

**Stress, Coping and Self-Efficacy: Designing an intervention to support
informal caregivers of people with dementia**

Lorraine Douglas

Submitted for the degree of Doctor of Philosophy

Heriot-Watt University

School of Social Sciences

May 2017

The copyright in this thesis is owned by the author. Any quotation from the thesis or use of any of the information contained in it must acknowledge this thesis as the source of the quotation or information.

Abstract

Informal caregivers of people with dementia are at an increased risk of negative outcomes, including stress, depression and physical ill-health (Ory et al., 1999). Attention has therefore been focussed on designing interventions to help prevent or reduce negative caregiving outcomes. Reviews have recommended that future research should provide interventions that are effective and cost-effective, theoretically-grounded and responsive to assessed needs (Gallagher-Thompson et al., 2012).

The current thesis includes the design and testing of an intervention written to reduce negative caregiving outcomes by focussing on self-efficacy in informal caregivers of people with dementia. The intervention, designed to be brief in comparison with existing interventions, comprises three sessions covering different types of caregiving challenge: coping with behavioural aspects of dementia, coping with difficult feelings, and taking breaks. The intervention was initially pilot tested before being delivered in a quasi-experimental controlled study with informal caregivers ($n=56$), with intervention participants being able to choose whether to take part individually or in small groups.

Intervention participants experienced significantly decreased caregiver burden compared to control participants ($U=93.50, p=.016$). Additionally, intervention participants reported being significantly less distressed by the symptoms of the person with dementia, compared to control participants ($U=86.00, p=.015$). However, no significant difference between groups was found on self-efficacy or depression, and possible reasons for this are discussed. A three-month follow-up ($n=14$) did not show sustained benefits of the intervention.

In addition to the intervention study, two qualitative studies were carried out. The first was based on semi-structured interviews with informal caregivers of people with dementia ($n=12$) and ran concurrently with the intervention study, exploring the range of stressors and coping resources used by caregivers. Interpretative Phenomenological Analysis (IPA) was used to analyse the transcripts, which generated four major recurrent themes: Dementia and Change, Caring and the Self, Caring and Others, and The Care System. This study provided insights into the context in which interventions may be received by caregivers; in particular, it highlighted the complexity of caregiving experiences and the centrality of relationships. For example, accounts were given of families, friends and service providers either being a positive source of support or a contributor to stress, depending on the nature of the relationships.

The second qualitative study followed the intervention study, and used IPA to analyse interviews with participants from both the group ($n=4$) and individual ($n=2$) intervention conditions. This study explored caregivers' experiences of taking part in the intervention, and generated two recurrent themes: Sharing Experiences with Other Caregivers, and Meeting Needs. The analysis provided further insights into perceived benefits of the intervention for participants, and highlighted differing needs between group and individual participants.

The results of these three studies are discussed in relation to current challenges and priorities for caregiver intervention research, and recommendations for practice are made. Further research is suggested to follow the outcomes of these studies, including development of a measure to gauge service-related sources of caregiving stress.

Acknowledgements

I would like to thank my PhD supervisors, Dr. Lauren Potter and Dr. Alan Gow, for their enthusiasm, positivity, advice and support throughout the PhD process. My thanks also to my initial supervisor Dr. Maarten Milders, who provided invaluable guidance during the first year of this research.

I am very grateful to the carers who took part in the studies reported in this thesis, and who shared their time and thoughts so generously. I would like to thank the organisations and individuals who assisted with recruiting and arranging activities.

The Scottish Interpretative Phenomenological Analysis group has been a valuable resource during this research, and I would like to thank the members of this group and Dr. Kirsty Darwent for the opportunity to discuss the analysis as it progressed.

Thank you to the members of the online group, PostgRAD Study Gang: School of Hard Thinkin', for friendship and support throughout the last three years.

To Jenny, thank you for too many things to mention, including our shared adventure of taking on a cat with intensive support needs in the middle of all this!

ACADEMIC REGISTRY

Research Thesis Submission

Name:	Lorraine Douglas		
School:	School of Social Sciences		
Version: <i>(i.e. First, Resubmission, Final)</i>	Final	Degree Sought:	PhD in Psychology

Declaration

In accordance with the appropriate regulations I hereby submit my thesis and I declare that:

- 1) the thesis embodies the results of my own work and has been composed by myself
- 2) where appropriate, I have made acknowledgement of the work of others and have made reference to work carried out in collaboration with other persons
- 3) the thesis is the correct version of the thesis for submission and is the same version as any electronic versions submitted*.
- 4) my thesis for the award referred to, deposited in the Heriot-Watt University Library, should be made available for loan or photocopying and be available via the Institutional Repository, subject to such conditions as the Librarian may require
- 5) I understand that as a student of the University I am required to abide by the Regulations of the University and to conform to its discipline.
- 6) I confirm that the thesis has been verified against plagiarism via an approved plagiarism detection application e.g. Turnitin.

* *Please note that it is the responsibility of the candidate to ensure that the correct version of the thesis is submitted.*

Signature of Candidate:		Date:	
-------------------------	--	-------	--

Submission

Submitted By (<i>name in capitals</i>):	LORRAINE DOUGLAS
Signature of Individual Submitting:	
Date Submitted:	

For Completion in the Student Service Centre (SSC)

Received in the SSC by (<i>name in capitals</i>):			
<i>Method of Submission</i> (<i>Handed in to SSC; posted through internal/external mail</i>):			
<i>E-thesis Submitted (mandatory for final theses)</i>			
Signature:		Date:	

Table of Contents

Abstract	I
Acknowledgements	II
Declaration Statement – Research Thesis Submission Form	III
Chapter 1: Introduction	1
1.1 Dementia and informal caregiving	1
1.2 Dementia: prevalence, costs and other facts	2
1.3 Research contributions and location of this thesis within caregiving research	7
1.4 Research aims and objectives	9
1.5 Organisation of the chapters	10
Chapter 2 – Caring for a Person with Dementia: Overview of stress and coping models and research into supportive interventions for caregivers	13
2.1 Introduction	13
2.2 Reviews of caregiver intervention research	14
2.3 Models of caregiver stress and coping	17
2.4 The role of self-efficacy in mediating between caregiver stressors and stress	25
2.5 Self-efficacy and related concepts	30
2.6 Self-management approaches	34
2.7 Interventions used in previous studies: practical implications and issues	35
2.8 Brief interventions	39
2.9 Moving towards person-centred interventions	40
2.10 Qualitative analyses of caregivers’ experiences	43
2.11 Summary	45

Chapter 3 – Self-Efficacy in Caregiving: Design and pilot testing of an intervention aimed at promoting self-efficacy in informal caregivers of a person with dementia	47
3.1 Introduction	47
3.2 Developing the aims and objectives of the research	48
3.3 Development of the Self-Efficacy Intervention	50
3.4 Content of the intervention manual	52
3.5 Language used in the intervention	59
3.6 Delivery of the intervention	60
3.7 Pilot-testing of the intervention	60
3.8 Participants’ feedback on the pilot test	61
3.9 Researcher’s feedback on the pilot test	62
3.10 Outcomes of the pilot test: changes made to the research proposal	63
3.11 Conclusion	67
Chapter 4 – Stress, Coping and Service Use in Informal Caregivers of a Person with Dementia: An Interpretative Phenomenological Analysis	68
4.1 Introduction	68
4.2 Selection of methodological approach	69
4.3 Interpretative Phenomenological Analysis: Origins and major areas of focus	70
4.4 Methods	73
4.5 Analysis	79
4.6 Results	84
4.7 Discussion	120
4.8 Conclusion	129
Chapter 5 – Caregiving Self-Efficacy, Depression and Burden: an effectiveness study of a manual-based intervention	131
5.1 Introduction	131
5.2 Methods	133
5.3 Results	141
5.4 Discussion	165
5.5 Limitations of the study	171
5.6 Conclusion	172

Chapter 6 – Caregivers’ Experiences of Taking Part in an Intervention: qualitative outcomes analysed using Interpretative Phenomenological Analysis	174
6.1 Introduction	174
6.2 Methods	177
6.3 Results	183
6.4 Discussion	198
 Chapter 7: Methodologies and Current Debates in Dementia Caregiver Research: a reflective discussion	 203
7.1 Introduction	203
7.2 Research design issues identified in previous intervention studies	203
7.3 Ethical considerations	210
7.4 Methodological implications of ‘mixed methods’ study design	212
7.5 Language and representation in dementia caregiving studies	218
Chapter 8: Discussion and Conclusions	223
8.1 Introduction	223
8.2 Main outcomes and contribution to the field	224
8.3 Implications for theory	230
8.4 Implications for practice	231
8.5 Limitations of the work	232
8.6 Suggestions for further research	234
8.7 Conclusion	238
 References	 240
Appendix A Information sheets for participants	263
Appendix B Consent forms	265
Appendix C Caregiver intervention manual	267
Appendix D Interview schedule used for Chapter 4	292
Appendix E Worked example of IPA	293
Appendix F Themes emerging from a single transcript	296
Appendix G Outcome measures	299
Appendix H Interview schedule used for Chapter 6	307

Chapter 1: Introduction

1.1 Dementia and Informal Caregiving

As the average lifespan increases in many parts of the world in response to better health care and cures for many previously untreatable illnesses, so too does the prevalence of dementia. Dementia, an umbrella term for conditions including vascular dementia and Alzheimer's Disease, has a profound effect on the memory, communication skills, behaviours and independent living skills of individuals (Alzheimer Scotland, 2013). As we grow older, the chance of being diagnosed with dementia increases, with the prevalence of dementia rising from one person in 50 aged 65-70, to one in five for people aged over 80 (Alzheimer's Society, 2007).

Many individuals continue to enjoy a good quality of life following a diagnosis of dementia. However, the progressive nature of dementia can mean an increasing reliance on loved ones, as well as professional services, for support with the activities of daily living. Informal caregivers – spouses, sons, daughters, other family members and friends – are also deeply affected when someone close to them has dementia, and the present research focusses on these informal caregivers.

We already have access to a lot of information about the effects of providing care for a loved one who has dementia. These effects can be psychological or emotional in nature (the focus of much research has been on depression and caregiving burden), but also include physical and social effects, or those related to employment (Ory, Hoffman, Yee, Tennstedt & Schulz, 1999) – in short, they can affect virtually all areas of the life of the caregiver.

Because of our awareness of these issues facing informal caregivers, and our need as a society for people to be able to go on providing informal care, there has been a body of research in recent years looking specifically at the needs of caregivers and focussing on interventions which might help alleviate some of the challenges they encounter. Many studies have shown promising results in reducing caregiver depression and burden (as reviewed, for example, by Pinquart & Sörensen, 2006), as well as increasing our understanding about the factors that may cause caregiver stress (Schulz, O'Brien, Bookwala & Fleissner, 1995) and factors which can help to alleviate stress and distress

(for example, Mausbach et al., 2012).

There is a large and diverse body of research on caring for a person with dementia. As can be the case with research areas which have seen intense activity, there have been multiple strands of enquiry into the caregiver experience. In Chapter 2, I will discuss the existing literature on research into supporting informal caregivers, and some of the challenges currently facing the field, identifying priorities for further research. This chapter will include summaries of the research that has been done in particular areas of relevance to the current work: research on caregiving self-efficacy, brief intervention research and research into how to make interventions more person-centred. I will explain how each of these fields is important in order to address current gaps in caregiver research and meet the identified priorities.

1.2 Dementia: Prevalence, Costs and Other Facts

The prevalence of dementia is increasing in many countries around the world. It is estimated that there are 35 million people worldwide who have dementia, a number which is predicted to increase to 115 million by the year 2050 (World Alzheimer Report, 2013).

As recently as 1982, nursing home placement was considered almost inevitable for a person with dementia. Zarit and Zarit (1982) described this situation as being the norm; they presented an argument for offering community-based treatment to the person with dementia and his or her family as an alternative, describing treatment approaches which could help. As I will discuss, the idea of maintaining a person with dementia in the community is supported by research which has raised questions about the effects of nursing home placement on survival in the person with dementia (Aneshensel, Pearlin, Levy-Storms & Shuler, 2000).

Nowadays, many people who have dementia are cared for informally by friends or family members. The Alzheimer's Society (2014) estimates that there are at least 670,000 people in the UK acting as primary carers for people who have dementia. When a person with dementia receives professional support, it is likely that he or she is also receiving informal support from friends and family members, meaning that the contribution from informal carers cannot be counted simply by looking at the number of

people with dementia who are not in formal care situations (World Alzheimer Report, 2013). In the UK, the contribution made by informal caregivers is estimated to save the economy £11 billion each year (Alzheimer's Society, 2014). There is a pressing need to preserve the ability of caregivers to go on providing care for as long as possible, with the increase in dementia diagnoses putting pressure on service provision, and the high costs associated with residential or nursing care.

Calculating the impact of dementia is a complex and challenging task. O'Shea and O'Reilly (2000) carried out a cost analysis of dementia care in Ireland, with a focus on how the burden of care was distributed and therefore where resources and support needed to be focussed. Their evaluation concluded that around 75% of people with dementia in Ireland were living at home. By placing a monetary value on the time and work given by informal carers, the authors estimated that this accounted for 50% of the total cost of dementia care, compared to 10% attributable to community supports. It was concluded that more support needs to be made available to informal caregivers for them to go on providing care at this level.

In a review of the causes of nursing home placement, Luppá et al. (2010) found that dementia was the most common reason for a person being placed in a nursing home. Some of the studies included in this review looked further to see which characteristics of dementia were associated with this increase in likelihood of nursing home placement, finding that behavioural problems, the severity of the dementia and burden on the caregiver were all significantly associated with the decision to institutionalise. In a longitudinal study carried out by Agüero-Torres, von Strauss, Viitanen, Winblad and Fratiglioni (2001), elderly people living in Stockholm, Sweden, were followed up over a three-year period, with dementia being the main determinant of institutionalisation in a nursing home. When the authors considered people who did not have dementia, lower levels of cognitive functioning were associated with nursing home placement.

It can be seen, then, that the presence of dementia increases the chance of an older person being placed in nursing care. As well as the concerns and challenges this raises in terms of service provision, some researchers have focussed on the possible additional risks to people upon being institutionalised.

Aneshensel et al. (2000) looked at the effects on mortality of nursing care, finding that

relocation into a care home was associated with a rise in mortality immediately following admission. The authors looked at two competing models for explaining this rise in mortality. Social selection suggests that those who are already in poorer health are more likely to be placed in institutional care, while social causation would posit that there is some additional risk which is attributable to institutional placement itself. The authors found some evidence to support the social selection model (the risk of death was greatest in those admitted in poor health) but also found that those who were not in poor health were subject to increased mortality risk following admission. The authors did not find evidence that poor nursing care led to this additional risk, but argued that perhaps it was the result of institutional placement itself; for example, being away from family members who may be the people most likely to spot illness at a very early stage.

Further research also explored factors associated with caregivers' desire to institutionalise the people for whom they were caring, as the desire to institutionalise (DI) is a predictor of placement in residential care (Gallagher et al., 2011). The authors found that the most important predictors of DI were caregiver depression and burden, two factors often targeted in research into interventions designed to help caregivers. As I will discuss in Chapter 2, caregiver depression and burden are characteristics which have the potential to be modified by focussing on factors like coping style in response to difficult situations. The findings of this study expanded on the earlier findings of Spitznagel, Tremont, Duncan Davis and Foster (2006), who found that caregiver burden was related to the desire to institutionalise. They also found that higher levels of knowledge about dementia were related to higher DI, suggesting that interventions aimed at helping caregivers cope with the stresses of caregiving must do more than simply deliver information.

A similar picture was found by Hébert, Dubois, Wolfson, Chambers and Cohen (2001), who conducted a five-year study following caregivers of people who had dementia, with a focus on identifying characteristics which were related to the placement in institutional care of the person with dementia. Factors significantly related to institutionalisation were type of dementia, degree of impairment, relationship to the caregiver, caregiver's age and caregiver burden. Caregiver burden was found to be related to the caregivers' level of depression and the extent of behavioural problems associated with the dementia. Again, the authors stressed a need to support caregivers with interventions focussed on modifying caregiver burden and depression, and

strategies for coping with the behavioural changes associated with dementia.

Informal caregivers are known to be at increased risk of negative outcomes such as stress, depression and caregiver burden, and caregivers of people with dementia are noted to be at particular risk. Ory et al. (1999) conducted a large-scale survey of caregivers in the US, comparing caregivers of people with dementia and caregivers of people with other conditions. The study found that dementia caregivers were at significantly higher risks of many different negative effects of caregiving, including risks to employment (for example, being unable to take up a promotion; having to give up work altogether), risks to social life (such as having tension in the family or perceiving that other family members did not give sufficient help) and risk to the psychological well-being of caregivers (for example, being under emotional stress).

Importantly, this survey found that when demographic variables (such as gender, age and income) and an index of caregiving involvement were controlled for, there was still something about being a dementia caregiver which accounted for a higher level of risk. The authors proposed that this increased risk may be due to the intensity of caregiving required, the challenging behaviours that are often a feature of dementia and the perception of caregivers that the situation is going to worsen at a pace and in ways that they cannot control or predict. This additional risk to caregivers also poses a challenge for the person with dementia: if a caregiver becomes too unwell to go on providing care then there is an increased likelihood that the person with dementia will need to access more intensive service provision such as nursing care.

Schulz et al. (1995), in their review of literature on outcomes for dementia caregivers, attempted to identify both demographic and caregiving-specific correlates of the psychological and physical risks to caregivers. This study found a number of factors to be related to depression in dementia caregivers, including relationship to the person with dementia (with spouses being at a higher risk of depression than other relatives), financial status, self-esteem and mastery, and problematic behaviour of the person with dementia. This latter finding is consistent with the conclusion of Ory et al. (1999), noted above, that the behavioural challenges specific to dementia play an important part in the distress experienced by caregivers, a finding which was repeated in a review which tested models of caregiver burden (van der Lee, Bakker, Duivenvoorden & Dröes, 2014).

Schulz et al. (1995) also considered the potential negative effects of caregiving on physical health issues, finding a less consistent connection between these and the specifics of caregiving. Financial status was again correlated with physical health, as were some psychological issues and the cognitive impairment of the person with dementia. Shaw et al. (1999) conducted a longitudinal examination of the effects of caring on caregivers' hypertension, and found that there was an elevated risk of hypertension throughout three years of assessment (the risk appeared to drop off after this point, which the authors attribute to the fact that some participants' situations had changed, with the person with dementia either being deceased or in residential care). More examination is needed to determine exactly what it is about being a dementia caregiver that causes this additional health risk: the authors found the elevated risk to be unrelated to specific aspects of caregiving, such as dealing with problematic behaviours.

Mausbach et al. (2007) investigated the impact of being a dementia caregiver on the development of cardiovascular disease. This study took a longitudinal view of caregivers who did not have cardiovascular disease at the start of the study, and conducted follow-ups at set intervals. Two factors were found to relate to higher risk of the onset of cardiovascular disease: caregiver distress in relation to problem behaviours of the person with dementia, and caregiver depression. The authors proposed that psychosocial interventions which can help caregivers manage depressive feelings and their reactions to challenging behaviours, may prove beneficial in terms of offsetting the increased risk of cardiovascular disease. Although the research reviewed in Chapter 2 focusses primarily on interventions aimed at reducing the negative psychological outcomes of caregiving, there has also been intervention research focussed on reducing risk markers for cardiovascular disease (Moore et al. 2013).

Other studies have looked at more general ratings of caregivers' physical health. Son et al. (2007) found behavioural problems of the person with dementia to be related to health outcomes for caregivers, with higher levels of behavioural problems related to poorer caregivers' health. Health in this study was rated by looking at frequency of use of health services, self-reports of health and occurrence of negative health behaviours. Caregivers' health was also found to be poorer with higher levels of overload. In a meta-analysis, Vitaliano, Zhang and Scanlan (2003) compared caregivers and non-caregivers on several indicators of health, finding that caregivers had higher levels of stress

hormones than non-caregivers. The authors recommended further work to look particularly at older caregivers with co-morbidities, arguing that there is a case for targeting health interventions to those most at risk.

Research has also explored specific negative outcomes of caring for someone with dementia. For example, Cooper, Balamurali, Selwood and Livingston (2007) noted that anxiety is a prevalent issue for dementia caregivers but that it has been relatively overlooked in intervention studies and may need to be targeted specifically.

To summarise, in recent years there has been a move towards sustaining people with dementia in the community and relying on informal caregivers. This has been underpinned by research looking at factors such as the costs associated with different types of care, and research looking at the possible health and mortality implications of institutional placements as opposed to informal care. However, it is acknowledged that people who provide informal care for a person with dementia are at increased risk of negative outcomes including psychological, social, financial and physical health issues. Additionally, some of these negative outcomes (for example, caregiver depression) are more likely to lead caregivers to want to seek an institutional placement for the person with dementia.

Taking these issues into account, there has been a great deal of research into the ways in which informal caregivers of people with dementia can be supported in their caregiving roles. Studies have focussed particularly on factors such as feelings of depression and burden, which can be modified using various types of intervention. Chapter 2 will continue this overview of the literature, exploring some of the previous intervention research. It will begin with an examination of review studies which have attempted to identify trends in intervention studies, and will move on to look at studies in relation to specific fields within the caregiving intervention literature.

1.3 Research contributions and location of this thesis within caregiving research

The work in this thesis is aimed at contributing to the body of research into how informal caregivers may best be supported. The studies contributing to the thesis include both qualitative and quantitative research, designed to explore the experiences

and support needs of caregivers of people with dementia, and to test an intervention written specifically for this research.

The intervention, which uses an intervention manual, is aimed at promoting self-efficacy in informal caregivers of a person with dementia. Chapter 2 includes a discussion of the relevance of self-efficacy theory (for example, Bandura, 1994) in understanding and alleviating caregiver stress. The intervention is intended to be delivered over three sessions, covering different areas of caregiving: coping with the behavioural changes symptomatic of dementia, coping with difficult feelings, and taking breaks as a caregiver. These areas were identified in previous research as being pertinent to caregivers' experiences of stress (Steffen, McKibbin, Zeiss, Gallagher-Thompson & Bandura, 2002). The intervention was pilot-tested and developed to be an accessible intervention, in terms of being available to both individuals and groups of carers, before going on to be tested in a quantitative evaluation.

Additionally, two qualitative Interpretative Phenomenological Analysis (IPA) studies were carried out. The first of these was based on semi-structured interviews with twelve caregivers and aimed to investigate further the nature of caregiving stressors and coping resources, to provide a sense of the context in which a supportive intervention might be received. The second IPA study involved caregivers who had taken part in the intervention study, and explored their experiences of taking part. As I will discuss, the use of IPA as a complement to an intervention study is a relatively underused way of applying IPA, and this study generated data and insights to be considered alongside the quantitative data obtained from the intervention study.

The contributions made in this thesis will be revisited in Chapter 8, which will reflect on the results obtained in each of the studies, and the ways in which these studies add to previous research.

1.4 Research Aims and Objectives

The work contained in this thesis was carried out with the aim of addressing four research aims. These aims were developed according to identified priorities for research into dementia caregiving, which will be discussed in Chapter 2. The four aims were as follows.

1. To explore the experiences of informal caregivers of a person with dementia, with a particular focus on caregivers' experiences of stress, coping strategies and use of supportive resources.
2. To examine the use of an intervention aimed at raising self-efficacy in three specific caregiving domains (Self-Efficacy for Obtaining Respite, Self-Efficacy for Responding to Disruptive Patient Behaviours and Self-Efficacy for Controlling Upsetting Thoughts About Caregiving, as defined by Steffen et al., 2002).
3. To examine the role of self-efficacy, within this intervention study, in relation to objective stressors, caregiver depression and caregiver burden.
4. To explore the experiences of informal caregivers who participated in the intervention study.

To address these research aims, the following objectives were planned.

1. To carry out semi-structured interviews with informal caregivers of people who have dementia, exploring experiences of caregiver stress and coping, and to use Interpretative Phenomenological Analysis (IPA) to identify relevant themes.
2. To carry out a controlled intervention study, using an intervention aimed at increasing self-efficacy in informal caregivers of people with dementia, and to carry out pre- and post-test measures to explore the possible effects of using this intervention.
3. To conduct semi-structured interviews with caregivers who participated in the intervention study, and to use IPA to identify experiential themes.

1.5 Organisation of the Chapters

Following this Introduction, the remaining chapters are as follows.

Chapter 2 – Caring for a Person with Dementia: Overview of stress and coping models and research into supportive interventions for caregivers

In Chapter 2, I will present an overview of existing research in the field of informal caregiving for a person with dementia. This chapter will examine previous attempts to design supportive interventions for caregivers. It will cover areas of the caregiving literature which are particularly relevant to the current work, including research looking at the role of self-efficacy in caregiving, research which attempts to take a more person-centred focus and qualitative research.

Chapter 3 – Self-Efficacy in Caregiving: Design and pilot-testing of an intervention aimed at promoting self-efficacy in informal caregivers of a person with dementia

In Chapter 3, I will introduce the intervention written for the current work, reporting on how this intervention was developed by carrying out a pilot study with five informal caregivers of people with dementia. The pilot study led to the subsequent research being developed in several ways; for example, observations from the pilot study suggested that there was a need for further qualitative as well as quantitative work. This chapter, in addition to detailing the pilot study, serves as a record of the ways in which the subsequent research studies evolved between the initial proposal and the research being carried out.

Chapter 4 – Stress, Coping and Service Use in Informal Caregivers of a Person with Dementia: An Interpretative Phenomenological Analysis

Chapter 4 reports a qualitative study in which twelve informal caregivers were interviewed about their experiences of caring for a person with dementia, and the results were analysed using Interpretative Phenomenological Analysis. In this chapter I discuss the themes emerging from these twelve interviews, with a particular focus on participants' own experiences of challenges, stressors and coping resources as they relate to caring for a person with dementia.

Chapter 5 – Caregiving Self-Efficacy, Depression and Burden: An effectiveness study of a manual-based intervention

Chapter 5 reports an intervention study, conducted using the intervention written for this work and pilot-tested in Chapter 3. This is a controlled, quasi-experimental study, in which the intervention was delivered to individual caregivers and small groups of caregivers. In this chapter, quantitative methods are used to explore whether the intervention can be used to improve outcomes for caregivers, including caregiver burden and depression.

Chapter 6 – Caregivers' Experiences of Taking Part in an Intervention: Qualitative outcomes analysed using Interpretative Phenomenological Analysis

Following on from the quantitative intervention study, semi-structured interviews were conducted with six intervention participants and the resulting data were analysed using Interpretative Phenomenological Analysis; the outcomes of this study are reported in Chapter 6. This qualitative study stands as a counterpart to the intervention study reported in the previous chapter, and explores the experiences of some of the caregivers who took part.

Chapter 7 – Methodologies and Current Debates in Dementia Caregiver Research: A reflective discussion

In Chapter 7, I take an overall look at the methodological issues concerning the research reported in the thesis; this includes consideration of the use of quantitative and qualitative methods together, the different types of research question that can be asked using these methods and the different types of knowledge obtained. This chapter is reflective in style, exploring the extent to which the current research was able to address issues previously identified with caregiver research and giving an account of issues currently pertinent to the field.

Chapter 8 – Discussion and Conclusions

Each of the study chapters has reported on the results for the individual study concerned; in Chapter 8, I consider the overall findings obtained. The research aims and

objectives are revisited and discussed in the light of the studies conducted, and suggestions are made for further research priorities. This chapter also evaluates the contribution made by the studies here to caregiver intervention research, and locates these studies within the field.

Chapter 2 – Caring for a Person with Dementia: Overview of stress and coping models and research into supportive interventions for caregivers

2.1 Introduction

In this chapter, I will give an overview of literature concerning efforts to support informal caregivers of people with dementia. This will include models of stress and coping, different approaches to designing and delivering caregiver interventions and current issues pertinent to the field of caregiver research.

The following review of caregiver intervention literature should be regarded as an examination of several major areas of focus, outcomes and priorities for further research. It is not intended to serve as an exhaustive or systematic review of caregiving literature, which is a large and diverse field of research.

2.1.1 Search strategy for identifying literature

To find literature relevant to the field of informal caregiving for a person with dementia, several approaches were used. Firstly, searches were carried out using a library catalogue search facility and databases including PsychINFO. Keywords included relevant terms such as ‘dementia caregiver or caregiving’, ‘informal caregiver’, ‘caregiver intervention’ and so on. As the search and the literature review progressed, more specific search terms were formed to explore particular sub-topics within the field; for example, ‘caregiver self-efficacy’.

Papers found during these initial searches were then used as a source of other papers which appeared as citations or in the reference lists of papers. When reading a paper, I made a list of potentially relevant papers cited in that paper, carrying out searches for these.

Additionally, I carried out website searches of relevant organisations to obtain the most recent annual reports or research papers commissioned by organisations; these included Alzheimer Scotland, Alzheimer’s Disease International and the Alzheimer’s Society. As dementia and dementia research have moved increasingly into the media and public

domain in recent years, I also set up news alerts using keywords such as ‘dementia caregivers’ and ‘dementia research’, to keep abreast of major developments or items of news. It should be noted that throughout this thesis, the word ‘dementia’ is used as an umbrella term to refer to certain conditions causing memory loss or problems with cognitive functioning: these include Alzheimer’s Disease, vascular dementia, frontotemporal dementia and other associated conditions.

Following on from the discussion in Chapter 1 about the prevalence of dementia and some of the risks to informal caregivers of people with dementia, this chapter will begin by exploring several review papers which have attempted to evaluate and identify trends in caregiver intervention research.

2.2 Reviews of Caregiver Intervention Research

Reviews of interventions aimed at supporting informal caregivers have found that overall, such interventions tended to lead to small, but significant, improvements in caregiver outcomes (Pinquart & Sörensen, 2006; Brodaty, Green & Koschera, 2003). Pinquart and Sörensen (2006) also found that only multicomponent interventions (those combining, for example, support, respite and education for caregivers) led to any significant reduction in institutionalisation of the person with dementia, considered a desirable outcome. This mirrored the outcome of reviews conducted by Schulz et al. (2002), which favoured multi-component interventions for relieving caregiver stress, and Boots, de Vugt, van Knippenberg, Kempen and Verhey (2014), who reviewed internet-based interventions, finding multi-component, tailored interventions to be most efficacious. Focussing solely on educational interventions providing skills training for caregivers, Jensen, Agbata, Canavan and McCarthy (2015) found this type of intervention to be moderately effective in reducing caregiver burden, to have small effects on depression and no clear effect on quality of life or the placement of the person with dementia in care. Hall and Skelton (2012) looked particularly at UK-based studies of interventions aimed at helping caregivers, and found that there was a dearth of well-designed evaluation studies, but that there was some support for interventions such as cognitive-behavioural therapy and reminiscence therapy.

A recent review (Gallagher-Thompson et al., 2012) looked at a wide range of

intervention types targeted at caregivers: for example, counselling, skills training, psychoeducational and technology-based interventions such as online programmes and support. The review highlighted that few studies to date have looked at the mechanisms by which these interventions work, and the authors stressed a need for interventions to be aligned to theoretical models to enhance our understanding of how and why they are effective.

A concern raised in the Gallagher-Thomson et al. (2012) review, and earlier by Zarit and Femia (2008) and Schulz et al. (2002) is that interventions need to be more carefully targeted to caregivers' assessed needs. For example, it is common for outcome studies to measure the effect of an intervention on depression, yet for the sample to include both those who are depressed and those who are not. This type of approach, argue Zarit and Femia (2008), weakens the findings of such studies: the inclusion of non-depressed people means that there are participants for whom no improvement is needed or possible, and so the overall observed effect of the intervention is diminished. For interventions to be more effective, assessment of caregiver needs should be improved, interventions should be matched to those needs and there should be cost-effective ways to measure outcomes (Schulz et al., 2002). Similarly, Van't Leven et al. (2013), in a review of dyadic interventions (interventions aimed at both the person with dementia and the caregiver) concluded that while interventions tended to be effective in a domain-specific way depending on the focus of the intervention, more work needed to be done on matching needs to interventions.

In addition to the review by Boots et al. (2014) into internet-based interventions, Godwin, Mills, Anderson, and Kunik (2013) and Lee (2015) focussed specifically on interventions which had used technology-driven means of assisting dementia caregivers. Only a small number of comparable studies had been conducted (Godwin et al. (2013) reviewed eight studies, while Lee (2015) reviewed five) and Godwin et al. (2013) concluded that this relatively new area for caregiver support needs more randomised controlled studies looking at the efficacy of technology-based interventions. This review also raised a point which is pertinent across caregiver research as a whole; there has been a great deal of variation in the measures used and outcomes studied, and a more standard approach would make it much easier to compare results across different studies.

A review by Pusey and Richards (2001) raised similar points to Gallagher-Thompson et al.'s (2012) findings that few interventions have been clearly underpinned by theory, making it difficult to build upon previous results when designing new interventions. The results of this review suggested that interventions which included problem-solving and managing problem behaviours had shown the most promising results. This review also discussed common problems with previous research, which included low numbers of participants and low statistical power, poor randomisation of subjects to conditions and selection problems (for example, participants choosing to receive interventions), researchers not being 'blind' to the measuring of outcomes, or studies involving one researcher who carried out the intervention and measured the outcomes. These issues are partly based on considering Randomised Controlled Trials (RCTs) to be the most appropriate means of testing interventions. This belief has been challenged by Zarit and Femia (2008) who argue, for example, that allocating treatments to participants may not always be appropriate, and can lead to participants seeking other treatments. As will be explained in Chapter 5, the quantitative intervention study used in this thesis does not follow an RCT design. However, the above criticisms are relevant to the present work, and I will return to these in Chapter 7, which will describe steps taken to minimise potential problems with the research designs used in this thesis.

Finally, a point raised by Pusey and Richards (2001) is that studies have tended to include a wide range of caregivers in terms of the length of time spent caregiving and the relationship to the person with dementia. They suggest that more tailoring may be needed as some factors may indicate that different interventions are preferable. This is similar to the argument that interventions should be more 'person-centred' and should target assessed needs.

Overall, then, the picture emerging from review studies is that certain types of caregiver intervention (for example, multi-component interventions) have shown modest but promising results. However, methodological problems and lack of a standardised approach have meant that it is difficult to obtain a clear overall picture or to move forward with improved interventions.

Taking into account recent debates and challenges as outlined in reviews of caregiver intervention studies, the current work was influenced by the following research priorities:

1. There is a need for interventions which are both effective and cost-effective to support informal caregivers of people who have dementia.
2. Research on interventions should be underpinned by theoretical models to enhance our understanding of how and why these interventions work.
3. Interventions should aim to be person-centred and focussed on addressing identified needs of caregivers.

Before moving on to look at specific studies and areas within the field of caregiver interventions, I will examine existing models of caregiving stress. These provide frameworks within which to understand the factors contributing to negative caregiving outcomes, and a basis for targeting these factors in caregiver interventions.

2.3 Models of Caregiver Stress and Coping

As discussed in Chapter 1, caregivers of people with dementia are at additional risk of a number of undesirable outcomes, including psychological stress, depression, caregiver burden and physical health problems. One priority identified for future research is to ensure that caregiver interventions are more closely linked to theory. Several different models have been proposed which attempt to account for the stress processes experienced by caregivers.

One area of research has focussed on giving an overall picture of what happens to a caregiver's psychological well-being over time. Pot, Deeg and van Dyck (1997) describe three different possibilities that can happen when one provides care:

1. 'Wear and tear model' – this model suggests that the psychological health of a caregiver will decrease over time, reflecting the declining health of the person with dementia.
2. 'Adaptation model' – this proposes that caregivers adapt to the challenges of caregiving over time, and that their mental health will remain stable or even improve during the course of providing care.
3. 'Trait model' – this suggests that caregivers' mental health will remain stable over time, due to the coping skills and resources of the caregivers.

Pot et al. (1997) carried out a two-year longitudinal study of caregivers who experienced one of three outcomes: they went on being informal caregivers, the person with dementia went into nursing care or the person with dementia died. They found that for the caregivers who went on providing informal care, their mental well-being tended to decline over time, supporting the 'wear and tear' model. Those who saw the person with dementia enter institutional care showed some improvement in well-being, while those who were bereaved showed no overall change. These results, argue Pot et al. (1997), cast some doubt over policies which advocate for people with dementia to remain at home for as long as possible, as this may lead to significant deterioration in the well-being of their informal caregivers, who at the very least need additional support.

In contrast to the 'wear and tear' model, a longitudinal study by Zarit and Zarit (1986) suggested that caregivers may become more able to cope with the stresses of caregiving as time progresses, lending support to the 'adaptation' model. Importantly, this study also highlighted the complexity of the relationship between the needs of the person with dementia and the caregiver's experience of burden: the authors found that it was important to measure both the problems associated with the dementia and the caregiver's ratings of how troublesome these problems were for them. As I will discuss, this observed complexity of the relationship between stressors and stress has formed the basis of several models designed to try to explain variations in stress responses.

Perhaps related to the three patterns described above ('wear and tear', 'adaptation' and 'trait' responses to stress) is the theory of resilience. This theory posits that we can make positive adjustments which help us to cope with difficult situations, through an interaction of risk and protective factors (Bekhet, 2013). In the case of dementia caregivers, a risk factor could be the burden experienced by the caregivers, while a protective factor could be the ability to remain positive and cheerful in the face of this risk. Bekhet (2013) looked at the effects of positive cognitions, and found that these served as a protective influence, mediating the effect of caregiver burden on caregiver resourcefulness.

The models discussed above looked at overall trends in well-being over time. I will now consider a different type of model, which looks in greater detail at what happens to

create caregiver stress, and at the factors involved. Stress and coping models are based on observations that different people respond differently even when placed under similar levels of objective stress. This is an important observation for research into caregiving: if we can show that there is variation in how people cope with stressful situations, and that different factors are involved in how people react to and manage stress, then we can begin to look at which interventions may be most helpful in terms of reducing negative outcomes for caregivers.

Lazarus and Folkman (for example, 1987) devised a transactional theory to explain observed stress and coping patterns. Their model is a complex one with many factors, and they point out that the factors can play different roles at different times – for example, ‘caregiver burden’ could be an antecedent of stress, but it could also be an outcome of stress.

Lazarus and Folkman’s theory rests on three key concepts, which they describe as the meta-theory; these will be described briefly.

‘Transaction’ and ‘relationship’: a situation only becomes threatening if there is some transaction or relationship between the environment and the person. An environment on its own cannot produce the threat, and the person cannot be threatened without an appropriate context.

‘Process’: stress happens as a process; that is, there is change over time. This process must be measured as something over and above the person’s normal thoughts and activities.

‘Emotion as a system’: many variables interact to produce emotions. There are antecedents, mediators and long- and short-term outcomes of emotions.

Based on this meta-theory, Lazarus and Folkman’s (for example, 1987) model of stress involves the following concepts.

‘Cognitive Appraisal’: people constantly evaluate situations and events and judge the implications for personal well-being. ‘Primary appraisals’ are appraisals of whether a situation poses a direct risk to our well-being. This kind of appraisal relies on our

having some stake in the situation. 'Secondary appraisal' is appraisal of our ability to exert control over a situation. A threat can be minimised if we believe we have the resources to cope with it.

'Coping': Lazarus and Folkman see coping as a mediating factor affecting short-term reactions to stress. Coping can be problem-focussed (which can lead to the actual terms of the stressful situation being changed) or emotion-focussed (which can alleviate distress).

In this model, there are relationships between the different components. For example, secondary appraisal, which involves appraisal of our ability to cope, can influence our decision about whether to employ coping mechanisms. Because of the complex and dynamic nature of this model, research has tended not to look at the whole model but rather to test specific relationships within it.

Haley, Levine, Brown and Bartolucci (1987) tested a model of stress dealing directly with the stresses of caregiving. Taking a similar approach to that of Lazarus and Folkman (1987), they proposed a dynamic model of stress in which mediating factors (such as self-efficacy and appraisal) could account for the individual differences in how people respond to the stressors of caregiving. Coping mechanisms and social support are also seen as being factors in the management of caregiving stress.

The model tested by Haley et al. (1987) can be represented by the diagram shown in Figure 2.1.

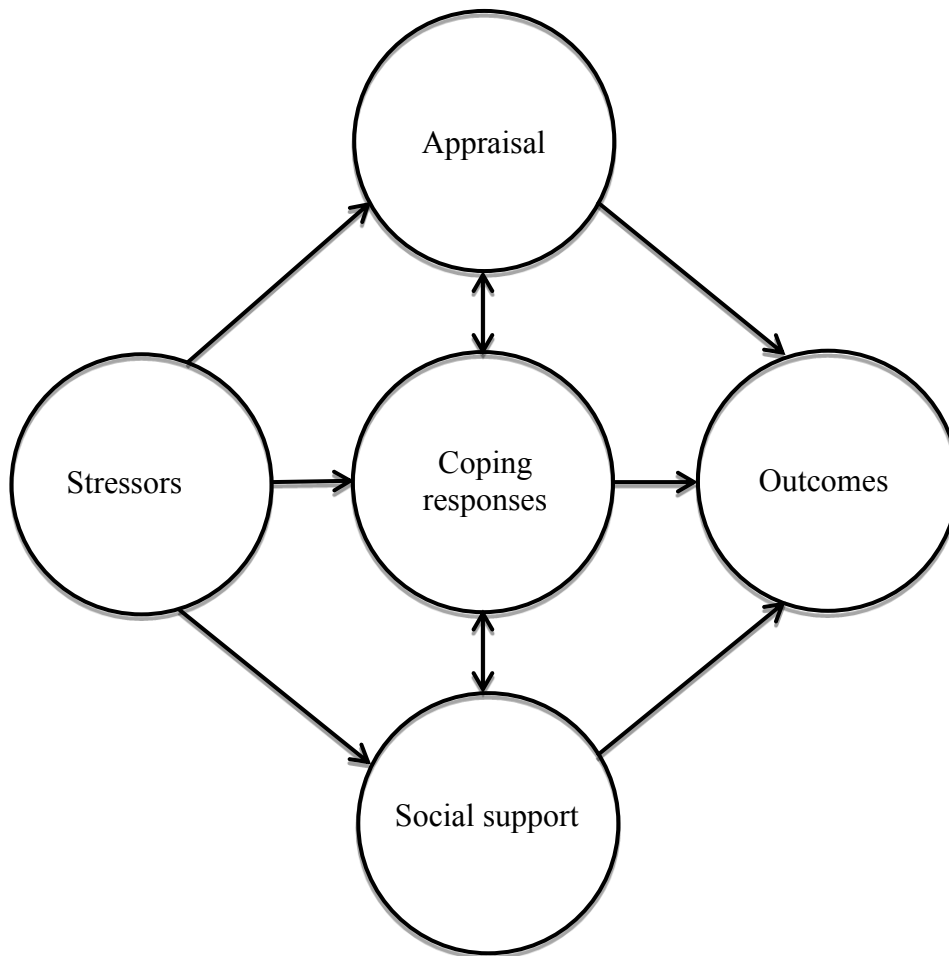


Figure 2.1 Stress and coping model proposed by Haley et al. (1987)

Caregiving stress, argue Haley et al. (1987), can be useful not only in increasing our understanding of the effects of caregiving, but in contributing to our understanding of stress in general. Caregivers are subject to intense, ongoing, unpredictable stress, and studies of the factors and relationships involved in creating and managing this stress may be useful in informing interventions for a wider audience.

Haley et al. (1987) found some evidence in support of their model of caregiving stress. One important finding was that different factors appeared to predict different outcomes. Caregiver appraisals of stress were more accurate than objective measures of stressors when it came to predicting stress levels. Self-efficacy for managing challenging behaviour was a significant predictor of depression in caregivers (as discussed in Chapter 1, behavioural problems have previously been found to be significantly related

to negative outcomes for dementia caregivers). Coping mechanisms were found to be related to health outcomes, and social support to life satisfaction. These outcomes suggest that research into caregiver stress should pay attention to more than one type of outcome, and should be aware of the complex nature of stress.

Another influential model of caregiver stress was proposed by Pearlin, Mullan, Semple and Skaff (1990). They defined caregiving as a natural part of a close relationship, but a part which comes to dominate and define the relationship in the presence of a condition such as dementia. Similarly to Lazarus and Folkman, Pearlin et al. (1990) focussed on the stress process, with relationships between components evolving over time. This model depicts four domains of caregiving stress: background and context, stressors, mediators and outcomes of stress. These domains are described below.

‘Background and context’ refers to characteristics which may make stress more or less likely; these include caregiver characteristics such as age and gender, economic and social factors, quality of relationship before diagnosis and support available. This type of information, Pearlin et al. (1990) argue, is often gathered simply as demographic information for studies, but needs to be included in our understanding of how stress is produced.

