to me...” (Mrs. Gill, Phase 3, p.21)

It is apparent from Mrs. Gill's words that, not only the belief itself, but membership of a religious community, is a valuable source of consolation. Similar examples were found amongst the carers of older people. In the excerpt below, Mr. Brown, a regular churchgoer with his wife Anne who lives with AD, alludes to the same sense of community, and the consolation of social interaction it provides:

“Well, we go there on Sundays and we always have a coffee afterwards and... with Neil and with Anne and, again, all the people talk... talk to... talk to us, you know.” (Mr. Brown, Phase 1, p.41)

It is evident that church attendance provides carers with an opportunity to maintain their social life, as well as with a system of belief which helps them to apprehend and accept their burden. In general terms this suggests that adherence to a religious belief may contribute importantly to the psychological well-being of carers. These findings accord with findings reported in a critical review by Lee and Newberg (2005). The review concludes that religion amongst carers results in a number of important benefits, including social and emotional support, and improved motivation. The review further suggests that these benefits may play a part in enhancing psychological health and encouraging physical well-being.

One carer from the older group in particular - Mr. Tobin (husband of Alison) has subscribed for many years to the Mormon church - made reference to specific tenets of his faith which seem to relate directly both to emotional and psychological equilibrium, as well as physical health:

“Very much so from the point of view that, as I said to you before, because it encourages service, encourages sacrifice. Yeah, I think... it’s guidelines...and if you ever get a chance have a look, and... Interesting, two things sometimes stop people joining the Mormon Church, one is they ask them to pay - ten percent of their earnings is tithing; and the other is asking to live a health code, which means cut the smoking out, cut the drink out, cut the tea out, cut the coffee out, you see? Cut the drugs out. And I’ve looked at it from the point of view that if I was ever going to fall away from the Mormon Church the thing I’d love to still do is have my pay tithed. Okay, if I didn’t pay it to the church I could give it to Oxfam or something like that, because it teaches you to... to budget and teaches you to be unselfish. And the other thing who wants to have a poor health code in life? You know?” (Mr. Tobin, Phase 1, 35-36)

Ballard (1996) explains that the law of sacrifice in Mormonism implies overcoming selfish desire, and putting the Lord first in one’s life, and further explains that a purpose of sacrifice is to put oneself to the test, or to prove oneself. It is clear from Mr. Tobin’s words that this faith provides him with a particular pragmatic intellectual perspective from which to view his situation, and accept the burden it presents, while

at the same time stipulating conduct which is positively conducive to the physical rigour which is necessary to cope with that burden. More generally, it also encourages him to adopt a charitable and generous attitude - a willingness to concern himself not only with his wife's difficulties and needs, but with the needs of others.

Other specific aspects of religious teaching were mentioned by Mr. Tobin. In the following quotation he explains how his belief in the possibility of eternal life enables him to accept, and see beyond the immediate difficulties of his situation:

“Well if you have a faith... this is only a small part of existence, you know? That life's eternal, then you have a different perspective, and... and I think you usually find that probably about half the people say, ‘well that's not the girl, or that's not the man I married’. Um. It's a very worldly perspective, you know, on the basis that you're only going to live once. ‘Grab everything.’ You know? So I think that's the difference, if you have an eternal perspective, you put things... you see it in a different light. And I think probably the other side is it helps you to accept things that you can't change.” (Mr. Tobin, Phase 2, p.16)

Other carers in the older group described the benefits of their religion in comparable terms - identifying particular elements of doctrine which gave them hope and strength. A statement from Mr. Brown illustrates this:

“... I mean, we look to the future; we look to life after this life and say ‘This is all part of preparation.’ God doesn't test you more than you can bear. So it's worth doing and it will be worthwhile, it will be worthwhile.” (Mr. Brown, Phase 3, p.8)

Several from this group spoke of faith being related to hope, or of life being a ‘vocation’; one described the conviction that his wife would have a free spirit and go back to normal after this life. Although these beliefs derive in different systems of faith, their common characteristic is that they encourage the individual to accept the trials of the present by looking forward to a brighter future. A number of previous studies confirm the benefits of religious belief among carers - particularly relatives of individuals who live with dementia (Burgener, 1999; Theis *et al.*, 2003; Paun, 2004). The findings of these studies confirm the general suggestion that religious beliefs and practices provide a framework which helps carers to cultivate hope and acceptance, and identify some greater meaning in their situations.



Such views must, of course, be balanced by those who do not share them. Mrs. Robinson (mother of Harry) provides an example of the irritation some carers felt with those who suggested a relationship between caring and religion:

“I got quite annoyed when people... some people will say to you ‘Oh, God must have chosen you’, you know, ‘because you’re a good person’, and you’d say ‘rubbish!’... You know... I don’t hold with that at all.” (Mrs. Robinson, Phase 1, p.28)

## **5.5 Summary**

Within this chapter, the findings of the study were presented. Four categories were identified from the data of both groups: My Life Changed, Commitment, Responsibility and Duty, and Support. The core category - My Life Changed is variously present throughout the other three categories. Within My Life Changed, changes of caring experience are identified over time; this category may thus be defined as representing the beginning of caring journey and the development and learning process of the carers. Each category includes discussion of various properties and dimensions in order to enhance the richness of the findings. Relevant literature is also discussed. In general, more similarities than differences were found between the two groups of carers which compared under each category.

In the following chapter, a further synthesis of the findings will be discussed, in order to outline and develop a Theory of Caring based on the philosophical underpinning of a grounded theory approach.

## **CHAPTER 6 EMERGENT THEORY OF THE EXPERIENCE OF CARING**

### **6. Introduction**

The overall aim of this thesis was to identify, describe and explore the changes in carer's experiences of looking after a relative living with dementia or adolescents with ID and the effect of caring on carer's autonomy and health over time. This chapter will provide a synthesis of the research and study process which has led to the composition of the thesis. For this purpose, the current chapter is divided into three major sections. Firstly, the nature of the study will be briefly outlined. Secondly, an account of the process by which categories were defined will be given. Data analysis resulted in the identification of four categories: My Life Changed, Commitment, Responsibility and Duty, and Support. The core category of My Life Changed emerged from the data because it is at this point that the caring journey begins and it signifies the essential elements of the experience of caring reported by the participants. A Core category is defined as being "the central phenomenon around which all the other categories are integrated" (Strauss and Corbin, 1991, p.116). One of the most important elements in this category was the idea of learning from experience. Thirdly, the emerging theory is presented, along with a discussion of how these four categories cohere.

#### **6.1 The nature of the study**

Over the past thirty years, the provision of care for older people with dementia or adolescents with ID has shifted from formal institutions to the community (Walker and Ryan, 1995; Barodawala, 1996). This has resulted in an increased burden for those who care for these individuals, with a consequent reduction in autonomy. It was considered that a true understanding of the nature of caring in these circumstances would be better achieved by eliciting the viewpoints of the carers themselves, rather than by speaking to caring professionals (Grant and Ramcharan, 2001). Further, it was decided that an essential element in developing this understanding would be an appreciation of the nature and degree of change experienced by family carers over time – an area which until the current study had not been investigated (Nolan *et al.*,

2002). The notion of comparing the experiences of spousal carers of individuals with dementia against the experiences of parental carers of adolescents with ID is also new, yet seemed to the researcher a potentially rich area for exploration. These two groups of carers were looking after those whose autonomy and personhood were particularly challenged which had huge implications for the caring journey.

A qualitative approach was selected in order to allow the phenomenon to speak for itself, while providing a subtler and more lucid understanding of the concept and process of primary care in the home. Grounded theory was chosen because it is a flexible approach which admits the development of new thoughts and perspectives in relation to a familiar phenomenon. A longitudinal research design was used, with the specific intention of exploring the process of change over time. The fundamental data collection process comprised a series of in-depth interviews with thirteen participants, conducted at six month intervals across a period of eighteen months. A literature review, undertaken prior to the interview process, contributed to the formulation of interview guidelines, and was used as a data set appropriate for integration in the subsequent analysis process, towards the identification of categories and development of theory.