‘Stressors’ in this model can be primary (those directly associated with the decline and needs of the person with dementia) or secondary (including role strain – often referring to family difficulties, but also occupational, social or economic – and intrapsychic strain, which includes damage to self-esteem, sense of mastery and so on). Secondary stressors are not seen as being less stressful, but are secondary in the sense that they tend to follow on from primary stressors. Pearlin et al. (1990) assume that in dementia caregiving, primary stressors will become greater over time.

‘Mediators’ are defined as factors which do not completely explain stress reactions on their own, but play an important role in regulating stress. Pearlin et al. (1990) focussed on two mediators, coping and social support. Mediators can serve more than one function in the stress process model – it is sometimes assumed that they merely mediate the relationship between stressors and outcomes, but they may also have an effect on the production of secondary stressors.

‘Outcomes’ described by Pearlin et al. (1990) include depression, anxiety, physical injury, health and ability to undertake usual activities. Another important outcome is the cessation of caregiving, whether through institutional placement of the person with dementia or through an increasing handing over of the caregiving to professional supports. Outcomes can affect each other: for example, sustained emotional distress may lead to depression or to the individual relinquishing the caregiving role. This model, like those proposed by Lazarus and Folkman (for example, 1987) and Haley et al. (1987) portrays the stress process as involving a complex and dynamic set of interactions.

Another group of researchers took a similar approach to the models described above, but represented their model of stress with a formula: ‘Distress = (Exposure to Stress + Vulnerability)/Psychological and Social Resources’ (Vitaliano, Russo, Young, Teri & Maiuro, 1991). They found supporting evidence for aspects of this formula: vulnerable caregivers with no resources were more likely to experience burden than vulnerable caregivers with resources. This work again points to caregiver stress as being created by several factors.

It is important to say something about the notion of mediating and moderating variables in the context of these models. Mediator variables are those which, when they are changed through some intervention, work to change the value of the dependent variables (Baron & Kenny, 1986). So in an intervention study looking at whether we can reduce caregivers’ depression by increasing self-efficacy, we would expect self-efficacy to mediate the relationship between objective stressors and the outcome of depression, acting in a protective way against depression.

Moderator variables are those which we would measure at the outset of a study and which could affect the outcome (Baron & Kenny, 1986). For example, in an intervention study looking at self-efficacy, we might find that people with a higher depression score at the outset of the study benefited more from the intervention than those with a lower depression score at the outset. Depression in this sense would be acting as a moderator variable.

For the purpose of the present discussion, the emphasis is not on identifying which of the above stress models is closest to being ‘correct’. Indeed, as the authors of the

models note, ongoing research is likely to lead to further refinement of the models and of our understanding of the complex sets of relationships that produce stress and coping responses. It is important at this stage to be aware that there are several models proposing theoretical frameworks for understanding how caregiver stress and negative outcomes are produced, involving sets of relationships between different factors.

It is important, argued Pearlin, Menaghan, Lieberman and Mullan in an earlier paper (1981) to clarify at the outset of a study the overall conceptual stance that is to be taken on the nature of the stress process. They give the example of a body of work based on the assumption that life events are in themselves stressful, because people like to feel stable, and when a life event happens it threatens our stability and we become stressed in trying to regain a sense of balance. This, argued Pearlin et al. (1981), is not always the case, and the potential for life events to be stress-inducing depends on how welcome the life events are, how much control we can exert over the events and so on.

Although the models described above have some differences in terms of which concepts are included and how they are defined, they have in common their view of stress as being complex, involving relationships between different factors. The research in this thesis is based on this understanding of stress, and on the notion that there are certain factors which can be altered to create a reduction in the subjective experience of stress.

These stress and coping models have provided a useful theoretical framework from which to start looking at the nature and origins of caregiving stress, and from there to develop interventions that might help caregivers to acquire the resources needed to combat some of the negative outcomes of caregiving. Indeed, the complexity of the models should also inform us immediately that it is unlikely that there will be a 'one size fits all' intervention: it is probable that different interventions will work for different people, and at different times. These models, then, could be argued to advance research dealing with two of the priorities identified earlier (for example, Gallagher-Thompson et al., 2012): creating interventions which are based on testable theories, and creating person-centred interventions.

2.4 The Role of Self-Efficacy in Mediating Between Caregiving Stressors and Stress

Self-efficacy, described by Bandura (for example, 1994), refers to the belief in one's ability to achieve tasks and goals and to be effective. Self-efficacy, it is argued, can affect many aspects of our lives including the goals we set ourselves, our commitment to achieving these in the face of obstacles and our experience of stress and anxiety in response to challenging situations.

Looking back at the models of stress and coping described above, self-efficacy has been suggested as a mediating factor which affects the relationship between caregiving stressors and caregivers' experience of stress (Haley et al., 1987). Self-efficacy for a task can influence our decision to use coping mechanisms and to continue using these despite on-going challenges, and it can influence the likelihood of negative outcomes such as depression.

On a practical level, self-efficacy is a promising factor to target in interventions because it is potentially modifiable. In a recent review, Tang and Chan (2015) looked at caregiver interventions in which self-efficacy was included as an outcome measure. The review identified that both group and individual interventions were effective in raising caregiver self-efficacy, with effective interventions consisting of approximately six sessions of 90-120 minutes each.

The proposed role of self-efficacy in mediating caregiver depression and burden has been researched to an extent, with studies mainly being cross-sectional rather than longitudinal (for example, Gallagher et al., 2011; Au et al., 2009; Romero-Moreno et al., 2011, Mausbach et al., 2012). These studies have found evidence to suggest that self-efficacy may be a protective factor against caregiver outcomes such as depression and burden, but have also highlighted the fact that longitudinal or experimental studies are needed to explore the relationship more fully. Self-efficacy has also been suggested as an indicator of caregiver vulnerability which could be used in determining support needs (Marziali, McCleary & Streiner, 2010).

Although caregiving self-efficacy is most frequently examined in relation to the negative aspects of caregiving (such as depression and burden), there has also been some research looking at the relationship between self-efficacy and caregivers'

appraisals of positive aspects of caregiving (Semiatin & O'Connor, 2012). Similarly, Mausbach et al. (2011) found links between caregiver self-efficacy and caregivers' experiences of pleasant events/activity restriction (for example, caregivers who took part in more pleasant events and had lower levels of activity restriction reported higher levels of self-efficacy). Because of the cross-sectional designs used in these studies, it is impossible to say whether higher self-efficacy leads on to more positive appraisals of caregiving and participation in pleasant activities, or vice versa.

Romero-Moreno, Márquez-González, Mausbach and Losada (2012) carried out a longitudinal study looking at factors mediating caregiver depression, and found that self-efficacy (as well as cognitive reappraisal and frequency of leisure activities) was involved in regulating depression. Further longitudinal and experimental work is needed to clarify the role of self-efficacy in caregiver outcomes. Although some studies (for example, Huang, Shyu, Chen, Chen & Lin, 2003) have focussed on improving self-efficacy by using interventions, and self-efficacy has been included as a focus for the development of programmes to assist caregivers (Ducharme et al., 2009), these studies have not explored its role in relation to depression or burden.

One important aspect of self-efficacy is that it is domain-specific: that is, we can have high or low self-efficacy in relation to different types of task or different challenges. Zhang, Edwards, Yates, Guo and Li (2013) found two aspects of self-efficacy to be important in mediating the relationship between stressors or support and caregiver mental health outcomes. These were self-efficacy for gathering information and self-efficacy for managing caregiver distress. As with previous studies, this paper found the behavioural problems of dementia to be an important stressor for caregivers, and the study supported the idea of targeting self-efficacy in interventions, paying attention to particular aspects of self-efficacy. Similarly, Gallagher et al. (2011) found self-efficacy for symptom management to be an independent predictor of caregiver depression and burden, while Gonyea, O'Connor, Carruth and Boyle (2005) found self-efficacy for symptom management (but not self-efficacy for social support) to be a predictor of caregiver burden. These studies underline the importance of targeting self-efficacy in specific domains.

Steffen et al. (2002) created a measure of three aspects of caregiving self-efficacy, The Revised Scale for Caregiving Self-Efficacy, which measures Self-Efficacy for Obtaining

Respite (SE-OR), Self-Efficacy for Responding to Disruptive Patient Behaviours (SE-DB) and Self-Efficacy for Controlling Upsetting Thoughts about Caregiving (SE-CT). This tool is based on the understanding that self-efficacy is domain-specific and can vary according to recent events and experiences. It also measures self-efficacy in relation to aspects of caregiving which have been shown to be central to caregiver stress, particularly coping with the behavioural disruptions caused by dementia.

Another self-efficacy measure, devised around the same time, gauged self-efficacy in two domains: self-efficacy for symptom management and use of community support services (Fortinsky, Kercher & Burant, 2002). More recently, Crellin, Charlesworth and Orrell (2014) developed a tool, the Caregiver Efficacy Scale, focussing solely on caregivers' self-efficacy for managing the behavioural and psychological problems of dementia (BPSD). The Caregiver Efficacy Scale was intended to be used alongside the Neuropsychiatric Inventory (Cummings et al., 1994), an assessment tool measuring behavioural and psychological problems.

Using the Steffen et al. (2002) Revised Scale for Caregiving Self-Efficacy, Au et al. (2009) found that caregivers' self-efficacy acted as a partial mediator of the relationship between social support and caregivers' depression. Au et al. suggest that interventions focussed on helping caregivers cope with negative thoughts may be beneficial. Also using the Steffen et al. (2002) measure, Kwok et al. (2013) found that a telephone-based intervention delivered to Chinese caregivers was able to significantly raise self-efficacy for obtaining respite, but did not significantly increase the two other sub-scales of self-efficacy.

Rabinowitz, Mausbach, Thompson and Gallagher-Thompson (2007) conducted a cross-sectional study looking at the three self-efficacy domains identified by Steffen et al. (2002). This study found that higher levels of self-efficacy for obtaining respite (SE-OR) and controlling upsetting thoughts (SE-CT) were related to lower levels of health risk (as measured by health behaviours and self-rated health) in caregivers. These results support the idea of a stress and coping model, with self-efficacy as a protective factor against the negative outcomes of caregiving, and they are consistent with cognitive-behavioural theory (Rabinowitz et al., 2007): caregivers who are more able to make cognitive changes (by controlling the negative thoughts associated with caregiving) and behavioural changes (by seeking and taking up opportunities for

respite) are more able to avoid some of the negative health consequences. Although this was a cross-sectional rather than an intervention study, the results support the designing of interventions with caregiver self-efficacy as a focus.

An intervention study looking at the impact of caregiving self-efficacy was carried out by Coon, Thompson, Steffen, Sorocco and Gallagher-Thompson (2003). They provided caregivers with anger management or depression management training, and found that the training had an impact on two types of self-efficacy (SE-DB and SE-CT, as defined by Steffen et al., 2002). Self-efficacy for controlling upsetting thoughts appeared to be acting as a mediator variable in this study, leading to differences in caregiver hostility and depression. This study demonstrated that caregivers could benefit from interventions in ways that were not explained solely by the topic of the intervention, and Coon et al. (2003) supported the idea of further research into the role of self-efficacy in caregiving and the development of interventions to raise self-efficacy.

Bandura (for example, 1994) describes four ways in which we can acquire self-efficacy:

1. **Mastery:** This term refers to the sense of accomplishment we get from achieving goals. Mastery is gained particularly from situations in which we need to persevere or face obstacles to complete some task successfully.
2. **Observing models:** Self-efficacy can be enhanced by seeing others achieve similar goals to our own. This is most effective when the models are people with similar characteristics.
3. **Social persuasion:** Appropriate persuasion from others can enhance the feeling that we are able to reach some goal. Conversely, self-efficacy can be reduced through persuasion from others that we are not capable of something, and it can also be reduced through unrealistic persuasion which is not borne out by our actual performance.
4. **Managing stress and emotional responses:** People experiencing high self-efficacy tend to interpret arousal as a positive, energy-giving quality, while those with lower self-efficacy interpret the same feelings negatively. Self-efficacy can be bolstered by reducing stress and reinterpreting physical and emotional responses in a positive light.

Boise, Congleton and Shannon (2005) used a manual-based intervention, *Powerful*

Tools for Caregiving (PTC), to enhance caregivers' self-efficacy. This programme used the four means of building self-efficacy noted above: for example, it included activities like action planning in which caregivers could gain practice of implementing and evaluating changes to their routines, to build a sense of mastery. In this study, self-efficacy was measured as an outcome measure rather than considered explicitly for its role in reducing stress or depression.

The *Powerful Tools for Caregiving* intervention, used in the Boise et al. (2005) study, has been used in other studies. Savundranayagam et al. (2010; 2011) also used this intervention in studies of caregiver self-efficacy, health risk, self-care and burden. They found changes in self-efficacy to be useful in explaining reduction in risky health practices, increased time spent managing stress and increase in use of relaxation techniques. These studies again point to the role of self-efficacy in regulating stress outcomes for caregivers. Savundranayagam et al. (2010) argue that when we use a programme like *PTC* to increase the self-efficacy of informal caregivers, there is a greater likelihood that they will take positive steps to look after their own health, which helps to address the problem of caregivers' health being a relatively low priority compared to the needs of the person with dementia.

Using a similar approach but working with professional caregivers, Mackenzie and Peragine (2003) used an intervention to target nurses' self-efficacy in meeting the challenges of working with colleagues, patients with problematic behaviours and families of patients. The intervention was designed to allow the nurses to develop their mastery over certain tasks, to learn by observing colleagues, to receive persuasive feedback and to learn in an environment which minimised the stress of learning, thereby meeting Bandura's four strands for building self-efficacy. Nurses' self-efficacy, as measured on a scale specific to this study, increased with the use of the intervention.

Harmell et al. (2011) carried out a study looking at the possible physiological benefits of having greater self-efficacy, and focussed on caregivers' blood pressure. They found that one self-efficacy measure (self-efficacy for using problem-focussed coping) was related to lower blood pressure measures, and proposed that psychosocial interventions focussing on raising self-efficacy might also have physical health benefits for caregivers.

To summarise, caregiving self-efficacy has been seen to be a promising concept used in research into caregiver stress, with previous research indicating its importance as a protective factor against the negative psychological and physiological outcomes of stress, as well as its role in more positive experiences of caregiving. For the purposes of designing caregiver interventions, one of the most important features of self-efficacy is that it can be modified via the processes described by Bandura (1994), making self-efficacy a reasonable target for therapeutic approaches. As I will now discuss, there are other concepts which have similarities to self-efficacy, and which have similarly been studied in relation to the caregiver stress process.

2.5 Self-Efficacy and Related Concepts

In the caregiving literature, several concepts are often measured which can be seen to have some parallels with self-efficacy. In particular, reference is often made to mastery, control and appraisal. The distinction made between these concepts often refers to their nature as global or domain-specific phenomena: as discussed above, self-efficacy is defined as being domain-specific rather than global, so self-efficacy tends to be measured in relation to different types of caregiving challenge (such as in the scale designed by Steffen et al., 2002). Mastery is often defined as being global; that is, a sense of mastery would be expected to have an impact on a range of situations and challenges. However, some researchers choose to break mastery down further into global and caregiving-specific measures.

Pioli (2010) looked at two different measures of mastery – global mastery and caregiving mastery – in relation to outcomes such as depression in caregivers. This work used as its framework the stress process model (Pearlin et al., 1981), and has clear parallels with the stress and coping model (Haley et al., 1987) and the role of self-efficacy already described. Pioli (2010) found that caregiving mastery had a moderating effect on the relationship between caregivers' subjective stress and depression, pointing out that earlier work by Gilliam and Steffen (2006) had looked at objective stressors and had found no moderating effect. Pioli (2010) argued that it is vital to pay attention to subjective stressors in this type of study: what is found stressful by one individual may not necessarily be found stressful by others.

Self-efficacy and mastery have tended to be considered closely together in the research

literature. For example, Pioli (2010) makes a direct comparison of his findings with those of Gilliam and Steffen (2006), with the former study looking at the role of mastery and the latter examining self-efficacy.

A further concept closely related to self-efficacy and mastery is that of control. For example, Krause (1994) argues that we all occupy different social roles in different situations, and that some of these roles are more important to us than others, with the more important roles being more likely to cause harm in terms of stress or lack of role fulfilment. Krause (1994) sees personal control as being a related concept, and describes a domain-specific nature of this control, echoing the work of researchers looking at self-efficacy and mastery. The Harmell et al. (2011) study, described above, discussed both control and self-efficacy when describing the resources available to caregivers in managing the effects of stressors (in this case, the study looked at effects on blood pressure).

Schulz et al. (2012) carried out work looking at the role of choice in caregiver distress. This study involved a telephone survey of 1397 caregivers of people suffering from different health problems, and found lack of choice to be related to increased caregiver stress even when other factors were controlled for (for example, amount of care given; relationship to the care receiver). The results of this study also suggested that conditions such as dementia may be associated with lower levels of choice in caregivers, who may feel that it is difficult to ask other people to take on this role and that it is something they must do themselves. Schulz et al. (2012) concluded that efforts to build a sense of efficacy in caregivers may enhance their feeling of being in control; similarly, giving caregivers a menu of choices within the caregiving role (for example, choices about respite options) may serve to alleviate the negative feelings associated with a lack of choice. In this sense, choice should be considered as another concept related to the ideas of self-efficacy, mastery and control in caregivers.

Mittelman, Roth, Haley and Zarit (2004) focussed on caregiver appraisals of problem behaviours, arguing that caregiver appraisal can affect caregiver depression and the institutionalisation of the person with dementia. This was a controlled trial of an intervention using counselling and support for caregivers, and the intervention was found to reduce caregivers' appraisal of challenging behaviours as being stressful (the actual extent of challenging behaviours did not reduce during the four years of the study

– these behaviours increased – but the caregivers perceived them to be less distressing). This study also fits in with stress process models, as caregiver appraisal is seen as a mediating factor which can be modified using interventions.

Vitaliano et al. (1991) conducted a longitudinal study, which found that caregiver vulnerability and caregiver resources interacted to affect the experience of burden, with vulnerable caregivers with low resources being the most prone to burden. In this study, caregiver vulnerability and resources predicted burden independently of the measure used to gauge objective stressors. Vitaliano et al. (1991) discussed the effect of personal factors on caregivers' appraisal of stressful situations, which in turn affected the likelihood of caregivers using certain resources to adapt to situations.

Caregiver appraisal of stress has been found to act as a mediating factor between caregiving stressors and negative psychological outcomes for caregivers (Pot, Deeg, Van Dyck & Jonker, 1998). One notable exception to these findings was that for caregivers who were spouses, there was no mediating effect of appraisal between behavioural problems of the person with dementia and negative outcomes for the caregiver: there was a direct effect of problematic behaviours on the spouses' experiences of distress. Pot et al. (1998) stress the importance of considering spouse and non-spouse caregivers separately in this type of study. The importance of appraisal in these results is useful in terms of forming interventions: appraisal of stress is more amenable to modification than actual stressors (for example, the problematic behaviours of a person with dementia may be difficult to change, but a helpful intervention might instead focus on helping the caregiver to prioritise other things).

In a later study, Pot, Deeg and Van Dyck (2000) looked for moderating effects of caregiver resources (including coping skills, personality variables, available support and physical health) and did not find any moderating effects of these variables. One notable feature of this study was that the authors looked for moderating effects between caregiver *appraisal* of stress and negative outcomes, rather than between stressors and outcomes. A possible reason for the results of this study might be that the caregivers' resources had in themselves affected their appraisal of stressful situations. This would concur with self-efficacy theory, in which those with higher self-efficacy for a given situation would be expected to judge the situation as being less threatening or stressful, because of having the resources to cope with it. If we accept that appraisal may be a

similar concept to self-efficacy, in the sense that both involve making a subjective judgement about a challenging situation and the resources we have for meeting the challenge, then it is likely that appraisal itself would be affected by factors such as coping skills. Nonetheless, it is worth noting the authors' point that caregivers may need additional support regardless of their apparent appraisal of a stressful situation, and that we should not assume that caregivers with certain coping resources are not in need of more support.

The results of Pot et al. (2000) appear to contradict the findings of Pioli (2010) described above; that is, both studies concentrated on subjective measures of stressful situations, with the Pioli study (2010) finding support for the presence of moderating variables and the Pot et al. study (2000) not finding any such support for moderating effects. However, these two studies used different measures of similar concepts: Pioli looked at the moderating effects of caregiving mastery between subjective measures of stress and caregiving outcomes, while Pot et al. looked for moderating effects of caregivers' resources between caregivers' appraisals and distress. The range of measures used in these two studies illustrates one of the central difficulties with caregiving literature to date; it is difficult to make a definitive comparison when different operational definitions and different measuring instruments are used.

Other studies have considered the role of caregiver appraisal in mediating the relationship between objective stressors and the physical health of caregivers. Son et al. (2007) found that caregivers' feelings of overload mediated between objective stressors (measured as behavioural and psychological problems in the person with dementia) and three measures of physical health: use of health services, self-rated health and unhealthy behaviours. This research used as its guide the Pearlin et al. (1990) stress and coping model described earlier.

The research described in this section has focussed on self-efficacy and related concepts as they apply to informal caregivers. Interestingly, these concepts have also been seen to have some application for professional caregivers of people with dementia, with a model of work-related stress leading to the measurement of 'self-perceived social competencies' of employees (Franzmann, Krause, Haberstroh & Pantel, 2014).

To recap, previous work has looked at a range of closely-related concepts which have

included self-efficacy, mastery and control. The decision to focus on self-efficacy in the current work is the result of consideration of both theoretical and pragmatic concerns. The work of Bandura (for example, 1994) is arguably the most extensive in terms of defining self-efficacy and describing its origins and its effect on our reactions to challenging situations. Within Bandura's work, mastery is seen as being one of the component sources of self-efficacy: by gaining mastery over challenging situations, we can experience an increase in self-efficacy for similar situations. Bandura also described other ways in which self-efficacy can be built, as described earlier: through modelling, social persuasion and managing and reinterpreting our physiological stress responses. In terms of building a multi-component intervention, then, it was felt that Bandura's self-efficacy theory gave the most complete and extensive account of how and why such an intervention might work, as well as a clear indication of techniques which might be used.

The decision to focus on self-efficacy was also a pragmatic one, as the concept has been operationalized in many previous caregiver studies, with the Steffen et al. (2002) Revised Scale for Caregiving Self-Efficacy having been designed specifically to measure three relevant domains of caregiving self-efficacy. This tool is evaluated in a report on outcome measures used in assessing outcomes for carers of people with mental health problems (Harvey et al., 2005). No other self-efficacy scales were reviewed in this extensive document.

2.6 Self-Management Approaches

An area which can be seen as related to the concepts described above (such as self-efficacy and control) is the idea of self-management techniques, in which treatment is seen as a collaborative process between professionals and those affected by a condition. Laakkonen et al. (2012) proposed a self-management programme, focussing on factors including problem-solving skills, with the aim of improving the quality of life of those with dementia and their caregivers. Self-management programmes can be seen to have parallels with the current work, in the sense of empowering individuals and equipping people with the skills and knowledge to tackle some of the challenges of dementia and improve outcomes. The idea of a self-management programme was also explored by Mountain and Craig (2012), who conducted interviews and group discussions with people with dementia and their carers, to identify suitable topics and interventions. The

focus of this paper was to develop a programme for the people with dementia, although it also took into account the views and preferences of caregivers.

Self-management has been the focus of the work of Kate Lorig (for example, Bodenheimer, Lorig, Holman and Grumbach, 2010), who developed the Chronic Disease Self-Management Plan. Self-efficacy is seen as a key aspect in this type of programme, and participants are asked to rate their confidence in achieving agreed goals, so that action plans can be made realistic and achievable.

The study by Boise et al. (2005), described earlier, used an intervention based on the approach of the Chronic Disease Self-Management Plan. This study included caregivers of older adults, some of whom had dementia diagnoses although the study was not limited to this caregiver group.

2.7 Interventions used in Previous Studies: Practical implications and issues

In designing an intervention to support caregivers, it is important to look closely at the nature of interventions used in previous studies, paying attention to the strengths of these as well as the areas for improvement noted by the authors. In this section I will focus more closely on the aspects of previous intervention studies which have proved beneficial to caregivers, and those which have been related to less favourable outcomes. The aim here is to build upon previous research in the development of an intervention for the current work, minimising those aspects which in previous studies have proved problematic and making use of approaches which have had support from prior studies.

A couple of studies have been cautious about the usefulness of using group-based interventions with caregivers. In their study looking at individual or family counselling compared with support groups, Zarit, Anthony and Boutselis (1987) found that there were improvements in caregiver burden, but that these improvements were not significantly different to the improvements seen in a waiting list control group. They noted that the results of this study were not positive about the use of support groups, although it is possible that peer-support groups would have been more favourable.

Similarly, Haley et al. (1987) found that there were no significant differences in outcomes for caregivers who were randomly assigned to a support group, a

support/skills group or a waiting list control. They proposed that such interventions may have limited scope for improving outcomes when compared to the actual needs of caregivers, including the need for better resources and more support. However, they reported a 'substantial' attrition rate (28 per cent) from the group conditions, which required caregivers to attend for ten meetings. It is possible that the caregivers who could not attend were the ones with the highest number of stressful events going on in their lives or, as Haley et al. (1987) noted, that drop-outs were related to unpredictable events such as developments with the person with dementia. It is also possible that the researchers' expectations for the intervention differed from those of the caregivers, who actually rated the group sessions very highly. Particularly useful aspects to the caregivers were the opportunity to meet other people in the same situation, the practical information given about the brain and behaviour, information on resources and being encouraged to try out new ways of managing situations. When designing an intervention study, we must always be aware of the possibility that our goals as researchers, or the outcomes measured, may not be the same as the desired outcomes for the participants.

Manual-based interventions have been used in many previous studies, with participants receiving a manual with information and exercises. The Boise et al. (2005) study described earlier used one such intervention, with all the information and practical exercises going on to be published in *The Caregiver Helpbook* (Legacy Health System, 2006). In their paper, Boise et al. (2005) noted that one possible drawback in the study was the time commitment required of caregivers, and they suggested that the length of the intervention may have contributed to a lowering of participation. Rosenberg and Gouge (2007) reported that shortened versions of the intervention used by Boise et al. (2005) have since been developed.

Burgio, Stevens, Guy, Roth and Haley (2003), in their intervention aimed at having multiple benefits for caregivers, used a skills development manual; this was delivered in 16 home-based sessions over the course of a year, and was supplemented by the use of video cassettes. The control condition in this study, defined as a minimal support control, involved telephone calls being made to offer caregivers support, as well as the use of brief information sheets on specific topics as requested by the caregivers. The Burgio et al. (2003) study was part of a project called REACH (Resources for Enhancing Alzheimer's Caregiver Health), which will be discussed more fully later in this chapter.

Pickett-Schenk et al. (2006) reported on the Journey of Hope, an eight-week family-led intervention based on a manual and also using lectures, videos and group discussions. This intervention was developed into the Family to Family Education Program (Dixon et al., 2004), expanded to a 12-week programme. These interventions also involved providing training to the family members who were going to provide the intervention in turn. The concept of training caregivers to provide support to fellow caregivers will be discussed in Chapter 8, as a possibility for further research.

Some of the literature on family- or peer-led interventions has focussed on family members affected by mental health in general, rather than a specific condition. *The Caregivers Helpbook* (Legacy Health System, 2006) was written to appeal to caregivers in a range of situations and was not restricted to dementia caregivers. As discussed in Chapter 1, however, there are particular risks of being a caregiver for someone who has dementia, and these risks have been suggested to relate to the difficult behavioural issues caused by dementia: agitation, walking, disinhibition and so on. It seems reasonable, therefore, to propose that an intervention designed specifically to help dementia caregivers could be more precisely targeted to the stressors facing this group of caregivers, and this may have the additional benefit of being a shorter intervention which would be less demanding of caregivers' time.

In addition to testing to see whether interventions offer measurable benefits (and often used as a precursor to this type of study), feasibility studies look at issues including the practicality and acceptability of interventions (Bowen et al., 2009). As well as proving feasible in terms of caregivers' time and busy routines, interventions for supporting dementia caregivers also need to be practical in terms of their professional resource requirements. Dementia support tends to be relatively underfunded, so for an intervention to be widely adopted following successful testing, it should ideally be inexpensive to deliver. This takes us back to the priorities identified earlier for developing helpful interventions: they need to be both effective and cost-effective, to stand any chance of being made widely available. An intervention which requires a great deal of intensive training at the start is likely to face challenges in getting off the ground.

It is important to balance between being too time consuming and offering insufficient

support, when designing this type of intervention. Zarit and Femia (2008) cautioned against using interventions whose intensity is insufficient to have the desired effect, and Zarit et al. (1987) found that caregivers went on looking for support after their intervention had ended, suggesting that a longer period of support may have been needed.

Some studies have looked into using different formats for interventions to try to make them more convenient for caregivers who may have busy lives. Kwok et al. (2013) found a good level of adherence to their telephone-based intervention, which may be suitable for caregivers who would have difficulty in committing to the time away from home required to attend an intervention. Other studies have looked at the possibility of using technological advances to deliver online interventions (for example, *Mastery over Dementia*, an internet-based intervention for caregivers, is being evaluated for effectiveness and cost-effectiveness (Blom, Bosmans, Cuijpers, Zarit & Pot, 2013), while Bass et al. (2013) looked at the use of email in conjunction with telephone support in an intervention, meaning that professionals could offer support to large caseloads of people).

Williamson and Schulz (1993) raised an issue important to the development of caregiver interventions, particularly ones which use techniques such as goal-setting and problem-solving. They found that some coping responses were actually associated with higher levels of caregiver depression: for example, using active problem-solving in response to memory deficits, which are clearly outside of the caregivers' control and unlikely to respond to problem-solving. Williamson and Schulz (1993) present a compelling case for interventions to promote both 'active' and 'passive' coping techniques to caregivers. An active coping technique could be something like forming an action plan to take more breaks, something which can be improved in an active way. Passive techniques would include things like developing greater acceptance of memory decline in the person with dementia, a factor which cannot be controlled using active responses.

Williamson and Schulz (1993) argued that caregiving cannot be seen as one overall stressor, and should instead be looked at as a collection of different stressful aspects which may require different response styles. Indeed, as Zarit (2012) notes, caregiving is not simply a stressor at all, but includes many positive aspects for caregivers, such as positive experiences, feelings and strengths, so any intervention must take into account

the breadth and complexity of the factors involved in caregiving and not assume that it is a single source of stress.

When designing an intervention to support caregivers, then, it is vital to pay attention to the information obtained from previous intervention studies. An intervention should be sufficiently intensive to address a support need, but we also need to ensure that the time commitment required is not so large that it rules out the very people who may have most need of the intervention. It should be borne in mind that the outcomes we desire as researchers may not be identical to the outcomes considered desirable by caregivers themselves. For interventions to be feasible, they should not be highly dependent on professional input or expensive resources. A successful intervention should be appropriately targeted to need and should reflect the range of possible stressors and coping responses, bearing in mind that different response styles may be more or less appropriate to different situations.

2.8 Brief Interventions

The term ‘brief interventions’ is usually associated with a different field of research and practice; namely, interventions designed to help people with drug, alcohol or mental health problems (for example, Winters, Lee, Botzet, Fahnhorst & Nicholson, 2014; O’Donnell et al., 2014). In the substance misuse field, a brief intervention can be as short as simply carrying out a screening assessment with an individual and giving brief advice (D’Onofrio & Degutis, 2002).

Although brief interventions are used widely in the field of behaviour change, there is little in the caregiving literature about this type of approach. Indeed, some of the caregiving interventions described as ‘brief’ are actually rather intensive. For example, Kurz, Wagenpfeil, Hallauer, Schneider-Schelte and Jansen (2010) describe a brief, practical educational intervention for caregivers, which involves caregivers attending seven sessions of ninety minutes each, followed by six refresher sessions, with the complete intervention taking fifteen months. This stands in marked contrast to the nature of brief interventions in the behaviour change field, in which such an intervention can take as little as a few minutes to carry out (D’Onofrio & Degutis, 2002). Within the dementia caregiving field, a ‘brief training’ intervention in mindfulness, lasting four hours, was found to lead to caregiver benefits including reduced burden (Hoppes,

Bryce, Hellman & Finlay, 2012), although the quantitative evidence from this study must be treated with caution as the sample comprised eleven caregivers with no control group.

As Czaja et al. (2009) have noted in their development of an assessment tool for working with dementia caregivers, the process of assessment can in itself be helpful for caregivers. However, the language of brief interventions at present seems to mean very different things in the fields of caregiving and behaviour change, and there appears to have been little exploration of the effects of using shorter interventions to support dementia caregivers. The concept of brief interventions is introduced here because, as will be discussed in Chapters 3 and 5, one of the aims of the current work was to explore the use of a relatively short caregiver intervention. If shown to be effective in supporting caregivers, shorter interventions could offer certain advantages in terms of reducing the commitment required of caregivers, making support more flexible and easily tailored to changing needs over time.

2.9 Moving Towards Person-Centred Interventions

There has been some movement towards creating interventions which can be adapted depending on the assessed needs of individual caregivers, which was one of the priorities identified earlier. Perhaps the most notable example of this to date has been the REACH (Resources for Enhancing Alzheimer's Caregiver Health) II programme, a USA-based programme in which risk assessments were carried out on six aspects related to caregiving (depression, burden, behaviours of the person with dementia, safety, self-care and social support). The intervention received focussed on individual challenges agreed between professionals and the caregiver (for example, Belle et al., 2006). REACH II used a complex intervention which was designed to target and measure several outcomes at once, and to be person-centred. The idea of using a multi-component intervention to target more than one source of caregiver stress has been supported in other research (for example, Schulz et al., 2002).

Also part of the REACH II study, Elliott, Burgio and DeCoster (2010) looked specifically at the issue of caregivers' health and how it responded to an intervention which included imparting knowledge and skills about self-care to caregivers. The results of this study suggested that the negative health impacts of caregiving could be lessened

by focussing on health promotion with caregivers, and that there should be a focus on identifying risk factors for poorer health outcomes, including burden and depression.

At the end of REACH II, Czaja et al. (2009) developed an assessment tool, the Risk Assessment Measure (RAM), designed to identify the particular needs of individual caregivers and to link in with evidence-based interventions. As noted earlier, Czaja et al. (2009) argued that the process of assessment is in itself therapeutic, as well as allowing us to develop individualised interventions and support plans; this resonates with the brief intervention work from other fields.

REACH II spawned many different studies and has shown promising benefits for caregivers, although it is difficult to evaluate the approach as a whole because of the complexity of the programme. This was also a resource-intensive, large-scale programme which may prove difficult to replicate using normal levels of resources available for caregiver support.

An adaptable intervention was examined by Zarit, Lee, Barrineau, and Femia (2013); the intervention had different components (such as ‘Roles and Relationships’) and caregivers completed a risk assessment which placed them at high, medium or low risk for each of the components. Individual programmes were then compiled, using different intensities of each of the components (measured by number of sessions) in line with assessed need. This study focussed on measuring fidelity and acceptability rather than outcomes of the intervention, and found that the approach was acceptable to caregivers and that counsellors were able to carry out the intervention in line with the risk assessment. Fidelity and acceptability have a particular relevance when designing a flexible or person-centred intervention; because there is no single protocol that is followed by everyone, it is important to check that programmes are being delivered as planned, and participants are often not involved or consulted on which individual programme they are to receive, an important aspect of carrying out person-centred work.

Research into the type of approach described by Zarit et al. (2013) is limited at this stage. It is possible that this way of delivering interventions may prove labour-intensive and dependent on professional counsellors for its delivery; however, it represents one approach towards creating interventions which address assessed need rather than

treating all caregivers as having the same support needs. It is important to move forward in a person-centred way, to avoid the problems associated with treating caregivers as a homogeneous group; specifically, the risks of weakening the study by including people who do not have the needs being addressed by the programme, and the risk that this can actually prove damaging for individuals (Zarit et al., 2013).

One important implication of looking at more person-centred ways of working is that reliable assessment is needed. Etters, Goodall and Harrison (2008) stressed the importance of good assessment in matching individuals to tailored programmes, and they looked at the role of nurse practitioners in assessing caregiver-patient dyads with a focus on caregiver burden. This approach is again reliant on professional input, and the authors' review of existing interventions led them to conclude that tailored, multi-component interventions are the most likely to address the issue of burden.

Another approach, which may help make interventions more tailored without risking their practical feasibility, is to look at how different sub-groups of caregivers respond to interventions. Kim, Zarit, Femia and Savla (2012) studied wives and daughters of people with dementia, comparing those who had the back-up of adult day services (ADS) with those who did not. They found that daughters benefited from the ADS in a more straightforward way than wives, who experienced a decline in positive affect over time and a smaller reduction in overload than daughters. Similarly, in a review paper, Van Mierlo, Meiland, Van der Roest and Dröes (2011) looked at previous studies which had reported results of interventions broken down into sub-groups of caregivers. They found, for example, more evidence of interventions working for female caregivers than male, although the review was not able to investigate the mechanisms behind this observation. In a review focussing on gender differences in the effects of caregiving, Yee and Schulz (2000) identified that female caregivers reported higher levels of psychiatric symptoms than male caregivers and were less likely to engage in protective health behaviours, suggesting that there may be a specific role for caregiver interventions in addressing these differences.

Interventions have been aimed at helping people who were very early in their caregiving 'career' (Ducharme et al., 2011; Cummings, Long, Peterson-Hazan & Harrison, 1998), noting that caregivers have different needs at different stages and that few interventions have been designed specifically to help those new to the role of caregiver. In an earlier

paper, Ducharme et al. (2009) carried out qualitative interviews with early-stage caregivers, identifying the particular needs associated with the beginning of the caregiving process. These included the need to understand more about dementia, the need to develop new communication and other skills to help the person with dementia and the need to be able to access resources, both in the professional sense and through negotiations with family members.

The effect of moderator variables (variables at baseline which can affect the outcome of an intervention; Baron & Kenny, 1986) has been the focus of some studies. Coon et al. (2003) in their intervention study noted the importance of aptitude treatment interactions (ATI); for example, differential treatment outcomes depending on depression score at baseline. Focussing on these effects can help make treatments more person-centred by improving our ability to determine which sub-groups of caregivers are most likely to gain benefits from particular interventions.

Although the sub-group approach does not offer the same level of refinement as the individual approach to tailoring interventions, it is useful to know which groups of caregivers should be the target of which interventions. One practical drawback of looking at sub-groups of caregivers is that studies need to have large numbers of participants for this to be feasible (Van Mierlo et al., 2011).

2.10 Qualitative Analyses of Caregivers' Experiences

Most of the studies discussed thus far have been of a quantitative nature, serving a range of purposes including evaluating models of caregiving stress, identifying trends in the elements of caregiving which cause most distress, or evaluating interventions designed to help support caregivers. Particularly in recent years, there has also emerged a body of work using qualitative methods to look at the experiences of informal caregivers.

While quantitative approaches are generally used to uncover overall trends within a population (for example, the relationships between different factors in a model of stress, or the general trend for a particular intervention to have a positive or negative outcome), qualitative methods tend to be used to obtain a more in-depth look at what is happening for a smaller number of people. However, the two approaches can be used in a

complementary way to enrich our understanding of a general phenomenon. Although qualitative methods tend to rely on much smaller samples and therefore generalisation may not be possible, it is still possible to relate the results of a qualitative study to previous work or to use the results to inform future developments. Smith, Flowers and Larkin (2009) refer to the ‘theoretical transferability’ of qualitative work; it is possible to link this work to existing research, models and theories. Indeed, many research projects now use a mixed-methods design in order both to capture quantitative patterns or trends and to give the depth of understanding and richness of data that qualitative work can generate.

Qualitative research can contribute to the development and understanding of theory and models of stress. Williams, Morrison and Robinson (2014) conducted a qualitative study in which 13 informal caregivers were interviewed and the interviews were analysed using Interpretative Phenomenological Analysis, an approach which will be described in detail in Chapter 4. One of the findings of this study was that although individuals may profess to have preferred coping techniques (such as the use of forward planning to deal with difficult situations) their actual use of strategies was dependent on context and their appraisal of situations (for example, one caregiver described a particular situation in which she avoided thinking about negative outcomes, rather than using planning or acceptance). Reflecting on stress and coping models that have arisen from observed differences between individuals in coping mechanisms and stress (for example, Haley et al., 1987), we can see from this qualitative work that there is also variation within individuals, depending on context and the individual’s perception and reactions. By taking an in-depth view of individual coping styles, it becomes apparent that the picture is more complex than one which accounts only for individual differences. This ties in with the domain-specific nature of phenomena such as self-efficacy (for example, Bandura, 1994), which would predict that an individual may have different means of coping within different contexts.

Stokes, Combes and Stokes (2014) interviewed spouse caregivers of people with dementia, focussing on post-diagnostic information, and again used IPA to analyse the interview data. This study explored carers’ perceived lack of support and further information in the period following a diagnosis of dementia. Toms, Quinn, Anderson and Clare (2015) used Thematic Analysis, a different type of qualitative analysis, in their interviews with both caregivers and people with dementia, looking at their use of

self-management techniques. They found that barriers to self-management included loss of confidence. These examples illustrate ways in which qualitative research can highlight the need for certain interventions, and can be used in the evaluation of therapeutic techniques, enriching our understanding of caregiver interventions.

Qualitative research can offer access to information that may not readily be accessible from conducting a study that is purely quantitative. Although qualitative work does not usually claim to give generalizable data, it can help to increase our understanding of the lived experiences of individuals, and can generate insights into why certain interventions may be helpful, as well as pointers to other factors which should be considered.

2.11 Summary

As the number of people diagnosed with dementia increases, so too does the number of informal caregivers involved in supporting a loved one who has dementia. These caregivers are subject to certain increased risks related to their caregiving roles, including increased risk of depression (for example, Ory et al., 1999). As discussed, a body of work has emerged which is directed at finding the most effective ways in which caregivers can be supported. This work has shown some promise for the use of certain types of intervention; however, review studies have highlighted priorities which should be the focus of further research (Gallagher-Thompson et al., 2012). These priorities include the need to find interventions which are both effective and cost-effective, the need for interventions to be more closely aligned to theoretical models of stress and the importance of making interventions person-centred and responsive to assessed needs.

Research has begun to address these concerns. Looking at the work which has been done on caregiving self-efficacy, there has been some support for the theory that self-efficacy can help to mediate the relationship between caregiving stressors and caregiving stress, and can act as a protective factor against negative outcomes of caregiving. There is a need for studies which allow us to see a longitudinal picture of this relationship, and a need for intervention studies.

There have been attempts to make caregiving interventions more person-centred, as exemplified by the US-based REACH II project and by studies attempting to look at the

effects of factors such as relationship type and stage of caregiving in relation to the effectiveness of different interventions. One relatively unexplored area of research with regard to caregiving is the use of shorter interventions; if these could be shown to be effective and acceptable to caregivers, they may help to meet the requirements for interventions which can be delivered in a flexible and tailored way, as well as being cost-effective and reducing the commitment required of caregivers.

Finally, there is a small and emerging body of literature which looks at the caregiving experience using qualitative methods. Qualitative research can allow us to gain an in-depth picture of the caregiving process by concentrating on a small sample of caregivers and obtaining rich, detailed data. In Chapters 4 and 6, I will return to these qualitative methods, starting with an exploration of some caregivers' experiences of the challenges of caregiving, their experiences of existing support and their thoughts about the types of support that are needed.

Chapter 3 – Self-Efficacy in Caregiving: Design and pilot-testing of an intervention aimed at promoting self-efficacy in informal caregivers of a person with dementia

3.1 Introduction

In Chapters 1 and 2, I gave an overview of existing literature on the topic of providing informal care for a person who has dementia. This included studies which have highlighted the particular risks and negative outcomes experienced by many informal caregivers (for example, Ory et al., 1999; Schulz et al., 1995; Mausbach et al., 2007), studies which have tested interventions designed to try to make caregiving less stressful (as reviewed, for example, in Pinquart & Sörensen, 2006) and studies which have aimed to shed light on the stress process itself, highlighting protective factors which may help reduce negative caregiving outcomes (for example, Haley et al., 1987; Pearlin et al., 1990).

Self-efficacy, a concept defined by Bandura (for example, 1994) and relating to the belief in our ability to meet challenges and achieve goals, has been suggested to be a promising mediating factor with the potential to protect against negative caregiving outcomes. With a few exceptions, the previous work on self-efficacy and caregiving has used cross-sectional study designs (Gallagher et al., 2011; Au et al., 2009; Romero-Moreno et al., 2011), with a need for both longitudinal studies and those using interventions to explore the effects of self-efficacy on caregiving outcomes.