### **6.1.1 Symbolic Interactionism applied**

As discussed in Chapter 3, the underpinning philosophy of a grounded theory approach is symbolic interactionism (Mead, 1934; Blumer, 1969). The aim of this approach is the generation of a substantive theory on the basis of data drawn from a social context, with simultaneous analysis and explication of that context. Symbolic interactionists suggest that human behaviour is shaped by the influence of social contexts, in which symbols or meanings emerge through the interaction of individuals. In other words, the self is a product of social interaction. Thus, when ‘always being there for someone’ is symbolic of love. Meaning evolves within, and builds upon, the process of interaction among individuals. Meanings are assigned and modified through an interpretive process.

This is particularly relevant to the current study, which concerns individual perceptions of the effects of the caregiving experience, and of the subsequent impact on the carer's life. The findings identify social processes by which carers assign meaning to themselves and others, and to situations, events and acts, as they encounter and adapt to aspects of change. Thus learning from the experience of caring was the explanation of caring.

The process of constant comparative analysis comprises the simultaneous collection and analysis of data. In the current study, data - comprising digital files and transcripts of interviews, plus field notes recording circumstantial factors (material surroundings, interim events in the participant's life), and aspects of non-verbal communication (facial expression, gesture and demeanour) - was subjected to a subsequent analysis process. In the course of this process, the information gathered was accorded significance with reference to three levels of coding, by which categories, properties and dimensions were identified. The procedure of coding was facilitated by the incidental composition of theoretical memos, enabling a systematic ordering of thoughts and recording of insights. Findings derived in data analysis inevitably influenced the orientation of subsequent interviews, which in turn yielded further data for analysis, progressively contributing to the formulation of theory. Self-reflection, in the form of a reflective journal, played a vital additional role, enabling assessment of the accuracy of meanings progressively assigned to the interactions recorded in the interview process.

## **6.2 Category identification**

A series of three interviews was undertaken over an 18-month period of investigation. Four major categories emerged in both groups:

- (1) My Life Changed
- (2) Commitment
- (3) Responsibility and Duty
- (4) Support

## (1) My Life Changed

The core category - My Life Changed - began to emerge in the course of the Phase 2 and Phase 3 interviews. An emergent core category is recognised by the frequent recurrence of its dimensional characteristics in the data, indicating its increasing relevance to other categories, and its potential for explaining variations within the information gathered (Strauss, 1987). My Life Changed denotes the beginning of a journey, initiated by change (the assumption of caregiving responsibilities) of a degree sufficient to imply the likelihood of ongoing change in the future.

Figure 11: The theoretical memos for the development of the core category of My Life Changed

15<sup>th</sup> of June, 2006

The category of My Life Changed was identified as a consequence of a child being born or receiving a diagnosis for the spouse. My Life Changed covers three properties and several dimensions. I understand this category is huge but I believe that this reality is followed by their accepting the role (this is a sequent category which was recognised at this time).

7<sup>th</sup> of July, 2007

The category of My Life Changed is recognised as a **core** category now which closely relates to other categories and builds up the whole concept of the caring experience. This category was not recognised at the initial stage of data collection and analysis because it required time to build up to become the fundamental part of the whole process. Importantly, My Life Changed is the beginning of caring journey although it might have not been recognised initially for some carers. Mr. Owen expressed that he lives with his caring situation through changing and adjusting (Phase 3, p.14).

The experience of caring can be recognised as a developmental and learning process for carers in both groups. For example, Mrs. Young refers to her experience of having a child as experiencing a growing process (refers to the quotation of her Phase 3, p.17); Mr. Owen mentions his caring journey is a learning and growing process (refers to the quotation of his Phase 3, p.14).

12<sup>th</sup> of July, 2007

My Life Changed is recognised as a dynamic process which also shows a continuous journey of caring. The diagram of category My Life Changed covers many properties and dimensions which presents below:

Category: My Life Changed

Property 1: Effects of Change

Dimension 1: Lifestyle

Dimension 2: Relationships

Dimension 3: Financial concerns

Dimension 4: Positive outcomes of caregiving

Dimension 5: Hopes and expectations

Dimension 6: Carers' autonomy

Dimension 7: Having a paternalistic attitude

Dimension 8: "He's just a shell"

Property 2: "...doing it with a sixteen stone man on my back..."- the nature of burden and the load of work

Dimension 1: "I can't stand this..."- psychological burden

Dimension 2: "It goes for your health..."- physical burden

Property 3: Coping Strategies

Dimension 1: "You learn from experience..."

Dimension 2: "Kicking the bed covers and screaming..."

Dimension 3: "I'm in control..."

Dimension 4: Approach to life

The notion of momentous life-change is generally associated with the birth of a child, whether disabled or not, so the impact of change was perhaps less severe for the participants in the younger group; the mothers in this group did not, as rule, speak overmuch of the issue of change in their lives. However, the reality and possible ramifications of change for the older participants, assuming caregiving responsibility for a spouse with dementia, were perceived to be more drastic, and more challenging. Many of the older participants, for instance, described the feeling of being 'on a treadmill' – i.e. finding themselves suddenly locked into an exhausting and monotonous routine, with no foreseeable end. As argued more fully in Chapter 5, the experience of such a 'sea-change' may be productive of both negative and positive meanings for the carer. For instance, Mrs. Campbell, one of the mothers, indicated that the experience of caring for her daughter had some beneficial effects within her family life. It is important to draw attention to this possibility here, since the notion of gain, or improvement in life context is perhaps contrary to common expectations of caregiving, and is therefore potentially an area in which a new perspective on caring may be identified and investigated.

A key dimension of the core category relates to the effects of caregiving on the carer's autonomy – an effect observed and reported by participants in both groups. The mothers were generally initially more pragmatic with regard to this effect – again, perhaps, because there is a common expectation that the responsibility of parenthood will be attended by a reduction in levels of personal freedom for the parent. For both groups, the restrictions imposed by caring were sometimes difficult to accept. Importantly, however, there was an observable alteration over time in the mothers' response to this aspect of caregiver burden – a growing discontentment at the necessity of sacrificing personal needs to the needs of their child. This finding sheds light on how the dynamic and changeable nature of the learning process is involved in caregiver's experiences.

## (2) Commitment

The category Commitment accrued on the basis of evidence collected in all three interview phases. Verbal descriptions regarding the concept of commitment tended to focus on the importance of marriage vows, or of the biological bonds existing between mother and child in the younger group. However, the experiences of the one adoptive mother in the sample were surprisingly similar in strength of feeling. The vitality and importance of this concept amongst participants was further confirmed by observation of non-verbal indicators, such as eye contact, touching, holding hands or nodding. For example, when Mr. Tobin was speaking about his wife he turned, looked at her, took her hand and said 'she is my wife' which was reconfirming the commitment which existed between them. This was also a good example of symbolic interactionism in practice because the interpretation of his actions revealed a deep level of commitment and almost reaffirmed a marriage vow.

## (3) Responsibility and Duty

Responsibility and Duty were identified in each of the three phases, specifically when participants described the sense of obligation which accompanied the various daily tasks in the care of their relative. These concepts of responsibility and duty emerged

as being distinct in the sense that carers spoke of being responsible for the behaviour and activity of their relatives. Alternatively, duty was exemplified by the undertaking of daily chores such as bathing, dressing and feeding the cared-for person. These two concepts derive from the same Kantian deontological perspective, whereby conceptual relations are explained in terms of an analogy to a tree (for example, Responsibility and Duty conceived as separate branches of an identical root). This means that when a carer feels a duty to care they have a responsibility to carry that care out. However such a sense of either duty or responsibility can be felt to be imposed from outwith the person.