Longitudinal and intervention studies would allow us to explore issues such as whether the mediating effects of self-efficacy are maintained over time and whether the relationships between different factors can be altered using interventions.

After reviewing the literature on caregiving stress, I planned to carry out an intervention study with two aims: to look at the effects of the intervention on caregiving outcomes, and to explore the effects, if any, of self-efficacy within the results. In this chapter I will describe the underpinnings of this work, the development of the resources to be used, a pilot study which was conducted and the ways in which this pilot study helped to refine and expand the research proposal for the remainder of the thesis.

3.2 Developing the Aims of the Research

When considering possible research aims for this work on caregiver interventions, it was important to maintain a focus on the challenges for intervention research identified in Chapter 2. To recap, these challenges were as follows:

1. Interventions to support caregivers should be both effective and cost-effective;
2. Intervention research should be supported by theoretical models to increase our understanding of how and why interventions do or do not work; and
3. Interventions should be person-centred and should address identified needs of caregivers.

With these challenges in mind, it was decided to conduct research which would build on previous work examining stress and coping models in caregivers of people with dementia. As discussed in Chapter 2, there has been a body of work looking at why caregivers experience differing levels of distress and burden in response to similar levels of objective stressors. Stress and coping models (including Haley et al., 1987) have proposed that there are mediating factors, such as self-efficacy, which can help regulate the negative outcomes of caregiving. This chapter represents an aim to expand on previous work by writing and pilot testing a relatively short intervention to try to promote self-efficacy among caregivers of people with dementia.

Paying attention to the need for cost-effective, practical interventions, I compiled a manual including exercises aimed at increasing self-efficacy in relation to certain caregiving challenges, and written in terms that meant that the manual did not depend on delivery by any specific group of professionals. As will be discussed, the manual was intended to be presented in three short sessions involving caregivers, with the aim of providing an effective intervention which does not require a great deal of time or costly resources.

When compiling the intervention manual, some consideration was given to the delivery of the three sessions. There is an emerging body of literature on technology-based interventions (as reviewed by Godwin et al. (2013) and Lee (2015)) and if shown to be effective, it is likely that the materials used in the current study could eventually be made available online. However, to make the study inclusive and accessible, a decision was made to test the intervention in a community setting in the first instance. An additional concern for the present study was that the materials were designed to use the

means of building self-efficacy defined by Bandura (for example, 1994). As self-efficacy includes the concepts of 'modelling' and 'social persuasion', a decision was made to test the intervention in a face-to-face-setting initially.

The exercises in the intervention manual were written to encourage caregivers to reflect on their own experiences, deciding for themselves which experiences were most relevant to the exercises. It was anticipated that this focus on the real experiences of the caregivers would mean that the intervention could address actual needs, rather than providing 'one size fits all' information to caregivers (such as that found in more formal training sessions). Additionally, although outside the scope of the work proposed towards this thesis, the intervention manual was written so that each of the three sessions dealt with a specific type of caregiving stressor (aligning with the three areas defined by Steffen et al. (2002) in their work on caregiver self-efficacy), meaning that sessions would have the potential to be used in a standalone way according to individual needs. However, for the purposes of this thesis, and as the intervention is a new one, it was important to test its feasibility as a whole in the first instance.

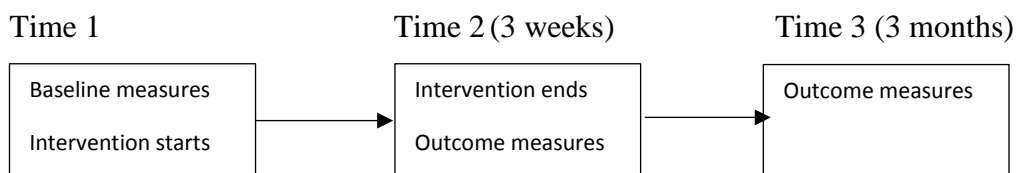
With these considerations in mind, the initial aims of the work in this thesis were defined as follows.

3.2.1 Aims

1. To examine self-efficacy and other outcomes (including depression and burden) in caregivers of people with dementia, using an intervention which has been designed with the aim of raising self-efficacy in three specific domains (Self-Efficacy for Obtaining Respite, Self-Efficacy for Responding to Disruptive Patient Behaviours and Self-Efficacy for Controlling Upsetting Thoughts about Caregiving, as defined by Steffen et al., 2002).
2. To examine the role of self-efficacy, within this design, in relation to objective stressors, caregiver depression and caregiver burden.

The figure below illustrates the initial research design, in which I proposed to deliver the self-efficacy intervention to small groups of caregivers, comparing these participants with a control group of caregivers.

Intervention Group



Control Group

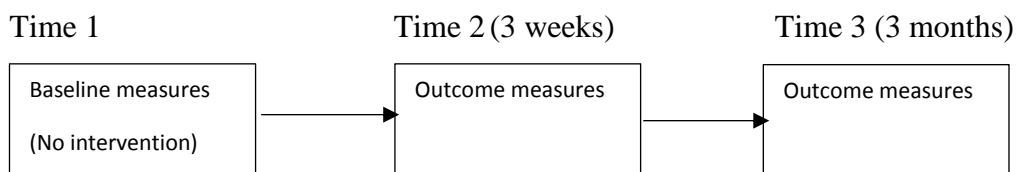


Figure 3.1 Initial proposal for intervention study

It was also proposed to carry out a follow-up qualitative study with some of the participants of the intervention group as detailed above.

As I will discuss in this chapter, a pilot study was carried out to gauge the feasibility and acceptability of using this manual-based intervention, and to allow the focus and aims of the work to be refined. The research aims will be revisited towards the end of this chapter, and revised in the light of the outcomes of the pilot study.

3.3 Development of the Self-Efficacy Intervention

The intervention used in this research was based on a manual written specifically for the study, and targeted towards informal caregivers of people with dementia. This manual was informed by previous research that has been done with this group of caregivers. For example, Boise et al. (2005) used a manual-based self-efficacy intervention (aimed at family caregivers as a general group), as discussed in Chapter 2, while Livingston et al. (2013) tested a manual-based intervention focussed on coping (START; Strategies for Relatives), finding benefits including lower incidence of depression in caregivers receiving the intervention compared to caregivers receiving usual treatment. Milders, Bell, Lorimer, MacEwan and McBain (2013), in a pilot study, successfully used a manual to train informal caregivers of people with dementia to carry out cognitive stimulation with their relatives. The manual used in the current work was also informed

by my prior professional experience of using techniques such as goal-setting and problem-solving with groups of adults, in a social care setting.

When designing and compiling the intervention, it was important to pay attention to both the content and the planned delivery of the intervention, to devise an intervention which should boost caregiving self-efficacy in the four ways described by Bandura (for example, 1994), which were as follows:

Mastery – Self-efficacy can be built by gaining mastery over a challenging situation. The intervention manual was written to include exercises aimed specifically at building mastery; for example, participants were encouraged to look at aspects of challenging situations and to work out which parts of the situations they could and could not control, and to set practical goals for modifying those things which they could control.

Modelling – Bandura’s work on self-efficacy posits that people who have similar characteristics can serve as useful models if they have overcome some challenge. The intervention was designed to be used in working with small groups of informal caregivers, with participants encouraged to speak about their own experiences and share strategies for coping if they felt comfortable doing so. In this way, it was hoped that group members would serve as role models for each other during the intervention sessions.

Social persuasion – Appropriate persuasion or encouragement can be effective in supporting self-efficacy. The language used was intended to be encouraging and positive, and I attempted to foster an atmosphere of creative problem-solving during the sessions (for a future roll-out of the intervention, a training version of the manual would include information on delivery style for the sessions). It was anticipated that the presence of other caregivers in the group setting would also provide appropriate encouragement.

Managing stress and emotional responses – It is useful to help participants to re-interpret any negative emotional responses or to encourage relaxation as a way of managing these. Relaxation exercises were included in the intervention manual, in order to encourage participants to spend some time reducing their own general stress levels, with the aim of helping participants to manage stress and emotional responses.

3.4 Content of the Intervention Manual

The manual was compiled in three sections – Coping with Behavioural Aspects of Dementia, Coping with Difficult Feelings and Taking a Break. The three subjects were chosen to align with the three domains of self-efficacy which would be measured in the quantitative intervention study (Self-Efficacy for Responding to Disruptive Patient Behaviours, Self-Efficacy for Controlling Upsetting Thoughts about Caregiving, and Self-Efficacy for Obtaining Respite (Steffen et al., 2002)). This self-efficacy measure will be discussed more fully in Chapter 5.

As previously discussed in Chapter 2, there has been limited research conducted on shorter interventions for use with caregivers, and another idea underpinning the manual for this research was that it could easily be delivered as three separate, smaller interventions. This would increase the option to use the intervention in a person-centred way: for example, if an individual gave scores suggesting a particular lack of self-efficacy in one area, the intervention could possibly be personalised to meet this need. However, as previously discussed, at this stage it was important to test the intervention when delivered as a whole.

Each section of the caregiver manual contained practical information on techniques, as well as exercises which could be completed as a group, or continued at home. The exercises were designed with the aim of being relatively easy to continue practising after the intervention, and caregivers were encouraged to keep using any of the exercises or techniques they found useful.

The whole manual can be found in Appendix C; however, a brief description of each of the three sections will be provided below, with sample exercises from each.

3.4.1 Section 1: Coping with Behavioural Aspects of Dementia

The first part of the intervention manual focusses on coping with the behavioural changes that may accompany dementia. Previous studies (for example, Ory et al., 1999; Schulz et al., 1995) have suggested that these behavioural symptoms are particularly stressful for informal caregivers.

During this session, caregivers are encouraged to think about which behaviours they personally find to be challenging; it is acknowledged that not everyone with dementia exhibits the same behavioural changes and that caregiver reactions to these changes can vary, with different behaviours found to be stressful by different individuals. In encouraging participants to take part in a personally meaningful way, the session was designed to heed findings of a review which indicated that group behaviour management interventions were ineffective because they did not target personally meaningful situations (Selwood, Johnston, Katona, Lyketsos & Livingston, 2007).

The session includes material and exercises designed to support the caregiver in working through the following aspects of coping with the behavioural symptoms of dementia: understanding why challenging behaviour happens; identifying things we can and cannot change; communicating with a person who has memory problems, and planning our own responses to difficult behaviours.

The figure overleaf shows a sample exercise, in which participants were encouraged to identify a behaviour felt to be particularly challenging, and to begin to look at the context surrounding this behaviour.

☀ Activity : Identifying and understanding behaviour that challenges us

Try to think of a behaviour that you find personally challenging. Remember that different people find different things to be challenging, so there are no right or wrong answers here. What we want to do is to look at something which you find difficult to deal with, and to ask certain questions to try to get a deeper understanding of why this behaviour might occur.

Describe the behaviour that you find challenging or difficult to deal with.

When does this behaviour tend to occur? Is there anything else which is happening at the same time?

Is your relative trying to communicate something – for example, discomfort, frustration, boredom, hunger or thirst?

Has something frightened or upset your relative - for example, not knowing who someone is, not being able to find something?

Figure 3.2 Sample exercise from section, ‘Coping with Behavioural Aspects of Dementia’

3.4.2 Section 2: Coping with Difficult Feelings

The second part of the manual concentrates on the emotional wellbeing of caregivers, starting with a relaxed breathing exercise which was chosen for being a well-established exercise which can be done in the caregivers' own time and using minimal resources. It has been established that caregivers are at increased risk of negative emotional outcomes (for example, Ory et al., 1999). Additionally, recommendations have been made for interventions to focus on dysfunctional thoughts about caregiving and the cognitive pathways by which these thoughts can contribute to emotional and behavioural outcomes (Losada, Montorio, Knight, Márquez & Izal, 2006), and the materials for this session were chosen to align with this approach.

This session encourages participants to develop an awareness of their own thoughts and feelings about caregiving, with the content looking at the following aspects: building awareness of the symptoms of stress; developing stress reduction techniques; building awareness of own unhelpful thoughts about caregiving; considering alternative perspectives; using positive self-talk, and overcoming guilt.

The sample exercise overleaf is one in which caregivers were asked to think about negative thoughts they might have about caregiving, and to re-appraise these thoughts.

☀ Activity : Changing Perspective

Sometimes negative thoughts can come about because of a particular perspective we have on a situation. For example, 'My relative is always taking it out on me' is one perspective, which involves us thinking that the person with dementia is annoyed with us and deliberately doing something to get back at us.

A different perspective might be to believe that the dementia itself is causing the person to behave in an agitated way (which is a much more likely explanation), and that the person is not frustrated with us at all. He or she might be trying to express something completely different.

It's not easy to change your perspective, especially in 'the heat of the moment' when you're dealing with a difficult situation. It can be worth taking a moment or two to reflect, though, and to think about different ways of looking at what is happening.

Can you think of different perspectives which might help counteract these negative beliefs?

- Nothing I ever do is good enough

- Family members don't give me enough help

- I'm letting my relative down if I have to ask services for support

- What did I/we do to deserve this?

Figure 3.3 Sample exercise from section, 'Coping with Difficult Feelings'

3.4.3 Section 3: Taking Breaks

The third part of the intervention is on the topic of taking breaks as a caregiver. It is acknowledged that the opportunities for longer, formal breaks may be limited and so participants are encouraged to think about using time for activities that they find enjoyable or refreshing. The content of this section was informed by previous work on the importance of pleasant events (Mausbach et al., 2011), as well as work by Steffen et al. (2002) which found self-efficacy for seeking respite to be related to perception of social support, cited as a factor in stress and coping models.

This session contains the following content in relation to taking breaks from caregiving: identifying others who can provide help; considering the benefits of taking breaks; developing assertive ways of asking others to help, and identifying and prioritising pleasant activities.

The sample exercise overleaf is taken from a section on assertive communication skills, which was included as part of the topic of enlisting the help of others to make breaks possible.

☀ Activity : Using assertive communication

In the examples below, say which style of communication (passive, assertive or aggressive) is being used. What could the person say instead, to increase the chances of getting a positive result?

Mary has been caring for her mother, who has Alzheimer's Disease. Mary has a brother, Steve, who visits once a week and takes their mother out for a coffee. Mary feels that she does all the day-to-day caring and that Steve just comes along once a week and does something enjoyable with their mother. Finally, one day she has had enough and says, 'You never do any of the hard work. I'm sick and tired of taking Mum to all her appointments, doing all the housework, helping her with everything and never having any time for myself. It's time you stopped being so useless.'

What type of communication is Mary using?

How do you think Steve is likely to respond?

What could Mary say instead, to get the results she wants (more help from Steve)?

Figure 3.4 Sample exercise from section, 'Taking a Break'

3.5 Language Used in the Intervention

When presenting the intervention in these studies, it was important to be aware of the language used and the possible implications of this. The intervention was written, as far as possible, in language which excluded 'jargon' or terms which may hinder participation. For example, 'self-efficacy' was mainly replaced by terms such as 'self-confidence' or 'control', because these terms are more widely used and I wished to avoid using unfamiliar technical language.

Another important issue concerned the labels 'caregiver' and 'carer'. Although these words are used throughout the caregiving literature to refer to the role played by informal caregivers, the reality is that people do not always use these labels to refer to themselves. In a qualitative study carried out by Mullin, Simpson and Froggatt (2013), a majority of the spousal carers referred to their roles as 'husband' or 'wife', rather than 'carer'. When presenting the intervention to the pilot-testing group, I was informed anecdotally that services' insistence on using 'caregiver' and 'carer' can dissuade some individuals from accessing support, because they are not comfortable with having their caring role formalised through language in this way. However, most participants also said they had gained an understanding of the terms 'caregiver' and 'carer' in applying for formal support such as Carers Allowance, and they had reached an acceptance of these terms as being necessary in dealing with formal support systems.

At the beginning of the pilot test, therefore, a brief discussion took place with participants about the words 'caregiver' and 'carer', noting that not all informal caregivers use these terms to define their role. For some individuals, it was very important that the caring role was seen in the context of the defining relationship with the person who had dementia; this echoes the writing of Pearlin et al. (1990), who view caring as a normal aspect of a close relationship, but one which becomes exaggerated in the presence of a condition such as dementia. It was hoped that through discussion and acknowledgement of the importance of labels, participants would be reassured that they were not being asked to take on a particular label through their participation in the pilot study.

3.6 Delivery of the Intervention

Based on the manual described above (see also Appendix C), the intervention was planned to be delivered in three sessions, with each session covering a section of the manual. Each session was designed to last between 60 and 90 minutes, and the sessions were designed as independent sessions, so that each did not rely on the participant having knowledge gained from another session. For the pilot test, I delivered the intervention to a small group of five informal caregivers, based on the sample sizes used in previous self-efficacy intervention studies and scaling this to an appropriate group for a pilot study. Intervention studies used in determining an appropriate sample included Carbonneau, Caron and Desrosiers (2011; intervention N=20 and control N=19) and Kwok et al. (2014; intervention N=26).

Although the three sessions of the intervention were designed with the aim of caregivers contributing examples from their own experiences and working through the exercises with a focus on their own situations, it was anticipated that not all caregivers would be comfortable with sharing personal information and experiences in a group. Therefore, I also wrote some brief case studies which could serve as the basis for completing the exercises.

Finally, the sessions were designed to be friendly and informal. It was hoped that the delivery of the sessions would help to put participants at ease and would be as non-threatening as possible, to minimise the risk of participants experiencing increased stress. It was envisaged that participants may be able to raise any caregiving issues that they found particularly stressful and may find it reassuring to compare these with others' experiences, in line with Bandura's proposition that self-efficacy can be increased by managing stress and emotional responses. Further, it was hoped to foster an encouraging atmosphere, in which the facilitator would take the lead in providing appropriate encouragement where participants appeared to have the resources to be able to address some issue, meeting the need for the intervention to offer a certain amount of social persuasion.

3.7 Pilot-Testing of the Intervention

The intervention was pilot-tested in a carers' centre in Glasgow. Staff at the carers' centre were contacted and asked to pass on information about the pilot group to

informal carers of a person with dementia. The five people who came forward for the pilot test were all children of a person with dementia, and the group included four female carers and one male carer. The carers' ages ranged from 34 to 65.

The intervention was delivered on three consecutive weeks, with each session lasting approximately ninety minutes. The three sessions were delivered in turn, before carers were asked to give informal, qualitative feedback on their experiences of the sessions. These caregivers were not asked to complete any other outcome measures, as the aim of the pilot test was to run the three sessions, noting whether these sessions appeared to be feasible and acceptable to informal caregivers of a person with dementia, and to note any suggested or required changes.

3.8 Participants' Feedback on the Pilot Test

When the manual was initially presented to the pilot test group of caregivers, one caregiver gave feedback that these initiatives are usually presented by people who have not themselves had the experience of caring for someone with dementia. This reinforced the plan to deliver the sessions in such a way that they harnessed the participants' own experiences in order to foster self-efficacy, rather than the researcher providing a more formal, training-style approach. It also reinforced the importance of having participants serve as models for each other in the small groups, as a way of building self-efficacy.

Participants were asked to complete a feedback sheet, asking them which elements of the intervention they found most and least useful, and whether there was anything that they thought should be added to the intervention.

Participants appeared to find the interactive nature of the sessions particularly useful, with the following quotes taken from feedback sheets:

‘Good to hear other people’s stories. You don’t feel so alone’.

‘Tips from other carers that have worked for them’.

‘Discussion [**participant’s underlining**] group. Hearing other carers’ stories, how similar or not they all are’.

Additionally, one person noted that the section on coping with difficult behaviours was particularly useful, and one person highlighted that the section on coping with difficult feelings was helpful.

When asked which aspects were least useful, participants' answers ranged from, 'none' to a comment stating that each of the sessions had been useful.

Finally, when asked if there was anything else that could usefully have been included in the intervention, participants appeared to highlight a need for practical information, as illustrated in the following quotes.

'Maybe bring in outside agencies, i.e. **[name of local care provider]** and other people who provide respite and information'.

'Who to contact within services when there is an issue with the person you are caring for'.

As this type of information tends to vary from one geographical area to another, I highlighted this feedback to members of staff at the carers' centre, and a further meeting was arranged directly by the centre staff to provide this information to the caregivers; this happened independently of the pilot test. However, this initial feedback does suggest that should the intervention have the potential to be used in different areas, it may be useful to deliver it with other sessions covering practical information about local services and contacts.

The feedback from participants was not subjected to any in-depth qualitative analysis, but was used as a source of guidance to gauge the appropriateness of the intervention and any changes that may be required.

3.9 Researcher's Feedback on the Pilot Test

The experience of running a pilot test suggested that the materials were useful in leading focussed discussion sessions with carers. Although there was space in the intervention manual for participants to write their thoughts and answers to the exercises included, participants chose not to do this but instead used the exercises as prompts for discussing their experiences in relation to the topics. The sessions were therefore run in a very informal way, with carers appearing to enjoy the opportunity to share and discuss their personal experiences with other carers, which supports one of the aims of the intervention; building self-efficacy through the use of peer models.

It was noticeable that at times, the group wished to discuss issues which were related to the content of the sessions but in a way that was outside of the scope of the exercises in the intervention manual. For example, carers would talk about other stressors such as

delays in accessing things they needed in order to provide care, or services that they thought were not appropriately personalised to their family member who had dementia. Because these issues were clearly prominent for the carers, a decision was made to include them within the scope of the subsequent research, and I made changes to the research proposal which will be described below.

To summarise, from both the participant feedback detailed above and from my own observations in running the sessions, the content and delivery of the intervention appeared to be relevant and acceptable to the participants. It was noted that through having these discussion sessions, other needs were indicated (such as caregiver stress due to difficulties in accessing other services, or lack of awareness about local options). To explore these other needs and sources of stress further, changes were made to the research design, and these will be detailed below.

3.10 Outcomes of Pilot Study – Changes Made to Research Proposal

3.10.1 Increased focus on qualitative work, exploring caregivers' experiences of stress

Initially, it was planned to carry out an intervention study, using the self-efficacy intervention manual, and to evaluate this using both quantitative and qualitative measures (see Figure 3.1). After examining the feedback given by participants in the pilot test, both informally during the sessions and in written comments, an additional qualitative study was planned, to explore in greater detail caregivers' experiences of stress and experiences of support. The reasoning behind this was that carers in the pilot sessions talked about many stressors and different situations, including family issues and issues with accessing support, and it appeared important to try to capture and analyse the complexity of the experiences of carers, to be able to keep the results of an intervention study in context.

Many previous intervention studies with caregivers have shown modest positive results when looking at outcomes such as caregiver burden and depression (see, for example, the review by Pinquart and Sörensen (2006), which found interventions to have statistically significant, but small, effects on these outcomes). After carrying out the pilot study, it appeared that a possible reason for these typically modest results might be the variety of stressful experiences being described even within this small group of carers, with some being outside of the scope of the intervention. A detailed qualitative

study was felt to be a suitable complement to the quantitative work planned; this qualitative study is reported in Chapter 4.

3.10.2 Development of New Questionnaire – Caregiving External Stressor Scale

As well as adding a qualitative study, a new questionnaire was created following on from the pilot study. This was to be used in addition to various other questionnaires which will be detailed in Chapter 5, as outcome measures for the intervention study.

The new questionnaire was designed to capture what I termed ‘external stressors’ experienced by the carers: issues such as problems with accessing services, lack of knowledge about entitlements or family issues. The initial study plan did not include any measures of this type of stressor, but it seemed clear from listening to the pilot-test participants that these and similar issues played a big part in their experience of caregiving stress. Again, looking at the mainly modest outcomes of previous caregiver intervention studies, it seemed appropriate to include a measure which could help account for stressors which were not being targeted in the intervention but which were nevertheless very prominent for caregivers, and which might help provide additional contextual detail against which to interpret the results of an intervention study. The new questionnaire, the Caregiver External Stressor Scale, can be found in Appendix G.

3.10.3 Change to Design of Intervention Study – Addition of ‘Individual Participant’ Condition

A further change was made to the initial proposal after conducting the pilot test. Staff members at the carers’ centre reported that other carers had agreed to take part in the pilot but had been unable to participate due to various situations relating to their caring roles; for example, the person with dementia was unwell and unable to attend a day centre, meaning that the carer could not go out to attend a group. The unpredictable nature of caring for a person with dementia can mean that informal caregivers find it difficult to attend planned events, and it has been recommended that to adequately reflect the reality of caring for a person with dementia, intervention studies should include caregivers who are not able to leave the home (Dura & Kiecolt-Glaser, 1990). Offering individual, tailored participation has also been linked to low attrition rates (Mittelman et al., 1993).

It was therefore important to adopt a flexible approach in delivering the intervention, in order to make it as easy and convenient as possible for carers to take part, and to make the intervention study inclusive of as many carers as possible. It was initially proposed to offer the intervention in small groups, but a decision was made to also offer it to individual participants, including those who could not leave the home. This therefore created another category of participants in the intervention study. Of course, given that modelling is an important aspect of self-efficacy and that pilot-test participants gave positive feedback on the interactive nature of the intervention, the inclusion of individual participants raised questions about whether or not the intervention would yield different results with these participants. This will be discussed further in Chapters 5 and 6.

3.10.4 Revised Aims and Research Plan

Following the pilot test, the research aims were expanded as follows, with bold type denoting an additional aim resulting from the pilot test:

- 1. To explore the experiences of informal caregivers of a person with dementia, with a particular focus on caregivers' experiences of stress, coping strategies and use of supportive resources.**
2. To examine the use of an intervention aimed at raising self-efficacy in three specific caregiving domains (Self-Efficacy for Obtaining Respite, Self-Efficacy for Responding to Disruptive Patient Behaviours and Self-Efficacy for Controlling Upsetting Thoughts About Caregiving, as defined by Steffen et al., 2002).
3. To examine the role of self-efficacy, within an intervention study, in relation to objective stressors, caregiver depression and caregiver burden.
4. To explore the experiences of informal caregivers who participated in the intervention study.

To address these aims, a plan was made to conduct three studies as follows:

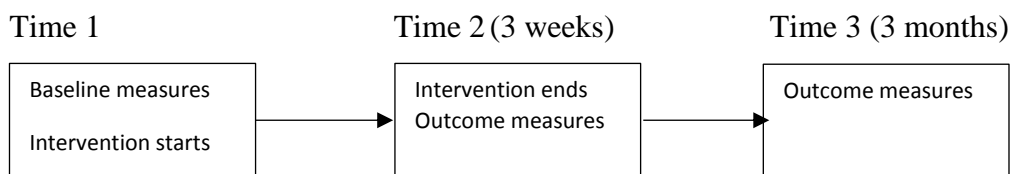
Study 1: An exploration of informal caregivers' experiences of stress, coping skills and supportive resources, conducted using semi-structured interviews and analysed using Interpretative Phenomenological Analysis.

Study 2: An intervention study using a manual-based intervention designed to raise self-efficacy in informal caregivers.

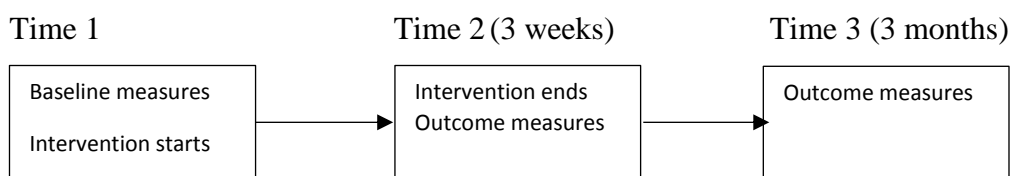
Study 3: A qualitative analysis of caregivers' experiences of taking part in the intervention study, conducted using semi-structured interviews and analysed using Interpretative Phenomenological Analysis.

The intervention study (Study 2) design was expanded as discussed above, with the revised version shown in Figure 3.5 below.

Intervention Group 1 – Group Participants



Intervention Group 2 – Individual Participants



Control Group

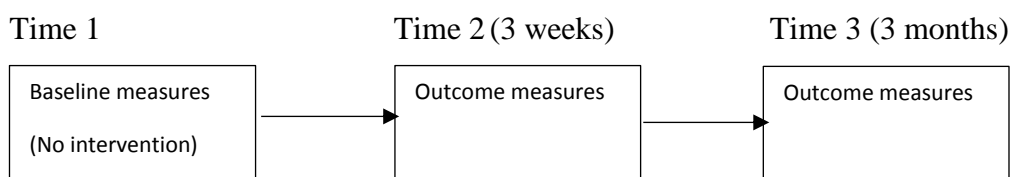


Figure 3.5 Revised proposal for intervention study

3.10.5 Changes to Materials

The pilot study allowed some insights into how the intervention manual would be used in practice in the sessions with caregivers. As discussed above, participants in the pilot study showed a clear preference for a discussion-based session, rather than spending the time writing out answers to the exercises in the manual. It was decided to run the intervention sessions similarly, with a focus on discussions but with pens made available and participants encouraged to write notes on the manual if they wished.

Some small changes were made to the intervention manual following the pilot study. For example, the problem-solving exercise at the end of the first session appeared to be too long and ‘wordy’ for the end of the session, and this was adapted and simplified.

3.11 Conclusion

The pilot study described in this chapter allowed changes to be made to strengthen the research proposal as a whole. Firstly, the pilot test allowed for early testing of feasibility and relevance of the intervention manual to informal caregivers; participants engaged with the topics and were able to relate the exercises in the manual to their own caregiving experiences, and they gave positive feedback on aspects such as being able to share tips and experiences with people in a similar situation.

Secondly, the pilot test was helpful in indicating several ways in which the original research proposal could be refined, including giving a greater focus to the context in which an intervention study takes place, practical ways in which caregivers could be enabled to take part in the intervention study and small changes which might help improve the materials and delivery of the intervention.

Chapter 4 will report the first qualitative study undertaken (Study 1), in which semi-structured interviews were carried out with informal caregivers of a family member with dementia, focussing on caregivers’ own accounts of their experiences of caregiving stress and analysing the data using Interpretative Phenomenological Analysis.

Chapter 4 – Stress, Coping and Service Use in Informal Caregivers of a Person with Dementia: An Interpretative Phenomenological Analysis

4.1 Introduction

As discussed in Chapter 3, a qualitative study was planned, to examine the experiences of informal caregivers of people with dementia, focussing particularly on their experiences of challenges encountered in relation to caregiving, and on resources and means of coping with these challenges. The aim of carrying out this study was to gain detailed insights into how caregivers experience the challenges of caring, and thereby to explore the context in which supportive interventions may be received by caregivers.

There is a history of qualitative research being used in the field of dementia caregiving, albeit that this is a relatively small section of the literature. In a review of qualitative studies looking at the experiences of carers of people with Younger Onset Dementia, Cabote, Bramble and McCann (2015) identified themes including relationship changes, loss and the processes of accessing formal care. Similarly, Lockeridge and Simpson (2013) focussed on Younger Onset Dementia, interviewing six partner carers and using Interpretative Phenomenological Analysis (IPA), an approach which will be detailed below, to identify experiential themes including denial and stigma.

In a study involving family members of home-living people with dementia in Norway, Myren, Enmarker, Saur, and Hellzen (2013) found themes including caregivers' sense of the situation as chaotic and unpredictable, feelings of grief and guilt, changing relationships and social lives, and on-going dilemmas about caring at home or seeking institutional help.

Qualitative studies have also looked at very specific elements of caring; for example, the experiences of caregivers who have a relative in long-term care (Mullin et al., 2013); the effect on relationships in which one partner has dementia and experiences falls (McIntyre & Reynolds, 2012); carers' experiences of hope (Wolverson, Clarke & Moniz-Cook, 2010), and relationships between people with dementia, their spouses and Admiral Nurses (UK-based nurses who are dementia specialists) (Quinn, Clare, McGuinness & Woods, 2013).

The topic of caregiver stress and coping has previously been explored using IPA by Kempenaar (2006) and by Williams et al. (2014). Kempenaar (2006) analysed interviews with caregivers of people with dementia, identifying themes including change and continuation in the relationship and certainty and uncertainty in coping. Williams et al. (2014) included both caregivers of people with dementia and of people who had experienced a stroke, looking at coping skills and sense-making in relation to illness. The results of this study suggested that differences in coping style were due in part to differences in individual sense-making, but also due to the context of specific challenges; caregivers used a variety of coping styles dependent on the situation. Active, information-seeking coping tended to be used when facing imminent challenges, while avoidant coping styles appeared to be used when caregivers considered an uncertain future.

The current study aimed to build upon these previous studies involving caregivers and coping, by adopting a slightly different focus. Rather than taking a very close focus on personal instances of coping, this study aimed to gain insights into the different stressors experienced by caregivers (informed by the pilot study reported in Chapter 3) and caregivers' experiences of coping resources (in line with the focus of the thesis on developing caregiver interventions).

Qualitative approaches to the caregiving experience can sometimes be seen to supplement quantitative research that has been carried out; for example, both Kempenaar (2006) and Williams et al. (2014) compared their findings to existing models of caregiver stress and coping. One advantage of carrying out qualitative research is that it can give rich insights into individual experiences, complementing the information obtained by quantitative methods.

4.2 Selection of Methodological Approach

This study was planned at the outset to have a qualitative focus, as described in Chapter 3. As there are several different approaches to qualitative research, consideration was given to the relevance of different approaches and their relationship to the research topic. Smith et al. (2009) discuss different types of research question that can be asked of each of the major qualitative research traditions. I will give a brief account of the qualitative approaches which were considered when planning this project.

Discourse analysis approaches were considered, however, these examine discourse itself rather than the underlying meaning for participants. A method such as Critical Discursive Psychology (for example, Edley, 2001), with its focus on shared units of understanding of a subject and the different subject positions taken by people when they discuss it, would have been an interesting approach to take with informal caregivers; however, this would not attempt to give an account of experience itself, and so it was not considered further in relation to this study.

Grounded Theory (for example, Strauss, 1987; Charmaz, 1996) represents a structured approach to gathering and analysing qualitative data, with a focus on generating theories and explanations for observed phenomena. Grounded Theory tends to involve large samples and blends data collection and analysis, with theoretical sampling used to check initial emerging theories. As it is embedded very firmly in individual participant accounts and rich qualitative data, Grounded Theory would be a useful approach in proposing theories of stress and coping. This would be a valid methodology to use with informal caregivers; however, as the purpose of the current study was not to generate explanatory models but rather to capture a sense of caregivers' experience itself, an alternative approach was sought.

Phenomenological methodologies were also considered. Interpretative Phenomenological Analysis (IPA), an approach developed in the 1990s (Smith, 1996) with a focus on experiential psychology, appeared to be an appropriate qualitative means of addressing the research aim. IPA involves a very detailed examination of participants' own accounts and sense-making, and was suitable for a study in which the aim was to capture a sense of caregivers' experiences of caring, how they saw these experiences, their understanding of stress and challenges and so on. I considered the type of conclusion that can be reached using IPA, which is an interpretative approach offering one possible understanding of a phenomenon, rather than an attempt to uncover a universal 'truth'. In Chapter 7, I will discuss the implications of using this approach as a companion to quantitative research, which does attempt to demonstrate objective, generalizable results.

4.3 Interpretative Phenomenological Analysis: origins and major areas of focus

An in-depth account of the philosophical theories and debates underpinning IPA would be outside the scope of this chapter. However, to carry out a study using IPA, it is

important to gain a sense of these major ideas and to use them to guide and inform the analysis, rather than follow a rigid series of analytical steps (Smith et al., 2009).

IPA draws upon three major theoretical or philosophical areas: phenomenology, hermeneutics and idiography. To carry out an IPA study, an understanding of each of these disciplines is necessary.

4.3.1 Phenomenology

Phenomenological approaches are concerned with capturing the essence of human experience. The work of Husserl, from the early 20th Century (and available in translation; for example, Husserl, 1982) was greatly influential in phenomenology; Husserl proposed that we could reach the heart, or essence, of experiences by using techniques known as ‘reductions’ (as cited in Moran, 2000). Central to this idea was the notion of bracketing, or setting aside everyday distractions and concerns in order to focus on our underlying experience of a phenomenon.

Heidegger, also a central figure in phenomenology and originally a student of Husserl, departs from Husserl’s work in his belief that we cannot separate inner experience from our connections to language, relationships and objects, and that we are always living in a connected way. Heidegger’s work leads to a more interpretative manner of making sense of experience, based on this belief that we are always acting in context and in relation to things (as cited in Larkin, Watts & Clifton, 2006). Similarly, Merleau-Ponty advocated a more context-based phenomenology, in which we can be seen as embodied in the world, related as ‘body-subjects’ (as cited in Smith et al., 2009).

Phenomenological work influenced by Husserl, then, would take the approach of attempting to define and set aside our own experiences and understandings in order to uncover the essence of a phenomenon. IPA, with its emphasis on interpretative activity, follows a more subjective and relativist path, in which the researcher’s own understandings form a crucial part of the analysis. The field of interpretative theory is called hermeneutics.

4.3.2 Hermeneutics

Hermeneutics is concerned with how we interpret texts. Heidegger proposed a hermeneutic phenomenology, in which things can have more than one meaning, and

interpretative or analytical work is needed to uncover meanings that may be hidden. Heidegger argued that in making such an interpretation, our own experiences and understandings can never be completely filtered out (as cited in Larkin et al., 2006). However, he cautioned that when interpreting, attention should be paid to the object of the interpretation first and foremost, and that it may be only in the light of this object that we can realise which aspects of our prior experience are crucial to the interpretation; we should not view interpretation as starting with our own understandings.

Gadamer describes a back-and-forth process of interpretation (as cited in Moran, 2000), in which as readers we project our own ideas about the meaning of a text, revising these ideas as we read on and sometimes holding competing interpretations as the meaning of a text becomes clearer. This idea complements the notion of the hermeneutic circle, central to IPA (Smith et al., 2009). The hermeneutic circle describes the ways in which we can analyse a text at different levels, moving between interpretations of the whole text and interpretations of smaller parts of the text. In IPA, a close analysis of a particular phrase used by a participant can reveal meanings that change our interpretation of the text as a whole. Similarly, an understanding of the text as a whole can inform our interpretation of a particular sentence or phrase. IPA tends to proceed in an iterative way, moving between different levels of analysis, until a satisfactory interpretation has been reached; this would be the stage at which the researcher (and anyone involved in auditing the interpretation, if included) deem the interpretation to have captured themes representing the main aspects of the participant's account and with clear links to the original account.

4.3.3 Idiography

IPA also takes an idiographic focus; that is, it concerns itself with detailed analysis of the experiences of individuals in particular contexts (Smith et al., 2009). IPA studies usually involve small, purposive samples in which there is homogeneity regarding participants' experience of the phenomenon being studied; in the case of this study, the experience of being an informal caregiver of a person with dementia. Because the samples used in IPA are small and the analysis is bound by context, there are implications for the type of knowledge we can obtain from an IPA study. IPA does not claim to offer results which can be generalised to a larger population, although the

results of an IPA study can be compared to previous work or theory and we can comment on whether or not an IPA study supports prior thinking on a topic (Smith et al., 2009). The subject of IPA and knowledge claims will be discussed further in Chapter 7, in a discussion of the methodology used.

As I will describe in the next section, IPA involves the careful exploration of one case at a time (IPA can also be done as a single case study), before moving on to examine areas of convergence and divergence between cases. An IPA study should allow for understandings and interpretations at both the group and individual level.

4.4 Methods

4.4.1 Recruitment Strategy

Recruitment of participants for this study took place in the Central Belt of Scotland, and included the cities of Edinburgh and Glasgow as well as areas such as Ayrshire and Fife. Although the provision of support services for caregivers varies by geographical area and local authority, the areas included in the study were those in which there was an availability of services such as carers' centres. Participants' actual usage of support services was gauged via demographic questions and questions asked during the interviews.

Participants were recruited to the study using several approaches. A database was accessed via the Scottish Dementia Clinical Research Network; this is a database of caregivers who have previously registered their interest in taking part in research. This database yielded several participants for the study. Subsequently, approaches were made to different services involved in offering support to carers, including local authority services, voluntary organisations, carers' centres and caregiver networks. Most of the participants for the study were recruited via their contacts with these agencies, and a small number of participants were recruited through 'word-of-mouth'; for example, they heard about the study from someone who had already taken part.

In order to identify suitable participants for the study, inclusion and exclusion criteria were defined. The main criterion for inclusion was that the individual was or had been a primary informal caregiver for a person with dementia. Primary care for the purposes of the study meant that the caregiver considered him or herself to be the main informal person involved in providing care, which could include emotional support, assistance

with the activities of daily living or carrying out practical tasks, such as liaising with professional services on behalf of the person with dementia. This definition was based on information for caregivers from organisations such as the Alzheimer's Society and Alzheimer Scotland. No minimum number of hours of care was specified for the study, and it was not necessary for the caregiver to be living in the same home as the person with dementia, although this information was gathered as demographic information, to give clarification on the sample used in the study.

The study included people who were caring for someone living at home, people who had cared for someone at home who had now been admitted to full-time residential care, and people who had cared for someone at home who had recently passed away; information for each participant is detailed in Table 4.1. For the purposes of an IPA study, homogeneity of participants refers to the fact that participants have shared the main experience being explored, so the inclusion criteria were defined to allow people who had had this experience to take part. There has been a recent discussion on the homogeneity of participants required for an IPA study (for example, Wilson, personal communication, September 17, 2015), proposing that homogeneity should focus on the shared experience rather than matching other demographic factors.

Exclusion criteria were also defined for the study. Caregivers were not invited to take part if they were not able to give informed consent to participate; this would include caregivers who also had a diagnosis of dementia or who were self-reporting depressive symptoms. The reason for these exclusion criteria was to avoid recruiting people who would be defined as vulnerable adults and whose wellbeing might be compromised by taking part in the study.

4.4.2 Ethical Approval

Ethical approval to carry out the study was granted in April 2014 by the ethics committee at the School of Life Sciences, Heriot-Watt University. Chapter 7 includes a discussion of the main ethical issues taken into account in this study, which are also applicable to the other studies reported within the thesis.

4.4.3 Interview Schedule and Procedure

In line with good practice for IPA interviews (Smith et al., 2009), semi-structured interviews were conducted, using an interview schedule which can be found in Appendix D. The questions used in the interviews were developed using my readings about informal caregiving (discussed in Chapter 2), the experiences reported by caregivers in the pilot study (Chapter 3) and guidelines for IPA interviews (Smith et al., 2009). In this type of interview, a schedule of questions is devised beforehand, but this is not followed in a step-by-step way during the interview. The interview progresses in a flexible way, so that the participant's answers affect the time spent on particular aspects of the topic being discussed, and the interviewer can ask follow-up questions to prompt the interviewee to clarify or expand on answers given. Questions are as open-ended as possible and the schedule acts more as a prompt to keep the interview centred on the topic rather than as a rigid set of questions.

Although a full interview schedule was devised for the present study, the interviews varied in the extent to which the pre-set questions were required or appropriate. In some interviews, the full interview schedule was used, while in one case only the first question was required, with minimal prompting for the participant to continue detailing her experiences. In all cases, the questions were there to help support and guide participants to talk about their experiences.

The location for each interview was decided according to the individual circumstances of participants. Most participants chose to be interviewed at home, with two preferring to be interviewed in a café. In each case, the caregiver was not accompanied by the cared-for person at the time of the interview, but was interviewed alone.

Before each interview took place, participants were given an information sheet about the study (Appendix A), and were encouraged to ask any questions they had about taking part. Participants gave signed consent to be interviewed, including consent for an audio recording of the interview to be made. Prior to starting this recording, a few minutes were spent gathering basic demographic information and talking about general issues, for the purposes of initial trust-building and putting participants at ease. Participants were advised that their interviews would be transcribed and anonymised; part of a transcript can be found in Appendix E.

Interviews lasted between 33 minutes and 1 hour 28 minutes, with a mean duration of 1 hour 2 minutes. At the outset, participants were advised that the interview should last

around an hour. Variation in the time of the interview reflected the preferences of the participants; for example, in one case the participant had somewhere else to go following the interview, while in others, the interview lasted slightly longer than planned as participants wanted to give more information.

During interviews, two participants who showed signs of being emotionally upset were asked if they would like to stop the interview and take some time out. However, both participants said they preferred to go on with the interview and were finding it therapeutic to talk about their experiences.

Following each interview, participants were informed clearly that I was no longer recording the conversation. Participants were then given information about the timeline for completing the study, analysing the interviews and writing up the results; participants were advised that they could receive a report letting them know the outcomes of the study. The meeting was finished with a conversation for de-briefing purposes and ensuring that participants were able to continue with their plans for the rest of the day; in particular, the two participants who had become upset were asked about their plans and we talked about sources of support they could access. All participants were made aware of services such as the Alzheimer Scotland telephone line for further support.