#### (4) Support

The category Support refers to a range of help offered to carers from various sources. Organised Support was reported to be problematical. Carers who received more formal support (from either professionals or voluntary organisations) described the experience of caring as being more manageable. On the other hand, Mrs. Miller received little support than other sources, because she is a very private person who chose not accept help. Most of the other participants did request help from a variety of sources and some of them found the multiplicity somewhat overwhelming. The majority of carers in both groups indicated that the high levels of family support they enjoyed motivated them to persevere with their responsibilities.

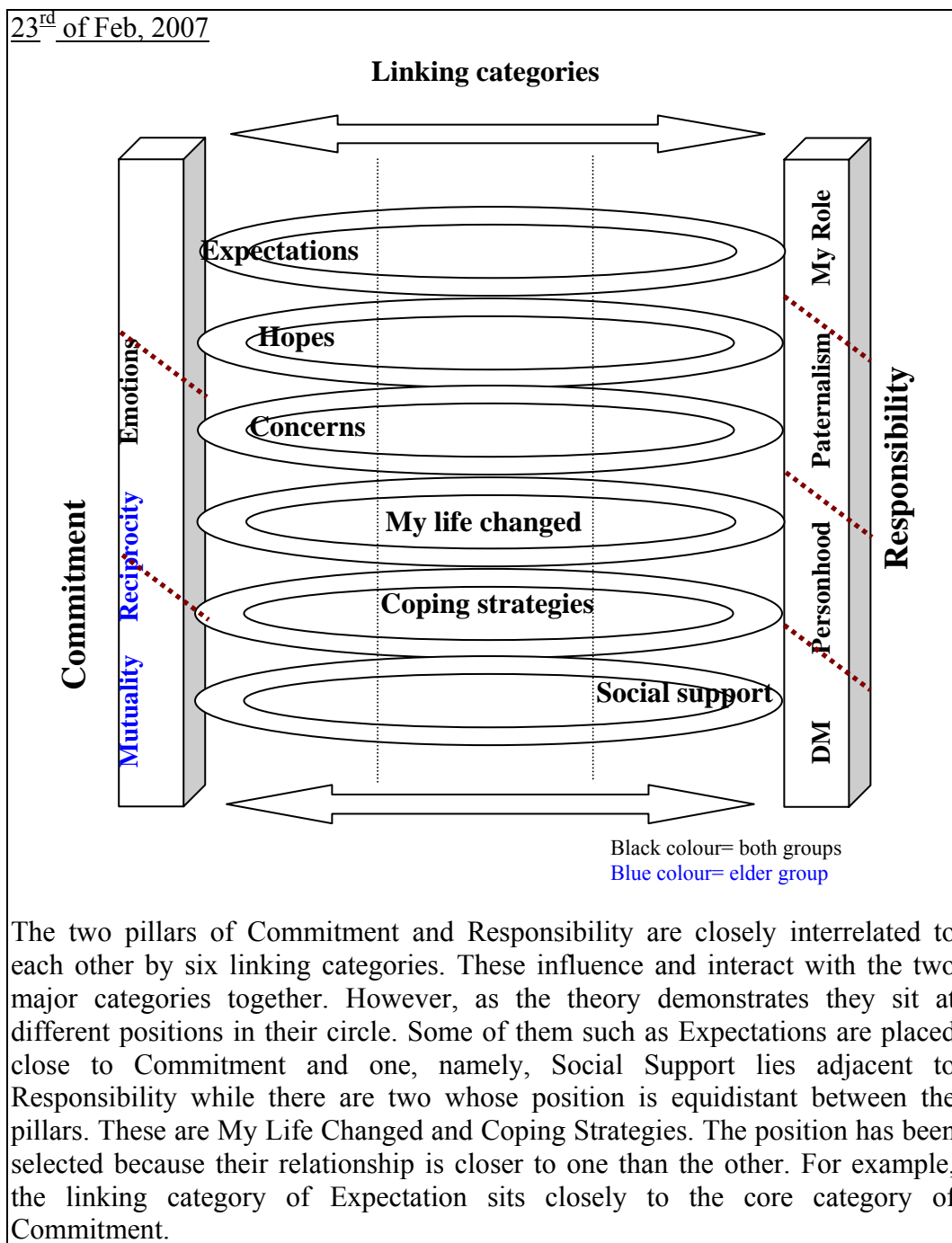
Although support was offered by professionals of different sorts it was not regarded in an exclusively positive light by participants. A number of mothers complained of being treated insensitively by members of the medical profession. Several of the older carers, Mrs. Miller for example, found the ministrations of support professionals a source of stress, particularly referring to the intrusion of her privacy. In addition, while it is obviously important that formal supporters keep family carers informed of likely developments and support needs in regard of the cared-for person's condition, such information, particularly if it is conveyed without appropriate sensitivity to the psychological state of the carer, could be frightening and disturbing.



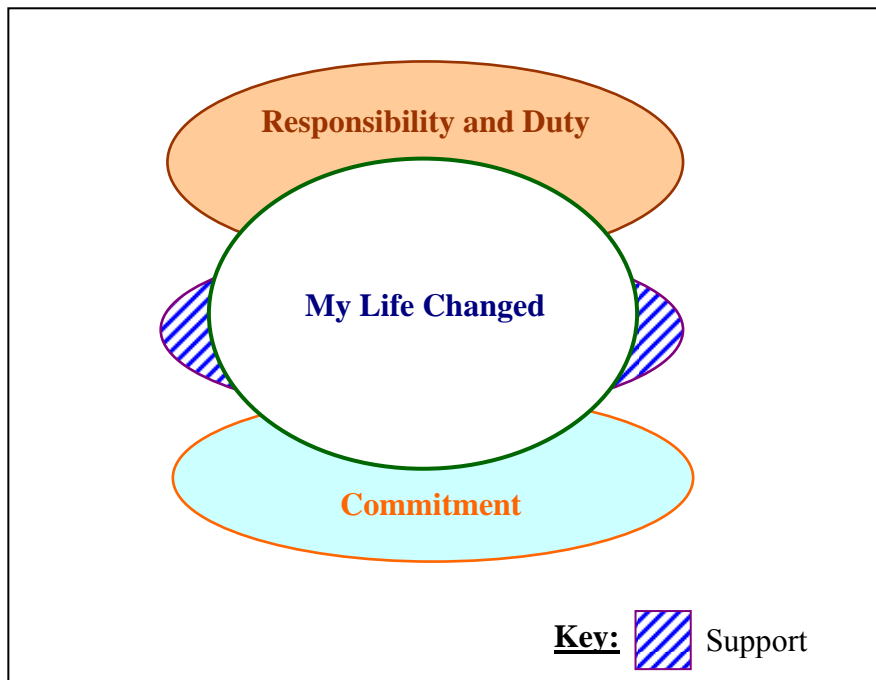
### 6.3 The Theory of Caring

The emergent theory derived from data drawn from the literature and interviews with participants in both groups. Its conceptual basis originates primarily in the properties and dimensions of the core category, and their relationship to properties and dimensions in the subsidiary categories.

Figure 12: The theoretical memos for developing the Theory of Caring



30<sup>th</sup> of Nov, 2007



I decided to draw a circle for the core category of My Life Changed which presents a dimension of continuing and dynamic process. Three other categories are linked each other as a three non-hierarchical chain of ovals which represents equal relationships between Responsibility and Duty and Commitment. Support is in the middle which shows it as an external resource. The shape of oval is also presenting as a dimension of process.

The reader will find it diagrammatically represented in Figure 13: The Theory of Caring. The core category, My Life Changed is depicted as an encompassing circle, representing the beginning of the caregiving journey, surrounding an oval and two pillars denoting the other three categories: Responsibility and Duty, Support, and Commitment. The figure is designed to demonstrate the dynamic and continuous process of caring, which also involves a process of learning.