4.4.4 Transcription of Interviews

Following data collection, the interviews were transcribed. As it is good practice in IPA to become completely familiarised with the interview data (Smith et al., 2009), each interview was listened to at least twice, to ensure that the participant's words were being recorded accurately and to get a sense of the flow of each interview, including features such as pauses or places in which participants appeared to be taking time to think about something. The interviews were transcribed verbatim, and pauses in participants' answers were noted. IPA does not require the degree of transcript coding involved in a discipline such as Conversation Analysis (for example, Wooffitt, 2001), in which very short pauses of a fraction of a second are timed and noted, but pauses in conversation were recorded so that their possible meanings for the participant could be considered (for example, a pause may denote difficulty or hesitancy in describing something).

To preserve anonymity, participants and their family members were given pseudonyms at the stage of transcription. An attempt was made to select pseudonyms which were

appropriate for the ages and backgrounds of participants. When reading the transcripts, any references to specific services, locations, membership of specific groups or other identifying factors were removed, as some of this information could lead to the identification of individuals. Similarly, I adopted a practice of not using any interview quote which contained unusual information that could compromise an individual's anonymity, such as a description of a high-profile experience.

4.4.5 Reflexivity

In IPA, reflexivity is important; that is, an awareness of the researcher's own experience, background, beliefs and values should be maintained during the research process. These factors can influence every part of the research process, from choosing a research question through designing the interview schedule and carrying out the interview, and making decisions during the analysis and write-up. As discussed in Section 4.3, there has been debate about the idea of 'bracketing' in phenomenological work. In IPA, rather than attempting to set aside one's own experiences, understandings, values and so on, there is an acknowledgement that these things inform the interpretation of the data, which should proceed cautiously and with the primary focus on the participant's own account (Smith et al., 2009). As noted by Tomkins and Eatough (2015), there should be an attempt to set aside prior theories and assumptions about the data at the stage of analysis.

Finlay (2002) discusses the importance of engaging in reflexive work from the outset, taking into account one's own relationship to a topic as the research proposal is developing. The current research was guided and influenced by several factors from my own experience and interests. Firstly, the study was informed by an interest in psychology and, more specifically, in the stress processes people experience as caregivers and the skills they develop for coping with stress. There are many alternative angles that could be taken when interviewing informal caregivers of a person with dementia, depending on the area of interest of the researcher.

Similarly, my professional background is in supporting people and using a range of therapeutic interventions, albeit with a different population; I previously supported people who had experienced problematic drug or alcohol use. This background influenced the type of questions I wanted to ask participants and my understanding of their answers; I was very interested to hear about which coping techniques helped or did

not help, and about participants' views on external sources of support. Because of the focus on stress and coping, it was important to ensure that there was some balance in the interview questions and that the interview did not assume that caregivers' experiences would be uniformly or mainly negative, so questions were included which asked about the positive experiences of caregiving.

My working background needed to be taken into account particularly when carrying out the interviews. My previous work has involved using therapeutic approaches to assist people in problem-solving or to encourage some behavioural change. Carrying out research represented a change in role, and I had to consider how to conduct interviews in an information-gathering, rather than a behaviour-changing way. While previous work gave me useful transferrable skills (such as experience in close, active listening and reflecting things back to participants to check understanding), for the purposes of this research I had to maintain an awareness that my role should be to listen to individuals' accounts, rather than to encourage change. This was difficult at times when participants were describing situations in which they were unhappy; for example, when they described feeling unable to access help they needed. When reading the transcripts of the interviews and beginning the analysis, I attempted to identify any occasions in which my choice of response may have been more directive than intended, and to take this into account in the analysis.

The selection of a research venue should also be considered reflexively in this type of research, in relation to issues such as power dynamics and choice (Ecker, 2017). In the current study, as research participants were invited to specify a suitable venue in which to be interviewed, it was anticipated that participants had an element of control over the research environment which may prove empowering (Elwood & Martin, 2000). As noted previously, ten of the participants elected to be interviewed at home, a setting in which the balance of power was felt to be in favour of the participants (although this should be considered alongside other sources of power held by the researcher, such as the power involved in designing the interview schedule, as well as the fact that the home environment allows certain observations to be made by the researcher). The remaining two participants chose to be interviewed in cafes, noted in this study to foster a greater sense of equity in terms of power between researcher and participant (echoing the findings of Ecker, 2017).

Reflexive practice is something which should run throughout this type of research (Smith et al., 2009) rather than being accounted for only at the outset, and I attempted to

work reflexively at all stages of the project. In agreement with Heidegger's beliefs described in Section 4.3, the research was led by an attendance to participants' words, which in turn touched upon relevant areas of my own experience and understanding. This approach is echoed in the writing of Finlay (2002), who discusses the need to analyse reflexively without overpowering the participant's voice. Alongside the presentation of results in this chapter, I will denote areas in the analysis in which drawing on my experience and background was useful to deepen the interpretation of the data. This practice of documenting reflexive thinking throughout the analysis was suggested as good practice in Wagstaff et al. (2014).

4.5 Analysis

4.5.1 Idiographic Analysis

As described in Section 4.3, one of the central features of IPA is its idiographic focus. In keeping with good IPA practice, therefore, the initial analysis for this study involved making an in-depth examination of each interview transcript in turn.

For each transcript, the analysis began by reading through the transcript, in order to gain a sense of the interview as a whole and to keep in mind the individual participant. As far as possible, I remembered the participant's delivery as I was reading the transcript. Smith et al. (2009) recommend this immersive process in the early stages of the analysis, in which the researcher almost tries to enter the participant's world and to capture a sense of the importance of the narrative. Transcribing was carried out as soon as possible following each interview.

After reading each transcript, I began to work through the transcript word-by-word and line-by-line, noting certain features of the participant's answers. Smith et al. (2009) give some suggestions of features of the transcript which may be of particular interest.

Although they stress that there is no prescribed way to approach IPA and that their worked examples should not be taken as a step-by-step guide to carrying out IPA, the suggested approaches were helpful when beginning the analyses. Initial coding included noting down particular linguistic features of the participants' speech that might be of interest (for example, lengthy pauses or repetitions which might indicate instances of thinking or processing before giving an answer; metaphors or unusual ways of describing something; changes from first to second person which might indicate something to do with how the participant saw him or herself in a given scenario).

Descriptive notes were also made to try to distil or summarise the content of participants' accounts. Thirdly, initial, more conceptual notes were made; these often took the form of questions about the participants' accounts (for example, questioning why a participant might have described something in a particular way, or how different aspects of the narrative may be connected to a broader concept). As Smith et al. (2009) note, this type of interrogative coding marks the beginning of moving the analysis in a more interpretative direction, by using the analyst's own understandings of the world to ask questions of the transcript. Smith (2004) discusses different levels of interpretation that can be involved in carrying out IPA.

Because the sample size of 12 participants for this study was relatively large for an IPA study (Smith et al. (2009) suggest samples of up to eight for PhD theses, although they stress that this is not prescriptive) and the interviews generated a lot of data, a decision was made to focus on aspects of the interviews which related to the research question and the topics being studied: challenges of caregiving, stress, coping skills and resources. Of course, participants did not stick rigidly to these topics at all times, and attention was also paid to parts of their accounts which were ostensibly about something else but were of relevance to the research question. However, there were other instances in the interviews in which participants' narratives would have been relevant to a different research question, and these instances were not included in the analysis, in order to move towards a cohesive analysis that addressed the research aim.

Alongside the initial analysis of each transcript, I kept a research journal in which I noted down thoughts I had about each interview, including possible emerging themes. This journal served as a means of reflecting on the interview and encouraging the interpretative work of the analysis; I tried to capture the overall sense of each interview and the important issues emerging from the participant's words. This in turn helped to keep the idiographic focus of the analysis, as each section of the journal served as a summary of the individual's 'story' and helped to keep each individual in mind while working on the later stages of the analysis.

4.5.2 Emerging and Superordinate Themes

After working through a transcript and highlighting interesting features of the conversation as described above, I began to look for possible emerging themes in the participant's account. This stage of the work represented a move away from the close

line-by-line reading of the transcript and involved working with the notes taken during initial coding. An example of this process is shown in Appendix E, which shows an excerpt from a transcript. In the right hand margin are the initial notes taken for this extract, and the emerging themes are shown in the left hand margin.

Having generated a list of possible emerging themes, I then created a Word document for the transcript, consisting of a long list of the emerging themes. I studied this list, looking for connections and similarities between the emerging themes and ways in which themes could be grouped (still working with a single participant's data), and moving emerging themes into groups. Smith et al. (2009) describe various ways in which superordinate themes can be determined: for example, abstraction (forming clusters of themes based on conceptual similarities), contextualisation (clustering themes based on their relevance to some important contextual feature; for example, themes which are to do with the stage of diagnosis of dementia), and subsumption (the grouping of themes under one theme which, on re-examination, serves as a superordinate theme and helps to organise others). The process of defining superordinate themes for a single transcript is illustrated in Appendix F.

4.5.3 Recurrent Themes

Although IPA has a strong idiographic focus, when conducting a study with more than one participant it is common practice to report on recurrent themes. Recurrent themes are themes which are found in a certain proportion of the transcripts, and the threshold for a theme to be defined as recurring can be set by the researcher (Smith et al., 2009). In order to determine which themes were recurring for this research, I examined the lists of themes and superordinate themes created for each transcript, as described above. This stage involved looking across the twelve cases for connections and themes in common, which in some cases involved re-naming themes or developing a new understanding of them in the light of the other cases.

I created a table of themes, noting which themes were present in each interview. This process resulted in four superordinate themes, each containing a group of smaller themes. For this study, the threshold for superordinate themes was that they were present in each of the twelve interviews. Table 4.2 in the Results section shows each of the superordinate themes, with the smaller themes nested within these, and details of the interviews in which each theme was found.

An important point to note is that recurring themes are not necessarily ones in which participants describe the same experience; there can be diverging accounts given under the heading of a common theme. For example, in a theme such as ‘Relationships with other caregivers’, it is possible that some participants could describe these relationships as a positive source of strength whereas others could feel that such relationships were problematic; the theme would be a recurring one because all or most of the participants had highlighted it in their interviews. The divergence of participants’ accounts for each theme helps to illustrate the idiographic aspect of the analysis.

4.5.4 Credibility Checking

Attempts were made to cross-check sections of the analysis, in keeping with the good practice guidelines for qualitative research developed by Elliot, Fischer and Rennie (1999). Through regular attendance at the Scottish IPA group overseen by Professor Paul Flowers and Dr. Kirsty Darwent, I was able to discuss and share the developing analysis with fellow researchers. In particular, a section of participant Ruth’s interview was used in a workshop and was analysed by all attendees of the workshop, who carried out initial coding and developed emergent themes for the transcript, under the supervision of Dr. Kirsty Darwent. I received copies of the other researcher’s notes and comments on this transcript, and was able to use these to check against and inform my own coding. The other researcher’s notes and emergent themes were broadly similar to the ones I had identified, with some small differences in the naming of the themes and ways of organising the data.

As discussed earlier, in IPA it is acknowledged that the researcher’s own experiences and values contribute to the interpretative element of the analysis, and so credibility checking in this sense does not mean that two analysts would be expected to produce an identical analysis; it is highly unlikely that they would do so. However, credibility checking serves an important function in ensuring that an analysis has been carried out according to the principles of IPA, and that it is tethered to participants’ own words and is a reasonable analysis.

4.5.5 Participants

Twelve informal caregivers took part in the study. These caregivers were family members of a person with dementia, and each participant had experience of providing day-to-day care or support to the cared-for person. Table 4.1 gives demographic information about the participants.

Following the main analysis in this chapter, three case studies will be presented. These case studies will illustrate in greater depth the caregiving situations, concerns, priorities and themes arising from three of the participants, to illustrate the idiographic focus of this study. Due to concerns about confidentiality and anonymity, it was not appropriate to provide this in-depth information about each of the twelve participants, so cases have been selected which will illustrate the emergence of some of the main themes without compromising the anonymity of any individual.

Table 4.1 Demographic information from participants.

Participant	Age Range	Relationship to PWD	Lived with PWD	Formal Support Received
Douglas	50-60	Child	No	Yes
Cathy	60-70	Spouse	Yes	Yes
David	80-90	Spouse	Yes	Yes
Michelle	40-50	Child	Yes	Yes
Monica	40-50	Child	No	Yes
Susan	40-50	Child	Yes	Yes
John	80-90	Spouse	Yes	Yes
Ruth	70-80	Spouse	Yes	Yes
Mary	70-80	Spouse	Yes	Yes
Angela	40-50	Child	Yes	Yes
Janet	70-80	Spouse	Yes	Yes
Barbara	40-50	Child	Yes	Yes

PWD denotes 'person with dementia'.

4.6 Results

4.6.1 Table of Themes

Four superordinate themes were defined from the analysis of the interview transcripts: **Dementia and Change**, **Caring and the Self**, **Caring and Others**, and **The Care System**. These themes were identified in all twelve interviews. Each superordinate theme contained several themes. Table 4.2 below details these themes, along with information about the transcripts in which each theme was found. The superordinate themes are titled in bold, with nested, smaller themes following each superordinate theme.

Table 4.2 List of themes and interviews in which each theme was identified.

Theme	Participants
Dementia and Change	All
Stages and Progression of Dementia	All except Susan, Barbara
Symptoms of Dementia	All except Michelle, Barbara
Unpredictability	All except Susan, Angela, Barbara
Separation and Loss	All
Person with Dementia	All except Douglas
Caring and the Self	All
Caring and Skills	All except John
Role and Self-Image	All except Cathy, David, Ruth
The Costs of Caring	All except Susan, Mary, Barbara
Coping Skills and Styles	All
Caring and Others	All
Families and Dementia	All except David
Friends, Neighbours and Communities	All except Douglas, Monica, John, Angela
Peers	All
The Care System	All
Positive Experiences of Support	All except Ruth, Barbara
Power, Authority and Conflict	All except Douglas, Michelle, Mary, Janet
Unmet Needs	All except Mary
System Versus Individuals	All except Douglas, David, Mary

4.6.2 Descriptions and Examples of Themes

I will now discuss and define each theme more fully, with examples from the transcripts to illustrate the themes. When choosing quotes from the transcripts, an attempt was made to select quotes which were in keeping with the overall ‘essence’ of each interview, thereby preserving the idiographic nature of the analysis as well as reporting convergence within the group. For example, if ‘Families and Caring’ was an especially strong theme for one participant, a quote was selected from that interview. A theme was considered to be particularly relevant for a participant if it arose several times within the interview, or if there was some linguistic or other indication from the participant that this was an important aspect of caring.

The following key applies to the interview excerpts used:

[...] A portion of text was removed from the excerpt, either to improve clarity or to remove identifying information.

[text] Clarifying text inserted by the researcher.

4.6.3 Dementia and Change

The superordinate theme, Dementia and Change, was defined as a result of looking at emerging themes relating to participants’ views and experiences of caring for a person with dementia. There was a strong sense from participants’ accounts that the ever-changing, evolving nature of dementia was significant for them, and contributed to the experience of caregiving stress. Participant’s references to dementia, and to the person with dementia, contained many features such as time markers (indicating an awareness of things changing over time), changes in the person with dementia, changes in relationships, routines and so on. Themes contributing to this superordinate theme were Stages and Progression of Dementia, Symptoms of Dementia, Unpredictability, Separation and Loss, and the Person with Dementia.

Stages and Progression of Dementia

Ten of the interview transcripts contained Stages and Progression of Dementia as a theme. Participants’ accounts of dementia suggested that the progressive nature of dementia was prominent in their understanding of dementia - dementia was described as

evolving over time, involving different stages and different degrees of symptoms. There were many temporal references, using words like 'still' and 'used to' to indicate participants' awareness of things changing over time.

For Michelle, her mother's dementia appeared to be marked out in uneven stages, involving an initial period of relative stability followed by a period of marked change.

[...] if we had power of attorney, if we were aware of that when she first got her diagnosis we could have got, cause she still had capacity, when you're diagnosed you're just diagnosed, you're not kind of on a big slope.

Michelle's description of the differences between 'just diagnosed' and 'a big slope' appeared to mark out different periods in the progression of her mother's dementia, with the first indicating a period when her mother had 'capacity' and could still make decisions such as consenting to a Power of Attorney arrangement, and the second being a stage of more rapid, uncontrollable change.

Similarly, Monica felt that there was an early stage of dementia in which it was important to act to help the person with dementia to cope in later stages.

I have spoke to people where the person's in denial or they've got to the stage where they don't remember but that's why early diagnosis is key, that's what I said to people, there's lots of things that my mum and dad and I put into place at the start, that are now their long term memory.

Douglas saw his mother's dementia as involving a progressive loss of skills, and he recounted some of the things she could no longer manage, using skills to gauge his sense of the stage of his mother's dementia. For Douglas, this loss of skills seemed to be connected to his worry that his mother would have increasing difficulty in staying in contact with the family.

[...] they lose skills, skills drop off day by day or week by week or month by month and they eventually lose the skill, they lose the skill in how to use the washing machine, they lose the skill of how to go and get the bus, they just lose these skills [...] it's the microwave, my mother's lost that skill, it was the one appliance that she could work, open the microwave, pick three minutes and away she was but she's lost that skill now [pause] so she's losing these skills and that's the concern, that's the only concern I would say that we're having because we know she can phone, use the telephone, we've got a telephone with

bigger numbers which has helped her and our telephone numbers are at the phone but there'll come a time when she'll lose that skill, phoning but she's not at that stage, she can still phone.

Symptoms of Dementia

As well as being attentive to the progressive nature of dementia over time, participants tended to make references to the signs and symptoms of dementia, particular to the cared-for person. This theme had some overlap with the previous one, in that these symptoms tended to be described as being part of an overall progression, mapped out with references to time and stages, but with attention given to the perceived differences in the wellbeing, capabilities, behaviour or personality of the person with dementia.

John describes how he noticed a deterioration in certain skills in his wife, reminiscent of Douglas's feelings about his mother's skills. John's awareness of these changes was rooted in his relationship with his wife, and he describes how some of the losses of skill were more noticeable or concerning to him than others.

And that was in 2000 and then one realised things that she'd said and things that she couldn't do which, my wife was never mechanical so I really didn't think very much of some of these things. And gradually the cooking wasn't up to, but I just thought this was maybe age coming on, but of course it wasn't.

Cathy describes a period of noticing changes in her partner's ability to remember things and carry out routine tasks, and how these changes led her to go back to the GP for a second opinion, having previously been advised that the symptoms were normal and age-related.

There was problems everywhere with keys, there was problems where he he'd forget to do things and stuff like that, he'd lose money em he em he was always great on a Saturday morning he used to go to the shops and do all the shopping you know it was really great, em it let me clean the house and we had the weekend together but em so em and he was coming back with all the wrong stuff and oh God, to be honest I was getting a bit agitated as well, I was concerned about him and getting a bit, God, so eventually I went back to the doctor's and I'd been keeping a diary so I'd written everything down that was happening over the last month, six weeks. We went back to the same doctor and I says you're not

going to fob me off today cause I'm not having it, I says there's what's been happening. He had a wee look at the diary, I think we'll need to send him for some tests. So then we went to eh, eventually got an appointment at the [...], this is 2000-and, gosh, was it eight, 2008 and em when we went up, still weren't sure what it was, maybe it was just forgetfulness, I didn't know what Alzheimer's was, I knew that it was a memory thing but I'd no idea what symptoms were.

Unpredictability

A further aspect to participant's accounts of dementia was that the progression of dementia tends to be unpredictable, uneven or uncontrollable. Cathy touches on this in her description of her partner's illness, with periods of relative stability interspersed with periods of marked deterioration.

[...] they go along and then there's a big dip and then they go along and you think, and then it's really it's really hard.

David describes a period when his wife, who now lives in a residential care home, appeared to have become very ill and yet this was followed by a marked and sudden improvement in her health.

She was in her bed all day, they would stay with her all day. See the next day? She was at the hairdressers in the morning.

For Monica, the unpredictable pattern of the progression of dementia was one of the most challenging aspects of the condition. Her words appear to convey a sense of balancing hope with anxiety.

The hardest time was the start and then the next hardest thing is the fact that there's no end in sight, pathway, it just is as long as a piece of string, my mum could get ill and then her dementia would get worse dramatically, but if everything goes as is, you know then so em yes it's very individual.

Separation and Loss

The theme of separation and loss was found in each participant's account of caring for a person with dementia. In some cases, participants described a feeling of separation from the person with dementia, bound to the changes that had occurred with the progression

of symptoms in the cared-for person. Douglas describes this separation in terms of living in a different 'world' from his mother.

When I open the door on my mother's house, I enter her world, that's her world and I live in that world when I'm in her house or when I'm with her, she's in a different world from me, when I shut the door at night and I leave her I'm back in my own world.

For some participants, there was a sense of the loss of joint pastimes and interests. David describes his struggles to enjoy the activities he previously did along with his wife, before she was admitted to residential care. There is a keen sense of the loss of his wife from the home.

I says you've got that, you've got your beautiful summer house, we used to sit out til ten or maybe eleven o'clock at night with the old couple underneath. And eh but I lost all that cause Christine wasn't here. Cause you done everything together, you were like a partnership, you know, ken. Your sort of wife becomes sort of your wife and your best friend and you know everything else you know. So you done everything together, and I don't know, you just couldn't be bothered, lovely mornings, oh I can't be bothered. So I'm hoping now next year or this year I'm going to determine how I'm going to get over that and go down and start taking an interest again and get it back how she would have liked it you know. But my wish was always that I could bring her home eh that's other stories.

John describes the mixture of feelings he had about the change brought about in his relationship with his wife, when waving her off to a day centre for people with dementia. There is a strong sense of the loss of communication and the ability to 'entertain' each other in this long-term relationship. John's hesitancy and repetition of certain words in this extract could possibly signal some difficulty in talking about these feelings.

It it it's very difficult and we'll have been married 57 years in April and I was going out with Sarah for five years I mean it's a long I mean it's really part of you and the the feeling of guilt when she went away on the bus didn't last all that long it suddenly became relief, realising that I just couldn't couldn't couldn't entertain her, she couldn't me.

For some participants, practical issues contributed to a loss of enjoyable activities and plans, with several participants describing difficulties around travelling and going out, leading to the loss of holiday and retirement plans. Ruth describes how these practical difficulties were contributing to the loss of things she previously enjoyed doing along with her husband.

Erm [pause] doing things becomes very difficult, travelling, well I've almost given up on that, if you can imagine going to an airport with someone with Alzheimer's it is horrendous. Airports are horrendous places anyway, but if you can imagine trying to go to the loo.

Person with Dementia

For eleven of the participants, their perception of the person with dementia emerged as a theme. This theme encapsulated descriptions of the cared-for person which specifically referenced the person having dementia and described his or her qualities in relation to this information. Although these descriptions of the person with dementia were mainly positive in nature, they appeared to perform a dual function in that they also attended to the expectation of the changes that accompany dementia.

Angela describes how her mother retained a core 'identity' despite her dementia, as well as a sense of her role as a mother.

I actually learned quite late on that Mum still wanted to be a mum to me so that when I looked tired or unwell or you know I once bashed my car [...] managed to give my mum a black eye and she was concerned, she wanted me to feel that concern from her, so I had to learn to take from her as well as to give, that was really important, it wasn't just a one way street. For her to be acknowledged as a person or the person that she was right up to the end she didn't lose her identity, I had to learn to accept what she was giving me and I had to learn to not be huffy and buffy and be all organised and doing stuff, I had to learn to listen to what she was saying, to what she was trying to convey to me, because her caring never stopped.

Susan, who spoke about particularly unhappy experiences of her father being admitted into hospital care, believed that her father retained an awareness of what was happening despite his illness.

He would have felt abandoned. It's like, what they did was the most cruel and illegal and heartless thing to somebody who was intelligent, even with dementia he knew what was going on.

For Barbara, it was important that her mother was perceived in the light of her own 'exceptional' character, and not stereotyped as a person with dementia.

My mother was an exceptional woman, she wasn't a typical old lady, she wasn't a typical old lady with dementia so [...] my mother was a unique individual.

Reflexive comments on this superordinate theme

When defining the superordinate theme of Dementia and Change, I drew on several aspects of my own understandings and experiences, both personal and professional. Despite not having had the experience of being a carer for a person with dementia, I was able to reflect on the experience of having family members living with dementia and loss of cognitive skills. For example, one family member exhibited strong signs of wanting to continue to be a mother and grandmother throughout her illness. This helped inform my interpretation of quotes relating to the identity of the person with dementia, and made it particularly easy for me to empathise with Angela's account of her mother's desire to go on being a mother. Hellowell (2006) discusses an 'insider-outsider' continuum he sees as being central to reflexive work and in the current analysis, my position was partly outsider (not having had first-hand experience of caring for someone with dementia) and partly insider (having had personal family experiences which helped me relate to the accounts given by participants).

In my supportive and advisory roles within the substance misuse field, I often worked with concerned others (mainly family members of a person with substance misuse problems). I was able to reflect upon some of the experiences described to me by people wanting to support a close family member through distressing, unpredictable times, and this helped with my understanding of some of the participants' experiences, such as trying to come to terms with changes in the loved one and balancing hopes and anxieties. As discussed previously, I was aware at times during the interviews of a need to be non-directive, and attempted to set aside techniques I would normally use as a practitioner to reassure and support people who were describing difficult emotional experiences.

4.6.4 Caring and the Self

The second superordinate theme, Caring and the Self, arose from extracts in which participants spoke about their roles as caregivers, reflecting on their experiences and the impact of caring on the self. The quotes in this section tended to contain many references to the attributes needed to be a carer, participants' evaluations of themselves in relation to the challenges of caring, personal meaning-making and coping. As will be illustrated in the extracts, the notion of the self as a carer relates both to experiences of stress and approaches to coping. The following themes were considered as contributing to the overall theme of Caring and the Self: Caring and Skills, Role and Self-Image, The Costs of Caring, and Coping Skills and Styles.

Caring and Skills

This theme arose from participants' accounts of the personal requirements of being a carer. There were many references made to skills and strengths needed to care for a person with dementia, and a recurring theme was to frame these qualities in terms of doing a job. For Michelle, caring should be valued as a difficult job and carers should be given the chance to acquire the skills needed for the job.

[...] the mental health of carers needs to be prioritised, it shouldn't be an aside, it shouldn't be a crisis management thing, it should be an appreciation right up the top, you're entering a bloody tough job here, and it should actually be an appreciation that you are doing a job. Em and those skills just like an employer needs to make sure you've got adequate training to do that job, it needs to be exactly the same.

Cathy describes how her previous professional experience enabled her to seek and ask for support as a carer, and expressed concern for other carers who might not necessarily have had this experience or the chance to develop the necessary skills.

I'm the way I am because I was office trained I'm an administrator in my work and that so you know, but some folk aren't, some folk older than me, I've just turned 65 but some people are probably older than me, maybe not used to computers and stuff, some people don't even like to speak on the phone, Lorraine.

In some cases, participants spoke about how they had needed to gain new skills in order to adapt to being a carer. For John, this involved taking on tasks that had previously been done by his wife, and he found this new division of labour quite difficult.

Life was very very easy and suddenly I'm doing all the shopping and what do I buy and I found the cooking very difficult not that I can't cook but she wouldn't eat anything [...] the the the eh washing of clothes and things was quite easy cause you just put it in the washing machine, whether it was the right amount of soap or not it didn't matter but it all seemed to be all right, em but I did find but suddenly you're 80, you're 70, what was I when it started, 76, 77 something like that, you're suddenly running the house which you've never ever done before em and you're shopping and you're having to think of menus.

Janet's account of her experiences was similar, in that she took over the jobs previously attended to by her husband. Reflecting on these skills after the death of her husband, Janet describes feeling more confident and able to cope with certain things as a result.

Things that he had done I had to take over, all the financial stuff, had to face up to that and I found I could. In a way I got more confidence about some things. And now I'm bereaved I can do these things you know I'm not having to learn them [pause] em it's strange that and [pause] and you do find out what's important.

Role and Self-Image

At times, participants' accounts of caring would include reflections on their own identities or self-images. Extracts included in this theme include ones in which there seems to be a sense of a core 'self' involved in the caring experience. In some cases, there is a sense of having to take on a particular role, or see something in a new way and challenge the self, in order to be a carer.

For Susan, there was a belief that something about her own personality or background drove her approach to caring.

The basis of me was well what, when things, some part of my background was always looking to see well, if he can't speak properly what can be done?

Michelle describes a type of role strain which can arise from performing the role of caring, if this does not necessarily play to the existing strengths of the individual carer.

If you're working in an area that's not in your strength that's really stressful. And there's not an appreciation, well there's far too many carers out there who are not working in their area of strength and therefore they are constantly every day of their life is stressful, just because they're not living to their authentic self if you like.

For Ruth, caring involves balancing control and safety with taking risks, and she describes her responses in the light of her belief that she is fundamentally an anxious person.

[...] what you realise is you're trying to anticipate crises which you know will come and that's the awful thing, you realise that you have to live always ahead of the game which is terribly exhausting. [and how did you do that, living ahead of the game?] Erm living ahead of the game means that you are always on the alert, always keyed up, ready to stop the glass of wine being knocked over, going over on the red light or always anticipating disa[ster]- now, this is not what everybody would do, this happens to be my erm nature and it's a very difficult one to know to know that you want, I want James to keep his independence as long as possible. What is safe, what is, you know that that and if you are an anxious person of course you chip away at the independence because you couldn't bear anything to happen if you felt that you had allowed something that you thought was perhaps unsafe.

For Monica, one aspect of caring for a parent was the taking on of things which are usually parental concerns; there a sense almost of a role reversal in the following extract relating to caring for a parent who has dementia.

Now I know what it feels like when the daughter goes to a night club and you're sitting up waiting for her to come in, you know she's fine when she comes doodling in at four in the morning but until she's in the house you are concerned and that's the kind of feeling I get.

The Costs of Caring

In this theme, extracts were considered in which participants gave direct descriptions of the stressful aspects of caring for a person with dementia. These descriptions often referred to feelings of being overwhelmed or of reaching some personal crisis point, as

seen in this quote from David in which he describes his experience of having a breakdown.

I don't know what happened but I just suddenly felt the whole house falling in on me and I just burst out started to cry and oh, just everything, and it just came crushing down. And eh by luck I managed to get in touch with her [neighbour] and she came and we phoned, we phoned up the doctor's and got an appointment really right away and I went across and they said I'd just had a sort of a breakdown. Cause they ask you all, they ask you all the questions of what happened, I said well it's really hard to really find out, I said I just felt as if everything just suddenly, all of a sudden it was just caving in and caving in and caving in, and they say it's just probably been the build-up of stress.

Angela talks in the next quote about her experiences of the end of the caregiving role, following the death of her mother. She likens this to the experience of going on holiday after coping with a stressful job, and becoming aware of how much stress you have been carrying.

From the carer's point of view em the big problem comes when the caring stops because suddenly you find that you you are, you may fall ill because a bit like a holiday, you may fall ill when you're on holiday because your body keeps going, keeps going, keeps going, you take off a day and suddenly everything goes wrong because you've actually stopped. And so a lot of the carers have been putting off, they can't do things for themselves because they're caring for someone else, their needs are greater.

Coping Skills and Styles

This theme arose from instances in which participants referred to their own personal coping styles, or factors which they felt had helped them to respond to the challenges of caring. For Douglas, it was important to be well informed, and to know at the outset about the types of challenge he may encounter. Douglas felt that there should be an opportunity for people new to the caring role to speak to people who already had experience of caring.

[...] forewarned is forearmed and they people should be forewarned, they shouldn't be saying, when they come out the hospital, eh mum's been diagnosed

with Alzheimer's so we'll just have to keep an eye on her, and then they sit down and say well what do we have to do now, whereas if they could just speak to somebody that's had that experience and say, here's what needs to happen, here's what's going to happen to your mum or dad, it might take a year, it might take two year, it might take two weeks, but here's the things that's going to happen and you need to be prepared.

For Mary, who cares for her husband, it is important to avoid being overwhelmed and to receive information at a pace that is suitable for the individual. The difference between Mary's account and that of Douglas demonstrates some of the divergence found within this theme, with Douglas drawing strength from information and Mary feeling that too much information can cause anxiety.

I've got a drawer through the desk through there and that's the drawer where everything gets shoved into and if there are things that maybe come in or you know I haven't even read my way through the whole brochure I got right at the beginning so I tend just to, because again I don't really want to be that far ahead and panicking myself. I can do that quite easily, I can do that myself without going for any help. Em but if I if I feel I need to just to check it and look at it then.

Janet describes how, as a carer for her husband, she used some of the same self-preservation techniques she had used when bringing up her children. For Janet, it was crucial to find a place in which she could be on her own for a short while.

When the children were little I did some criminal things and I locked myself in the loo and read when I couldn't cope [laughs] with three of them any more, they were quite close together. Sometimes I did this [...] made my husband comfortable and I'd take myself off and it would be the loo cause the door would be locked and he would know I was in there in the loo. So it was somehow legitimate and em [pause] I found that a great tonic, that was a a place to be in a separate place in my head, other stories you know.

David made references throughout his interview to an 'inner strength' which he felt must have helped him to cope with being a carer. In this excerpt, he refers to this strength and also alludes to his coping with certain aspects of personal care being based on the relationship he has with his wife.

I must have been quite strong I gather cause I coped with it right after Christine, when she had it and it didn't bother me, didn't seem to bother me, as I said it was your wife so it didn't bother me that way.

Also contributing towards this theme was the notion of 'counting blessings', which featured in many participants' accounts. Participants tended to compare themselves favourably with others, and describe themselves as 'lucky' or 'fortunate'. In some cases, the idea of 'counting blessings' seemed to perform more than one role: it functioned as a kind of coping strategy, but also as a warning that things could be worse, as illustrated here by Mary.

I'm fortunate you know, I can drive, have my health, you know I'm a very active soul, you know I can take William out and we can do things cause I mean to be fair, there are a lot of people who who just cause they're older or not fit or not well themselves couldn't do these things so I can see why you know that would be a problem then.

Reflexive comments on this superordinate theme

My interpretations of the theme, Caring and the Self, were informed by an interest in looking at the different strengths and resources that come into play in determining how well an individual copes with a challenge. When looking at the meanings of references to individual strengths, requirements of caring and so on, I was reminded of my experiences of supporting individuals to set goals and to appraise their own strengths and weaknesses. I was able to draw upon this experience in attending to and forming an understanding of participants' references to their own roles in coping with the challenges of caregiving. In this sense, I was bringing a practitioner's perspective to my understanding of participants' accounts; although my role here was not to guide participants through an evaluation of their perceived strengths and weaknesses, I was able to perceive that at times they were judging the 'fit' of their skills for the challenges they faced. My understanding came partly from an 'outsider' perspective (practitioner/researcher, as opposed to peer) as discussed by Hellawell (2006).

It is possible that in some instances, participants' accounts were influenced by my age and gender as a researcher; for example, John's accounts of the difficulties of learning to run a house, and Janet's comparisons of her caring role with her earlier role of bringing up her children. Although it is impossible to determine the extent to which

interviews may have been influenced by the identity of the researcher, reflexive practice involves a consideration of intersubjective factors (Finlay, 2002) and it is plausible that participants may have found it easy to prioritise these aspects of their accounts in the current study. Similarly, when participants described taking on skills and responsibilities which were previously the domain of their partners, the gendered nature of these responsibilities was apparent to me as someone interested in the gendered division of tasks, and the participants may also have been considering this aspect in regard to taking on new roles.

4.6.5 Caring and Others

The third superordinate theme, Caring and Others, serves as an umbrella theme for the roles of others with whom carers have informal relationships, including family members, the wider community and other caregivers. Participants' accounts illustrated how these other people could play important roles in caregivers' overall experiences of stress and coping, with these roles sometimes being complex: families, for example, could contribute to both perceived stress and to the relief of stress, depending upon a number of factors.

Families and Dementia

Family members played an important role in participants' experiences of caregiving, and were referenced by all caregivers. However, descriptions of the roles and input of family members were very varied. For Michelle, when family members came to visit they did not really contribute in terms of helping with caregiving, but added to her experience of being busy due to their perceived roles as visitors.

[...] it's more giving me a pressure cause they're expecting me to do teas and coffee and you know, my brother with the kids comes over then I'm looking after the kids while he's em kind of lording it up [pause] I'm [pause] very assertive when it comes to that kind of thing and I'm quite happy to say, Richard that's not on, but it's a fine line between, mum's living in my house and I need to make sure everybody's welcome so when she dies there's no animosity. So it's managing the family dynamic. Managing families without caring responsibilities is all full of politics anyway but when you add in a caring responsibility [...]

John, in the following humorous description of the skills of his children and son-in-law, felt that the specialist knowledge of family members had been crucial to his knowing where to get help when he first became his wife's carer. For John, these family members had helped him negotiate the 'ins and outs' of professional care.

Happily both my children are very very supportive so that and my eh daughter's husband, that's how they met, he's in the eh caring sector as well so he knows all the ins and outs of it. He's got two Social Work degrees, bulging with brains. So he, so really we're probably in a luckier position than many many people I think.

Cathy describes an instance in which family members wanted to invite her on holiday without her partner, who has Alzheimer's. For Cathy, this invitation was upsetting, as it seemed to her to indicate that people 'don't want to know' when someone has dementia. In this and other instances described by Cathy, she appeared to feel that her family expected her to start moving away from her partner, to whom she remained committed. Cathy's perception was that her family thought that dementia signalled a need to move towards closure on the relationship.

She says you know Cathy I think we should try having a holiday without Paul, it probably would be much better for you and less stressful, I thought that was horrible, you know. But hey, that's the way people are regarding well mental health and dementia, anything to do with mental health, depression, eh dementia, psychotic, whatever, people just they don't want to know.

Monica describes having mixed feelings about being an only child caring for parents with dementia. Although being an only child increases her stress levels, she can see the benefits in being the sole decision-maker and avoiding family conflict. She describes with some humour her perception that she has both sole responsibility and power.

[...] there's the whole thing about not having siblings which is great most of the time, because all I've seen with siblings is that they all get resentful [...] so even though it's more stressful having been an only child, the buck stops with you which is great [pause] I'm the master of decision making.

Friends, Neighbours and Communities

Friends, neighbours and the wider community also featured in many participants' accounts. In some cases, these people played a key part in making caring more manageable, as referenced in David's account of the help he received from his neighbour.

[...] maybe I was lucky cause I had a neighbour round the corner, she used to sleep with her mobile at her bed, just if I needed any help, any time, it didn't matter twenty four hours a day, I seen me often just phoning her up later on you know, comes round if maybe Christine's been struggling and she used to just sort of take over and you know, that idea, so I was lucky that way as well that I had her. So I had an extra carer you could say, you know, aye.

Janet describes the importance of being supported by a network of friends through her local community and church. This account also ties in with the section in the previous theme about 'counting blessings' and feeling lucky compared to others.

I also had immense support because we'd been attending [name of church] for thirty years, this is really like our community, people come and go but we've some very old friends there and he knew as well as me they were behind us, we were kind of supported and um [...] so we really had quite a good experience when I think about it now that um [...] that other people aren't nearly as well supported eh and so it makes me feel community is very important in people's lives, you know they talk about people living alone um and yet they're living amongst lots of others who are alone, so I think community centres and [local area] has wonderful connections and you don't have to try very hard to get in to something that might interest you.

There was also divergence within this theme. For Ruth, the support of friends should be accessed as an 'emergency' and not relied upon. Ruth appeared to be taking into account the limitations on others and feeling that she should not ask for regular help.

I've always said I would rather leave it for an emergency than have it as a part of, cause I do feel I have got to get things organised not relying on on friends because you can't. They're not always available so you can't have that as your day to day thing. Erm most of our neighbours now are elderly, well we're elderly [laughs] you know.

Peers

The accounts made many references to the role played by fellow carers. Although it was common for participants to have met peers through services such as carers' centres and local community groups and this theme might have been included in the following superordinate theme, The Care System, a decision was made that it had a more natural fit with Caring and Others. Participants tended to speak about other carers in a way that was separate from their accounts of more formalised systems of care, reflecting on relationships with their peers and whether or not they found other carers' stories helpful. Angela makes a direct distinction between the support of other carers and the support of professionals, noting that peers are more likely to give out-of-hours support and contribute their own 'ideas'.

The great thing about [name of discussion forum] is that it is carers talking to other carers and giving them the benefit twenty four seven because, you know what's the point of having a helpline if it closes at five? Very often things on the NHS or special services shut down at five. Em it's it's carers who are giving ideas to other carers.

In the following two extracts, Cathy describes two different benefits she has had from meeting other carers; information that she feels she would not have had from anywhere else, and emotional support. Participants' positive accounts of peer relationships tended to focus on these two different types of benefit.

[...] they'd tell you their story em so you learned so much from these other carers that you wouldn't have found out otherwise.

[...] the three girls came in and three of them cuddled me and they says Cathy, we've been there, we know exactly what you're going through.

For some participants, however, meeting other carers could be an unsettling or upsetting experience, as described in the following two quotes from Barbara and Ruth, respectively. For Barbara, it was difficult to listen to other people who were also experiencing difficult times, and she described feeling emotionally upset following a carers' meeting. For Ruth, there was a sense that she needed 'time out' from thinking about caring, and that carers' meetings could be repetitive and unhelpful.

Barbara: You would think that it would be helpful but instead it was a lot of talking about how hard their lives are.

Ruth: [...] No good to me because they sit round telling the same story over and over and over and over again. [...] I think if I have a couple of hours, I want to do something for me that is away from, and I think this is really what we're, the nub of the thing, what do carers need.

Reflexive comments on this superordinate theme

When identifying this superordinate theme, I was again able to relate some of the participants' accounts and experiences to my own experiences, both personal and professional. In particular, participants' views on peer support resonated with me in the light of my experience of working in another field, in which peer support groups can play a large part in individuals' attempts to move away from substance misuse. I have previously heard accounts from people who found peer support groups very helpful and who described similar benefits to those described by the participants in this study. Similarly, I have supported people who did not find peer support to be a useful thing and who identified problems with it. Again, my interpretation of these experiences was informed partly by an 'outsider' perspective (Hellowell, 2006) – that of practitioner looking in on the experience of peer support – and partly as an 'insider', by relating to my own experiences of group events such as training, and the feeling of being in a group.

Another aspect to be considered here is the fact that participants knew (from receiving information about the study, and from pre-interview chats about the study) that my interests lay in exploring caregivers' experiences of things or people which may alleviate stress. Enosh and Ben-Ari (2016) discuss the fact that reflexive practice is not solely the domain of researchers; participants may also work reflexively during the course of a research study. One example here is the following comment from participant Ruth:

[...] I think this is really what we're, the nub of the thing, what do carers need.

Here, Ruth appears to be taking a step back from simply describing her experiences, and is commenting on what she sees as the central question being considered – 'what do carers need?'. This serves as an example of the reflexive work that may be done by

participants in the context of an interview, in which they may consider or contemplate their own experiences in response to questioning and the research situation.

4.6.7 The Care System

The final superordinate theme, The Care System, was identified through the many references and accounts given by participants about their use of formal support. I have considered towards this superordinate theme accounts of both support to help the carer and the cared-for person, as participants did not draw any clear distinction between the two when describing their use of services. In fact, there was often a strong sense that accessing help for the cared-for person offered a great deal of relief to the carer, so there was no clear dichotomy between the two types of service in terms of their potential to relieve stress. Themes contributing to this superordinate theme were Positive Experiences of Support; Power, Authority and Conflict; Unmet Needs; and Systems versus Individuals.

Positive Experiences of Support

This theme emerged from participants recalling the positive contributions made by formal services, both directly to the carer and to the cared-for person. Mary gives a positive account of accessing various services via her GP, and gives a sense of a network of support being facilitated by services making onward referrals. There is a sense of this process flowing quite naturally and without requiring a lot of input from Mary. For Mary, these services are a kind of safety net.

We've got a wonderful GP, she's actually great and just various things that have happened, we were at [name of hospital] this morning on the train and eh through them we were put in touch with the home care team the dietician and the occupational therapist all things like that [pause] I don't know it'll work but I'm quite glad it's there in case, just in case.

For John, the home support his wife received was a 'good package' of care, and he describes how support was available throughout the day while his wife was living at home.

[...] from what I hear from other people, we had a pretty good package and I don't think, I mean we couldn't have any more people in the house unless they

were here full time. A girl for an hour and a half in the morning, a girl for two and a half hours in the afternoon and giving Sarah her tea, then a girl coming in for an hour at night putting her bath on and putting her to bed, and you couldn't really have had any more than that unless they were full time and I would say we had a pretty good care package.

Good relationships with professionals featured prominently in positive descriptions of support. For Michelle, controlling her own care budget and employing a professional carer directly was a good experience, and she describes here the extra level of shared responsibility she feels she has with the professional carer, and her perception of the carer's personal qualities.

I could not do it without her, she is like a little, little angel, she's amazing [...] I wanted somebody that I could share responsibility with, I didn't just want somebody to come in and be a carer.

David describes the importance of having positive relationships with care providers. In this account, he speaks about how these positive relationships and small, personal gestures, which were not necessarily part of the care package, led to good experiences of receiving care.

I was actually lucky when the carers came eh we all got on quite well together, and this was their last call say before they had their breaks maybe, and it's the same as night time and they maybe come early [...] instead of maybe doing something they would come up here and we used to have say cups of coffee or they'd bring cakes or something [...] part of it is how you get on with people you know, and I've had occasionally the odd one they've phoned up, how are you doing David and how's Christine, you know.

Similarly for Susan, a positive experience was related to the fact that her father's home carers had a positive regard for him, and good relationships with him. Her description of the 'home care women' seems a little more personal than the more usual label, 'home carers'.

[...] the home care women were really good, loved my dad, thought he was wonderful.

Power, Authority and Conflict

The second theme under the heading of The Care System concerned experiences in which there was an indication of service providers being in a position of power or authority, or there being some conflict between participants and professional service providers. In some cases, participants used the language of conflict, including references to ‘battles’ and ‘fighting’ in their encounters with services. In this extract from Cathy’s interview, she describes feeling that she had to engage in repeated fights to get support for her partner.

I says right well I’m going to take this further, and I put the phone down. Three minutes later it was him back on the line, he said I managed to get you a – so eh it’s not shouting loud enough you see so I fought every step of the way for Paul, whatever I’ve tried to get for him it’s been a fight. And we as carers we shouldn’t have to do that, we’ve got enough going on, but you’re, doors blank blank blank and they won’t open, just no-one wants to know.

Barbara believed there was a conflict of interest between her own views and those of her mother’s social worker in terms of the best support plan for her mother, and that the social worker was looking for ‘evidence’ to move her mother into full-time care against Barbara’s wishes. This appears to be a relationship of suspicion rather than trust.

[...] battles with social work, um social work was meant to be supporting me but I always got the impression that they were looking for evidence to justify taking her away from me and putting her into residential care.

In some instances, the power held by services played a much more benign role, as in these excerpts from David, in which he describes with some humour the attempts of services to persuade him to look after his own needs.

[...] the social came to see us and all that and they found out what I had been doing and of course I got a row. And I got told I was to go away for a holiday out the road.

I’ve had it drummed in God knows how many times, you’ve got to look after yourself. If your wife’s looked after, well looked after, you’ve to look after yourself.

Susan describes the distress of feeling powerless when her father was admitted into care against her wishes, describing the feelings as being similar to those of parents whose

child had been removed by social workers. In other excerpts, Susan described being 'banned' from seeing her father while he was in nursing care, which also tied into the theme of power, authority and conflict.

[...] to me it's like a child, I felt as if my child had been removed from me. You wouldn't do that to a parent and their child. [...] one day you think you're coming home to see, the next day that person's away, removed, and you don't know what's happening, you don't know when it's, and you can't communicate with him.

Another aspect of power arose through participants' descriptions of gatekeepers or other barriers to service access. In the following excerpt, Monica discusses the language of caring, and how she feels that complying with the language of services is essential in order to access help.

It's a bit like a magic word, if you resist the word because you don't like it you're going to come a cropper because it's the government computer says no if you don't say the right word.

Related to the idea of gatekeepers and barriers was the feeling expressed by some participants that accessing help involved onerous, tiresome processes, as referenced in this extract from Ruth's interview. Her repetition of the word, 'endless', conveys a sense of feeling drained by her attempts to secure help.

I don't wonder that people can't manage because I I can hardly cope with it just it's endless, endless and you fill in the forms but you've then got to go and get the doctor to sign, it's just, and then you ring the GP and they say we can see you in February [interview conducted early in January].

Also related to the balance of power was the fact that for some participants, there was a sense that care could sometimes be felt as an intrusion. Despite his overall positive experiences with his team of home carers, John expressed that the professional visits sometimes led to his feeling that he had lost control of his home environment.

But somehow or other having all these people in the house I found difficult, because the house is not your own, do you know what I mean?

Unmet Needs

The theme, Unmet Needs, relates to the participants' experiences of times when there was a poor fit between either their own or the cared-for person's needs and the services that were offered. This theme encapsulates many different types of negative service experience. For Douglas, his local council's use of private agencies to outsource care was a concern, as it meant that there was no continuity of personnel in his mother's home care. Douglas weighs up what he perceives as the needs of a person with Alzheimer's disease against the service being provided.

[...] in the six month spell it was 2013 my mother had saw fifty seven different carers in a six month spell, fifty seven, and that cannot be helpful to someone with Alzheimer.

Michelle expressed similar sentiments to Douglas's about the level of care provided by private agencies. In this extract, Michelle expresses very clearly the importance to her of having the right level of care for her 'mammy', and her belief that this care cannot be provided by workers who may have poor conditions of employment. There is a sense in this extract of a discrepancy between the importance of good care to Michelle and the level of importance Michelle imagines it will be afforded by the agency.

[...] the carers through the agencies tend to be on minimum wage, which I completely and utterly disagree with, because it's, they're looking after my mammy, it's a really really important job, they're doing personal care, I'm looking for that responsibility.

The theme of Unmet Needs applied to the needs of carers as well as the person with dementia. Ruth recalls her initial hope when she received a carers' assessment and was advised that she had an entitlement to periods of respite, but her needs were then not met due to service constraints. Many of Ruth's accounts of services were characterised by this sense of having her hopes raised and then dashed.

I know that statutory I'm entitled to six weeks of respite care a year so Social Work Department, I said that's marvellous cause that's what I need and they said oh, well there's no hope because the the erm waiting list is so long, which is strange when they say you are entitled to it but you can't have it.

The stage of diagnosis seemed to represent for participants a particular time when their needs, and the needs of the cared-for person, stood in sharp contrast to the help that was

provided. The diagnostic stage featured in the accounts of most participants, and was originally considered as a theme in its own right, but had significant overlap with the theme of Unmet Needs. Cathy describes here the initial shock she and her partner felt when he received a diagnosis, and how the lack of information or support tied in with their feelings. Again, there is a sense here of disconnect between the intense personal effects of the diagnosis on Cathy and her partner, and the level of support offered at this stage.

[...] then we came out of there, we didn't get any info, we got no pamphlets, she didn't give us anything, we were just absolutely in shock, crying, em I says, oh let's just get home, so we came home and we just cried and cried.

For many of the participants, there had been an awareness for some time prior to diagnosis that something was wrong. Ruth describes her difficulty in securing a diagnosis for her husband and feeling that she was not being listened to by professionals.

[...] we had a very bad start to the whole proceedings because I knew there was something wrong but couldn't get anyone to actually take it seriously.

Also initially considered as a theme in its own right, but eventually contained within the theme of Unmet Needs, was the notion of professional help actually being the main source of stress in caring for a person with dementia. Several participants made a direct reference to this when discussing the challenges facing carers, as shown in the following quotes from Angela and Barbara.

Angela: And so I go back to the same point I made before, from the carer's point of view it's the professions who make your life a misery [pause] the professionals are so locked up in their in their boxes of how, what the process is that they've lost sight of the people.

Barbara: My life as a carer was not down to being a carer, it was down to the people that I had to work with as a result of being a carer.

Some participants made a direct contrast between the personal qualities of professionals and the organisations in which they worked, as shown in this quote from Michelle, in which she seems to be conveying that there is some problem with Social Work as an entity, despite the positive commitment of its staff.

Social Work are only aware of their own situation and while they have hearts of gold they're kind of part of the problem.

Systems versus Individuals

The final theme contributing towards The Care System is Systems versus Individuals. This theme arose from instances in which participants made some reference which seemed to indicate that the care system was working in a way that disregarded the individuality of the cared-for person. Although this theme had some degree of overlap with Unmet Needs, extracts in this case seemed to indicate more of an issue with the underlying ethos of care provision, in which the person with dementia was often not seen as central but was expected to fit in with an existing system. Janet describes this phenomenon in relation to hospital care.

[...] you have to pay [for car parking] in the in the [name of hospital] and you have to learn the rules of this game of being in hospital. So that was a quite distinct period, he was in hospital for three months and eh I felt I was em learning new things all the time because you have to find out how it works and how you might be able to fit in.

Angela also describes the hospital system, and how its rules and regulations can lead to care that is unsuitable for a person with dementia, in this account of her mother's hospitalisation. She describes her feelings of discomfort about the lack of privacy and control afforded to her mother in a hospital ward.

And nobody can touch her, nobody can lift her up, it's all hoist this and hoist [that] they make a funny noise, they have no control, people are looking at them you know like they were a little beetle under a glass, it's the most awful thing.

For Susan, there is a direct difference between being a 'human being' and a 'patient', referencing the difference between being cared for by a loved one and cared for within a hospital setting.

I treated him as a person, a human being, never a patient. When they removed him from his home they treated him as a patient.

Barbara talks about the importance of reaching a type of compromise with the 'system', acknowledging and sticking within its limitations while using her own knowledge as a carer and her relationship to the person with dementia. Barbara describes taking her

mother to a sports event, an occasion which she felt would not have met with approval from social workers. There is repetition of the phrase, 'find your own way forward' in this extract, suggesting that this was important to Barbara.

[You have to] find your own way forward in terms of what you thought was best within the boundaries of the system [...] By that I mean if you think it's a good idea, you or the person you're caring for, I took my mother to the [sports event] last year, now we were looked after really well, there was no danger involved and had I sort of suggested to the social workers well, Can I take my mother to the [sports event] they'd have said oh no, no, no, it's too much of a risk. But you know you have to find your own way forwards and I knew that there wasn't going to be a risk involved, I knew we would've had energy and pace to make sure that we were both looked after, so you need to find your own way forward and do what you think is best and I know how much she enjoyed the [sports event].

Reflexive comments on this superordinate theme

When considering participants' accounts of engaging with the 'care system', I was reminded of a key piece of training which is often delivered to substance misuse workers, as an awareness-raising tool. Workers are asked to draw a map of what they imagine 'Service Land' to look like, in terms of the different types of services that may be accessed by people with drug or alcohol issues. Workers are then asked to draw a different area on the map, representing a more typical, mainstream way of living, and to consider how to support people gradually to move away from the specialised services in 'Service Land' and towards a more integrated life within the wider community.

Listening to participants' stories about using services, I was struck by the fact that carers of a person with dementia may find themselves unexpectedly engaging with a different sort of 'Service Land', using specialised services without necessarily having any prior knowledge or experience of such services. I gained a strong sense of participants trying to learn about new services, engage with them, learn new sets of rules and form new relationships, at times feeling that the processes and approaches they encountered were quite alien to their own perceived needs and those of their family members. In this sense, I was again approaching the analysis as an 'outsider'

(Hellowell, 2006), drawing upon a professional framework in order to try to make sense of the feelings and experiences reported by participants.

The 'care system' was notably prominent in participants' accounts in this study. This may have been for a combination of reasons. It is possible that in giving participants information about the study, they were oriented to talk about their experiences of using services, and were doing the kind of reflexive work discussed in the previous section, by stepping outside of their own experiences and offering accounts relevant to the research question. It is also possible that my own professional background and knowledge of services meant that participants were able to detect a particular interest or understanding of their accounts about services; the interview situation itself can produce some reflexive work (Enosh & Ben-Ari, 2016). Perhaps more straightforwardly, experiences of the 'care system' may have been central to participants' experiences of stress and distress, as some of the accounts appeared to indicate (for example, Barbara attributed her caregiving stress directly to having to work with care professionals, while Susan prioritised distressing service experiences throughout her interview). It was notable during this study that a small number of participants wished to waive their right to confidentiality, suggesting that they may have seen participation as a way to make their experiences public; this necessitated a discussion about the opportunities and limitations of research.

4.6.8 Case Studies

In this section, I will present three case studies based on individual participants from this study. These case studies have been selected to illustrate variation in terms of demographic information, caregiving situations and themes and priorities, and to highlight some of the in-depth, idiographic information that was obtained during this study. Each case study begins with a summary of the participant's caregiving situation, and moves on to highlight some of the emerging themes from the interview, with a discussion about how these themes contributed to the recurrent themes identified in the main analysis.

Case Study 1: Ruth

Summary of caregiving situation

At the time of Ruth's interview, she was in her late seventies and living with her husband, James, in a central part of a large Scottish city. Ruth and James had been married for over thirty years, with their marriage being a second marriage for both parties. They had adult children and step-children. Ruth was James' primary carer, with no additional daily support.

Ruth and James had professional backgrounds and had previously enjoyed a social life including foreign holidays with friends and family. Ruth notably highlighted what she saw as a loss of social status attributed to the stigma surrounding dementia, and she described an increasing sense of isolation from friends, as well as practical barriers to doing things she and James used to enjoy.

At the time of the interview, James had been diagnosed with Alzheimer's Disease for several years. When he was initially diagnosed, Ruth had felt hopeful that a cure would be found, and they had enrolled in clinical trials. Ruth had found this to be a disappointing and depressing experience. Her accounts of this time, as well as more recent service experiences, tended to describe a sense of hopes being raised and then dashed. Ruth expressed a loss of hope and a gradual acceptance that her experience as a caregiver was going to be marked by a series of challenges.

Selected themes emerging from Ruth's interview

Raising and frustrating of hopes

Ruth tended to frame many of her experiences in terms of an initial sense of hope, followed by disappointment. In the following quote, she describes her initial hopes that James' dementia may not be too advanced and that he may experience benefits of taking prescribed medication (Aricept).

In the beginning you try to be extremely positive because you think well, erm his score is not bad, erm he goes on to Aricept and so you start off incredibly optimistic cause you think, this is the way to do it, right, more or less like this. Erm and then the realisation dawns that actually this is not a fight erm it all it is a series of challenges one after the other. Erm you deal with one challenge, the shoulders go down and another one comes along.

This quote contains references to stages and progress, including the phrases ‘in the beginning’ and ‘start off’. Ruth’s descriptions of the loss of hope, the ‘series of challenges’ and the stages of caring contributed to the themes involving loss and the sense of dementia as being progressive and uncontrollable.

Authority of services

Ruth described in her interview two different types of experience regarding the power and authority held by services. In the first of these quotes, Ruth appears to have had a positive experience regarding her GP’s authoritative advice, while in the second, she gives a more negative account concerning gatekeeping.

My GP, this is where the GP was wonderful, she said she said two or three very wise things [...] she said [...] you have to accept that and say, here I am in this situation, now she said with James let’s divide the day into three parts, morning afternoon and evening, you really should not be with him for more than two out of the three parts, now I know that sounds very simple but it actually gave me permission to think right, after lunch I can say it, I felt as if I was banishing him but I was given permission to say, you go upstairs to your study, I need to sit down and have a rest [...]

[...] the local day centre erm they do a one to one befriending service which I’m just applying for you have to be referred, it all takes, all takes so long I I don’t wonder that people can’t manage because I I can hardly cope with it just it’s endless, endless and you fill in the forms but you’ve then got to go and get the doctor to sign [...]

Ruth’s accounts of accessing services helped to inform the broader emerging themes concerning the care system, including positive and negative experiences of the power held by professional services and the sense of there being a struggle to receive support.

Own attributes and caring

A further theme to emerge from Ruth's interview concerned her perception of herself and her own personality in relation to the challenges of caregiving. At several points in her interview, Ruth appeared to be describing herself as an anxious person with a need to control things, as highlighted in the following quote.

[...] I long to have a day off to just be on my not be aware not be anxious about the traffic lights whether he's going to walk out we [sighs] my next door neighbour who's really quite elderly was knocked down by a bus the other day and I thought, she doesn't suffer from dementia but she is very old, and I thought well these things happen. I spend my life anticipating things that could go wrong [...]

Ruth appeared in this and other excerpts to be weighing up what she saw as her personal attributes against the situation facing her; in the quote above, she seemed to be trying to rationalise the existence of risk alongside her feelings of anxiety. Ruth's self-awareness and consideration of her 'fit' for the tasks of caregiving were important in forming an analysis of how the participants viewed themselves as caregivers, and how equipped they felt to meet the challenges presented by caregiving.

Case Study 2: Douglas

Summary of caregiving situation

At the time of interviewing, Douglas was in his fifties and living in a small town in Central Scotland. Douglas was the main informal carer for his mother, who had dementia, but who was living separately in her own home and receiving daily support

from professional carers. Douglas had been caring for his mother since late 2011, and his sister also provided some informal care; he also had a brother who did not contribute to their mother's care.

Douglas, who was in full-time employment, had come to a flexible working arrangement with his employers so that he could provide support for his mother. Douglas expressed a strong interest in employment rights and had been a union representative within his workplace. His understanding of care agencies and informal carers' rights appeared to be informed by Douglas's interest in human and workplace rights. Douglas described throughout his interview a keen interest in helping others, and expressed the view that changes were needed in order for caregivers to be fully supported.

Selected themes emerging from Douglas's interview

Professional care agencies and unmet needs

Douglas felt that his mother's needs were not met by the professional support accessed via his local authority, and attributed the unmet needs to the outsourcing of care to private agencies. In the first quote below, Douglas is commenting on his mother's claim not to have been visited by any carers; although Douglas acknowledges that his mother has difficulties with memory, he also clearly feels that the carers may not always be keeping appointments, and Douglas feels that their conditions of employment are not suitable. In the second quote, he identifies a lack of personalised care.

I know there's got to be times when it's the carer, it's human nature because they're under such a tight schedule with the privatised company. I don't think they get a very good rate of pay, I don't think they get proper training [...]

[...] it doesn't help the person that's ill in the slightest or the family who watch this bizarre ritual going on every week and all the different people coming with different notes, saying I didn't know your mum had Alzheimer's, just it's just they need to up their game and I'm surprised that the council allow that, there should be some regulatory body looking at them.

Although Douglas had a particular understanding of employment rights and a framework within which to interpret the failings of care as he saw them, his experiences

contributed to the broader themes of unmet needs, and of services not being appropriately person-centred.

Self and peers

Douglas made several references in his interview to his own perceived role in helping peers. In the following quote, he describes an occasion when he got chatting to a woman at a hospital who was also visiting her mother. Douglas describes his actions in passing on information to the woman.

[...] there was a woman who was walking out that evening with me back to her car and she was asking how my mum was and I said, how's your mum and she said she's just come in she's eh been diagnosed with dementia, I said well do you know what the next steps are that you need to take and she says no, she says I've never been told what I need to do. I said well I'll tell you what to do, I said here's a card I gave her the Alzheimer's card, I says phone that number and they'll send you some documentation and they'll give you a bit of help.

The above excerpt touches on a few of the themes to emerge from Douglas's interview. Firstly, it appeared from this and other accounts that Douglas saw his own role as that of helper and information provider in relation to other carers. Douglas appeared to be maintaining a similar status to the one he had established in his professional life. Also represented by this quote, and found in other quotes in Douglas's interview, was his belief that information was a positive factor in coping with dementia. As discussed earlier in the main analysis, this helped to form an understanding of the variation in coping styles used by caregivers, with other participants reporting on the avoidance of too much information. Additionally, this quote contains an account of a peer support encounter, seen by Douglas as a positive event, in contrast to his experiences of professional support; this helped with the classification of peer relationships as being different to professional helping relationships.

Case Study 3: Cathy

Summary of caregiving situation

Cathy, who was in her mid-sixties at the time of the interview, was living on the outskirts of a large Scottish city. Cathy met her partner, Paul, when they were both middle-aged; Cathy was a widow and Paul was a divorcee. Cathy referred throughout her interview to the idyllic life and relationship she felt she had with Paul prior to his illness.

Paul had been a successful businessman early in his relationship with Cathy, and one of the first symptoms Cathy noticed was that he was suddenly unable to manage money. Paul, who was diagnosed with early onset dementia, experienced a rapid and marked decline in his health. Cathy described distressing experiences in which Paul had become agitated and violent towards others, and as a result had been excluded from some services, resulting in his being accommodated longer-term in a hospital setting. At the time of the interview, Paul had started to lose his verbal skills. Cathy continued to be committed to her relationship with Paul, and this had resulted in some isolation from her friends and family, who felt that it was in Cathy's best interests to begin to move on from the relationship.

Selected themes emerging from Cathy's interview

Loss of partner

Central to Cathy's account was the theme of loss, with Cathy describing her sense that she was experiencing a slow loss with no definite end. In the following quote, Cathy compares her experience with that of a bereaved friend.

But it was a release for her [...] he just went to sleep and it is a wee blessing, it's a blessing for the carer as well. It's there's no light at the end there's not light on the horizon, it's like a bereavement, I feel like I've lost the Paul that I knew but he's still there so you can't, there's no closure Lorraine you know.

In this quote, Cathy appears to be describing a dilemma in which she is experiencing bereavement and yet the person is still alive. This and other excerpts from Cathy's interview helped to convey the sense of gradual loss of a relationship, a theme which was central to several participants' accounts.

Relationships with professionals

Cathy's interview contained diverse accounts of the experiences and relationships she had with different professional figures. In the first quote here, Cathy describes a very positive experience of the staff in a hospital ward; notably, this experience followed the exclusion of Paul from several services due to his agitated and aggressive behaviour. The second quote refers to a less happy experience in a different care setting, in which Cathy felt the staff wanted rid of Paul.

[...] one of the staff nurses he did work, voluntary work he's such a great guy, [he's] studying dementia and why it stops people walking and stuff, but he's also still working in the [name of hospital] maybe twice a week, so [name of nurse] was there and as soon as he saw Paul because he used to go on the outings with him, Paul's face lit up and the staff were beautiful.

[...] staff nurse used to pounce on me and tell me what he'd been doing wrong, every single time. I says look [...] it's not his fault you're not meeting his needs. So there was meetings with this manageress and when I went in to pay it's, how's he doing oh isn't that good, it was her she was wanting rid of him he was too much trouble [...]

These two excerpts illustrate the difference between, in Cathy's perception, good relationships with dedicated staff (underlined here by her account of the nurse's voluntary work and research interests) and poor relationships with staff who seem to view the person with dementia in terms of behavioural challenges. Cathy's account contributed towards themes of positive professional relationships as well as unmet needs and conflict.

Relationships with family

Cathy's interview touched on the issue of family relationships, and the ways in which separation can occur if people do not seem to understand the needs of the person with dementia and the primary carer. Cathy mentioned in several parts of the interview her feeling that her family wanted her to begin to separate from Paul; this is made explicit in the following account of a meeting between Cathy and her sister.

And then my sister's saying well you need to get on to the bereavement website em, I said why? She says well Paul's gone now and you could meet somebody

else on the bereavement website and I went, you're missing the point [name of sister]. I says you're missing the point the one point is that Paul's not dead, the second major point is that I'm still very much in love with him [...] She just couldn't get her head round that.

This quote illustrates the breakdown in understanding experienced by Cathy and her sister, and the feeling of separation from family experienced by Cathy. This helped with the understanding of the range and complexity of family relationships in the case of caring for a person with dementia, in which family relationships could be tested even when people were ostensibly being supportive. Interestingly, this excerpt also reflects Cathy's own feelings, described earlier, that she was experiencing bereavement while the person with dementia was still living; her reaction to her sister's comments may reflect the extent of this emotional dilemma.

4.7 Discussion

Before moving on to discuss each of the four superordinate themes in turn, it is important to say something about the analysis as a whole, and about areas of overlap between the themes. The four themes, Dementia and Change, Caring and the Self, Caring and Others, and The Care System, arose from spending time looking at different ways of grouping extracts and themes arising from each of the interviews, and appeared to provide a cohesive and coherent system for organising and making sense of trends within the data, while still being able to reflect a sense of individual stories.

To reach this structure, decisions had to be made about what to include and exclude for each theme. At the level of data, this sometimes meant deciding that a particular quote was more suitable for one theme than another. This was not always easy, as participants' accounts were richly detailed and sometimes touched on several of the themes. In such cases it was necessary to make an interpretative decision about the most important point being made by the participant.

At the level of the themes themselves, similar decisions had to be made. For example, it took some time to decide whether the theme, Peers, belonged with the superordinate theme, Caring and Others or the superordinate theme, The Care System. This decision again involved looking closely at the extracts and trying to decide whether participants were describing their own relationships with their peers or their experiences of services in which they met peers.

Having identified the four superordinate themes, it could have been possible to carry out a further level of analysis, looking at broader underlying themes. In particular, each of the four themes seemed to be connected by an underlying theme of ‘relationships’. In Dementia and Change, there was a strong sense of the changing and gradual loss of a central relationship; in Caring and the Self, a sense of self emerged against a backdrop of observations of others; Caring and Others centred on the nature and testing of important relationships, and The Care System included a set of relationships with professionals and processes. For the purposes of the current study, however, focussing on carers’ experiences of coping with the demands of caring, the identification of the four superordinate themes took the analysis to a level at which the research question could be answered, although it should be borne in mind that an analysis of this nature could continue, with further connections and themes emerging.

Smith et al. (2009) discuss the ways in which the results from an IPA study can usefully be compared to other work within a field. Although IPA focusses on small, homogenous, purposive samples and does not aim to give generalizable results, it is possible to comment on the ways in which an IPA study may agree with or differ from previous research. In the following sections, I will look at each of the four superordinate themes in turn, considering how the analysis sits within the existing field of caregiver studies and models of stress and coping.

4.7.1 Dementia and Change

The theme of Dementia and Change has implications for the body of work which has tried to identify what it is about caring for a person with dementia that is challenging for informal caregivers. Previous quantitative studies (for example, Ory et al., 1999; Schulz et al., 1995) have proposed a number of factors thought to be related to caregivers’ experiences of stress, including the behavioural changes that can be symptoms of dementia.

Although symptoms of dementia did feature in the interviews conducted for this study, these tended to be described in a contextual way, concerning changes in the person with dementia. It was clear that many of the caregivers did find behavioural symptoms of dementia to be stressful, but that these symptoms occurred alongside changes in their relationship to the person with dementia, losses associated with dementia and the

unpredictability of dementia. These results support the proposition made by Ory et al. (1999) that the uncontrollable, unpredictable progression of dementia may help to explain the particular levels of stress found in carers of a person with dementia. A similar point was proposed by Schulz et al. (2002), who argued that interventions to help caregivers tended to focus on practical steps to reduce 'burden', but that another source of caregiving distress might be the ill-health and impending loss of a loved one. The results of this study would seem to agree with this reading of the caregiver experience, in which distress occurs not only due to the presence of changed behaviours and symptoms of dementia, but to less easily-defined issues concerning change and loss.

Issues around loss have previously been examined in relation to caring for a person with dementia. In a report examining 16 qualitative caregiver studies, Pozzebon, Douglas and Ames (2016) found 'loss of partner' to be the most prominent theme overall, and proposed it as a central theme in the caregiver experience. Collins, Liken, King and Kokinakis (1993), in a qualitative, longitudinal study looking at the experiences of caregivers both prior to and after the loss of the person with dementia, found several themes relating to loss and grief. These included loss of the person and the relationship which started to happen before death, mirroring some of the experiences described by participants in this study. Relationship changes and loss of shared activities also emerged in the accounts of early-stage caregivers in a study by Quinn, Clare, Pearce and van Dijkhuizen (2008).

Looking at the stress process model for caregivers proposed by Pearlin et al. (1990), discussed in Chapter 2, the model accounts for different types of 'primary stressor' associated with caregiving. The authors describe two types of 'primary stressor': Objective Indicators, which are measures of the needs of the person with dementia and listed as Cognitive Function, Problematic Behaviour, dependency regarding Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL); and Subjective Indicators, which are defined as Overload and Relational Deprivation. The Objective Indicators described in this model are used throughout the caregiving literature and are often measured as indicators of caregiving stressors, using scales such as the Revised Memory and Behavior Problems Checklist (Teri et al., 1992). Pearlin et al. (1990), as well as proposing a model of caregiving stress, devised items for measuring each component of the model, and so their scales also include items to measure Overload and Relational Deprivation. The results of the current study would

support the inclusion of measures looking at aspects such as losses or changes to the relationship between caregiver and cared-for person, as well as concepts of control and unpredictability.

Although this study was carried out in order to get a sense of the experiences of a sample of informal caregivers, it is possible to comment on how these participant accounts might fit with existing approaches to supporting caregivers. The complexity of experiences described here would support the notion that there is no ‘one size fits all’ approach that would be effective with all caregivers. As participants tended to ground their accounts of symptoms and changes in terms of their overall concerns about the individuals with dementia, describing aspects such as their concerns about losing contact, their feelings that dementia progresses in an uneven way, or the personal loss of activities they used to enjoy with the cared-for person, it would seem reasonable to suggest that interventions should be written to be delivered in a flexible way, enabling the content to be personalised to each caregiver.

4.7.2 Caring and the Self

The second superordinate theme, Caring and the Self, highlighted another aspect of the caring experience. Participants described what they perceived to be the requirements of caregiving, including many accounts of the skills they felt they needed to care for a person with dementia. There was a tendency for participants to reflect on their own perceptions of their existing skills or personalities in relation to the requirements of caring. Different approaches to coping were described, and there were accounts of times when participants felt overwhelmed, or when their experiences of stress appeared to reach a critical point.

The concept of caregiver ‘burden’ runs throughout the caregiving literature, although this term has been criticised for being non-specific (Black & Almeida, 2004). Looking at what is meant by ‘burden’, the term is often used in reference to the direct demands of caregiving and perceived needs of the person with dementia, as measured, for example, by the Zarit Burden Interview (Zarit, Reever & Bach-Peterson, 1980). The current results suggest that attention also needs to be paid to other, associated demands on the caregiver. For example, participants in this study spoke about feeling that they needed to have confidence and certain skills in researching and seeking support, and in communicating with services. For some participants, it was also notable that the

division of labour had changed within their relationships, with the caregiver taking over household and administrative duties previously carried out by the person with dementia; this could be a source either of increased confidence or stress.

Looking at stress process models, participants' accounts here would seem to be relevant to those aspects of stress and coping models which involve individual appraisal of stressors and the ability to cope. For example, in the Haley et al. (1987) model, 'appraisal' helps mediate between the occurrence of stressors and the subjective experience of stress; that is to say, an individual's own judgement of the scale of a challenge is important in determining whether or not it is found to be stressful. Looking at participants in this study, there were accounts of people gauging their own abilities in the face of what they perceived to be the demands of caregiving and the skills they needed. In some accounts, the caregiver referenced a feeling of increased confidence in being able to take on new tasks successfully, which is highly reminiscent of Bandura's theory of self-efficacy (for example, Bandura, 1994) or the concept of mastery (Pioli, 2010).

Looking again at the Pearlin et al. (1990) model of stress and coping, and the inclusion of 'Overload' as a primary stressor, there is certainly a sense of overload in some of the participant descriptions in this study, including accounts of how a build-up of stress can lead to some crisis point, such as a breakdown. Also included in the Pearlin et al. (1990) model, as secondary stressors, are 'intrapyschic strains', including role captivity and loss of self. The current study would point to these concepts as being useful in helping to gauge individual experiences of stress. Some of the accounts covered issues such as the necessity of caring for a loved one and the challenges this posed for the 'authentic self', as defined by participant Michelle.

Participants also gave differing accounts of coping styles and factors which were helpful. While Douglas felt 'forearmed' by information about what would happen in the future, Mary gave an account of keeping information in a drawer until she was ready to access it. An IPA study carried out by Wawrziczny, Pasquier, Ducharme, Kergoat and Antoine (2015) also found this divergence, with the results suggesting that there was a temporal element to information-seeking; participants appeared to seek information at crucial points (such as diagnosis) but to avoid it at other times as a strategy for minimising distress.

There was divergence in terms of how caregivers saw their own abilities or personalities in terms of 'fit' for the challenges. While some participants described an increase in self-confidence gained by facing up to challenges, others appeared to feel that some core aspect of their selves could be working against the accomplishment of challenges, such as Ruth's feeling that her anxiety interfered with her ability to deal with the inherent risks of caregiving. These findings were echoed in a Singapore-based IPA study by Tuomola, Soon, Fisher and Yap (2016), who found that participants either felt that they were developing in positive ways or that they were failing.

There were also accounts of caregivers feeling that they were working outside of their own comfort zones in caring, indicating a sense of role strain and the taking on of roles for which they could not have prepared. These accounts would appear to indicate that attempts to support caregivers should pay attention to the fact that individuals may feel more or less comfortable with the caregiving role and more or less challenged personally by its requirements.

4.7.3 Caring and Others

The next superordinate theme, Caring and Others, arose from accounts of significant other people in the participants' lives. There was both convergence and divergence among participants. For example, the theme of Families and Dementia came up for all participants, but with a great deal of variety in the accounts: in some cases, family members had provided crucial support or information to the caregiver, while in others, their input had contributed to stress and distress. There was often a sense of family relationships being tested in some way or seen in a new light following the diagnosis of dementia; for Cathy, a history of enjoyable holidays with family members was transformed into a negative experience when the family members began to want to exclude her partner. Cathy's experiences echo some of those found by Stokes et al. (2014), an IPA study in which caregivers described becoming more isolated from friends and family who did not know how to respond after a diagnosis of dementia.

Similarly, some participants saw the wider community as an important source of support, while others felt they did not want to rely on such support, and felt that others would not be in a position to offer it. There was also divergence between participants on their perceptions of peer support, with some participants feeling that peers could offer

information and emotional support that they could not get from anyone else, while others felt that time spent with peers could be difficult.

Looking at the role played by others in stress and coping models, Haley et al. (1987) included Social Support in their proposed model, mediating between stressors and the experience of stress. Pearlin et al. (1990) painted a more detailed picture of various ways in which families and other people can come into play in the stress process, describing their importance at several different stages. For example, family composition can be an important aspect of the context or background in this model, as well as being a secondary source of stress (due to family conflicts) and a mediating factor (social support). The experiences described in the present study would agree with the more complex reading of the range of roles which can be taken by family members and significant others.

Bunn et al. (2012), in a review of qualitative studies, propose some possible sources of relationship tension arising when a person is diagnosed with dementia. For example, they propose that people with dementia, their carers and families may be torn between acknowledging the changes brought about by dementia and striving to maintain the identity of the cared-for person prior to the diagnosis. Factors such as peer support or maintaining a social life could be seen as either positive or negative, considered alongside these competing aims. This study, like the present one, captures some of the complexities and tensions found when looking at the impact of dementia and caring on relationships with others.

These results in turn would suggest that any approach to supporting caregivers should allow for the fact that other people in the caregiver's life may be a potential source of support or a potential source of stress and distress. In particular, since a lot of supportive work is carried out in the form of groups and group work, it should be borne in mind that caregivers do not have uniform experiences of this type of support, and it may be necessary to consider offering support in a range of ways, or to monitor closely group dynamics and instances when the company of peers may not be a positive experience.

4.7.4 The Care System

The final superordinate theme, The Care System, arose from indications in the participant interviews about the roles played by formal support services, including services aimed both at the caregiver and the cared-for person. This theme was

referenced by all participants and in fact was notably prioritised by some participants over other themes; it appeared that services were highly prominent in participants' accounts of stress and coping. Although all participants gave at least one account of receiving positive support or having a positive relationship with a service provider, the overall picture was typically complex, with themes around Power, Authority and Conflict, Unmet Needs and Systems versus Individuals also emerging.

Looking at stress and coping models of caregiving stress, there appears to be only a minimal focus on the role of services. 'Social support', described as a mediator in the Haley et al. (1987) model, may include support from services, although this is not discussed explicitly in the paper. In the more detailed model by Pearlin et al. (1990), 'Program Availability' is named as a factor in the background and context to caregiving stress, and information-seeking behaviour is considered as an aspect of caregivers' management of their situation. However, these models do not include any wider discussion of aspects such as relationships between caregivers and services. Rather, stress and coping models have been used to inform the design of interventions, as discussed in Chapter 2; many previous intervention studies have been based upon the aspects of these models that are modifiable and could potentially alleviate stress.

Previous attempts have been made to examine dementia caregivers and service use. Brodaty, Thomson, Thompson and Fine (2005) looked at reasons for lack of service uptake in community-based caregivers in Australia, and found that non-use of services was due mainly to people either not knowing about services or feeling that they did not need help. The questions used in that study were developed from a literature search exploring instances of non-use of services and possible reasons for this, so there was no in-depth exploration of caregivers' feelings in relation to services or professionals. Sutcliffe, Roe, Jasper, Jolley and Challis (2015) carried out focus groups with UK caregivers and people with dementia, asking about their experiences with support services. The results of this study had some overlap with the current study, in terms of the issues raised about services by caregivers; for example, some concerns were raised about support at the diagnostic stage. However, a study by Boots, Wolfs, Verhey, Kempen, and de Vugt (2015), again using focus groups, identified what the authors described as an 'early-stage needs paradox'. In this study, participants who were at a later stage of caregiving spoke about their earlier needs in retrospect, defining gaps in the support they believed they had needed at this stage. Caregivers who took part at the early stage of caregiving did not easily identify these issues, however, but appeared to

have more difficulty in acknowledging and defining their needs. As the present study involved participants who had been caregiving for some time, the Boots et al. (2015) study may have some relevance to the findings here.

Previous research has also indicated the impact of positive working relationships with professionals. Karlsson et al. (2015), in a large-scale study using focus groups in eight European countries, found that people with dementia and their carers prioritised person-centred care and a trusting relationship with a single contact person when they spoke about their definitions of good practice. Looking at long-term care situations from the point of view of professional caregivers, interpersonal relationships also emerged as a central theme (Canham et al., 2016).

Using focus groups with caregivers, Landmark, Aasgaard and Fagerström (2013) found that relationships with home care providers were threatened by factors such as care being too task-oriented rather than person-centred, relevant to the theme of 'Systems versus Individuals' found in this study. Participants in the IPA study by Stokes et al. (2014) communicated a lack of partnership working as a problem with formal services.

Looking at the results of this study, it appears that for participants, services and the care system did not play a simple role in addressing the stressful aspects of caregiving. The role of services was a much more complex and varied one, ranging from experiences in which professional workers were seen as contributing additional positive relationships, to ones in which caregivers felt that they were in direct conflict with workers. There was a sense that the 'care system' was something to be negotiated, involving a new set of rules and relationships, new information to be sought and learned and a new range of settings and situations in which participants had to consider their own and their relative's positions.

It was notable that participants often described their positive service encounters in terms of the personal qualities of individual workers, or their relationships with these workers. Participants also described a range of negative experiences, which in some cases appeared to involve a feeling of conflict between the views of the professional and the caregiver, and sometimes appeared to reflect some problem with the 'system' itself (notably, Michelle described the 'hearts of gold' of social workers against their being 'part of the problem').

Although interventions aimed at helping caregivers tend to take place in locations such as carers' centres, or in specific groups aimed at carers, in reality these are often

accessed via the same ‘gatekeeping’ or referral agencies as care for the person with dementia. In some cases, services for caregivers and the cared-for person are delivered by a local authority, or there is some formal system of referral in order to access support. The results of the current study would suggest that this is an aspect of supporting caregivers which would benefit from further exploration, as it is possible that caregivers’ experiences of and feelings about professional help may well feature in their decisions about seeking this type of support for themselves.

4.8 Conclusion

The interviews conducted for this study have helped to construct an in-depth picture of the experiences of a sample of informal caregivers, in terms of their experiences of stress and coping. The use of IPA facilitated an exploration of convergence and divergence in participants’ experiences; for example, while The Care System appeared to feature prominently for all caregivers in managing stress, their accounts, feelings and experiences reflected a great deal of individual difference.

Comparing the results of this study to existing models of caregiving stress and coping (Haley et al., 1987; Pearlin et al., 1990), there was support for dynamic models of stress, which allow for individual factors such as appraisal to influence the stress experienced by caregivers. The results here would support more complex models of stress and coping; for example, participants’ accounts involving families, friends and communities suggest that these figures can contribute in various ways, being both a source of additional stress and a source of coping, as suggested in the Pearlin et al. (1990) model.

Additionally, the results of this study would support a greater focus on caregivers’ experiences of, and relationships to, services and professionals. Although stress and coping models are used to inform interventions for supporting caregivers, the current study would support an increase in attention paid to factors such as relationships between workers and caregivers, the overall service structure in which caregiver support is accessed, an individual’s prior experiences with services, the delivery of support in groups or individually, and so on. A consideration of these factors, which tend not to be taken into account in intervention literature (studies based on the Haley et al. (1987) or Pearlin et al. (1990) models have focussed primarily on reducing negative outcomes by targeting modifiable factors such as confidence and self-efficacy), would assist in the rolling out of caregiver interventions into real-world, community settings.

In summary, the in-depth accounts here have illustrated a complex picture of caregiving stress, with many individual factors coming into play. Based on these accounts, attempts to support caregivers should be delivered with sufficient flexibility to respond to the needs of individuals. Caregiver stress appeared in this study not to relate solely to the needs of the person with dementia or to the symptoms of dementia, but included issues around loss and changing relationships, and the progressive, unpredictable nature of dementia. Individuals could feel personally challenged by the caregiving role in a number of ways, and often appeared to engage in weighing up their own skills and personalities in relation to the demands of caregiving. The role played by other personal relationships, including those with peers, was varied and could not be gauged simply by measuring the presence or availability of others. Finally, services themselves played a highly prominent role in participants' accounts, and it would seem prudent for services delivering support to focus on the nature of relationships between workers and service users, the ease with which support can be accessed, and the flexibility of programmes to enable individual caregivers to relate the content to their own experiences. The results here would suggest that during the design and planning of interventions, attention should be paid to the ways in which the intervention will be delivered (for example, the type of service likely to offer the intervention, and how this will be accessed), information needed at the start of the intervention, and ways of building positive relationships between service providers and receivers.

Chapter 5 – Caregiving Self-Efficacy, Depression and Burden: an effectiveness study of a manual-based intervention

5.1 Introduction

As discussed in Chapter 2, self-efficacy (for example, Bandura, 1977) has been suggested in previous research to be a promising protective factor against negative outcomes for caregivers of a person with dementia. As there is an identified need for studies using an intervention or longitudinal design, an intervention study was designed to target three aspects of caregiving self-efficacy identified in previous work: Self-Efficacy for Dealing with Disruptive Patient Behaviours, Self-Efficacy for Controlling Upsetting Thoughts About Caregiving, and Self-Efficacy for Seeking Respite (Steffen et al., 2002).

The aim of the present study was to deliver a manual-based intervention, based on three relatively short sessions addressing these three aspects of caregiving, and to explore outcomes related to caregiving stress. As discussed in Chapter 2, there is also a dearth of literature on brief interventions intended for caregivers of a person with dementia, and the manual written for this study was designed to be used as a shorter intervention which would take into account the time constraints on caregivers, the changing demands of caregiving and the resource limitations of services. The aim was to produce an intervention which, should it prove to be beneficial, could be disseminated relatively easily within a community setting.

Following the pilot test of the intervention reported in Chapter 3, the current study targeted informal caregivers, using the intervention manual which had been written for the pilot study. The manual, which can be found in Appendix C, was subjected to minor modifications following feedback obtained during the pilot study; in particular, a goal-setting exercise at the end of Section 1 was shortened for clarity and to fit with the pace and timing of the sessions.

A further change made for the present study, described in Chapter 3, was to offer the intervention to individual participants as well as groups of caregivers. It was anticipated that this would allow the study to have greater reach and by implication, greater utility with busy caregivers who may find it difficult to attend groups at fixed times without the cared-for person. Dura and Kiecolt-Glaser (1990), in a study addressing selection

bias in caregiver research, recommended that interventions should be offered to people at home as well as people able to travel, as they found that caregivers who could not travel tended to have higher levels of depression and to be caring for people with higher levels of behavioural difficulties.

As the current study used a design in which participants were asked to take part in groups, individually or in a control condition according to their own preferences, it should be stated from the outset that this study has a quasi-experimental design, with the purpose of examining the intervention as it might be used in a realistic setting. This point is relevant to the debate around efficacy and effectiveness studies (Singal, Higgins & Waljee, 2014). Briefly, efficacy studies tend to take place under controlled conditions, with strict exclusion criteria, controlling for concurrent interventions and standardised conditions of delivery of the intervention. A randomized controlled trial would be an example of an efficacy study. Effectiveness studies look at the intervention with more of a 'real world' focus, allowing for participants to have concurrent involvement in other treatments, using fewer exclusion criteria and using a more flexible approach in the delivery of the intervention. The current study was aimed at capturing a sense of the effectiveness of an intervention, and involved making pragmatic recruitment decisions in order to offer participation to as wide a range of informal caregivers as possible.