Figure 13: Showing the Theory of Caring

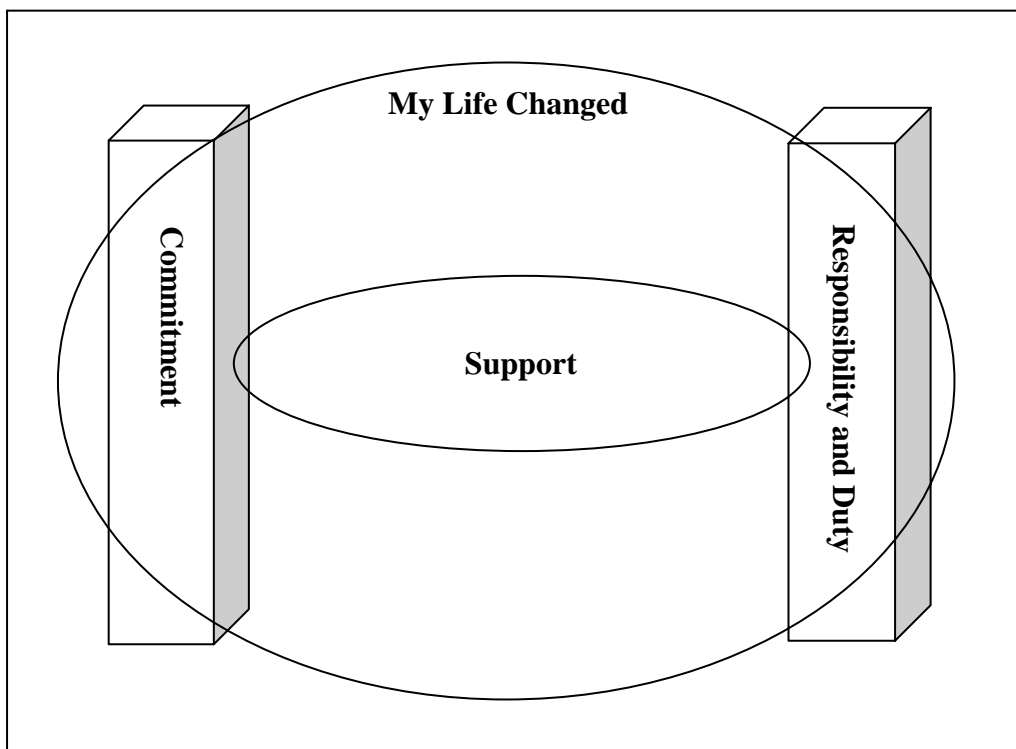


Figure 14: The theoretical memos for final model of Theory of Caring

11<sup>th</sup> of April, 2007

The core category, My Life Changed is a circle which represents the beginning of the caregiving journey, surrounding an oval and two pillars denoting the other three categories: Responsibility and Duty, Support, and Commitment. The idea of the circle is to show the dynamic and continuous process of caring, which also involves a continuing process of learning.

Commitment and Responsibility and Duty, two pillars, represent the equal relationships within the caring journey. The downward movement of the pillars also indicates that during the journey they become more burdensome or heavier. The category of Support refers to the area of material and emotional provision by external sources to those living the caring journey. The relationship among the categories of Commitment, Responsibility and Duty and Support is clear. For example, Mrs. Hope describes that she receives support from family and from formal resources which helps to motive her commitment to care (Phase 1, p.43). Also, Mr. Owen expresses that this formal support helps him to manage his responsibility for caring effectively (Phase 1, p.8).

Carers in both groups spoke about their sense of commitment, describing a willingness to provide care, engendered by social and emotional bonds to the cared-for relative. This category's position (as one of the pillars) in the figure represents its relevance as a fundamental feature of the relationship element of the core category – starting with the social contract of marriage vows for carers in the older group and the biological bond for mothers in the younger group.

The category of Responsibility and Duty comprises two elements, namely moral obligation and societal obligation, which are essential aspects of the foundational security of the caregiving situation. This category is depicted as the matching pillar to Commitment sharing a parallel relationship, denoting their equal importance as subsidiary aspects of the core category. Their delineation as separate entities is intended to indicate the way in which, in the process of data analysis, they have resolved into distinct and explicit areas of concern. The downward movement of the pillars also indicates that during the journey they become more burdensome or heavier.

The element in the figure is the category of Support, which refers to the area of material and emotional provision by external sources to those living the caring

journey. Its fundamental nature is indicated by its position as the oval in the centre of the diagram but still linked to the pillars of Commitment, Responsibility and Duty as support helps carers to deliver care. Again, the development and significance of this category, denoting the need of support in the carer (and, by implication, in the cared-for person), exist in the encompassing life-changes denoted in the core category. The relationship between the two illustrates the way in which the level of support required correlates to the nature and extent of change in the participants' lives - irrespective of whether the impact of such change is perceived as positive or negative. Commitment relates to Support insofar as the level of support received clearly influences carer motivation. Responsibility and Duty relates to Support insofar as the level of support received contributes to the carer's effective ability to manage caregiving duties.

This model works for both groups. Once the life-change happens, each category becomes interconnected in a dynamic process. In Taiwan there is a very different health and social care system, which relies even more heavily on family members to provide care it would therefore be necessary to investigate the understanding of Taiwanese carers in order to be able to know the transferability of the current model.

Change happened for all carers but it is not an identical process for all but is affected by individual circumstances and experiences. In other words, the pattern of change is unique to every individual. On the basis of data from the current study, it may be proposed that the characteristics of change in the caring experience over time are as follows:

- Carer's experiences were dictated by the condition of individuals with dementia who condition consistently deteriorated or by the forward development of adolescents with ID, albeit more slowly than their normally able peers;
- concomitantly increasing demands for care were evident in the older group, whilst in the younger group, the physical demands decreased;
- inevitably, as carers in older group aged, their own health needs increased; similarly, some of the mothers faced increasing health needs with the advent of the menopause;

- the need for increased formal support was evident in both groups - in the older one, to accommodate the effects of the partner's ongoing deterioration and in the younger one, to support the cared-for child's transition to adulthood and their continuing education;
- the caring journey throws up unexpected changes which may give rise to feelings of uncertainty in carers with regard to their ability to continue caring in the future;
- the journey gave all carers the ability to learn from those experiences to manage their lives.

## **CHAPTER 7 FINAL DISCUSSION**

### **7.1 The effects of the limitations of the study**

This is a qualitative study to investigate the concepts involved in caring and how they interrelate. However since the data were collected in one city in one country it is impossible to claim that these findings have universal acknowledgement and that further work in other places will be needed to establish the culture dependence of the current theory. The limited sample size meant that to achieve transferability it will be necessary to make sure that the theory is not culture dependent. Despite the small sample size there was a sufficient amount of data which allowed a good grasp of a complex concept and the learning experience of the caring journey.

Although longitudinal in nature this project would have benefited from a much longer study period. However it remains true that the present investigation does afford insights into this complex area. The older people certainly experienced the reality of caring in increasing measure until relatives had to be given residential care. This continuing aspect of caring would benefit from further investigation for spouses do not lose their responsibility, sense of duty or challenged autonomy and so on when they are not living with them. In the current work only one case provided a glimmer of information about this aspect of care.

The rise of male carers both as the carers of the young as well as the old group was responded to in this study but only 3 were recruited. Certainly, the findings would have benefited from a higher number being included. However this could be resolved by simply conducting a similar study recruiting more male carers.

The different cultural background of the researcher might also play a part of limitations of the study, especially, interpreting the complex process of caring. However, writing a reflective journal and supervision receiving from the academic team could solve or reduce such problems.