5.1.1 Research Questions and Hypothesis

The current study aimed to address three research questions in relation to the caregiver self-efficacy intervention:

1. Were there observable improvements in caregiver outcomes immediately after the third intervention session, in participants who took part in the intervention versus controls? Improvements would be indicated by reductions in depression, burden and reaction to stressor scores, and by increases in self-efficacy scores.
2. Were there observable improvements three months after the third intervention session in the same outcomes, in participants who took part in the intervention versus controls?
3. What role, if any, was played by self-efficacy in the results?

Related to these research questions was the hypothesis that participants who received the intervention would experience improved outcomes (reductions in depression, burden

and reaction to stressors, and increases in self-efficacy), compared to control participants. These questions and hypothesis were used to guide the analytical approach used in this study, and they will be revisited in the Results section.

5.2 Methods

5.2.1 Recruitment Strategy

Participants were informal caregivers of a person with dementia. Participants self-defined as caregivers and no external measure of their caregiving responsibilities was required. Caregiving for the purpose of the study incorporated a range of caregiving tasks, including providing assistance with activities of daily living, providing emotional support, and providing practical assistance to the person with dementia. Spouses, children of a person with dementia and other close friends or family members were included in the study, and there was no restriction on whether or not the caregiver was living with the person with dementia.

Inclusion and exclusion criteria were used to identify suitable participants. Inclusion criteria involved the participants being adults aged over 18. Exclusion criteria focussed on the presence of any condition which would make it difficult for the individual to give informed consent for participation, such as a diagnosis of dementia or self-reported depression. The study therefore did not include any participants who would be classed as vulnerable adults. These criteria were applied using the advice of staff members in agencies who helped with recruitment, in addition to self-reporting from potential participants.

Recruitment took place in the Central Belt of Scotland, including Glasgow and Edinburgh and the surrounding areas. Initially, the study was adopted by the Scottish Clinical Dementia Research Network, which meant that an existing database could be accessed as a potential source of participants. Letters were sent out to caregivers using this database, enclosing information about the study, and individuals were asked to indicate whether they would be interested in finding out more about the study or taking part. To accommodate the other commitments of caregivers and to take into account advice from the pilot study, caregivers were asked to indicate whether they would be interested in taking part in a group intervention, an individual intervention or by completing questionnaires (that is, participating in the control condition).

Following this, suitable agencies were identified and contacted. These included carers' centres, dementia services which could be accessed by the caregiver as well as the person with dementia, local council services, private care agencies and carers' networks. These agencies were sent information about the studies, including information that could be passed on directly to carers, and they were asked if it would be possible for me to visit, either to speak with staff about my research or to speak directly to carers. Recruitment continued over a period of approximately two years, and Figure 5.1 below illustrates the number of agencies who took part in recruitment, and the number of participants recruited to the study as a result. The numbers in the top two boxes of this figure refer to number of organisations, while the numbers in the remaining boxes refer to number of participants.

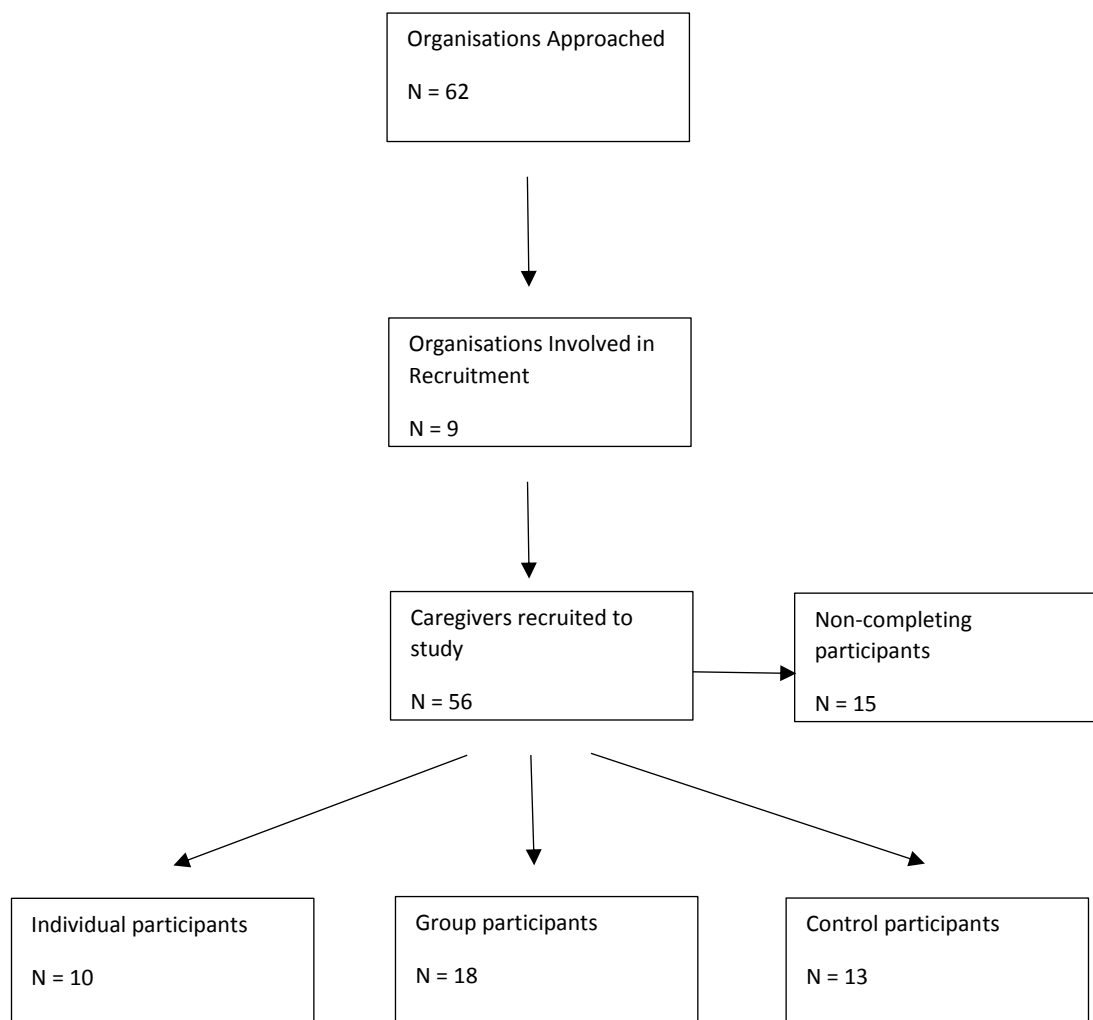


Figure 5.1 Recruitment flow chart for the intervention study

The role played by gatekeepers (people or organisations in a position to control access to research participants) is discussed by McFadyen and Rankin (2016), who followed up contact with gatekeepers to clarify their reasons for agreeing or refusing access to participants, and used reflective practices to determine areas of good practice and areas for improvement. Although no formal follow-up with gatekeepers was conducted in the present study, some information was offered by organisations who had been approached to take part.

Consideration was given to the reasons given by agencies about whether they could or could not become involved with the recruitment, as these reasons may have some relevance to the study. One carers' centre fed back that the reason they had wanted to become involved was that the study appeared to offer something positive to the carers, rather than simply gathering information from them. Staff at this centre saw the study as being something they could offer in addition to their usual programme.

Various reasons were given by agencies for not wanting to become involved with the study. These included being involved with other research already and not wanting to overload staff or carers, previous experience of involvement with research in which few carers had wanted to take part, and a reluctance to ask carers to do something else in addition to their existing busy schedules. These reasons have some similarities to the feedback from gatekeepers reported by McFadyen and Rankin (2016), in relation to recruiting vulnerable young people; among the feedback from gatekeepers in this study was the belief that individuals and organisations would not want to take part in research.

For the purposes of conducting research, it is important to identify ways of involving gatekeepers which may increase the likelihood of gaining access to participants. Ideas suggested by McFadyen and Rankin (2016) include involving potential gatekeepers at the planning stage of the research, and requesting the involvement of gatekeepers in designing a recruitment strategy. Similarly, Sixsmith, Boneham and Goldring (2003) discussed a process of identifying gatekeepers and the need to focus on issues around gatekeeping, including the possibility of gatekeepers selecting certain people to put forward as participants, which can in turn influence the course of research.

Although the current research involved the intervention being led by the researcher, it is also possible that some of the reservations expressed by gatekeepers would have to be considered in any future roll-out of the intervention, to overcome potential barriers.

56 caregivers gave signed consent to participate in the study, with 15 not completing all stages (most withdrawals occurred after one or two sessions of the intervention). Most of these caregivers withdrew giving a reason, including family emergency (n=5), placement of the person with dementia in residential care (n=1), holiday commitments (n=1) and death of the person with dementia (n=1). In addition to the 56 people who gave signed consent, a further group of seven caregivers verbally agreed to take part, but this did not proceed due to organisational difficulties concerning the referral service.

Of the 41 caregivers who completed the study, 10 chose to take part as individual participants, 18 as group participants and 13 as control participants. Control participants were those who had agreed to take part by completing outcome questionnaires initially, and who were subsequently offered the intervention; 7 control participants opted to receive the intervention.

Individual interventions were delivered mainly in caregivers' homes, if they felt this was appropriate and could identify some time in which they could have one-to-one discussions at home. Two of the individual caregivers chose to meet outside of the home instead, in suitably quiet public places. The group interventions took place in carers' centres or in meeting rooms. Consideration was given to the conditions for the control group, and it was initially proposed that control participants could be invited to informal meetings, to provide a contrast between meetings involving the intervention and unstructured meetings. However, the preferences and commitments of the control participants indicated that this was not possible for everyone and so, in order to have a control group, it was agreed that these participants would complete the same pre- and post- measures without having to attend any meetings. Control participants were given information and support where needed to complete the outcome measures. As will be shown in the demographic information below, all but one of the control participants already had some service involvement, minimising the chance that any observations about this group could be attributable to social isolation. The control group conditions for this study, therefore, were similar to 'usual care' control groups described in other caregiver intervention studies (for example, Teri et al., 2005; Jensen et al., 2015; Ducharme et al., 2011).

5.2.2 Intervention

The intervention used for this study is described in Chapter 3. Following on from the pilot study reported in Chapter 3, minor changes were made to the intervention manual, mainly to improve the timing and flow of the sessions. A full copy of the intervention manual can be found in Appendix C.

The intervention was delivered in three sessions of approximately 90 minutes each, with each session covering one section of the manual. The three sections were Coping with Behavioural Aspects of Dementia, Coping with Difficult Feelings and Taking Breaks. Although the three areas covered by the intervention were aimed at the same areas defined by Steffen et al. (2002), slightly different titles and language were used in the intervention and its delivery, to make the language of the intervention more neutral and to avoid the use of terms such as ‘patient’, which are increasingly seen as examples of ‘negative’ language in reference to people with dementia. The impact of using ‘positive’ and ‘negative’ language in relation to dementia will be discussed further in Chapter 7.

Because participants were offered the choice between group, individual and control participation, the study design was quasi-experimental and there was no attempt to achieve random allocation; this was necessary to work with the availability and preferences of participants. In practice, groups tended to be formed around carers’ centres in which staff were particularly proactive in arranging group spaces and inviting caregivers to take part, although within these centres, some participants did choose to take part individually rather than in the group.

Group sizes in the current study ranged from three to eight participants. There has been a small body of literature exploring optimal group sizes for therapeutic interventions, with a broad consensus indicating that groups should contain fewer than ten participants (for example, Fulkerson, Hawkins and Alden (1981) found five participants to be optimal, while Hollon and Shaw (1979) recommended no more than six participants for one therapist). These recommendations have arisen from a broader intervention literature and are not specific to the field of caregiver interventions. Comparing the current study with other caregiver intervention studies, Coon et al. (2003) used small groups of eight to ten participants, while Losada et al. (2011) specified a maximum of eight participants per group.

At the beginning of Session 1 of the intervention, a short period of time was allocated for introductions and information about the study. Participants were given time to ask

any questions they had about the study, and were then asked to give written informed consent to take part. Following this, participants were asked to complete demographic information and an initial set of outcome measures; these measures are described below. The first intervention session was then facilitated, using Session 1 of the intervention manual (Appendix C) as the basis for the discussion and activities, and encouraging participants to consider their own experiences wherever possible when carrying out the activities.

The delivery of the session was informed by the four ways in which Bandura (1977) proposed that self-efficacy could be built: gaining mastery over tasks, observing appropriate models, social persuasion and minimising stress reactions. For example, it was anticipated that activities which involved trying out new techniques could, if practised successfully, foster a sense of mastery. In the group settings, participants were encouraged to share tips or experiences which may be helpful to others, meeting the criteria for modelling. Social persuasion was provided via the leading of the sessions (for example, through the use of encouraging comments), while there was a focus on having a relaxed, informal atmosphere, as well as the explicit use of relaxation techniques in the second session.

The second and third intervention sessions were delivered at weekly intervals thereafter. Each of these sessions began with a 'check in', in which participants were encouraged to raise any particular experiences they wanted to talk about from the last week, or to talk about something they had tried following the previous session. A similar 'check in' format was reported by Coon et al. (2003). The remaining parts of these sessions were based on Sessions 2 and 3 in the intervention manual, with participants again encouraged to base their participation on their own experiences if they felt comfortable doing so.

Directly following the third session, participants were asked to complete a second set of outcome measures. Participants who consented to being contacted again were contacted three months after the third intervention session, and asked to complete the outcome measures for a final follow-up.

5.2.3 Demographic information and outcome measures

At the first meeting with each participant, demographic information was collected. This included the participant's age, sex, ethnicity, time (in years) involved in caring for the

person with dementia, and whether the participant lived with the person with dementia. Participants were also asked for brief details of any formal support they received; this could include carers' services, respite or assistance with caring for the person with dementia. As will be discussed below, this demographic information was used in the analysis, to explore possible differences between participants who elected to take part in the different conditions of the intervention.

At each time point in this study (pre-intervention, post-intervention and three months after intervention, or equivalent times for the control participants), participants were asked to complete outcome measures as detailed below. Copies of these questionnaires can be found in Appendix G.

Revised Scale for Memory and Behavior Problems Checklist

The Revised Scale for Memory and Behavior Problems Checklist (RMBPC), developed by Teri et al. (1992), provides a measure of presenting issues of the person with dementia (including memory, affect and behavioural symptoms) and a corresponding measure of the reactions of the caregiver. The questionnaire requires caregivers, for a list of 24 problems, to circle 'yes' or 'no' to indicate the presence or absence of each problem in the last seven days (for example, 'Asking the same question over and over'). For any item which has been circled 'yes', the caregiver is then asked to indicate, on a scale of 0 ('not at all') to 4 ('extremely') how bothersome the problem was. This measure therefore serves both as an indicator of the presence of potential stressors (used in the present work to indicate an objective measure of stressors) and of reactions (used in the present study as a gauge of stress experienced). Teri et al. (1992) reported good reliability scores for the scale, with Cronbach's alpha values of .84 for the behavioural symptoms list and .90 for the caregiver reaction scale.

Caregiver External Stressors Scale

The Caregiver External Stressors Scale (CESS) was devised specifically for this study, in response to external sources of stress disclosed by participants in the pilot study reported in Chapter 3. Although the present intervention study did not target external stressors and no significant change was anticipated in this measure as a result of the intervention, it was included as an attempt to gauge the extent of other sources of stress

experienced by participants. The development of this scale was informed both by issues arising from the pilot study and consideration of appropriate formatting and scoring of the questions; however, it should be noted that this scale requires further testing and development.

The CESS follows a similar design to the RMBPC, by including both an objective indicator of the presence of stressors and a gauge of stress experienced. For each of six items, participants were asked to indicate the presence or absence of a problem in the last three months and, for any item indicated by circling 'yes', to use the same scale of 0 to 4 detailed above to describe how stressful or bothersome the problem was for the participant. Items included 'problems with finances or benefits', 'not knowing where to get help' and 'problems with professional care'. The timescale of three months for these problems was determined in response to caregivers' accounts of the timescales for experiencing these issues.

Revised Scale for Caregiving Self-Efficacy

The Revised Scale for Caregiving Self-Efficacy (Steffen et al., 2002) is a measure aimed specifically at measuring self-efficacy of caregivers of people who have dementia. The questionnaire consists of 15 items presenting different caregiving challenges, and caregivers provide a percentage (0-100) to indicate how confident they would feel about meeting each of these challenges. Questions include, 'How confident are you that you can control thinking about unpleasant aspects of taking care of ___?' The scale consists of three sub-scales: self-efficacy in relation to obtaining respite (SE-OR), self-efficacy in managing difficult behaviours presented by the person with dementia (SE-DB) and self-efficacy in controlling difficult thoughts about caregiving (SE-CT). Each sub-scale is measured using five items. Steffen et al. (2002) reported Cronbach's alpha values of over .80 for each of the three sub-scales, and adequate test-retest reliability (Cronbach's alpha values between .70 and .76 for each of the sub-scales), arguing that self-efficacy scores can be reflective of recent events and would not be expected to remain stable.

Centre for Epidemiologic Studies Depression Scale

The Centre for Epidemiologic Studies Depression Scale (CESD) is a 20-item, self-rating scale devised by Radloff (1977). Each item represents a possible feeling (for example, 'I was bothered by things that didn't usually bother me'), and participants indicate how often in the last week they have experienced that feeling (ranging from 'Rarely or none of the time (less than one day)' to 'Most or all of the time (5-7 days)'). The CESD is not a dementia- or caregiving-specific questionnaire; it was written as an indicator of depressive signs in the general population. Radloff (1977) looked at the reliability of the CESD across different demographic groups, and found alpha values exceeding .80 for each group.

Zarit Burden Interview

The Zarit Burden Interview (ZBI), conceived originally as a 29-item list by Zarit et al. (1980) and later revised, was used here as a measure of caregiver burden. This questionnaire is aimed at caregivers of people who have dementia, and consists of 22 questions, such as, 'Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?'. Responses for each question are on a 0-4 scale, with 0 representing 'never' and 4 representing 'nearly always'. Hébert, Bravo and Prévile (2000) examined the reliability and validity of the ZBI, finding it to have an alpha value of .92 and to correlate positively to behavioural problems of the person with dementia and the depression (CESD) score of the caregiver.

5.3 Results

5.3.1 Data input and audit of dataset

Before beginning any statistical analysis for this study, questionnaire scores for each participant were calculated using the paper copies of outcome measures completed during the study. A dataset was created using the statistical program, SPSS. Following data input, a full data entry audit was completed. This allowed any errors to be identified and corrected prior to analysis.

5.3.2 Demographic information and baseline scores

Demographic information for participants, including those who did not complete the intervention or equivalent control period, is shown in Table 5.1. Two of the non-completing participants did not give baseline paperwork, and so are not represented in this table. Chi-square and Kruskal-Wallis tests were used to determine whether or not there were any significant differences between the individual, group, control and non-completing participants at baseline. Because several of the control participants had indicated at sign-up that they were available for any of the conditions, and to avoid overstating any differences at baseline due to the presence of these participants, baseline comparisons were repeated omitting the control participants. These results are also reported in Table 5.1.

Looking at the baseline comparisons, significant differences were found between the groups on the demographic factors of Relationship to Person with Dementia (individual participants were more likely than group or non-completing participants to be spouse carers), Age of Caregiver (individual participants were on average older than participants in the other categories) and Living with the Person with Dementia (individual participants were more likely to be living with the person with dementia than group or non-completing participants). Each of these results was significant at the $p < 0.05$ level. For baseline scores on the outcome measures (Table 5.2), no significant differences were noted when excluding control participants.

Table 5.1 Demographic Information (* denotes significance of $p < 0.05$).

	Individual (N=10)	Group (N=18)	Control (N=13)	Non- Completing (N=13)	<i>p</i>	<i>p</i> <i>(control participants omitted)</i>
Gender of Caregiver						
<i>Female</i>	9 (90%)	13 (72.2%)	10 (76.9%)	11 (84.6%)	0.68	0.47
<i>Male</i>	1 (10%)	5 (27.8%)	3 (23.1%)	2 (15.4%)		
Relationship to PWD						
<i>Spouse</i>	8 (80%)	4 (22.2%)	9 (69.2%)	2 (15.4%)	0.08	0.01*
<i>Child</i>	2 (20%)	11 (61.1%)	4 (30.8%)	9 (69.2%)		
<i>Other</i>	0	3 (16.7%)	0	2 (15.4%)		
Age of Caregiver						
<i>Mean (S.D.)</i>	69 (9.0)	57 (15.3)	62.2 (9.5)	52.6 (15.4)	0.02*	0.02*
<i>Range</i>	52-80	19-76	40-80	26-83		
Length of Caregiving (Years)						
<i>Mean (S.D.)</i>	5.2 (3.8)	3.2 (4.0)	3.6 (2.2)	4.2 (2.9)	0.07	0.06
<i>Range</i>	1-15	1-18	1-10	1-10		
In Receipt of Formal Support?						
<i>Yes</i>	9 (90%)	10 (55.6%)	12 (92.3%)	10 (76.9%)	0.07	0.13
<i>No</i>	1 (10%)	8 (44.4%)	1 (7.7%)	3 (23.1%)		
Living with PWD?						
<i>Yes</i>	10 (100%)	10 (55.6%)	10 (76.9%)	6 (46.2%)	0.03*	0.02*
<i>No</i>	0	8 (44.4%)	3 (23.1%)	7 (53.8%)		

Note: Baseline information was available for 13 of the non-completing participants.

PWD denotes person with dementia.

Table 5.2 Baseline Scores by Condition (* denotes significance at $p < 0.05$)

	Individual (N=10)	Group (N=18)	Control (N=13)	Non- completing (N=13)	<i>p</i>	<i>p</i> <i>(control participants omitted)</i>
RMBPC						
score						
(Number)						
<i>Mean (S.D.)</i>	13.0 (2.1)	11.3 (3.4)	10.2 (3.6)	15.4 (4.8)	0.03*	0.07
<i>Range</i>	10-17	6-16	4-16	8-23		
RMBPC						
score						
(Reaction)						
<i>Mean (S.D.)</i>	25.6 (9.2)	21.8 (14.7)	18.0 (8.2)	33.4 (20.2)	0.14	0.26
<i>Range</i>	6-34	6-50	4-34	9-66		
CESS score						
(Number)						
<i>Mean (S.D.)</i>	1.0 (1.1)	2.4 (1.9)	1.4 (1.3)	2.2 (2.0)	0.25	0.19
<i>Range</i>	0-3	0-6	0-4	0-5		
CESS score						
(Reaction)						
<i>Mean (S.D.)</i>	2.8 (3.7)	5.6 (6.1)	3.4 (3.4)	5.6 (5.3)	0.48	0.35
<i>Range</i>	0-10	0-19	0-11	0-15		
CESD score						
<i>Mean (S.D.)</i>	14.7 (7.2)	14.6 (12.5)	15.2 (10.6)	19.1 (9.3)	0.56	0.38
<i>Range</i>	4-27	0-46	0-31	3-34		
SE-OR score						
<i>Mean (S.D.)</i>	53.9 (38.6)	73.4 (28.8)	51.1 (31.5)	51.3 (31.4)	0.15	0.16
<i>Range</i>	0-100	10-100	0-100	8-100		
SE-DB score						
<i>Mean (S.D.)</i>	57.2 (32.1)	76.7 (20.4)	55.8 (26.0)	63.4 (29.9)	0.15	0.18
<i>Range</i>	4-97	40-100	0-100	10-100		
SE-CT score						
<i>Mean (S.D.)</i>	66.9 (24.0)	74.1 (21.1)	76.9 (19.9)	62.1 (30.6)	0.48	0.42
<i>Range</i>	32-98	26-96	50-98	0-100		
ZBI score						
<i>Mean (S.D.)</i>	35.6 (15.7)	29.6 (16.1)	35.0 (15.3)	39.7 (20.9)	0.38	0.23
<i>Range</i>	9-67	5-68	12-60	3-78		

The maximum scores for the measures used were as follows:

Revised Memory and Behavior Problems Checklist (RMBPC) (number) – 24

RMBPC (reaction) – 96

Caregiver External Stress Scale (CESS) (number) – 6

CESS (reaction) – 24

Centre for Epidemiologic Studies – Depression (CESD) – 60

Self-Efficacy for Obtaining Respite (SE-OR) – 100

Self-Efficacy for Responding to Disruptive Patient Behaviors (SE-DB) – 100

Self-Efficacy for Controlling Upsetting Thoughts about Caregiving (SE-CT) – 100

Zarit Burden Interview (ZBI) – 88.

5.3.3 Inferential statistics addressing Research Question 1 – pre- and post-intervention comparisons

The first step in using inferential statistics concerned Research Question 1: ‘Were there observable improvements in caregiver outcomes immediately after the third intervention session in participants who took part in the intervention versus controls?’ Improvements would be indicated by reductions in depression, burden and reaction to stressor scores, and by increases in self-efficacy scores.

To compare the pre- and post-intervention scores of the intervention and control participants, Mann-Whitney tests were carried out for each outcome variable using SPSS. This non-parametric test was selected as a conservative approach to analysing the data, due to the non-normal distributions of scores. Table 5.3 details the pre- and post-intervention means for intervention participants and control participants. At this stage in the analysis, individual and group participants were grouped together as ‘intervention participants’, to gain a direct comparison with the control group.

Table 5.3 Pre- and post-intervention mean scores for intervention vs. control participants, and results of Mann-Whitney comparisons of change scores (* denotes $p < 0.05$)

	Intervention (N=28) Mean (s.d.)	Control (N=13) Mean (s.d.)	Mann-Whitney U	p
RMBPC-number (pre)	11.9 (3.1)	10.2 (3.6)	124.50	.272
RMBPC-number (post)	10.6 (4.1)	11.1 (3.7)		
RMBPC-reaction (pre)	23.1 (12.9)	18.0 (8.2)	86.00	.015*
RMBPC-reaction (post)	17.9 (12.4)	20.1 (10.8)		
CESS-number (pre)	2.0 (1.8)	1.4 (1.3)	129.50	.986
CESS-number (post)	2.0 (1.7)	1.4 (1.4)		
CESS-reaction (pre)	4.7 (5.5)	3.4 (3.4)	127.50	.931
CESS-reaction (post)	4.9 (5.2)	4.2 (4.6)		
CESD (pre)	14.6 (10.8)	15.2 (10.6)	118.00	.075
CESD (post)	11.9 (8.5)	15.8 (11.4)		
SE-OR (pre)	66.4 (33.3)	51.1 (31.5)	123.00	.346
SE-OR (post)	70.1 (26.5)	56.9 (31.4)		
SE-DB (pre)	69.7 (26.4)	55.8 (26.0)	151.50	.631
SE-DB (post)	77.1 (20.3)	67.1 (25.7)		
SE-CT (pre)	71.5 (22.0)	76.9 (19.9)	123.50	.192
SE-CT (post)	77.8 (13.9)	74.7 (18.9)		
ZBI (pre)	31.9 (15.9)	35.0 (15.2)	93.50	.016*
ZBI (post)	29.9 (15.8)	38.5 (13.4)		

RMBPC: Revised Memory and Behavior Problems Checklist; CESS: Caregiver External Stress Scale; CESD: Centre for Epidemiologic Studies – Depression; SE-OR: Self-Efficacy for Obtaining Respite; SE-DB: Self-Efficacy for Responding to Disruptive Patient Behaviors; SE-CT: Self-Efficacy for Controlling Upsetting Thoughts about Caregiving; ZBI: Zarit Burden Interview.

The results displayed in Table 5.3 show that when a direct comparison is made between intervention and control participants, significant differences are found for two of the outcome measures: RMBPC-reaction (caregiver reaction to behavioural stressors; $U=86.00, p=.015$) and ZBI (caregiver burden; $U=93.50, p=.016$). These results mean that from pre- to post-intervention, participants receiving the intervention showed significantly reduced reaction to caregiving stressors, and significantly reduced burden, when compared to control participants. These results support the hypothesis underlying the first research question; the intervention led to improve outcomes as predicted for two of the outcome measures. No significant benefits were observed for the other outcome measures (depression and self-efficacy scores).

To examine these results more closely, the category 'intervention participants' was then broken down further into 'individual participants' and 'group participants', and further Mann-Whitney tests were carried out, to explore whether the individual or group delivery of the intervention had any bearing on the results. Table 5.4 below gives the mean pre- and post-intervention scores for individual, group and control participants, and Table 5.5 displays the results of Mann-Whitney tests making these further comparisons.

Table 5.4 Pre- and post-intervention mean scores for individual, group and control participants (standard deviations are reported in brackets)

	Individual (N=10)	Group (N=18)	Control (N=13)
RMBPC-number (pre)	13.0 (2.1)	11.3 (3.4)	10.2 (3.6)
RMBPC-number (post)	11.8 (2.8)	9.9 (4.6)	11.1 (3.7)
RMBPC-reaction (pre)	25.6 (9.2)	21.8 (14.6)	18.0 (8.2)
RMBPC-reaction (post)	22.8 (9.8)	15.2 (13.1)	20.1 (10.8)
CESS-number (pre)	1.0 (1.1)	2.4 (1.9)	1.4 (1.3)
CESS-number (post)	1.2 (1.4)	2.3 (1.7)	1.4 (1.4)
CESS-reaction (pre)	2.8 (3.6)	5.6 (6.1)	3.4 (3.4)
CESS-reaction (post)	3.2 (4.7)	5.5 (5.4)	4.2 (4.6)
CESD (pre)	14.7 (7.2)	14.6 (12.5)	15.2 (10.6)
CESD (post)	12.6 (6.3)	11.4 (9.7)	15.8 (11.4)
SE-OR (pre)	53.9 (38.6)	73.4 (28.8)	51.1 (31.5)
SE-OR (post)	61.0 (28.2)	75.2 (24.9)	56.9 (31.4)
SE-DB (pre)	57.2 (32.1)	76.7 (20.4)	55.8 (26.0)
SE-DB (post)	64.0 (23.3)	84.4 (14.4)	67.1 (25.7)
SE-CT (pre)	66.9 (24.0)	74.0 (21.1)	76.9 (19.9)
SE-CT (post)	72.1 (14.0)	81.0 (13.2)	74.7 (18.9)
ZBI (pre)	35.6 (15.7)	29.6 (16.1)	35.0 (15.2)
ZBI (post)	33.7 (17.0)	27.6 (15.1)	38.5 (13.4)

RMBPC: Revised Memory and Behavior Problems Checklist; CESS: Caregiver External Stress Scale; CESD: Centre for Epidemiologic Studies – Depression; SE-OR: Self-Efficacy for Obtaining Respite; SE-DB: Self-Efficacy for Responding to Disruptive Patient Behaviors; SE-CT: Self-Efficacy for Controlling Upsetting Thoughts about Caregiving; ZBI: Zarit Burden Interview.

Table 5.5 Results of Mann-Whitney tests comparing individual vs. control and group vs. control participants (* denotes $p < 0.025$; significance level corrected for multiple comparisons)

	Ind. vs. Control		Group vs. Control	
	M-W U	<i>p</i>	M-W U	<i>p</i>
RMBPC-no.	45.5	.232	97.0	.441
RMBPC-reac.	36.0	.123	50.0	.013*
CESS-no.	36.5	.762	87.0	.906
CESS-reac.	38.0	.897	89.5	.981
CESD	34.5	.057	83.5	.183
SE-OR	49.5	.705	73.5	.256
SE-DB	50.0	.539	101.5	.787
SE-CT	50.5	.539	73.0	.146
ZBI	36.0	.077	57.5	.025*

RMBPC: Revised Memory and Behavior Problems Checklist; CESS: Caregiver External Stress Scale; CESD: Centre for Epidemiologic Studies – Depression; SE-OR: Self-Efficacy for Obtaining Respite; SE-DB: Self-Efficacy for Responding to Disruptive Patient Behaviors; SE-CT: Self-Efficacy for Controlling Upsetting Thoughts about Caregiving; ZBI: Zarit Burden Interview.

Table 5.5 shows that when comparing the Individual participant group with the Control group, using the change in outcome scores from pre- to post-test, no significant differences were found. Comparing the Group and Control conditions using the change in scores from pre- to post-test, Table 5.5 shows significant differences on the RMBPC-Reaction (stress in response to behavioural issues) scores. Participants who received the group intervention experienced significant improvements in caregiver reaction to problematic behaviours of the person with dementia, as compared to the control group. This result is consistent with the hypothesis that the intervention would be associated with positive caregiver outcomes (in this case, a reduction in subjective evaluation of

the stressfulness of difficult behaviours) as compared to a control condition. Looking at the result for caregiver burden (ZBI) between the group and control participants ($U=57.5, p=.025$), this result is borderline non-significant when adjustment for multiple comparisons is taken into account.

To gain a clearer view of what was happening for each of the three participant groups over the course of the intervention (for example, whether the intervention did not benefit individual participants at all, or whether the above results could be related to the small number of individual participants), within-group comparisons were made. Within-group changes can also show whether an intervention has had a positive effect on participants, or whether intervention participants have remained stable while control participants experienced a decline (Elvish, Lever, Johnstone, Cawley & Keady, 2013). The Wilcoxon signed-rank test in SPSS was selected here, due to non-normal distribution of the outcome measure scores. The Wilcoxon test is usually considered to be a non-parametric test similar to a t-test, and was used in this case to explore within-group differences between pre- and post-test scores.

Table 5.6 below demonstrates the results of conducting the Wilcoxon test for each group of participants. In this case, the test was one-tailed, as the direction of change in the outcome measures could be predicted by a hypothesis: it was hypothesised that participants receiving the intervention would show improvements in outcomes (decreases in depression, burden and subjective stress scores; increases in self-efficacy scores).

Table 5.6 – Wilcoxon test results for individual, group and control participants

(showing Z score with p values in brackets; significant values at the $p < 0.05$ level are denoted by *)

	Individual (N=10)	Group (N=18)	Control (N=13)
RMPBC-number	-.983 (.163)	-1.071 (.142)	-.675 (.250)
RMBPC-reaction	-.766 (.222)	-1.967 (.025*)	-1.837 (.033*)
CESS-number	-.412 (.340)	-.225 (.411)	.000 (.500)
CESS-reaction	-.135 (.446)	-.171 (.432)	-.511 (.305)
CESD	-.949 (.172)	-1.685 (.046*)	-.046 (.482)
SE-OR	-.296 (.384)	-.245 (.403)	-1.120 (.132)
SE-DB	-1.604 (.055)	-1.744 (.041*)	-2.143 (.016*)
SE-CT	-.866 (.193)	-2.137 (.017*)	-.561 (.288)
ZBI	-.970 (.166)	-1.348 (.089)	-1.939 (.026*)

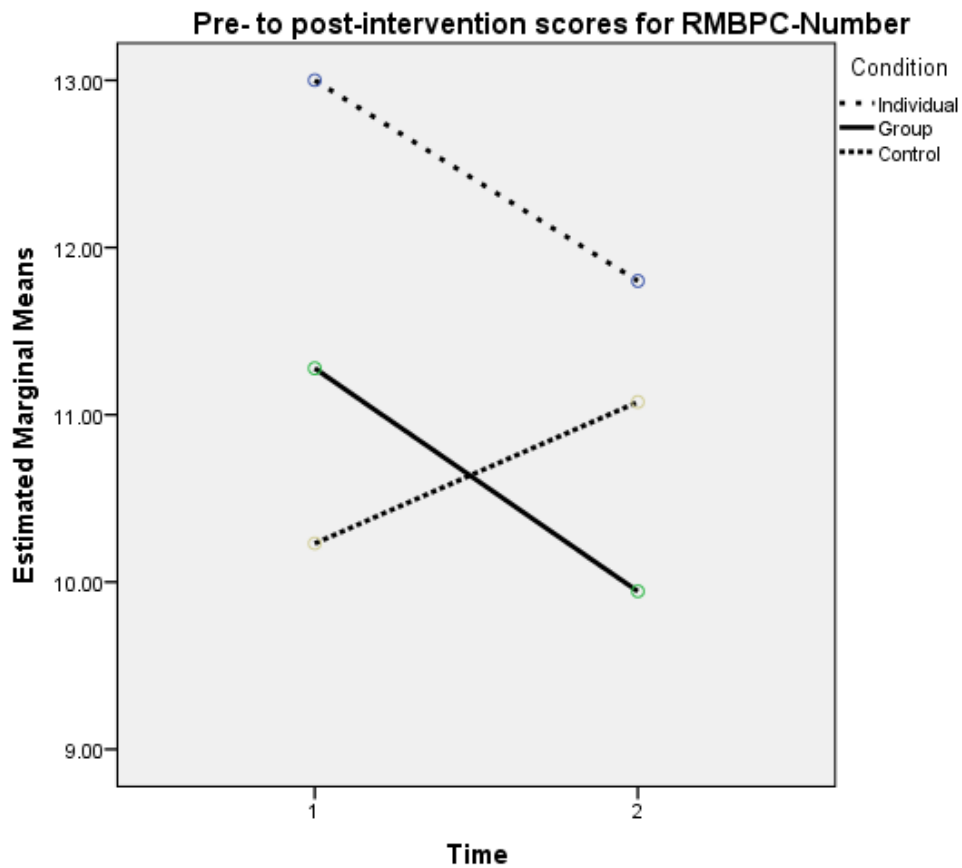
RMBPC: Revised Memory and Behavior Problems Checklist; CESS: Caregiver External Stress Scale; CESD: Centre for Epidemiologic Studies – Depression; SE-OR: Self-Efficacy for Obtaining Respite; SE-DB: Self-Efficacy for Responding to Disruptive Patient Behaviors; SE-CT: Self-Efficacy for Controlling Upsetting Thoughts about Caregiving; ZBI: Zarit Burden Interview.

The results of the Wilcoxon tests show no significant differences between pre- and post-test scores on any of the measures for participants in the Individual condition. For participants in the Group condition, significant differences were observed at the $p < 0.05$ level for the measures RMBPC – Reaction (subjective experience of stress relating to memory and behavioural problems of the person with dementia), CESD (depression), SE-DB (self-efficacy relating to coping with difficult behaviours) and SE-CT (self-efficacy for controlling difficult thoughts about caregiving). For Control participants, significant differences were observed in the measures RMBPC – Reaction, SE-DB, and ZBI (caregiver burden).

It is, of course, necessary to describe the direction of these differences in scores for each of the groups; for most of the outcome measures used in this study (for example, measures of depression and burden), a reduction is a desirable outcome, while for the

self-efficacy measures, an increase would be desirable. Looking at the significant change in ZBI scores in the Control group, for example, and comparing it to the pre- and post-test scores shown earlier in Table 5.4, this change actually represented an increase in caregiver burden across time, which is a negative outcome.

The directions of change between pre- and post-test scores for the three participant conditions on each of the outcome measures are illustrated in Figures 5.2-5.6.



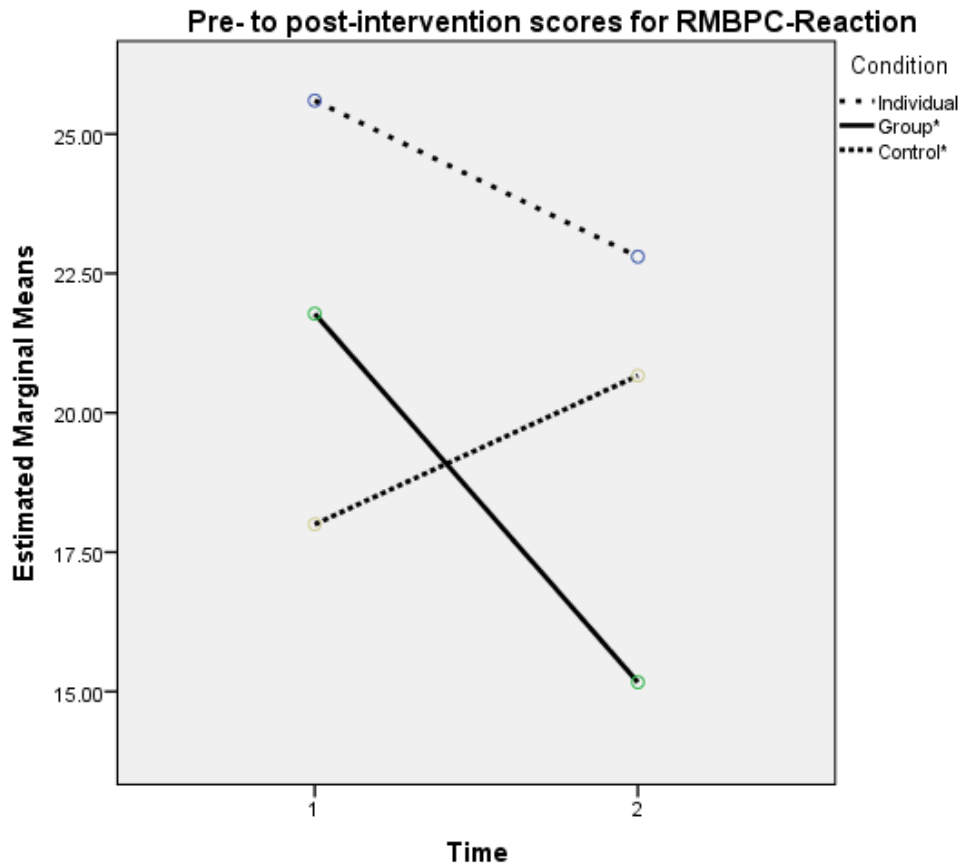
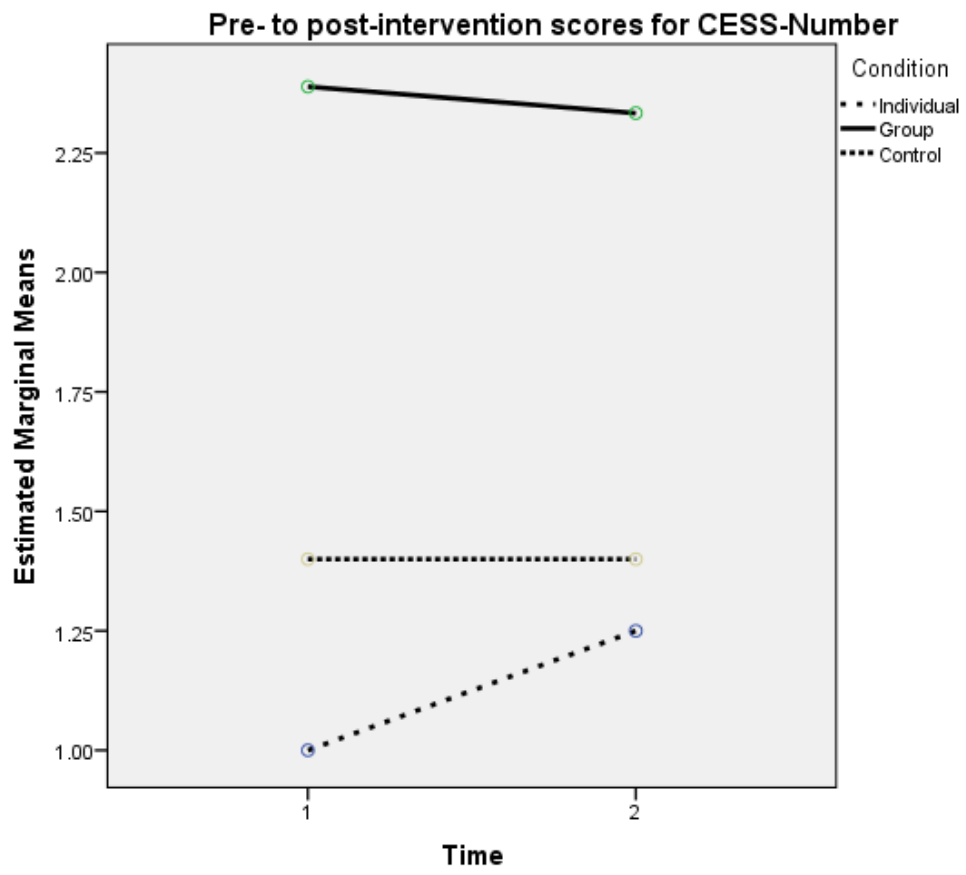


Figure 5.2 Change in RMBPC-Number and RMBPC-Reaction for each of the three conditions. (* denotes significant pre- to post-intervention change).

Figure 5.2 illustrates the direction of change for each of the three conditions (Individual, Group and Control) on the two components of the RMPBC scale – number of behavioural and memory problems exhibited by the person with dementia, and caregiver reaction (or subjective stress) in response to these. The graphs show that for the Individual and Group Conditions, the number of behavioural symptoms, and the experience of associated stress, reduced between pre- and post-test, with the opposite trend being observed in the Control participants. In the second of the two graphs, the drop in caregiver stress appears to have a steeper gradient for the Group participants than for the Individual participants; this represented a significant within-group change for Group but not Individual participants.



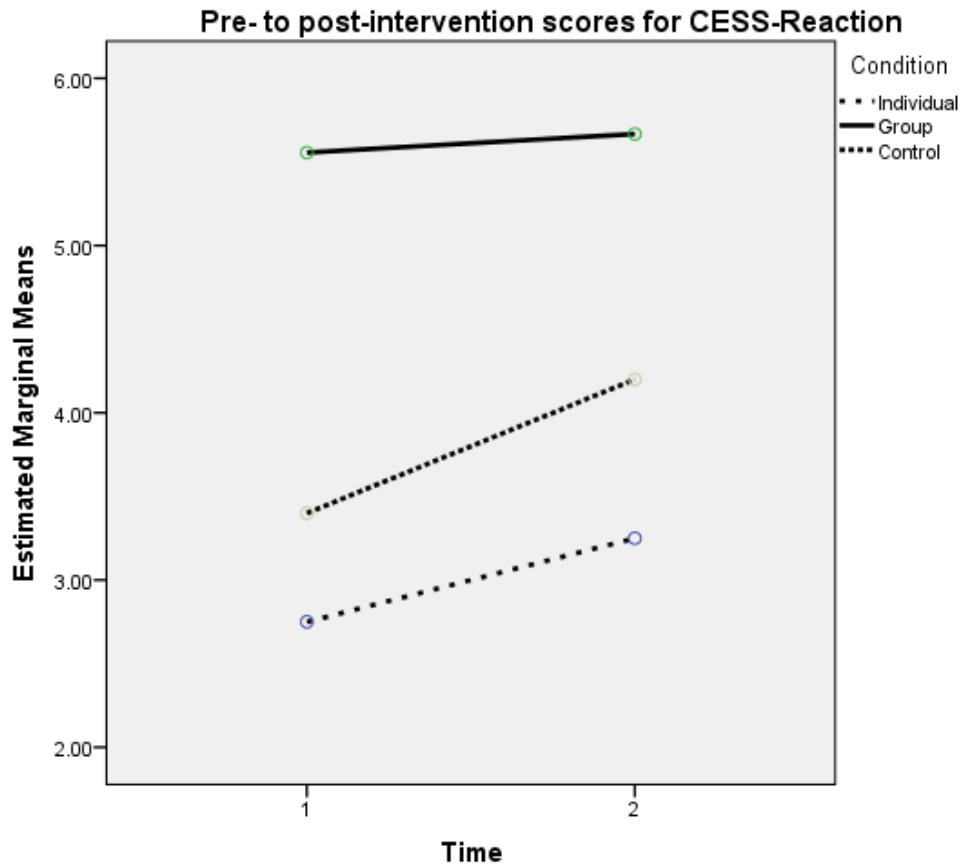


Figure 5.3 Change in CESS-Number and CESS-Reaction for each of the three conditions.

Figure 5.3 shows the direction of change for each of the three groups as measured by the two components of the CESS scale – number of external stressors and subjective experience of stress due to external factors. Each of the three groups appeared to experience a slight increase in externally-related stress over time, despite the number of external stressors remaining stable (Control participants) or showing a slight increase (Individual participants) or slight decrease (Group participants). As external sources of stress were being measured in the study but not targeted by the intervention, we would not expect to see any change in the experience of external stress attributable to the presence or absence of the intervention.

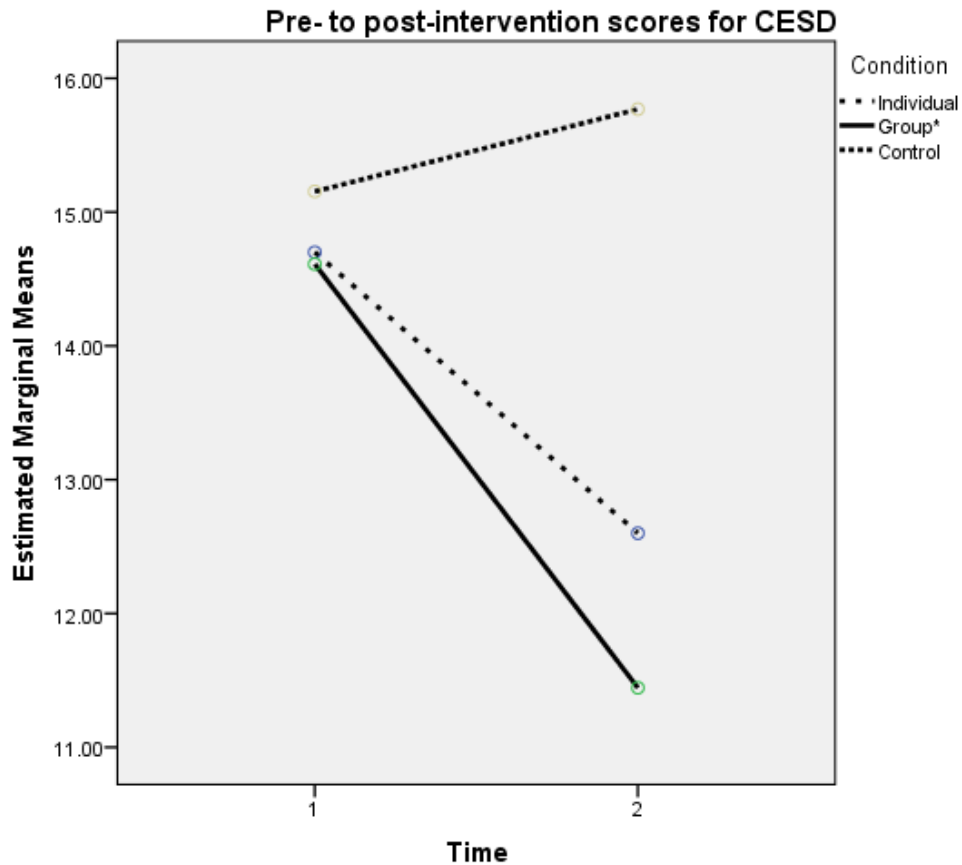
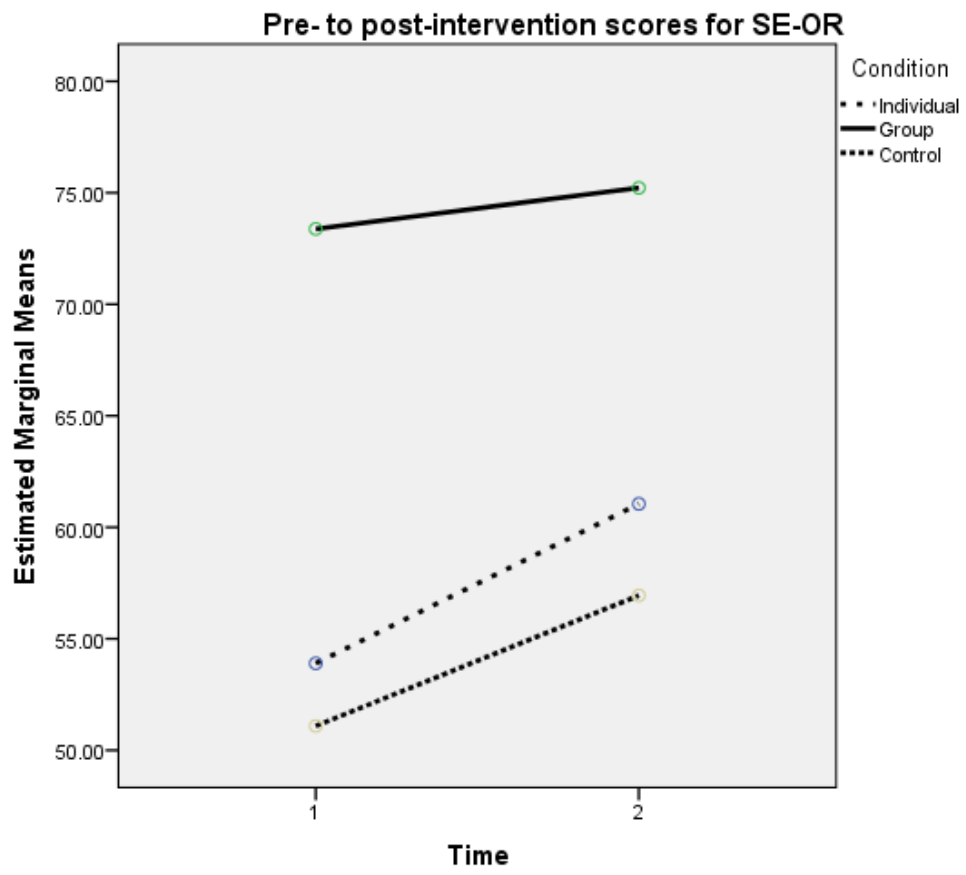
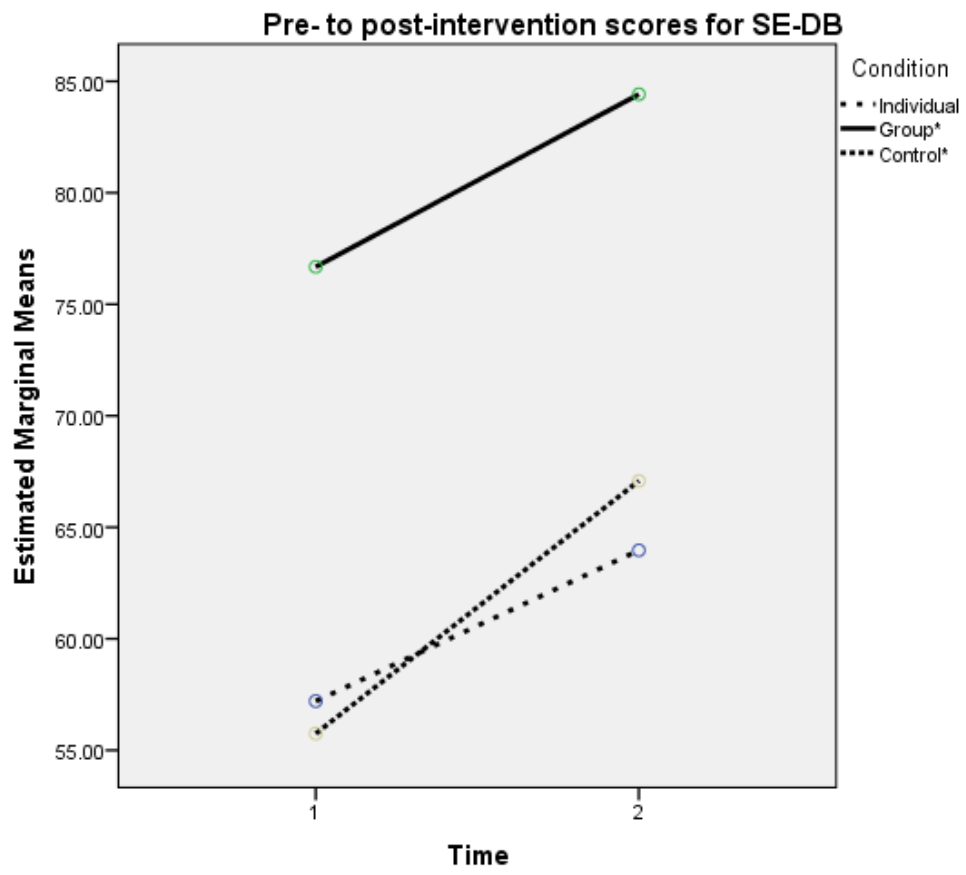


Figure 5.4 Change in CESD for each of the three conditions. (* denotes significant pre- to post-intervention change).

Figure 5.4 compares the three participant groups across time in terms of the CESD scale, measuring depression. While the Control participants showed a small average increase in depression score between the pre- and post-test periods, both the Individual and Group participants showed a reduction in depression score. This direction of change is consistent with the hypothesis that the intervention would relate to a reduction in caregiver depression, and this reduction was significant for Group participants.





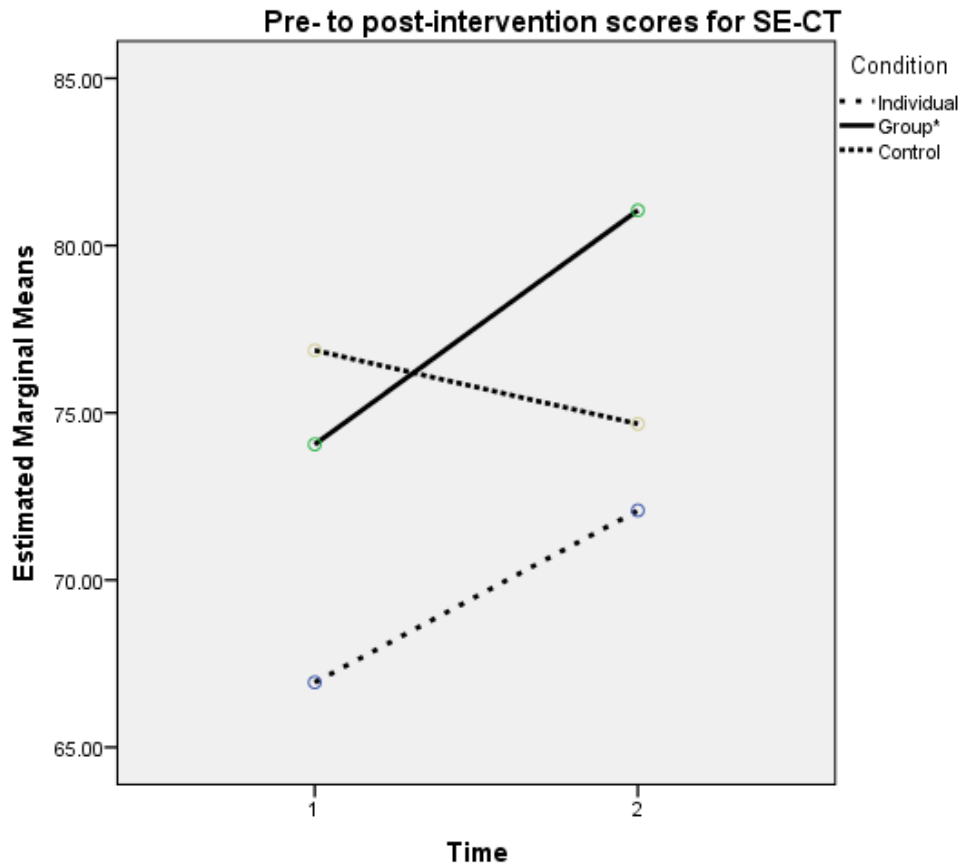


Figure 5.5 Changes in SE-OR, SE-DB and SE-CT for each of the three conditions. (* denotes significant pre- to post-intervention change).

Figure 5.5 illustrates the direction of change for each of the self-efficacy sub-scales (self-efficacy for obtaining respite, dealing with difficult behaviours and controlling difficult thoughts about caregiving) from pre- to post-test. For SE-OR and SE-DB, each of the three participant groups showed an increase over time, while for SE-CT, the Control group showed a small decrease over time while the Individual and Group participants showed an increase. As the intervention aimed to build self-efficacy, the observed patterns for the Individual and Group participants are as hypothesised; however, the fact that improvements were also observed in SE-OR and SE-DB in the Control group was not as predicted.

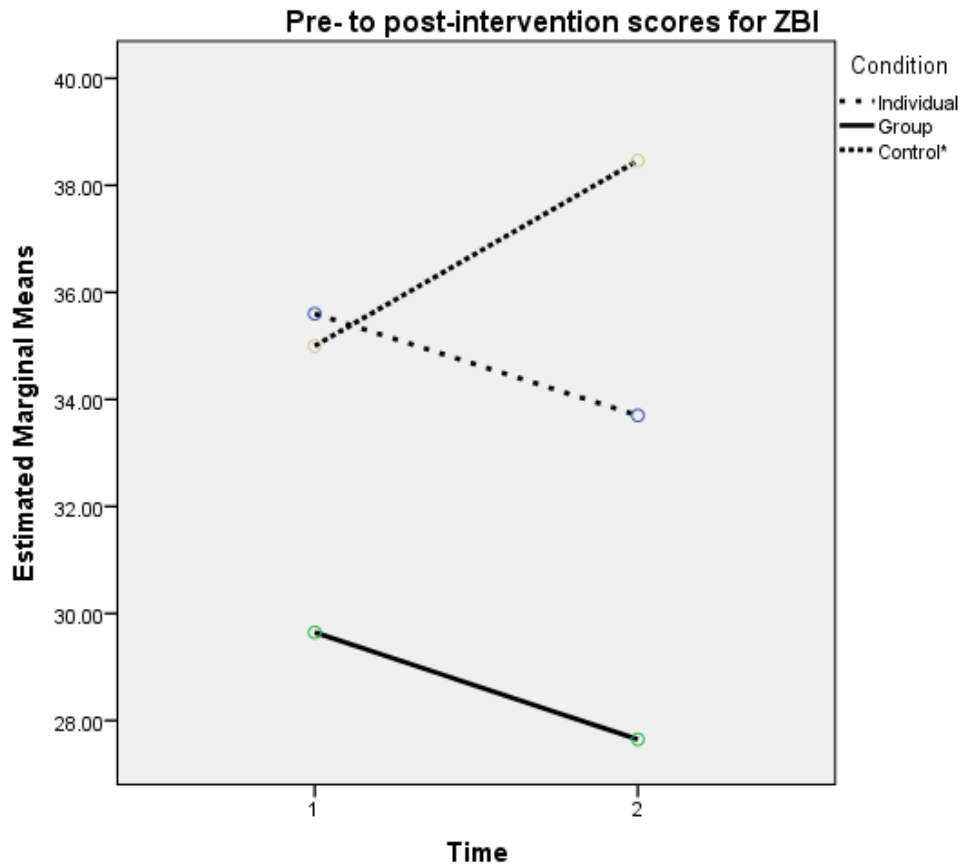


Figure 5.6 Changes in ZBI for each of the three conditions. (* denotes significant pre- to post-intervention change).

Figure 5.6 shows the direction of change for each of the three participant groups in terms of the ZBI (caregiver burden) scores. The Control participants had a significant increase in burden score over time, while the Individual and Group participants showed a non-significant reduction. This direction of change is consistent with the hypothesis that the intervention would have significant benefits for burden when compared to a control group; in this case, the intervention may have acted as a protective factor against the increases in burden experienced by Control participants.

In several of the figures above (particularly those showing depression, burden and reaction to behavioural stressor scores), the Individual and Group participants clearly showed similar trends between pre- and post-intervention, with these trends being in the opposite direction to the Control participants' scores. It is possible that the lack of significant benefits to Individual participants may reflect low participant numbers and

lack of statistical power to detect changes. Lack of statistical power has been raised as an issue in studies with comparable sample sizes (such as Gaugler et al, 2011).

5.3.4 Inferential statistics addressing Research Question 2 – three-month follow-up

The second research question in this study was, ‘Were there observable improvements three months after the third intervention session in the same outcomes, in participants who took part in the intervention versus controls?’ The study design included a follow-up, with participants invited to complete the outcome measures three months after the end of the intervention, or similar time point for control participants. The decision to conduct a three-month follow-up was informed by previous literature; Pinquart and Sörensen (2006) reported an average follow-up period of 11 months, with a minority of intervention studies including a follow-up. For the present study, using a shorter intervention and bearing in mind issues such as attrition, a three-month follow-up was deemed suitable.

The response rates at the three-month period were lower than at the post-test, with a total of 14 participants (7 Group, 3 Individual and 4 Control) taking part at this stage. For these participants, Mann-Whitney tests were conducted, comparing intervention participants (Group and Individual participants together) with control participants. Because of the modest participant numbers at this stage, no further Group/Individual comparison was made. Table 5.7 below shows the mean scores at pre-intervention and three-month follow-up for each of the measures.

Table 5.7 Pre-intervention and follow-up means for intervention and control participants (standard deviations are shown in brackets).

	Intervention (N=10)	Control (N=4)
RMBPC-number (pre)	12.3 (3.1)	9.5 (5.5)
RMBPC-number (3M)	11.1 (4.0)	10.2 (5.6)
RMBPC-reaction (pre)	24.1 (13.0)	13.7 (8.4)
RMBPC-reaction (3M)	19.9 (11.5)	15.0 (15.4)
CESS-number (pre)	2.6 (2.1)	1.5 (2.1)
CESS-number (3M)	2.0 (1.6)	1.0 (1.4)
CESS-reaction (pre)	6.7 (6.6)	2.0 (2.8)
CESS-reaction (3M)	4.8 (4.0)	3.0 (4.2)
CESD (pre)	16.0 (14.1)	6.0 (5.9)
CESD (3M)	11.2 (9.6)	8.0 (9.1)
SE-OR (pre)	70.2 (28.0)	69.2 (31.8)
SE-OR (3M)	72.7 (21.4)	76.0 (23.3)
SE-DB (pre)	73.6 (22.1)	52.2 (46.3)
SE-DB (3M)	74.9 (18.2)	87.7 (12.5)
SE-CT (pre)	72.0 (24.5)	94.8 (2.8)
SE-CT (3M)	78.5 (17.1)	96.2 (1.5)
ZBI (pre)	32.3 (18.3)	24.8 (14.3)
ZBI (3M)	32.9 (14.1)	28.5 (24.8)

RMBPC: Revised Memory and Behavior Problems Checklist; CESS: Caregiver External Stress Scale; CESD: Centre for Epidemiologic Studies – Depression; SE-OR: Self-Efficacy for Obtaining Respite; SE-DB: Self-Efficacy for Responding to Disruptive Patient Behaviors; SE-CT: Self-Efficacy for Controlling Upsetting Thoughts about Caregiving; ZBI: Zarit Burden Interview.

Looking at these pre-intervention and three-month follow-up means, there are some examples of the general trend being towards that predicted at the outset of the chapter. For example, intervention participants experienced a decrease in depression score over the period, while control participants experienced an increase. Intervention participants' burden scores at three months appeared very close to baseline, while those of the control

participants had increased. To test for significance, Mann-Whitney tests were carried out, with the results shown in Table 5.8.

Table 5.8 Results of Mann-Whitney tests comparing intervention and control participants from pre-intervention to three-month follow-up

	Mann-Whitney U	<i>p</i>
RMBPC-number	17.00	.733
RMBPC-reaction	17.50	.733
CESS-number	9.00	1.000
CESS-reaction	4.00	.400
CESD	12.00	.414
SE-OR	16.00	.825
SE-DB	4.50	.100
SE-CT	18.00	1.000
ZBI	15.00	.710

RMBPC: Revised Memory and Behavior Problems Checklist; CESS: Caregiver External Stress Scale; CESD: Centre for Epidemiologic Studies – Depression; SE-OR: Self-Efficacy for Obtaining Respite; SE-DB: Self-Efficacy for Responding to Disruptive Patient Behaviors; SE-CT: Self-Efficacy for Controlling Upsetting Thoughts about Caregiving; ZBI: Zarit Burden Interview.

Table 5.8 shows that, using the differences between pre-intervention and three-month follow up scores as the basis for a Mann-Whitney test, there were no significant differences between the change scores for intervention and control participants. That is, any improvements in outcomes found at the post-intervention stage were not observed at the three-month follow up. It is possible that any positive effects of the intervention were not sustained at three months after the intervention (perhaps due to the relatively short nature of the intervention) or, alternatively, that any effects at this stage were not detectable due to the small participant numbers and lack of statistical power.

5.3.6 Self-efficacy and the intervention – Research Question 3

The third research question concerned the role, if any, played by self-efficacy in the intervention study. The intervention was initially written with the aim of raising self-efficacy in the three caregiving domains identified by Steffen et al. (2002).

As seen in Figure 5.5, self-efficacy did increase across all three domains for participants in the individual and group interventions (with group participants experiencing a significant increase for SE-DB and SE-CT). However, it also increased across two of these domains (SE-OR and SE-DB) for the control participants, with SE-DB being a significant increase. The net effect of these changes was that there were no significant differences between intervention and control participants on any of the self-efficacy sub-scales, when comparing the changes over time.

One observation, from having carried out this study and from the comments of Steffen et al. (2002), is that the Revised Scale for Caregiving Self-Efficacy asks rather complex questions compared to other outcome measures, and requires participants to rate their own confidence levels against a range of scenarios. An issue identified in the current study was that participants would voice difficulties in rating their confidence in dealing with scenarios they felt did not apply to their personal situations; for example, some of the questions ask about coping with repetitive questioning from the person with dementia, and many participants said that the person they cared for did not exhibit this symptom. The scale does give participants the option to leave out items if they cannot gauge their confidence in coping with the scenarios, and the self-efficacy questionnaire in this study was the measure most frequently not completed or partially completed.

A further issue with the Revised Scale for Caregiving Self-Efficacy is that each of the sub-scales is prone to a ceiling effect; if participants rate themselves as being 100 per cent confident on the items in a sub-scale, then their subsequent scores can only stay the same or decrease, and this was observed in some participants in this study.

However, bearing in mind these experiences of using the Revised Scale for Caregiving Self-Efficacy, the results of the current study did not indicate any significant differences between intervention and control participants in terms of the trend in the self-efficacy scores over time. Because of this, it was not appropriate to carry out further testing to explore whether, for example, self-efficacy was mediating between stressors and the group differences in burden score.

5.4 Discussion

5.4.1 Measures of subjective stress or reaction

This study used two different scales to measure the stressors and stress experienced by participants. The first of these, the Revised Scale for Memory and Behavior Problems Checklist (RMBPC, Teri et al., 1992) is an established scale for gauging stress in relation to the memory and behavioural symptoms exhibited by the cared-for person.

Looking at the two sub-scales of the RMBPC, which measure the number of stressors present and the subjective reactions of caregivers, Group participants experienced a significant reduction in subjective stress during the course of the intervention: the actual number of stressors (memory or behavioural problems) did not change significantly during this time, but participants' ratings of subjective stress showed a significant decrease. This was significant both when looking at the within-group change for Group participants, and when carrying out a direct comparison with the Control participants, who experienced a significant increase in subjective stress. No significant difference was observed for Individual participants, although the direction of change was the same as for the Group condition.

The pattern of results obtained in this study for the RMBPC scale mirrors those obtained by Mittelman et al. (2004), who carried out a four-month intervention with caregivers, followed by on-going support as required. In this study, participants continued to experience less distress in response to problematic behaviours over a four-year period, compared to a control group. Although the present study demonstrates that a relatively short intervention can bring about the same direction of change in caregiver reactions to stressful situations, it may be that ad hoc follow-up support would help to sustain this pattern of results in the longer term.

The second stress scale used here was the Caregiver External Stress Scale (CESS), written and piloted in this study. This scale concerned external sources of stress such as not knowing where to get help, or problems with accessing services and financial problems. As these stressors were not being targeted by the intervention, the purpose of using this scale was to get a sense of whether or not these stressor types were relevant to participants' experiences, and to observe any potential differences between the groups on this measure. No significant changes were detected during the study using this measure. The issues measured by the scale appeared to be relevant in terms of caregivers' experiences, with all three groups reporting the presence of external

stressors. Although not significant, all groups experienced a small increase in externally-originated stress during the three weeks of the intervention; coupled with feedback from the pilot test reported in Chapter 3, it is possible that a future update of the intervention could include a session looking at some of these stressors and providing practical information about accessing help and resolving issues.

5.4.2 Depression

The Center for Epidemiologic Studies Depression scale (CESD; Radloff, 1977) was used in this study as an operational measure of depression. In stress and coping models of caregiving, depression can be seen as an outcome, and it has frequently been targeted in dementia caregiving intervention studies (for example, Burgio et al., 2003; Cjaza et al., 2009; Dixon et al., 2004; Elliott et al., 2010; Losada, Márquez-González & Romero-Moreno, 2011).

In the current study, participants in the Group condition experienced a significant decrease in CESD scores between the start and the end of the intervention. However, there was no significant difference between groups when comparisons were made with the Control participants. Although the overall trend was for intervention participants to experience a decrease in depression score, and for control participants to experience an increase, it is not possible to state that the intervention had any significant effect on depression when making a comparison between groups. It has been suggested (Sörensen, Pinquart & Duberstein, 2002) that between 7 and 9 intervention sessions may be required to have an impact on caregiver depression scores, so the results here may reflect the length of the intervention.

5.4.3 Caregiver Burden

Caregiver burden, measured here using the Zarit Burden Interview (ZBI; Zarit et al., 1980), also features as an outcome in stress and coping models, and is frequently reported as an outcome in caregiving literature (for example, Kwok et al., 2013; Gaugler, Roth, Haley & Mittelman, 2008; Belle et al., 2006; Bekhet, 2013). Looking at the within-group differences reported in this study, Control participants experienced a significant increase in ZBI score across the pre- to post-test time period, while Individual and Group participants experienced small, non-significant decreases.

Between-group comparisons revealed a significant difference between the changes in scores of the Intervention and Control participants, suggesting that the group intervention may have had some protective effect against the increases in burden experienced by people who did not receive the intervention.

5.4.4 Self-Efficacy

As discussed in the Results section, there was no effect of the intervention on self-efficacy scores as compared to the Control condition. Using the Revised Scale for Caregiving Self-Efficacy (Steffen et al., 2002), some significant changes were found within groups (the Group participants' scores on SE-DB and SE-CT increased significantly from pre- to post-test, while the Control group also experienced a significant increase in SE-DB). It is not possible to say that the intervention participants had any advantage over Control participants in terms of improvements to self-efficacy as measured in this study, as there were no significant between-group differences. Because of this, no conclusion could be reached about the role of self-efficacy in mediating between stressors and the outcomes of depression and burden.

It is, of course, possible for self-efficacy to build with or without an intervention, as caregiving involves carrying out daily tasks which could lead to an increased sense of mastery; this could help to explain the lack of significant differences between groups, and the significant increase in the Control participants in terms of coping with problematic behaviours. The adaptation model of caregiving stress, described in Chapter 2, proposes that caregivers will become more able to deal with the challenges of caregiving as time progresses, and Zarit and Zarit (1986) found evidence in a longitudinal study for this pattern of increased coping.

Another possible issue here is that although attempts were made to map the three sessions of the intervention to the three subscales of the Steffen et al. (2002) self-efficacy questionnaire, this measure may still not have captured changes relating to the intervention. Some studies using self-efficacy as the target of an intervention have used measures designed specifically for the study (for example, Boise et al., 2005; Huang et al., 2003) or have simply asked participants to rate their confidence for certain tasks (Gitlin, Corcoran, Winter, Boyce & Hauck, 2001). It is also notable that Boise et al. (2005) was not a controlled study and reported only within-group improvements in self-efficacy, although some studies have found that interventions can be used to raise self-

efficacy significantly when compared to a control group (Coon et al., 2003; Ducharme et al., 2011; Huang et al., 2003).

The results here in relation to self-efficacy may also be explained by reflecting on the findings of Tang and Chan (2015) that six-session interventions tended to produce measurable self-efficacy benefits for caregivers. This review identified that studies using smaller treatment dosages did not produce significant self-efficacy differences between intervention and control groups, reflecting the results of the current study. Although the intervention used here was designed to explore the effects of a shorter intervention, it is possible that further sessions would be needed to see an effect on self-efficacy, or that the post-test scores for self-efficacy should be obtained at a period following the intervention, rather than immediately at the end of the third session. Alternatively, it may need to be considered that the observable benefits of the intervention happened via some mechanism other than self-efficacy (as discussed in Chapter 2, there are a number of similar concepts, including mastery and control, which may mediate in stress and coping relationships).

5.4.5 Suitability of the intervention for different groups

As discussed in Chapter 2, there have been attempts to identify sub-groups of informal caregivers for whom interventions may be more or less suitable (Zarit et al., 2013; Kim et al., 2012). Previous caregiver research has indicated that more attention should be paid to the caregiver's relationship to the person with dementia, as daughters of a person with dementia were found to experience greater benefits from using Adult Day Services than wives (Kim et al., 2012).

While demographic information is sometimes gathered to ensure that groups are matched at the beginning of a study, or to illustrate the sample being studied, in this study this information played a different role due to the quasi-experimental design. As participants were invited to choose between participating individually, in groups or in the control condition, differences between these groups highlighted important information in terms of caregiving needs and the choices made about how to participate. For example, individual participants were on average older than group participants (mean age of 69 compared to 57), more likely to be spouses of the person with dementia and more likely to live with the person with dementia. It may be the case that the needs

of older, spousal caregivers are such that individual discussion is a more appropriate way to offer support, or simply that the practical constraints on these caregivers make it more difficult for them to attend group activities. Conversely, the group condition had comparatively larger numbers of children of the person with dementia, and people not living with the person with dementia, suggesting that a group was felt to be more appropriate, or feasible, for these caregivers.

Although these baseline differences between groups need to be taken into account when considering the overall results of this study, they do begin to reveal a picture of how an intervention might work if made available in the community, a setting in which people would also choose whether to attend a group or to seek individual means of support. It can be argued that the current study has a focus on the ecological validity of the intervention in relation to caregivers and the services they access within a community setting. Green, Glasgow, Atkins and Stange (2009) state that intervention studies have tended to be evaluated with a focus on internal validity at the expense of external validity. They propose that greater attention needs to be paid to the community context and relevance of research, to improve the links between research and practice.

Looking at the baseline scores for the outcome measures, although no significant baseline differences were detected, it is worth looking at the trends of these. For example, group participants had the highest mean scores on two of the self-efficacy measures, SE-OR (organising respite) and SE-DB (coping with difficult behaviours). This would suggest that participants attending groups, perhaps unsurprisingly, felt more confident about accessing respite, but also more confident at the outset about dealing with the behavioural changes associated with dementia. Looking at the ZBI (burden) scores, non-completing participants had the highest mean levels of burden, followed by individual participants. These results may help to understand why, for some people, taking part in an intervention study at all was felt to be difficult, while for others an individual arrangement was more suitable than committing to a group.

As argued by Zarit and Femia (2008), random allocation may not always be the most suitable way to conduct an intervention study, as it can lead to participants being allocated a treatment that they do not feel is suitable in terms of the current demands of their caregiving situation. The results of the present study suggest that there were important demographic differences between groups in terms of which form of participation was judged to be suitable by the participants themselves. By including this element of participant choice, the current study may reflect more closely the way in

which the intervention would be applied in a ‘real world’ setting, placing the study in the context of an effectiveness study (Singal, Higgins & Waljee, 2014).

Looking at the results for the different groups, while the intervention appeared to offer significant benefits compared to control participants (reduced burden and subjective experience of stress), no significant effects of the intervention were observed in the Individual participants. This may be related to the small number of Individual participants, with the trends for these participants showing similar patterns to the Group participants (see Figures 5.2-5.6), or it may simply mean that the intervention did not have any significant effect when offered individually. As discussed in Chapter 3, one important difference between the Group and Individual interventions was the presence or absence of other caregivers to model coping behaviours; it is possible that this helped account for the benefits experienced by the Group participants.

To take a more in-depth view of the experiences of Group and Individual participants in this study, follow-up interviews were carried out with a number of participants and the results of this qualitative follow-up will be reported in Chapter 6. This work was planned with the aim of exploring further any observed differences between participants in the Individual and Group conditions.

5.4.6 Results from three-month follow-up

As reported in the Results section, no significant between-group differences were reported when looking at the differences in scores from pre-test to the three-month follow-up. This suggests that the benefits experienced by intervention participants were not sustained at three months after the intervention. These results were based on a small number of participants who completed the follow-up outcome measures. In their review of caregiver interventions, Pinqart and Sörensen (2006) found that intervention studies did tend to report some significant effects at follow-ups of several months after the intervention; however, of 127 studies included in this review, only 32 had reported any follow-up, with fewer significant effects being observed at follow-up.

It has been argued that interventions need to be of a suitable duration and intensity to be effective (Zarit & Femia, 2008), and the studies included in the Pinqart and Sörensen (2006) review had a median number of nine intervention sessions each, compared to three in this study. This suggests that the relative brevity of the intervention may have contributed to the results. In part, this is due to the current study taking a slightly

different focus, looking at obtaining a balance between creating an effective intervention and creating one which could feasibly be disseminated within a community setting, without requiring the longer-term input of specialists or a longer time commitment from caregivers.

It is, of course, also possible that the evolving demands of caring for a person with dementia mean that caregivers will require on-going support and interventions as time progresses. Samia, Hepburn & Nichols (2012), in a qualitative study exploring the needs of previously-trained caregivers, identified the need for on-going intervention; for example, participants reported needing further help to reinforce the idea of making time for themselves.

The relatively short nature of the intervention used in this study means that it may be relevant to consider it alongside brief interventions, which normally have the remit of being used to support improvements against a backdrop of crisis and instability (as seen in the drug, alcohol and mental health fields). It has been proposed that crisis intervention, which has tended to be overlooked in the dementia caregiver setting, may be an appropriate approach for social workers involved with people with dementia and their carers, as referrals are often made in times of crisis (Parker, 2007).

The results from Chapter 4, which identified complex and evolving sources of caregiver stress, would support the idea that there may be a place for shorter activities to assist caregivers of a person with dementia at specific times. Taking this into account, it is possible that the intervention used in this study could form part of a toolkit to be used by agencies working with informal caregivers, to be used as indicated by the needs of small groups of caregivers. Further studies could help to shed light on the usefulness of the intervention if used at specific times in response to identified needs.

5.5 Limitations of the study

A limitation of the current study was that it was carried out using modest participant numbers for each of the three conditions, which meant that the analysis had to proceed in a cautious, conservative way. Recruitment in this field is typically time-consuming and precarious, due to issues such as the uncertain timeline of caring for someone with dementia and constraints on caregivers' availability. Participant numbers were similar to other intervention studies in this field, such as Haley et al. (1987). A larger-scale replication of the study would give an insight into the reliability of the results obtained

here, and may be able to confirm whether the lack of significant benefits in the Individual condition related to the small number of participants or to this particular way of using the intervention, given that the results reported for the Individual condition largely followed the same trends as the Group condition.

A further, related limitation to the study was that the outcome measures were administered by the person carrying out the intervention, due to the resources available. An improvement would be to carry out a replication in which a second person was available to administer the outcome measures, to avoid any instance of participants feeling under pressure to report positive outcomes of the intervention. To mitigate this issue in the current study, I introduced the outcome measures to participants in terms of gaining an insight into the feelings and experiences of caregivers over time, rather than relating them directly to the intervention; this and other pragmatic decisions will be discussed further in Chapter 7.

The quasi-experimental design of the study means that although the results appeared to support the use of the intervention on a group basis, it is impossible to rule out the role that may have been played by baseline differences between the groups of participants. There are possible confounding factors, including the relationship between the participant and the cared-for person, which could have contributed to the results. The balance between internal and external validity was skewed in favour of external validity in this study, with the intervention being used as realistically as possible, at the expense of controlling for baseline differences.

5.6 Conclusion

This study used a relatively short, three-session intervention, aimed at fostering self-efficacy in three aspects of caring for a person with dementia: coping with difficult behaviours, coping with difficult thoughts and obtaining respite. By inviting informal caregivers to choose whether to take part in groups, individually or in a control condition, it was possible to observe significant differences in the preferences of different groups, with older, spousal caregivers more likely to choose individual interventions and children of a person with dementia more likely to attend group sessions.

The results indicated that the intervention appeared to offer significant benefits to participants, with intervention participants experiencing a reduction in caregiver burden

and subjective stress compared to control participants. The individual intervention did not show any significant benefits, and this will be explored in the subsequent qualitative work looking at the experiences of participants who completed either the group or individual intervention.

Chapter 6 – Caregivers’ Experiences of Taking Part in an Intervention: Qualitative outcomes analysed using Interpretative Phenomenological Analysis

6.1 Introduction

In the previous chapter, the quantitative outcomes of an intervention study were reported. In the current chapter, a more in-depth qualitative approach is taken to complement this, with the aim of looking at caregivers’ subjective experiences of taking part in the self-efficacy intervention. While quantitative data can illustrate overall trends and outcomes of carrying out an intervention study, qualitative research can contribute a more detailed picture of what taking part in the intervention was like from participants’ points of view. Previous research has established that while caregiver interventions may have only modest measurable outcomes, participants themselves frequently rate the interventions as favourable and appraise their skills as having improved (Brodaty et al., 2003), suggesting that a focus on caregivers’ experiences of interventions may add to our understanding of the benefits of an intervention.

There are examples in the dementia caregiving literature of qualitative research being used in the evaluation or understanding of interventions. Vernooij-Dassen, Joling, van Hout and Mittelman (2010) conducted interviews with counsellors who had provided family counselling to people affected by dementia; the authors described this approach as looking into the ‘black box’ of how interventions are delivered, and the study uncovered aspects including barriers to helping caregivers (for example, the counsellors reported that there was a reluctance to accept help).

The idea of opening the ‘black box’ of interventions also underpinned a study by Lavoie et al. (2005). The authors conducted semi-structured interviews with caregivers in order to identify the processes which were effective or ineffective in a group intervention. Their intervention had consisted of fifteen sessions dealing with using different coping skills. The qualitative study helped identify that caregivers had found reframing to be particularly effective (understanding certain behaviours to be a feature of dementia, rather than attributable to the will of the person with dementia). Some of the coping

skills used in the intervention were not reported as helpful by the caregivers (for example, problem solving).

Ducharme et al. (2009) used semi-structured interviews with early-stage caregivers both to inform the design of a new intervention and to validate it. The intervention was aimed at helping new caregivers adjust to the role, and the interviews explored participants' needs, allowing the intervention to be based on these needs. The intervention was then delivered to two caregivers and a qualitative evaluation was conducted, informing a subsequent quantitative, randomized study. The qualitative work undertaken in this case therefore served as a precursor to the quantitative evaluation and this, the authors argued, allowed them to measure outcomes identified as relevant by caregivers, rather than the standard outcomes (such as depression) more usually measured in intervention studies.

Qualitative research has also been used in a pre-test/post-test design. Semi-structured interviews were used by Sørensen, Waldorff and Waldemar (2008) to look at the experiences of people with dementia and their caregivers, before and after taking part in an intervention which included counselling, education and support. The authors reported that both people with dementia and their caregivers appeared to benefit from the intervention (people with dementia appeared more able to talk openly about their difficulties following the intervention, and caregivers stated that they felt more able to cope with situations). Following the intervention, both people with dementia and caregivers sought further support.

In a mixed-methods study used by Hoppes et al. (2012) to look at the effects of mindfulness training on caregivers, qualitative and quantitative components revealed different aspects of the training effects. For example, the quantitative measure showed that caregiver burden reduced during the intervention, while the qualitative data, analysed using Thematic Analysis, identified that participants felt increased acceptance, peace and sense of presence. The authors stressed that quantitative and qualitative methods should be considered 'separate but equal', a stance also advocated by Smith et al. (2009), but perhaps more importantly, quantitative and qualitative methods can answer different research questions to give more than one perspective on the usefulness of an intervention.

Qualitative research has also been used to evaluate interventions which use technology rather than face-to-face approaches. Chiu, Marziali, Tang, Colantonio and Carswell

(2010) looked at email exchanged between caregivers and therapists, examining the use of email to provide person-centred support. Qualitative evaluation has also been conducted to look at website-based support (Chiu & Eysenbach, 2011) and telephone support (Salfi, Ploeg & Black, 2005).

The studies described above have used a range of different qualitative approaches; for example, Thematic Analysis (Hoppes et al., 2010), template organising (Sörensen et al., 2008) and interpretative grounded theory (Chiu & Eysenbach, 2011). Because the present study was designed to capture a sense of participants' experiences and understandings, IPA was selected as a suitable methodology; a detailed account of this approach was given in Chapter 4. The selection of IPA will be discussed further in Section 6.2.

Although IPA has not often been used in connection with an intervention study, Smith et al. (2009) discussed the ways in which this can be appropriate, using a mixed methods approach. They argue that while quantitative statistics can point to whether or not an intervention has an effect, IPA can offer an account of what the intervention was like from the perspective of participants, and can potentially answer questions about how the intervention did or did not work for those participants, as well as highlighting aspects of individual experiences.

Working in a different field of research, Newton, Larkin, Melhuish and Wykes (2007) used IPA as a means of conducting a qualitative evaluation of an intervention. They interviewed young people who experienced auditory hallucinations and who had taken part in group therapy, reporting that the use of IPA allowed the authors to learn more about the experiences of the young people and, in turn, about the intervention itself. Newton et al. (2007) point to the idiographic nature of IPA, and the use of semi-structured interviews, as being particularly useful in generating the richly detailed accounts they were able to access.

In addition to using IPA to evaluate an intervention, the present study involves a second way of using IPA: the use of IPA to explore experiences from more than one perspective or group of people. In this case, participants from both the individual and the group conditions of the intervention study (Chapter 5) were invited for interviews. The use of multiple perspective studies in IPA again represents a small field of research, although Larkin (personal communication, May 12, 2016) advises that IPA can indeed be used to examine different perspectives; this is described more fully by Larkin,

Flowers and Shaw (2015). Multiple perspective IPA studies have been used in exploring topics including comparing accounts of risk between recreational drug users and participants in dangerous sports (Larkin & Griffiths, 2004), experiences of foster care breakdown from the perspectives of young people, social workers and foster carers (Rostill-Brookes, Larkin, Toms & Churchman, 2011) and different family groups' attitudes towards testing for hereditary cancers (Dancyger, Smith, Jacobs, Wallace & Michie, 2010). Within the dementia caregiving field, although not specifically using IPA, Lee and Smith (2012) used a phenomenological qualitative approach to compare the experiences of spouse and child caregivers in Korean American society.