## 7.2 The strengths of the study

This work has a number of particularly important contributions. It is important to note that the sample was of those looking after people with dementia however these carers were relatively young with ages ranging from only 64-72. This may be a consequence of their being recruited from a voluntary organisation and so it could be posited that only the younger people had the interest, energy and mobility to participate in such activities as the organisation provided. This could well have been a benefit in that these participants were more than willing to take part in a long term project and were willing and able to try and ‘unpick’ the ideas that were relevant to the process of caring. Since it has been revealed that the experience of caring is in fact a learning process this sample might well be a particularly capable group to understand this and how it works. It is interesting to note that the mother’s group was aged 36-50 years and though this group has been generally referred to as being young they were in fact a mature group and were therefore not so different from the spouses.

One of the key contributions of this work was the new understanding of the learning which occurs throughout the caring journey and is based on the experience gained during that journey. ‘Learning from experience’ presents a personal and individual reflection from carers who were able to review their previous understanding and practical skills. Not only had this but they all managed to build on such reflections and handle the problems they faced in light of their new knowledge and abilities. Learning is a process which requires a developmental progression from carers’ recognition of an issue and findings ways of circumnavigating it. The maturity of both groups may well have had an influence on the way in which they learned from their experience. Presumably, mothers of the younger group learn from experience so the fundamental block of experience seems to be the primary source for gaining learning. It may well be that the older groups (more mature) do this more seamlessly or with greatly speed because it is an art or skill already mastered.

Because of the temporal nature of care, another major contribution to knowledge is the fact that caring is a journey over time. The journey begins with biographical disruption in the shape of either diagnosis of dementia or the birth of a child with ID. This journey continues for as long as that person is alive, including any period of long



term or respite care. However this last section of the journey, from the limited data here, is profoundly painful for the carer and instead of feeling the positiveness of continuing to learn and being able to manage life, suddenly they feel bereft and useless and therefore unable to manage. However the ability to continue to care albeit in a different form can make this misery more bearable if the reality of feelings of guilt that they have not been able to retain the focus of caring at home can be kept in check.

This particular understanding must be seen in light of the core category of My Life Changed where multiple effects of change can be seen. The reality of the burdensome nature of undertaking such a journey has to be balanced by the more positive aspects which some carers were happy to report. Sadly a number of professional carers appear not to acknowledge the importance of multiple relationships of My Life Changed and so it must be addressed. Although the Theory of Caring (Figure 13) does not intrinsically depict the relationship between the caring journey and changes in it over time it does indicate which how each category may alter, but its circularity does indicate that it does move all the time.

The category My Life Changed represents the beginning of the caring journey, and refers to the onset of a developmental learning process in both groups which includes three properties (1) Effects of change (comprising eight dimensions), (2) "...with a sixteen stone man on my back" (two dimensions), and (3) Coping strategies (four dimensions). In the younger group, childcare was naturally regarded as a normal activity. In contrast, the responsibility of caring among participants in the older group was something which had not been anticipated. Consequently, for these participants, the necessity of learning new skills and adapting to new perspectives was, in many cases, more difficult. Having said this, in one case, the inevitable life change came to be regarded as a positive, not a negative, outcome. Also, negative effects on carer autonomy were identified – several carers complaining that their freedom was restricted by the commitment to provide care. These complaints came predominantly from the older group; a number of mothers initially reported no perception of such infringement on their liberty. Again, this should not surprise us, since the acceptance of parenthood is generally attended by a concomitant understanding that former levels of freedom and self-determination will be sacrificed – a sacrifice often willingly made.

However, over time, all carers described an increasing threat to their freedom.

In both groups, the hopes and expectations of the participants altered over time, in response to changes in the condition of the cared-for person. Carers of older people generally entertained realistic expectations of their partners, and of themselves – particularly with regard to their personal capability of continuing to care for their partners. In the younger group, although the mothers seemed to accept that their children would continue to require physical assistance, they were initially less realistic, expressing the hope that their children might eventually lead more or less independent lives. Most carers in both groups set out with expectations of professional support, but progressively complained of a lack of information, understanding, empathy, and respect from formal services. In addition, many complained of the stress and difficulty of applying for financial backing and welfare support. Furthermore, health challenges were found in both groups and involved emotional stress and physical burden. “I can’t stand this” was related to emotional stress which included feelings of frustration, guilt, loss, sadness, worry and depression. “It goes for your health” was associated with physical burden, such as sleep disturbance and general fatigue.

The understanding of the nature of commitment is also addressed in this work. The category Commitment refers to a voluntary resolution to care, which is driven by the perceived, or innately felt, bond between carer and cared-for person. In the older group this bond obtains in the vow and contract of marriage; in the younger group, it derives in an innate ‘biological’ bond. This category comprises three properties: (1) “I love her”, (2) “She’d have done the same for me”, and (3) “He’s been my left arm”. Property number (1) derives from evidence given by both groups; numbers (2) and (3) are specifically related to the experiences in the older group. A review of the nursing literature revealed that though researchers were prepared to acknowledge its existence no study provided significant exploration of the concept of commitment in relation to care. However since this study was conducted in Scotland it is interesting that participants were prepared to speak of their commitment though they were reluctant to speak about love which is a concomitant dimension of commitment particularly within the context of family life. This may be a dimension of the cultural basis of this work. One culture may feel that commitment is the evidence of love and so feel that

it is not necessary to speak of it while another may feel more free to speak of love of which commitment is the underpinning. This would require further investigation.

Moreover, the understanding of the differences between a sense of responsibility and duty is clearly noticed and discussed from the findings of the study. Responsibility is defined as a moral accountability; in contrast, duty is the notion of obligation. The category Responsibility and Duty are closely related and both arise from participants' notions of obligation and societal expectations – for example, from their descriptions of 'having to' and 'needing to' perform tasks for their relatives' benefit. This category comprises a single property, related to the experiences of both groups: "It is what I do". Interestingly, there is no any nursing literature which focuses on how family carers view and identify their responsibility and duty to care. Presumably, nurses might take for granted what it is that family carers are doing and ignore the complex process of their sense of obligation in providing care.

The category Support was also found in the study which shows multiple sources and both positive and negative impacts. Support divides into four properties: (1) Organised, (2) Family, (3) Friends, and (4) Religious support. Respite care was also identified as being a beneficial intervention support for those carers who received it. However, in the younger group concerns regarding other aspects of formal support were voiced, particularly regarding the insensitivity, and lack of understanding and empathy they perceived in their dealings with health professionals. Many mothers felt these attitudes devalued their children. Organised support in general appears to be a problematic issue for carers in both groups. A certain level of support was offered by voluntary organisations to both groups, in the shape of information, advice, and opportunities to share experiences with others. Interestingly, however, this sharing of experiences was by no means exclusively positive for all participants. In addition, the necessity of having to fight to receive financial and social welfare support was reported to be a source of stress in both groups. The issue of support from educational bodies was also problematic; although schools were willing to offer the help and advice mothers requested, many felt the level of support was uneven, and unfairly distributed. Furthermore, family support was identified as the most common and reliable source of help in both groups. Support from friends provided emotional strength, and religious connections encouraged hope and positive attitudes amongst

carers who espoused a faith. Even in these areas, however, problems were reported, particularly in connection with the incidence of conflict amongst family members. The findings show the complex interaction among carers, cared-for persons and external supporters which is similar to previous literature (Schilling, Schinke & Kirkham, 1985; Scott, Roberto & Hutton, 1986; Frey, Greenberg & Fewell, 1989; Beckman, 1991; Beresford, 1994a; Aneshensel *et al.*, 1995; Beresford, 1995; Fudge, Neufeld & Harrison, 1997; Atienza, Collin & King, 2001; Neufeld & Harrison, 2003; Wiles, 2003; Hassall, Rose & McDonald 2005; McGill, Papachristoforou & Cooper, 2006). However, these previous studies only focused on particular support types (for example, family support or professional support) and so this ignores the complex relationships and interactions among many sources of support which makes it hard to manage.

It was important to explore this journey of caring by comparing the two apparently disparate groups because they are more similar than different. The carers were looking after people with similar degrees of dependency and challenged autonomy or inability to make decisions which raised questions about their personhood. On the other hand the differences related only to the ages of the carers (though these are not as disparate as might have been expected) and the duration of the journey. Despite this, there are major consistencies in the experience and nature of the caring journey with the reservation that any journey is individual in nature.

Changes in caring over time were also identified in both groups; these were chiefly related to the process of ageing (in carers and relatives), the status of the cared-for person's health (particularly in the older group) and the developmental stage of cared-for adolescents. Other changes observed related to alterations in caring demands and the availability of support, as well as the necessity of having to deal with unexpected events, however these have to be seen through the prism of learning how to manage to do things by the very experience of caring, and this was common to both groups.

In summary, the Theory of Caring does contribute to knowledge by depicting the four categories and their relationship to the caring journey. The dynamic nature of caring in an important aspect of its reality and the understanding of the interconnectedness of its parts is vital. However since the data were collected in one centre it is not clear if

it is culture specific. The findings shown here have to be considered when teaching nurses and other professionals to make the support element more relevant and sensitive to individual carers needs.

## **CHAPTER 8 RECOMMENDATIONS**

### **8.1 Recommendations for nurse education**

- To ensure that the nursing curriculum explores the multiple effects of caring and how they can help carers learn how to manage their lives while focussing on the learning they have gained from experience throughout the caring journey and value the carer's experience.
- To facilitate nurses in recognising the importance of understanding the experience of caring as a whole rather than focusing solely on the caregiver burden of carers' experiences.
- To teach nurses to be aware of the holistic nature of caring and the importance of understanding their various needs based on individual circumstances.
- Disseminate the Theory of Caring to health professionals and encourage further discussion of its inherent parts.

### **8.2 Recommendations for school staff in practice**

- To encourage the inclusion of disability issues into the school curriculum to institute preventative measures to stop bullying and discrimination on the part of either staff or students.
- To encourage School Nurses to develop a knowledge of teaching sex education to adolescents with ID and to help parents or carers in this task.
- School teachers, either in the mainstream or special education settings, should be able to assess the specific requirements of children with Special Education Needs, and the related needs of their parents or carers.
- School teachers, particular in secondary schools, need to have close links with the parents of children with special education needs. This may require teachers to be proactive, by actively enquiring after the needs of young people by creating a system by which parents can be given informal or formal advice as necessary but also to act on the knowledge and experience of managing the care of the child.

- Social workers and school teachers should prepare educational and support packages for young people as they make the transition from school to adulthood. These should be made available and relevant to both adolescents with special education needs and their parents, before the adolescents leave school.

### **8.3 Recommendations for nurses, doctors and social workers in practice**

- Professionals need to understand the Theory of Caring to aid their interactions with patients and carers.
- Professionals should be aware of, and act sensitively towards, carers who might have difficulty in asking for help, have had negative prior experiences, and have not been appropriately assessed.
- Professionals should listen and strive to understand carers' individual needs and also be aware of the issue of confidentiality.
- Carers should be valued by professionals with regard to their caregiving skills and experiences, and offered greater involvement in care plans and evaluations.
- Professionals should be able to provide the relevant information and resources needed by carers, so building a reliable and trusting relationship between themselves and carers is vital and aid the provision of a good standard of continuity of care.
- Health professionals should be aware of the carers' potential anxiety attendant on the transition from home-based care services to institutional formal services for older people; they should also be aware of the discontinuity of provision in the transition from children's services to adult services. They should also make sure that the knowledge of how to manage the cared for person is utilised and so enhance the continuity of care initiated by the carer.
- Due consideration and active support must be given to those carers who are left on their own when the cared-for person goes into care, or dies.
- The assessment of carers' needs should be prioritised, and undertaken on a regular basis by health professionals and so reflect the changes in the caring journey.

- Health professionals should be aware of the complex emotions of carers, and be respectful of the individual's responses, seeking to empathise and understand matters from the carer's point of view.
- Social workers should be responsible for mitigating the 'fighting processes involved in applying for financial help from the welfare system.

#### **8.4 Recommendations for future research**

- Carry out a qualitative study to explore the impact of caring on secondary support resources for carers – such as, children or grandchildren of people with dementia.
- Carry out a qualitative study specifically to explore the experiences of men as the primary carers of either people with dementia or children with ID.
- Carry out a cross-sectional study to investigate the changes experienced by carers looking after people with ID until they die.
- Carry out a cross-sectional quantitative study to investigate how different groups of carers are given financial help as they go through the caring journey.
- Using a longitudinal grounded theory approach carry out a replication study to investigate the experiences of carers of people with dementia or adolescents with ID in Taiwan to ascertain if the Theory of Caring is affected by cultural differences.
- When the Theory of Caring has been shown not to be affected by cultural differences carry out a large scale survey to test the Theory of Caring on a sample of carers from a variety of ages of groups.



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## **APPENDICES**

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Appendix 1: Literature search from database of CINAHL, British Nursing Index or MEDLINE

**CINAHL literature search**

#	Query	Results
S1	Carer or caregiver and experience	1848
S2	Dementia or Alzheimer's	11280
S3	(S1 and S2)	235
S4	Mental retardation or learning disability or intellectual disability	6203
S5	Parenting stressing or parenting burden and children with intellectual disability	219
S6	Parents or mother and children with intellectual disability	24569
S7	TI parents or TI mother and AB children with intellectual disability	5673
S8	TI intellectual disability or TI mental retardation and TI children	513
S9	AB parental stress or AB parenting stress	310
S10	(S8 and S9)	11
S11	AB coping strategies and TI caregiver or TI carer	239
S12	(S11 and S2)	30
S13	Support or social support	82123
S14	AB support or AB social support	52588
S15	(S14 and S3)	71
S16	(S14 and S9 and S7)	20
S17	Caregiver burden or carer burden	3307
S18	(S17 and S3)	97

S19	AB caregiver burden or AB carer burden	412
S20	(S19 and S2)	103
S21	S17 and parent	144
S22	Mother and children with intellectual disability or children with mental retardation	53
S23	Father and children with intellectual disability or children with mental retardation	53
S24	Children with intellectual disability or children with learning disability or children with mental retardation	113
S25	(S24 and S9)	7

(TI: Title; AB: Abstract)

Accessed Jan. 07, 2008

### British Nursing Index literature search

#	Query	Results
S1	Carer or caregiver and experience	2641
S2	Dementia or Alzheimer's	2419
S3	(S1 and S2)	417
S4	Mental retardation or learning disability or intellectual disability	3172
S5	Parenting stressing or parenting burden and children with intellectual disability	11
S6	Parents or mother and children with intellectual disability	2028
S7	TI parents or TI mother and AB children with intellectual disability	807

S8	TI intellectual disability or TI mental retardation and TI children	263
S9	AB parental stress or AB parenting stress	20
S10	(S8 and S9)	1
S11	AB coping strategies and TI caregiver or TI carer	647
S12	(S11 and S2)	101
S13	Support or social support	5213
S14	AB support or AB social support	4160
S15	(S14 and S3)	59
S16	(S14 and S9 and S7)	1
S17	Caregiver burden or carer burden	46
S18	(S17 and S3)	8
S19	AB caregiver burden or AB carer burden	15
S20	(S19 and S2)	5
S21	S17 and parent	1
S22	Mother and children with intellectual disability or children with mental retardation	4
S23	Father and children with intellectual disability or children with mental retardation	4
S24	S4 and parent stress or parenting stress	11
S25	(S24 and S9)	7

(TI: Title; AB: Abstract)

Accessed Jan. 07, 2008

### MEDLINE literature search

#	Query	Results
S1	Carer or caregiver and experience	1888
S2	Dementia or Alzheimer's	88500
S3	(S1 and S2)	341
S4	Mental retardation or learning disability or intellectual disability	51745
S5	Parenting stressing or parenting burden and children with intellectual disability	392
S6	Parents or mother and children with intellectual disability	83260
S7	TI parents or TI mother and AB children with intellectual disability	11285
S8	TI intellectual disability or TI mental retardation and TI children	1146
S9	AB parental stress or AB parenting stress	565
S10	(S8 and S9)	14
S11	Coping strategies and TI caregiver or TI carer	27
S12	(S11 and S2)	4
S13	Support or social support	424809
S14	AB support or AB social support	351872
S15	(S14 and S3)	90
S16	(S14 and S9 and S7)	28
S17	Caregiver burden or carer burden	764
S18	(S17 and S3)	47
S19	AB caregiver burden or AB carer burden	703
S20	(S19 and S2)	296
S21	S17 and parent	27



S22	Mother and children with intellectual disability or children with mental retardation	436
S23	Father and children with intellectual disability or children with mental retardation	436
S24	S4 and parent stress or parenting stress	396
S25	(S24 and S9)	376
S26	S22 and Caring	3
S27	S23 and Caring	3
S28	(S14 and S3)	90
S28	(S14 and S24)	122
S29	(S14 and S24) and caring	3
S30	S5 and caring	10
S31	S3 and caring for	60

(TI: Title; AB: Abstract)

Accessed Jan. 07, 2008

## Appendix 2: The CD of transcriptions

## Appendix 3: Interview Guide Phase 1, 2 and 3

### Interview Guide (Phase 1)

Hello, \_\_\_\_\_, it is very kind of you to volunteer to take part in the project and let me come and meet you. Are there any questions that you would like to ask me? Do you mind if I tape record our conversation? I promise that anything you tell me will be treated confidentially. You can stop me at any point and if you don't want something recorded then I'll turn the machine off.

### Caring experience

- As you know, I am interested in your experiences of being a carer. First, can you tell me who are you looking after? Could you tell me more about that?
- When did you start being a carer?
- What's wrong with her, why are you caring for her?
- How did you get on with her? Has it changed?
- Can you describe a typical day when you are looking after her?
- Can you tell me about the most difficult day of looking after her so far?
- How does that make you feel?
- Do you work? How do you manage work and caring?
- Does caring for her affect your relationship with other family members? Could you tell me more about that?

### Impact on health

- How has your own health been?
- How does this affect your ability to care for her?

### Support

- Do you get help to look after her? How does that work?
- What support do you get for yourself?
- How do you cope with or switch off?

### Autonomy

- Does caring for her affect your decision or choices about what you do? Could you tell me more about that?

## Expectations

- How do you manage to keep going?
- How do you foresee things happening in the future?

Is there anything else you would like to tell me or you want to add what are you said?

Thank you very much indeed. It is really kind of you and I look forward to seeing you again.

## Interview Guide (Phase 2)

Hello, \_\_\_\_\_, it is very kind of you to volunteer to take second part in the project and let me come and meet you. Are there any questions that you would like to ask me? Do you mind if I tape record our conversation? I promise that anything you tell me will be treated confidentially. You can stop me at any point and if you don't want something recorded then I'll turn the machine off.

### Caring experience

- How have things been since we last met?
- Are there any changes in health condition of your wife since we last met?  
Does that affect you?
- Are there any differences of caring for your son and your wife?

### Personhood

- According to what you said last time, 'in the sense that the person you married is not there any longer'. Could you explain that further?

### Impact on health

- How has your own health been during past 6 months (heart problem, prostate problem, diabetes, sleep disturbance)?

### Support

- Are you still having three days of day care services? Has it changed?
- How did you get on with your family? Has it changed?
- How do you get on with the volunteer group (Alzheimer's Scotland), and is it helpful? What kinds of help have you received from them?

### Autonomy

- According to what you said last time, you want to care for her.  
What do you feel about that now?
- You had mentioned about caring has limited your choices about what you want to do. What do you feel you about that?
- As you told me before that you will not be able to have a holiday as you will be caring for your wife.  
Is that still the same? Are you having a break?
- Are you still able to go bowling?

- ‘She can’t make any choice; I always have to choose what she wants (p.13).’  
What is your feeling about that?
- ‘It’s justified giving up... (some work for care) (p.21)?’ How do you feel about that?
- ‘It’s acceptance that that’s my life (my time being restricted) (p.47)?’ How do you feel about that?

Is there anything else you would like to tell me or you want to add what are you said?  
Thank you very much indeed. It is really kind of you and I look forward to seeing you again.

### Interview Guide (Phase 3)

Hello, \_\_\_\_\_, it is very kind of you to volunteer to take third part in the project and let me come and meet you. Are there any questions that you would like to ask me? Do you mind if I tape record our conversation? I promise that anything you tell me will be treated confidentially. You can stop me at any point and if you don't want something recorded then I'll turn the machine off.

#### Caring experience

- How have things been since we last met?
- How have you been getting on since last time we met? (How have things been since we last met)
- Are there any changes in your wife's health condition since we last met? How does that affect you?
- Do you still feel you are on a treadmill?
- How are you coping?
- 'Family impact'

#### Personhood

- The first time you said, 'in the sense that the person you married is not there any longer'. Last time you told, 'She is not the same... she doesn't respond the same, we can't discuss things...' which seems there is no change at all. Has it changed now?
- Last time you said, 'She's not the same person I married; she's the same person I love...'? What does that mean? Could you tell me more about that?

#### Impact on health

- How has your own health been during past a year (heart problem, prostate problem, diabetes, sleep disturbance)?

#### Support

- Are you still having three days of day care services? Has it changed?
- 'Support increased' has it changed? (Pay for other morning?)
- 'Respite care is a bit of mixed blessing in that it gives me a break but I worry about she's being dealt with...' what does that mean?
- How did you get on with your family? Has it changed?

- How do you get on with the volunteer group (Alzheimer's Scotland), has it changed?

#### Autonomy

- According to what you said last time, you want to care for her. What do you feel about that now?
- As you told me before you cannot go for holidays. Is that still the same? Are you having a break? What do you feel you about that?

#### Expectations

- 'I hope I'll still carry on loving her and looking after her as long as I can.' I hope... what does that mean? Can you find other words for me? Can you explain that?
- '... is always the fear that you're looking forward to deteriorate ...'
- What expectations do you have?

#### Etc.

- As you said last time, you made all the decision for both of you. Has it changed? Could you tell me more about that?
- 'You've just got to take what life gives you, in a sense, and make the best of what you've got.' (Phase 2, p.22) Could you explain that to me?
- Have you gained any benefits from your caring experience?

Is there anything else you would like to tell me or you want to add what are you said?

Thank you very much indeed. It is really kind of you and I look forward to seeing you again.



Appendix 4: Cover letter for carers' organisations

Address of carers' organisations

24/10/2004

Dear Sir

**Lay carers' experiences of caring for individuals with  
dementia or intellectual disability**

I am a nurse from Taiwan undertaking a PhD course at Napier University, Edinburgh. The aim of the research project is to explore, identify and describe the changes in 'caregiver burden' over time, and the related effects on the carer's autonomy and health. To do this I am looking for lay carers of dementia sufferers to volunteer to take part. I wonder if it would be possible to get help from your organization to get access such lay carers.

My Director of Studies, Dr Maureen S Macmillan and I would be very pleased if we could come and tell you about the project and get your guidance. It would be most helpful if you could please indicate when such a meeting would be convenient for you. If of course you feel that you are not the most appropriate person to do this for us then I'd be grateful for your advice.

I deeply appreciate your help and look forward to meeting you.

I deeply appreciate your help again.

Yours sincerely,

---

Miss Mei-Chun Lin  
Research Student  
Napier University,  
74 Canaan Lane, Edinburgh  
(0131) 455-5681

**Information about the Carers of People**  
**with Dementia Study**

Dear \_\_\_\_\_

My name is Mei, which sounds like May. I am an overseas student from Taiwan and am studying for a PhD degree in Nursing at Napier University. I want to find out what it is like to be the carer of an elderly person suffering from dementia. I would be most grateful if you could spare the time to help in this project.

**What will take part in the project mean for me?**

If you are willing to take part in the study, I will come and meet you in your home or wherever you think convenient. I would like to meet you three times at six monthly intervals because I expect that people's experiences change. It would be a great help if you would let me tape-record our conversations. That will mean I can really listen to what you have to say.

**When will the interviews happen?**

You will be able to choose the time that is suitable for you. But the second interview will be about six month after the first and then the last one will be about six months later.

**How long will the interviews be?**

I expect that the first one will be about an hour and then the others might be shorter but that depends a bit on how much you want to tell me.

**What will happen to the tape recordings?**

All the information that you give will be kept confidential and nothing will be written that will let anyone else identify you. I intend to give everyone false names to help hide your identity. When the final report is written the tapes will be destroyed.

**What if I change my mind?**

You are free to refuse to participate or to withdraw at any time. Or, if there is something that you don't want recorded then you can just let me know and I will turn the machine off. If you change your mind and want to change something after I've

gone away then you can just contact me and tell me and I will follow your instructions.

### **Is it safe for me to do it?**

The University Ethics Committee has looked at the proposal and has given permission for the project to go ahead. As you know the Alzheimer Scotland also knows about this project and gave you my name. However, really it depends on what you want to say to me.

### **What do you do now?**

After reading this sheet, do talk to anyone you want to, about it. If you want to talk to someone who knows about the project, but is not directly involved in it, then do feel free to contact.

### Name and address and phone number of Independent Advisor

Name: Ms. Elaine Kwiatek

Address: Napier University, Comely Bank Campus, 13 Crewe Road South, Edinburgh

Phone number: 0131-455-5330

She does only work for three days a week so she might not be there when you phone. However, if you can't find her the receptionist will take your name and number and Elaine will call you back.

### **How do I get started?**

When you are sure that you want to take part, please sign the Participant Consent Form. Then tear-off the slip at the bottom of the sheet and return it to me in the prepaid envelope to me in the enclosed. When I get this, I will get in touch with you to arrange a good time for our first interview.

### **I still have questions who do I ask?**

If you want any more information, please do not hesitate to get in touch with me. My direct telephone number is (0131) 455-5681. I'm there during the day on weekdays.

I am looking forward to hearing from you.

Thanks for your help again.

Miss Mei-Chun Lin

Research student

Direct Telephone Number: 0131-455-5681

E-mail address: [00013706@napier.ac.uk](mailto:00013706@napier.ac.uk)

Address: Napier University, Canaan Lane Campus,

74 Canaan Lane, Edinburgh, EH9 2TB

**Information about the Carers of adolescents**  
**with Intellectual Disability Study**

Dear \_\_\_\_\_

My name is Mei, which sounds like May. I am an overseas student from Taiwan and am studying for a PhD degree in Nursing at Napier University. I want to find out what it is like to be the carer of an adolescent with intellectual disability. I would be most grateful if you could spare the time to help in this project.

**What will taking part in the project mean for you?**

If you are willing to take part in the study, I will come and meet you in your home or wherever you think convenient. I would like to meet you three times at six monthly intervals because I expect that people's experiences change. It would be a great help if you would let me tape-record our conversations. That will mean I can really listen to what you have to say.

**When will the interviews happen?**

You will be able to choose the time that is suitable for you. However, the second interview will be about six month after the first and then the last one will be about six months later.

**How long will the interviews be?**

I expect that the first one will be about an hour and then the others might be shorter but that depends a bit on how much you want to tell me.

**What will happen to the tape recordings?**

All the information that you give will be kept confidential and nothing will be written that will let anyone else identify you. I intend to give everyone false names to help hide your identity. When the project is totally finished, the tapes will be destroyed.

**What if you change your mind?**

You are free to refuse to participate or to withdraw at any time. Or, if there is something that you don't want recorded, then you can just let me know and I will turn the machine off. If you change your mind and want to change something after I've

gone away then you can just contact me and tell me and I will follow your instructions.

**Is it safe for you to participate?**

The University Ethics Committee has looked at the proposal and has given permission for the project to go ahead. As you know, Down's Syndrome Scotland also knows about this project and gave me your name.

**What do you do now?**

After reading this sheet, do talk to anyone you want to, about it. If you want to talk to someone who knows about the project, but is not directly involved in it, then do feel free to contact.

Name and address and phone number of Independent Advisor

Name: Ms. Elaine Kwiatek

Address: Napier University, Comely Bank Campus, 13 Crewe Road South, Edinburgh

Phone number: 0131-455-5330

She does only work for three days a week so she might not be there when you phone. However, if you can't find her the receptionist will take you name and number and Elaine will call you back.

**How do you get started?**

When you are sure that you want to take part, please sign the Participant Consent Form. Then sign it and return it to me in the pre-paid envelope. When I get this, I will get in touch with you to arrange a good time for our first interview.

**If you still have questions who do you ask?**

If you want any more information, please do not hesitate to get in touch with me. The direct telephone number is (0131) 455-5681. I'm there during the day on weekdays.

I am looking forward to hearing from you.

Thanks for your help again.

Miss Mei-Chun Lin

Research student

Direct Telephone Number: 0131-455-5681

E-mail address: [00013706@napier.ac.uk](mailto:00013706@napier.ac.uk)

Address: Napier University, Canaan Lane Campus,  
74 Canaan Lane, Edinburgh, EH9 2TB

## Consent Form

**Title of the proposed research:**

- Lay carers' experiences of caring for individuals suffering from dementia

**The name of the investigator and contact detail:**

- Miss Mei-Chun Lin, Research Student  
Canaan Lane Campus, Napier University, 74 Canaan Lane, Edinburgh, EH9 2TB  
Tel: (0131) 455-5681

- I have read and understand participant information sheet and had the opportunity to ask questions about it
- I agree to participate in this study.
- I understand that I am under no obligation to take part in this study.
- I agree for the interview to be tape recorded.
- I understand that any information will be kept in a locked file.
- I understand that there will be three conversations at 6-monthly intervals
- I understand that my participation is voluntary and that I have right to withdraw from this study at any stage and that to do so will not affect my family's treatment.
- I understand that on completion of this study the researchers will erase all the tapes and records.
- I understand that all the information I give will be kept confidential.

-----  
**Participants signature:** ..... **Date:** .....

**Please Print your name:** .....

**Address:** .....

**Contact Phone Number:** .....



## Consent Form

### Title of the proposed research:

Lay carers' experiences of adolescents with intellectual disability

### The name of the investigator and contact detail:

Miss Mei-Chun Lin,  
Canaan Lane Campus, Napier University, 74 Canaan Lane, Edinburgh, EH9 2TB  
Tel: (0131)-455-5681, E-mail: 00013706@napier.ac.uk

I have read and understand participant information sheet and had the opportunity to ask questions about it

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I understand that there will be three conversations at 6-monthly intervals.

I understand that my participation is voluntary and that I have right to withdraw from this study at any stage and that to do so will not affect my family's treatment.

I understand that on completion of this study the researcher will erase all the tapes and records.

I understand that all the information I give will be kept confidential.

**Participants signature:** ..... **Date:** .....

**Please Print your name:** .....

**Address:** .....

**Contact Phone Number:** .....

**NAPIER UNIVERSITY**  
EDINBURGH

Ms Mei-Chun Lin

---

6<sup>th</sup> December 2004

Dear Mei-Chun

**APPLICATION FOR ETHICAL APPROVAL FOR A RESEARCH PROJECT**

I refer to the above and can advise that following the meeting of the Faculty Ethics Committee on Friday 3<sup>rd</sup> December approval has been granted.

If you have any questions please do not hesitate to contact me.

Yours sincerely

  
 Dr Maureen Macmillan  
Senior Lecturer  
Email: [m.macmillan@napier.ac.uk](mailto:m.macmillan@napier.ac.uk)  
Tel: 0131 455 5663