Although the present study does not have a directly comparative design in the sense of treating participants (group and individual participants from the intervention study) as discrete groups, it is acknowledged that participants have had different experiences in terms of the delivery of the intervention, and that this difference may influence their accounts of taking part. However, there are other important differences between participants which could influence their accounts (for example, the difference between being the spouse of a person with dementia and being the child of a person with dementia). Given the idiographic focus of an IPA analysis, it is important not to overstate here the effect of having taken part in the original study in either the individual or group category, but rather to consider this along with other individual factors when examining the resulting themes.

6.2 Methods

6.2.1 Selection of Methodological Approach

Different qualitative approaches were considered in the proposal for this study. As discussed in Chapter 4, some approaches were not suitable for the nature of the study (Grounded Theory (for example, Strauss, 1987) typically uses large samples, and the current study was planned as a small-sample exploration of participants' experiences).

Consideration of approaches focussed particularly on IPA and on Thematic Analysis. Thematic Analysis (for example, Braun & Clarke, 2006) is a method of identifying and reporting themes in qualitative data, and is not attached to a particular theoretical standpoint. Thematic Analysis is a relatively straightforward way to analyse qualitative data, although its flexibility can mean that it is perceived as lacking in rigour; this issue

has been the focus of Braun and Clarke (2006), who proposed steps for carrying out Thematic Analysis.

Because of the centrality to IPA of participants' own accounts of their experiences, the ways in which IPA has been developed from phenomenology and hermeneutics (as discussed in Chapter 4) and the well-defined role of the researcher in interpreting the data, IPA appeared to provide an accountable approach to analysing the data in this study. IPA allowed the study to address the research aim of exploring participants' own experiences of taking part in the intervention, and to take an idiographic focus as well as looking at themes across cases (Smith et al., 2009). Following the practice introduced in Chapter 4, two individual case studies will follow the main analysis in this chapter, illustrating the idiographic focus that was maintained in this study and the ways in which the recurrent themes were based on themes emerging from individual accounts.

6.2.1 Recruitment

Recruitment for this study involved approaching caregivers who had participated in the intervention study carried out and reported in Chapter 5, and inviting them to take part in a short telephone interview (post-three-month follow-up) about their experience of the intervention. Participants from each of the intervention conditions described in Chapter 5 were invited to take part. The number of participants was set at six (two individual participants and four group participants), to preserve the small-sample nature of an IPA study (Smith et al., 2009) while still capturing a number of views from different people who had taken part in the intervention study. As the present study was carried out before analysing the quantitative data in Chapter 5, there was no researcher bias in terms of knowing which participants had benefitted from the intervention, although it is acknowledged that participants may have self-selected for the present study on this basis (approximately ten people were approached to take part in this study, with six giving consent).

As detailed in Chapter 5, inclusion and exclusion criteria were used in recruitment. Inclusion criteria in this case were that the participants were informal caregivers of a person with dementia who had taken part in the intervention study. Exclusion criteria involved people who could be classed as vulnerable adults; for example, caregivers who themselves had a diagnosis of dementia or other condition which would make it difficult for informed consent to be given.

6.2.2 Interviews

Semi-structured interviews were used in this study. An interview schedule was devised and was used to guide and encourage participants to talk about their experiences of taking part in the intervention study. The interview questions were written to elicit accounts of participants' feelings about and experiences of taking part, rather than inviting them directly to evaluate the intervention. It was aimed to arrive at the rich, experiential data suitable for an IPA study.

The interview questions were not followed rigidly or in order, but were adapted for each participant, in line with good practice for an IPA study (Smith et al., 2009) and so that the participants' own accounts were prioritised. A copy of the interview schedule can be found in Appendix H.

Interviews for this study were conducted by telephone and an audio recording was made, having obtained consent from participants. Participants were informed at the beginning and end of the recording. Prior to each recording being started, there was a brief conversation with the participant, aimed at putting the participant at ease and re-orienting to the topic of the intervention sessions. Following the recorded part of the conversation, there was also an informal debrief which included thanking the participant and explaining that a period of analysis would follow, after which the participant could receive information on outcomes from the study.

The recorded interviews lasted between 11 and 17 minutes, with a mean duration of 12.5 minutes. The nature of the interview schedule in this case meant that it was anticipated that these would be relatively brief interviews, although it is also noted that interviews carried out by telephone tend to be shorter and less informative than face-to-face interviews (Oltmann, 2016). The choice of telephone interviews was made by considering the pros (for example, ease of taking part; reduction of potential bias due to body language as I was asking follow-up questions about an intervention I had facilitated) and the cons (such as possible barrier due to technology) of this method. The consideration of pros and cons was recommended by Brocki and Wearden (2006), in a

paper exploring the different approaches that have been taken in conducting IPA studies.

It is worth noting that although the analysis for the present study was based on the data obtained from telephone interviews, I had already met each of the participants at least three times ‘in person’, via their participation in the intervention study reported in Chapter 5. These previous meetings clearly could not be admissible as data for the present study; however, the experience of having met and worked through the intervention with each of the participants meant that the need for initial rapport-building and information-gathering was minimal in this follow-up study. Additionally, my prior understanding of the participants’ caregiving situations and concerns facilitated the idiographic focus of the study.

Although in-depth, face-to-face interviews have tended to be the primary mode of data collection for IPA studies, there are examples of alternative methods being used. Brocki and Wearden (2006), in their review of 52 IPA studies, noted that 46 of the papers had used semi-structured interviews, with most of these being conducted face-to-face (although also included in this category was a paper by Turner, Barlow and Ilbery (2002), which used telephone interviews). Interviews have also been conducted via email (for example, Murray & Rhodes (2005)) or by a combination of methods (Murray and Harrison (2004) combined email and face-to-face interviews). Other IPA studies have favoured data collection methods other than direct interviews. For example, Dunne and Quayle (2001) conducted an IPA study based on data from focus groups, while Smith (1999) used diary entries from participants. The current study is situated within the group of IPA studies using semi-structured interviews without face-to-face contact.

6.2.3 Reflexive Practice

As discussed in Chapter 4, reflexivity was an important element in this study, and the format of this chapter will follow that introduced in Chapter 4, in which relevant reflexive information will follow each theme reported in the analysis, adhering to the advice reported in Wagstaff et al. (2014).

Before moving on to the analysis, however, it should be noted that the initial study design and development of the interview schedule were influenced by certain aspects of my own interests and experience. As previously discussed in Chapter 4, my interests in the topic included a focus on how people experience stress and how they may best be

supported to minimise stress. More specifically in this study, I was interested in participants' subjective experiences of taking part in the self-efficacy intervention designed for these studies, and in knowing how participants felt about various aspects of taking part.

It was also important to maintain an awareness of the fact that different roles were involved in carrying out these studies. Using the resources available, I facilitated the intervention sessions, administered the outcome measures and conducted the follow-up interviews for this study. Clearly, this practice was not without risks to the integrity of the studies: it was possible that my hopes for the success of the intervention could lead to bias in the follow-up interviews, or that participants may feel unable to report any negativity they felt about taking part.

Attempts were made to acknowledge and counter these possible sources of bias: for example, the interview questions did not ask for any direct evaluation of the intervention, but were designed to focus on participants' experiences of taking part. It was stressed to participants throughout the process that my role was that of researcher, looking into things which may or may not help to support carers, and that I was interested in their own thoughts and experiences. Participants were not informed that I had written the intervention materials, in order to minimise any social pressure they may have felt in giving feedback. Additionally, although the interviews for this study were necessarily conducted after the intervention, the current qualitative analysis was carried out before the results of the quantitative analyses were known, to reduce any unintentional bias in identifying themes.

6.2.4 Analysis

The analysis for this study followed the same steps as described in Chapter 4. To recap, each interview was transcribed verbatim, and the transcript was checked with a further listen to each audio recording. Each transcript was then examined closely in turn, paying attention to the idiographic focus of IPA (Smith et al., 2009). Initial coding for each transcript included highlighting aspects of the participant's account which may be relevant to the analysis, including particular words or phrases used, making descriptive summaries of the participant's account and noting initial interrogative remarks on the transcript.

For each transcript, a list of emerging themes was then generated. Once this had been completed for each interview, a cross-case analysis was carried out, looking for recurrent themes. For the purposes of this study, a recurrent theme was one which was identified in at least half of the interview transcripts. This process resulted in two superordinate recurrent themes, with each including a number of smaller recurrent themes. These themes are summarized in Table 6.2 below, and will be discussed in detail with relevant supporting excerpts from the interview transcripts.

6.2.5 Participants

Six participants took part in this study. Demographic information from participants is provided in the table below. Participants have been given pseudonyms in order to preserve their anonymity; these pseudonyms were chosen to be appropriate for participants' ages and other demographic factors.

Table 6.1 Demographic information from participants

Participant	Age Range	Relationship to person with dementia	Lived with person with dementia?	Formal Support Received	Group or individual participant in original study
Colin	60-70	Child	No	No	Group
Sarah	60-70	Spouse	Yes	Yes	Group
Irene	70-80	Spouse	Yes	Yes	Individual
Tricia	50-60	Child	Yes	Yes	Group
Andrew	70-80	Spouse	Yes	Yes	Group
Jane	70-80	Spouse	Yes	Yes	Individual

It is notable that Irene and Jane, the two Individual participants here, are both spouses in the 70-80 age group. This is reflective of the demographic norms for Individual participants in Chapter 5, in which participants electing to take part tended to be older, spousal caregivers.

6.3 Results

6.3.1 Superordinate Themes

Two superordinate themes were identified in this analysis: Sharing Experiences with other Caregivers, and Meeting Needs. These superordinate themes were identified in all six interviews. Each superordinate theme contained smaller themes; these are detailed in Table 6.2 below, along with information about which interview transcripts supported each theme. The superordinate themes are shown in bold and the smaller themes are listed below each superordinate theme.

Table 6.2 Distribution of Themes

Theme	Participants
Sharing Experiences with Other Caregivers	All
Learning from others	All except Irene, Jane
Comparing self to others	All except Sarah, Jane
Social contact with peers	All except Sarah, Andrew, Irene
Group dynamics and stages	All except Irene, Jane
Safety to talk and self-preservation	All except Sarah
Meeting Needs	All
Stages of caring and own needs	All except Sarah
Positive attention for caregivers	All except Colin, Andrew, Tricia

As shown in Table 6.2, certain participants appeared to be exceptions on a number of the themes. Perhaps unsurprisingly, the two participants from the Individual condition (Chapter 5), Irene and Jane, did not support the themes concerning peers in the same ways or to the same extent as the participants from the Group condition. Additionally, one participant, Sarah, appeared in her interview to be more oriented than the others to the experience of being a research participant.

6.3.2 Descriptions and Examples of Themes

I will now discuss each of the above themes in turn, with relevant excerpts from the interview transcripts to illustrate each theme. Excerpts have been selected both to highlight the recurring nature of the themes and to preserve the idiographic focus of an

IPA study so, for example, a theme may be illustrated with excerpts showing that the theme was identified in several interviews, but individuals' actual experiences or feelings may be quite different. Following each superordinate theme, I will give a brief reflexive account of prior knowledge and experiences which informed the interpretation of the data, following the format introduced in Chapter 4.

The following key applies to the interview extracts used:

[...] A portion of text was removed from the extract, either to improve clarity or to remove identifying information.

[text] Clarifying text inserted by the researcher.

6.3.3 Superordinate Theme: Sharing Experiences with other Caregivers

The superordinate theme, Sharing Experiences with other Caregivers, was identified in each of the six interviews. Although two of the participants had taken part on an individual basis in the intervention study, these two caregivers also had previous experience of attending groups, and drew on this in a comparative way when relating their experiences of the intervention. Participants made frequent references to other caregivers, with this appearing to be a salient feature of their thoughts about having taken part. Five themes were identified as part of this superordinate theme: Learning from Others, Comparing Self to Others, Social Contact with Peers, Group Dynamics and Stages, and Safety to Talk and Self-Preservation. Each of these themes will be illustrated using excerpts from participants' interviews.

Learning from Others

The theme Learning from Others emerged from each of the four interviews with participants who had taken part in the group intervention. When discussing aspects of the group intervention that they had found useful or had put into practice, participants referenced the other members of the group. In the following excerpt, Tricia describes how she gained practical information from listening to another member of the group.

One of the girls was saying about holidays [...] getting like a respite person and all that. So that was quite interesting. Then one of the other, the men, can't remember his name [...] recommended eh that [non-prescription herbal

remedy] for sleeping at night time, and I've tried that for my mum it kind of helps her to sleep.

Sarah refers to a two-way process of learning within the group, noting an awareness that she may also have passed on useful information to fellow participants. There is a sense in this quote of the self-efficacy technique of modelling (for example, Bandura, 1994).

I quite liked the group because you find out things that you don't know already yourself about you know dementia, em and you know it's quite helpful [...] and also you could say something that would help someone else.

Similarly, Colin describes an exchange of information. Colin references the idea of an ongoing process of finding out about things, noting that he feels like a 'pioneer' and would be able to share more information with others now. This extract appears to point to Colin's feeling that the information shared within the group depends on the particular stages of caregiving of individual group members, and the particular experiences they have had.

A lot of it is maybe just what you've experienced yourself em that you bring into it, so it was more you know I've actually had some more interactions with say the medical side with my mum and so I've got more to add if you like with her health maybe, share with people, so it would depend at what point maybe you catch the carers, what they've already experienced [...] I wouldn't have known much about that side of it unless I'd already had a bit of involvement so if I went back now, I could share more of that with people who maybe haven't encountered problems eh for whoever they care for, or indeed learn from other people who have had similar experiences to me because I now feel as if I'm a kind of pioneer.

Comparing Self to Others

Four of the participants referenced comparisons between themselves and other caregivers. In particular, the group intervention appeared to serve as a focal point at which participants could put their own situations into context by listening to others; this may be related to the concept of appraisal in terms of stress and coping. In the following

two short extracts, Andrew describes this process of gauging whether he is ‘better off’ or ‘worse off’ compared to others in the group.

Some of the things that they talk about, you realised that you’re actually quite quite fortunate or quite lucky.

One of the best things in a group is that you’re eh listening to a lot of other problems and realising you’re not on your own, people are worse off or better off or whatever.

For Colin, the son of a person with dementia, the predominance of spouses in the group seemed to be connected to some reflection on his caregiving role. In the first of the following extracts, Colin reflects on how he was ‘struggling’ with his particular role, while in the second, he appears to be feeling that the child-parent relationship offers some protection from the challenges facing spousal caregivers. In these extracts, Colin seems to be using comparisons with other participants to clarify his thinking about his own role.

A lot of the people I met if I think about it were were, it was directly their partner or whatever, and I was I was still struggling a wee bit with this business of being one step back.

Most of the people who were there I think it was maybe their wife or their husband and I could see that it was a very different eh set up for them. I could be behind the fence a wee bit.

Social Contact with Peers

The next theme, Social Contact with Peers, emerged from three of the interviews, and relates to participants’ accounts of forging on-going peer relationships which continued beyond the intervention study. Tricia recalled meeting one of her fellow participants after the three intervention sessions had ended.

I was out on Friday night there and I met one of the girls, I bumped into her in the pub down the road and we got talking so we’re going to make arrangements to meet up one day for coffee and a blether. So that was, that wouldn’t have happened if I hadn’t have met her in the group, if I wouldn’t have went to the group that wouldn’t have happened.

This social contact appears to have been a positive in Tricia's experience, and could signal an increase in informal social support following the intervention. There was some divergence in participants' accounts under this theme, however. In the following extract, Colin describes meeting fellow group members outside of the group and exchanging only a 'hello'. It appears from Colin's description of these situations that there may have been some expectation of further contact with the other group members, as he said, 'maybe they don't recognise me'. However, later in Colin's interview, he related this behaviour to the 'safe space' nature of group work and the possibility that there was an implicit understanding that conversations should not continue outside of the group.

I've seen people outwith and I've you know I've never, maybe they don't recognise me but I've recognised them and we've just nodded and said hello, we haven't stopped and we haven't talked about anything in our circumstances so it's more a kind of casual, because, that makes me feel, well I guess it was just when we were in the room and it just stayed there.

Group Dynamics and Stages

For all the group participants who were interviewed, there were signs that they had considered the possible dynamics of taking part in a group, or the different stages of formation of new groups. Andrew described progressing from an initial feeling of strangeness to being able to find similarities with other group participants, and felt that this process of easing into the group took 'two or three sessions'; this may be a consideration when designing short interventions.

The first time you go it's strange and then you feel people realise that they're all eh much in the same boat cause after you've been to two or three sessions it gets you can inter-, interact with each other.

Tricia describes an initial feeling that other group members may already have known each other, possibly indicating a similar feeling to Andrew's about the start of the group (notably, in this particular group, two pairs of participants had come along as family members and so Tricia's feelings were partly grounded in the make-up of the group). In the second quote shown below, Tricia's account bears similarities to Andrew's, in terms of spotting connections with the other participants.

The impression I got when I first came into the group, the first week, the people that were there, they already knew one another.

[...] but then again, see when you sit and think about it, everybody's in the same boat, they're all carers, you know what I mean and they all know what's going on with their, well whoever they're looking after [...] it was kind of like swapping stories or whatever. I felt okay.

Safety to Talk and Self-Preservation

The theme of safety and emotional self-preservation emerged in five of the interviews. Participants appeared to be alert to the risks inherent in speaking about potentially emotive issues, and to consider these risks in relation to participating either in a group or on an individual basis.

For Andrew, speaking here about his decision to take part in the group intervention, the group setting offered a more 'light-hearted' way to take part. For Andrew, the risk of becoming upset appeared to have been a factor in his choice, although he felt that certain personal issues would be more appropriate to discuss in a private conversation rather than in a group.

I would find actually the one to one would be more, I would think it would be more upsetting, I think group's a bit lighter [...] eh if you're in a group if you're at a, light-hearted you know comments get made, it tends to make it a lot easier to speak. One to one, unless it was really something that was, you didn't want to discuss or would be embarrassed in front of a group, then no I would think it would be better, it's certainly a better idea for me personally.

Similarly, Tricia, who also participated in a group setting, appeared to feel that the group offered a certain protection against becoming upset. This may signal a form of coping, in terms of the avoidance of negative emotional states.

I'd rather speak to ten different folk at the one time, get to know people, rather than just doing it myself cause I would end up crying or whatever. I think a group helps better.

Conversely, Irene, who took part as an individual participant, appeared to find that she could cope better by dealing with her own problems, rather than listening to the accounts of others. During Irene's interview, she made references to feeling tired and

worn out, and there is a sense in the following excerpts that Irene feels that listening to others' problems may worsen these feelings or cause her to 'think more' about things, perhaps a variation on avoidant coping techniques.

[...] they all have problems, you know we all have problems and you know you just want to get on with your own as best you can as I say, without listening to other people's you know.

[...] if you think more about stuff than normal, it's even worse you know.

Reflexive Comments on this Superordinate Theme

When considering the emerging themes contributing to the superordinate theme, Sharing Experiences with Other Caregivers, I drew upon prior knowledge and experience of therapeutic group and individual work. In particular, I was reminded of group work training which covered the stages of group development outlined by Tuckman (1965) and this was brought to mind by participants' references to the stages of the group and their associated feelings.

The theme of safety, including safety to talk and emotional safety, also arose when considering participants' accounts and drawing upon previous knowledge of group work. In previous experience of facilitating groups within a different field, a new group would start with a discussion of informal 'ground rules', such as keeping discussions within the safe space of the group. Although the caregiver intervention groups did not begin by making this kind of agreement, it became clear during the interviews that participants had considered their safety; for example, Andrew had considered topics he might discuss in a group and topics that he felt were more suitable for a one-to-one conversation. It is possible that participants had prior experience of groups in which 'ground rules' had been set or, alternatively, that something about the group situation itself led to this consideration of safe disclosure.

Additionally, the priority given by participants to the presence, or absence, of other caregivers, resonated with my interest in Bandura's self-efficacy theory (for example, Bandura, 1977), in which modelling is one aspect of how self-efficacy is gained. The theme, Learning from Others, illustrates participants' awareness of the transmission of useful information between themselves and peers in the group situation.

One interesting aspect of this study is that participants and researcher had the shared experience of having attended the intervention sessions, albeit in the differing roles of participant or facilitator. This meant that my interpretation was based on having a combination of insider and outsider perspectives in relation to the participants (Hellowell, 2006). It is possible that in some of their answers to the questions in this study, participants were drawing upon this experience and offering updates based on this shared knowledge – for example, both Tricia and Colin gave examples of meeting other participants following the study.

6.3.4 Superordinate Theme: Meeting Needs

The second superordinate theme, Meeting Needs, was identified in all six interviews, and relates to instances of participants indicating that they were gauging the extent to which the intervention had met their own needs. Each participant made references to his or her own situation, and there was a sense that participants were taking an active role in being aware of their personal needs and evaluating the intervention with regard to these needs.

Stages of Caring and Own Needs

When recounting their experiences of taking part in the intervention study, five participants discussed their perceptions of the different stages of caregiving and how the intervention did or did not fit with their perceived needs. This theme arose from excerpts in which participants described caregiving as a process, involving different stages, or referred to their individual needs.

Jane, in the following two excerpts, described two different ways in which she perceived her caregiving had changed: firstly, she felt that her ability to get out to groups had lessened as the caregiving process went on, and secondly, she felt that her needs had moved from being practical in nature to more emotional, personal needs. Jane chose to take part as an individual participant in the intervention study.

The trouble is that as the person gets more dependent that you're looking after, you're less able to have the time to go out to groups.

In the early days when you're coming to terms with the diagnosis [...] how do you take over the finances, how do you get respite, how do you do all the

practical things? Later on you've got the practical things set up, so it's more [pause] more support for you on a personal level I think.

In the following excerpt, Colin describes finding the stress management session to be the most useful part of the intervention. In this and other parts of his interview, Colin referred to his perception that he was finding caregiving difficult at the time of the intervention study, with the timing of this benefit appearing to be important.

[...] the thing I found I guess overall most useful was how to deal with stress you know and I think we did, that would have been at the point I guess you were handing out, you know giving handouts and support, you know cause that was my main thing for having decided to go along, I wasn't coping very well and that helped a lot and still does.

Sarah felt that despite living with the person she cared for, she knew 'nothing' about caring and had gone along to the sessions open to learning more about caring. She describes one of the benefits of the group being that it could lead to thinking about different ways to 'do' caring.

I know nothing about it you know, I'm just I'm just going on instinct and to hear anything that would have helped to do, you know is good because it doesn't really maybe sometimes tell you what to do but the information you hear makes you think, how could you do things differently than you're already doing.

Positive Attention for Caregivers

For three participants, a benefit of the intervention was that it offered a source of positive attention. This theme emerged from references to participants' perceptions that they were an overlooked group, or that they benefitted in some way from having personal time out from caregiving.

For Sarah, who appeared to place more emphasis on the intervention being part of a research project than the other participants in this study, there was a benefit in knowing that research was being carried out in an area which she perceived to have been neglected. There is a sense that Sarah felt that research tended to be going on at a 'higher' level which carers generally did not get to hear about.

I thought before the sessions that nobody really was paying much attention to dementia but to find out that you were actually researching [...] at that level, a

people level you know rather than away up where no-one knows about, to me that's exactly where we should be doing a lot of research, how people are, how they're handling it and how they're living with it, and that's where all the work should be going on for us.

Irene, who made references during her interview to feeling very tired and busy, described how a beneficial aspect of the intervention was that it offered her some time for herself.

[...] it gave me a wee bit time away for myself eh during that time you know, so I found that good. [...] I need that, I really do, I need to get away for a wee while.

The second extract from Irene here gives a context to her need for time away; Irene mentions time more than once in this extract, which conveys her feelings that she does not have enough time, and that time is passing her by because she is so involved in the practicalities of caring.

I just feel I don't have time, I don't have a lot of time really. I've always got jobs to do, always stuff to do and then with having no car, I've got a good friend who takes me shopping, I've been there today actually shopping [...] you know the day goes by and it's evening before you realise it.

For Jane, the role of caregiver tended to be overlooked in relation to the attention given to the person with dementia. Both Jane and Irene appeared to stress the importance of personal support, which appears to be linked to their decision to take part as individual participants in the intervention.

There is so much emphasis on the person with dementia, who is happy in his own world a lot of the time and I think that the stress is more on the carer [...]

Reflexive Comments on this Superordinate Theme

When considering the superordinate theme, Meeting Needs, I was reminded of professional experience of assessing service users' needs and giving tailored advice or referrals. Although aware of the importance of service user involvement, I had not used in-depth questioning of the type done in semi-structured interviews before, in soliciting individual's understandings of their own needs and how they see the 'fit' of a service. It was enlightening to step outside of the role of professional 'helper' and to be able to focus on individuals' perspectives in gauging the appropriateness of an intervention or

service, although it should be kept in mind that from participants' point of view, I may have been perceived to be in the role of 'helper' or practitioner due to having facilitated the intervention sessions. One participant, Sarah, clearly indicated that she saw the experience as research and my role as researcher; however, for the other participants, there may have been less role clarity and it is possible that their responses were influenced by a perceived social pressure to be positive about the intervention.

The theme, Positive Attention for Caregivers was reminiscent of comments made (usually outside of the recorded part of the meeting) by participants in the study reported in Chapter 4. Some of these earlier participants had expressed similar sentiments regarding caregivers being an overlooked group or dementia in general not receiving public attention, and my earlier experience of interviewing these caregivers gave me an insight into the comments of the participants in this study. As IPA begins with a close focus on participants' own words and only later considers links with other theories or ideas (Smith et al., 2009), it was important to try to set aside these understandings from the previous IPA study in the initial stages of the analysis and to draw upon them only when full consideration had been given to the data from this study.

6.3.5 Case Studies

Two case studies will now be presented, to illustrate the idiographic focus of this study and the links between individual participant accounts and the recurrent themes identified earlier. An attempt has been made to reflect the differing demographics of the participants in this study, as well as the different modes of participation in the intervention.

Case Study 1: Colin

Summary of caregiving situation

At the time of the study, Colin was sixty and living in a large town in the West of Scotland. Colin had taken early retirement from the electronics industry, in which he had held a senior role.

Colin identified himself as the main informal caregiver for his mother, who had recently been diagnosed with dementia. Colin did not live with his mother, but provided regular

support to her. Colin described himself as an early-stage caregiver, who was just beginning to negotiate the services he and his mother may need to access, and he described some difficulties in doing so. Colin had also begun to explore the support available to him as a carer, and had had an initial meeting at his local carers' centre, where he heard about the intervention study.

During the intervention sessions and his follow-up interview, Colin expressed some anxiety about his role as a carer. He appeared to feel that his situation (as a child of a parent with dementia, and living separately from the person with dementia) was different to his perception of most carers, who Colin believed to be spouses.

Selected themes emerging from Colin's interview

Own experience and role as group member

When talking about his experience of being in the group intervention, Colin drew upon his work experience, appearing to feel that his professional role had given him practice and confidence useful for being in a group. This is illustrated in the following excerpt.

I probably came across as if I was reasonably comfortable I think, cause I mean 25 years em in the electronics industry kind of brought you out of your shell if you like so I think I had maybe more exposure to that as a, due to my working career so I'm always apprehensive, that's a different type of group [...] I feel like an environment at work where you were encouraged to speak up so I I felt as if I settled in reasonably well [...]

Colin appeared to be considering his adjustment to the new role of being a member of a different type of group, a group of caregivers, and to be reflecting on how he came across to the others. Colin's understanding of this was helpful in judging the themes around group membership, including themes about being safe or comfortable talking in a group, and about group dynamics. In the following quote, he refers explicitly to 'group dynamics' and being 'safe' in the group. Colin's use of these phrases may signal his familiarity, perhaps in a professional capacity, with groups. The excerpt here also illustrates the comparisons Colin was making between his own and others' roles and participation in the group. This contributed towards the understanding of how comparisons with others were used by participants in considering their own participation and concerns.

[...] I also noticed they sort of developed and opened up a bit and my guess is they became a bit more comfortable so I guess it's the usual kind of group dynamics you would get that, some people might always remain fairly kind of insular because especially the topics we were on, you have to open up a bit you know but it felt safe enough to talk [...]

Own stage of caring and needs

The following quote is one of several from Colin in which he seemed to be actively reflecting on his own needs at the time of the intervention study, and judging whether or not participation was helpful. This quote contains references to time and stages, including 'at the same time' and 'get me started', showing that Colin was considering issues around his perceived early stage of caring and the timing of help offered.

I was struggling a wee bit before anyway as a lot of people do and made my way along to the actual centre, but then the fact that your study was em running at the same time really helped it because it helped me continue a wee bit [...] I haven't em I haven't yet gone along to the centre to any of their other [...] sessions they run [...] group sessions, so I did a one to one with them, but that's enough to get me started.

Colin's account helped to form an understanding of the ways in which participants were actively gauging their needs and the fit of the intervention to meet these. There is a sense here of Colin's expectation that his needs will evolve over time, and that different types of input may help him 'continue a wee bit'. Colin's account here is also relevant to the notion that interventions can be used to provide specific types of support at specific times, an idea discussed throughout this thesis (see, for example, the discussion of brief interventions in Chapter 2).

Case Study 2: Irene

Summary of caregiving situation

Irene, at the time of the interview, was in her seventies and living in a large town in Central Scotland with her husband, who had been diagnosed with dementia several

years ago. Irene provided daily informal care for her husband, who was not receiving any home care, although he did attend weekly day care meetings with other people who had dementia. Irene had accessed some support via her local carers' service, although did not describe any regular contact.

Irene felt that her husband's dementia symptoms were progressing, and she described difficulties with motivating him to take an interest in things or to complete tasks which Irene felt he could manage. Irene described herself as a lively person who enjoyed going out and being involved in social events, and she felt frustrated by her husband's withdrawal as she saw it from social life. Irene had organised a holiday for the two of them and was feeling very anxious about whether or not this would go ahead.

During the interview, Irene expressed feeling very busy and weary, and felt that caregiving was becoming more of a strain for her as her husband became less able to do things.

Selected themes emerging from Irene's interview

Needing time out from caring

Irene made several references during her interview to needing time for herself, or time away from caring, and she described how individual participation had been her choice in relation to this. The following quotes were given by Irene as examples in relation to needing 'time out'.

[...] trying to motivate somebody to do something who doesn't want to do anything, it can wear you down after a time [...]

[...] what would be helpful would be if somebody could take him out and [...] he does go to things like I told you before, but this week there has been nothing on until Friday. Now see if there had been something midweek, that would have helped the situation, you know every day just somebody wanting to sit about and close their eyes and do nothing, it's frustrating.

In these and other excerpts, Irene appeared to be describing a divergence between her husband's needs and her own, and a need for respite in the form of someone else providing company or distraction for her husband. Irene's accounts were helpful in making sense of the ways in which stages of caregiving and feelings about caregiving

could relate to a sense of what might help. In the intervention study, Irene chose individual participation, but her descriptions here suggest that she may also need different kinds of ‘time out’ in the form of more input with her husband’s care. Irene’s descriptions of her husband’s behaviour tended to focus on what she perceived to be his lack of motivation or interest in doing things; this suggests that Irene may have been struggling at the time of the interview with the symptoms of her husband’s dementia and with perceiving them as such.

Stages of caring

Related to Irene’s accounts of needing time out were references made by Irene to her stage of caring. In the following quote, Irene refers to a situation in which an expert had called round to the house to fix a bicycle. Irene recalls how her husband was not able to play an active part in the scenario.

[...] my husband was just standing there like a spare part and I thought, I felt sad for him really because that’s not him. That’s just not him. And I thought Jesus, what a shame really you know, he wanted to help him but he was really in his road, you know how that goes. Just things like that cropping up now, which I know will happen really.

Irene’s repetition of ‘that’s not him’ emphasises her sense of the changes brought about in her husband’s presentation. There is a feeling of resignation in Irene’s phrases, including ‘you know how that goes’ and ‘I know will happen’. Irene’s account here was markedly different in tone from participants who saw themselves as being at an earlier stage of caregiving, who tended to be more actively problem-solving. Considered alongside Irene’s feelings about needing time out, there was a sense that Irene needed not only individual support but a different type of support; this may be a need for emotional support (centred on issues such as loss) rather than information-based support.

Feelings about peer groups

Possibly related to her perceived need to have ‘time out’ from caring, Irene was very clear that she did not think that being in a group with other carers would be helpful. Irene drew on past experiences of groups, as illustrated in the following quote.

I did do it, I did go somewhere for about three weeks, a month and really I just listened to everybody and they were beginning to get on my nerves to be quite honest. And I thought oh, can't be bothered.

Irene illustrates here an aspect of peer groups which was also identified in the study reported in Chapter 4: that is, some caregivers perceive that listening to others' stories is not helpful and may even contribute to a sense of overload. It is possible that this experience may reflect some aspect of the particular group described here by Irene; however, her experiences contributed to the sense of a need for choice when offering interventions to caregivers, and a need to appreciate that for some individuals, the presence of peers may add to feelings of stress.

6.4 Discussion

The results of this qualitative study illustrate the ways in which qualitative methods can generate a different type of outcome or feedback to that obtained using quantitative methods. As discussed in Chapter 5, the caregiver intervention has already been evaluated using standardised questionnaires to measure outcomes such as depression and caregiver burden. The aim of the current study was to generate more richly detailed accounts of the caregivers' actual experiences of taking part in the intervention.

The issues raised by using quantitative and qualitative methods alongside each other, and the different types of information gained in doing so, will be discussed in Chapter 7. Bearing in mind that IPA studies typically use small samples and have an idiographic focus, and therefore attempts to link findings to a bigger picture should proceed cautiously (Smith et al., 2009), the themes generated in this study will now be discussed and possible connections with existing literature will be proposed.

6.4.1 Sharing Experiences with Other Caregivers

The superordinate theme, Sharing Experiences with Other Caregivers, contained themes relating to participants' accounts of their connections to other caregivers. This superordinate theme was identified in all six interviews, and the frequency with which peers were mentioned signals that this was an important aspect of the intervention for participants. As described earlier, this study contained a small subset of participants who had taken part in the individual condition of the intervention study; however, these

participants had previous experience of being in groups with other caregivers. Each of the individual participants spoke during the interview about why they had not wanted to join in with a group at this particular time, showing divergence in experience within the theme. This theme has some common ground with a finding by Steffen and Mangum (2012), who identified similarity of experiences and support from other group members to be predictors of on-going group attendance.

The themes identified here show a degree of overlap with the research by Newton et al. (2007), despite the different context; they interviewed young people with auditory hallucinations who had taken part in a group intervention. There were similarities in terms of the prominence of other group members, the accounts of learning from peers and the role played by peers in adjusting one's view of a situation. In the Newton et al. (2007) study, participants spoke about how listening to peers had helped them to normalize and destigmatize their own experiences, while in the current study participants made comparisons between themselves and other caregivers, and appeared to re-assess their own situations according to their perceptions of the challenges faced by others; there is a sense here of the appraisal of personal challenges, as proposed in stress and coping models (for example, Pearlin et al. (1990)).

The intervention used in Chapter 5 was based upon Bandura's (for example, 1977) theory of how we acquire self-efficacy; Bandura posits that self-efficacy can be built through Mastery, Modelling, Social Persuasion or Managing Stress and Emotional Responses, as described in Chapter 3. The theme, Learning from Others, appears to be similar to Bandura's notion of Modelling, in which appropriate role models can be influential in fostering self-efficacy. In participant Tricia's account of picking up tips from other participants and putting them into practice (for example, trying remedies to help her mother sleep), it is possible to see that Tricia's experience could also relate to Mastery. Although the analysis in Chapter 5 showed no significant overall effect of the intervention on caregiving self-efficacy when compared to a control group, it is possible to see how some of the themes emerging from participants' own accounts are congruent with self-efficacy theory.

In a review of interventions targeting social support among caregivers, Dam et al. (2015) found that increased social support tended to arise as an outcome from qualitative studies, rather than being measured in quantitative studies. The theme, Social Contact with Peers, found in the present study, would support the idea of increased social support as a possible outcome from an intervention study which was not designed

specifically for this purpose. Dam, de Vugt, Klinkenberg, Verhey and van Boxtel (2016) argue that social support outcomes should be the focus of further quantitative work.

6.4.2 Meeting Needs

The second superordinate theme, Meeting Needs, arose from times when participants showed an awareness of their own needs, the evolution of their needs over time and their feelings about being a caregiver of a person with dementia, in relation to having taken part in the intervention. One of the themes here, Stages of Caring and Own Needs, had some overlap with the qualitative study reported in Chapter 4, in which participants spoke about the changing nature of caring for a person with dementia. For participant Jane, the decision to take part as an individual participant appeared to relate to the change in her needs over time (both in terms of her available time and the change from needing practical information to needing personal support in the later stages of caring).

Looking at ways in which the intervention was or was not able to meet specific needs of the participants, there were examples given by participants themselves. Colin felt that the stress management session had been most useful to him as it coincided with a particular need he had, while Sarah referred to the sessions making her think about, ‘how you could do things differently’, referring perhaps to the non-directive nature of the exercises, and the focus on making decisions based on caregivers’ own experiences. However, there was also a more general sense here of participants considering the ‘fit’ of the intervention to their own situations, rather than referring to specific techniques and outcomes. This partly mirrors the findings of Lavoie et al. (2005), who found that participants did not easily link interventions to outcomes but described overall positive experiences of an intervention; it is perhaps unrealistic to expect that participants would use the systems or language of the researcher in talking about their experiences of taking part in this type of study.

The other theme identified under this superordinate theme, Positive Attention for Caregivers, described a different type of benefit of the intervention, and included accounts both of feeling overlooked as a group, and of needing ‘time out’ as an individual. Sarah’s feeling that there was a lack of attention given to ‘how people are’ has been borne out by previous research; for example, Riedel, Klotsche and Wittchen (2016) found that physicians tended to under-estimate levels of depression in caregivers

of a person with dementia, and to over-estimate the degree to which caregivers were informed. The emergence of this theme in three of the six interviews suggests that, for some participants, there was a need for positive attention, whether at the group or individual level. For the individual participants, the notion of positive attention appeared to relate more clearly to their perception of being at a stage in their caring in which it was difficult to prioritise their own needs. It is possible that a future test of an individually-delivered intervention should focus on the extent to which participants feel personally supported.

6.4.3 Implications of these findings for the intervention

The use of IPA to explore participants' experiences has generated insights into the self-efficacy intervention which would not otherwise have been obtained. Firstly, this analysis has shown the extent to which the issue of shared experience with peers was prominent in participants' accounts. Secondly, it has illustrated some of the complex ways in which participants gauged their own needs, knowledge and experience in relation to the intervention.

Looking at the inclusion of individual and group conditions in the intervention study, the results of this qualitative study appear to support the different ways of delivering the intervention. The two individual participants interviewed here, Jane and Irene, gave accounts of their stages of caregiving and personal needs in relation to taking part individually. As the benefits described by these participants included personal support and time out from caring, it is possible that individual caregivers may benefit from the fact that a one-to-one intervention can be tailored and made less structured. Looking back at descriptive statistics of the different groups reported in Chapter 5, two thirds of the group participants (66.7%) had been caregiving for up to two years, with only one individual caregiver (10%) falling into this early caregiving category. Individual participants were also more likely to be older, spousal caregivers living with the person with dementia. It may then be the case that these caregivers have a reduced need for the more formal setting and social support offered by a group, and an increased need for more personal focus and support.

For all participants, the issue of peers arose in the interviews. Peers appeared to be important to the group participants for learning and exchanging information (echoing Bandura's idea of Modelling (for example, Bandura, 1977)), for social support and for

providing a context against which participants could appraise their own situations, in some cases gaining a new perspective on how their challenges compared to others'. It could be argued that some of these benefits would also be found in a less formal caregiver support meeting. However, the caregiver intervention kept a focus on problem-solving and the sharing of experiences, ideas and tips, and this may account for group participants reporting that they were able to learn from other carers, contrasting with Irene's previous experience of caregiver groups in which she felt she was listening to others' problems.

Specific benefits of the intervention, as described by interview participants, included the use of stress-management techniques and the sharing of ideas and tips. It was notable that participants appeared very well able to consider their own needs and stages of caregiving in relation to the suitability of the intervention; this would support the notion of inviting caregivers to decide whether to take part individually or in a group. It is possible that the flexibility of future interventions could be taken further, with the intervention being considered as a 'toolbox' which could be tailored to address different needs. Overall, participants' accounts appeared to support the delivery of the intervention as one which prioritised participants' own expertise and experiences, rather than being a formal training intervention.

The results of this and the previous two studies will be discussed further in Chapter 8, which will look at overall conclusions to be drawn from this research, as well as gaps and priorities for further work. Before this concluding chapter, Chapter 7 will reflect on some of the practical and theoretical considerations of using qualitative and quantitative work together, factors influencing the research designs used, and how the work in this thesis fits with current debates in dementia care.

Chapter 7: Methodologies and Current Debates in Dementia Caregiver Research: A reflective discussion

7.1 Introduction

The studies conducted as part of this thesis have been described separately and in detail in their respective chapters. However, it is important to reflect on methodological issues which apply to the work as a whole, including issues concerning the research and current debates pertinent to the study of dementia. In this chapter, I will look at some points which affected the research plan or needed to be taken into account when carrying out the studies.

I will examine various issues which have been identified in previous intervention research involving informal carers, considering the extent to which these issues could be addressed in the current thesis. Points will be identified which can inform the design of new studies, so that there is a continual process of refining research design and learning from the outcomes of earlier research projects. Ethical issues pertinent to the research will also be discussed.

I will discuss the use of a ‘mixed methods’ design, combining quantitative and qualitative research methods, and the implications of this type of design on the research questions that can be asked, the type of knowledge we can expect to gain, and the different ways in which the validity of research can be assessed.

Finally, I will consider an issue which is being debated within the field of dementia research, the contested area of language use and its implications, looking at the relevance of this debate to the materials and methods used in the studies forming this thesis.

7.2 Research design issues identified in previous intervention studies

As has been discussed earlier in the thesis (see Chapter 2), caregiver intervention studies have tended to yield modest results (for example, a review by Pinquart & Sörensen (2006) concluded that many caregiver interventions led to small but significant improvements in outcomes), and there have been attempts to focus on weaknesses in

research designs which may help account for this. Zarit and Femia (2008) for example, discussed features typical of caregiver intervention studies which could be contributing to the observed patterns of results.

The following points describe relevant issues raised by previous research and I will discuss the implications of these for the current work, including limitations of the studies and steps taken to try to mitigate these limitations and strengthen the research design. These points were particularly important in designing the intervention study reported in Chapter 5, although they also helped to inform the thesis as a whole.

7.2.1 The use of randomised controlled trials

The randomised controlled trial (RCT), in which participants are randomly allocated to an experimental or control condition, is often deemed to be the ‘gold standard’ of intervention studies, and some review articles will consider only those studies which have employed an RCT design (for example, reviews by Schulz et al, 2002, Godwin et al, 2013, Olazarán et al., 2010 and Jensen et al., 2015 included only RCT-based studies).

However, the use of the RCT design is far from uniform in caregiver intervention studies, and there are valid reasons for this. Firstly, RCT studies tend to be resource-intensive; in order to randomly allocate participants to different conditions, we must have relatively large numbers of participants and the resources to provide these different conditions across different locations or at different times. The nature of caregiving intervention research, which often relies on the participation of caregivers who are subject to unpredictable life events and challenges, means that many intervention studies are conducted with modest participant numbers (for example, Hoppes et al., 2012; Gaugler et al., 2011). An RCT design was not feasible for the present work, which was similarly planned to use modest participant numbers. Secondly, as argued by Zarit and Femia (2008), RCT studies can lead to complications such as control group participants deciding to seek treatment for themselves, and to intervention participants withdrawing or failing to adhere to protocols because they believe the treatment is not needed or suitable. They suggest that as long as control and intervention group participants do not differ in some important aspect that could affect the outcome of the study, it is sometimes better to use a research design in which participants elect to take part in an intervention.

An alternative to the RCT is to use a quasi-experimental design; for example, allocating participants in one location to the experimental group, and participants in a second location to the control group. This has obvious advantages for a study in which resources are limited, but also has certain implications: if using a quasi-experimental design, we must either ensure that participants in both locations are evenly matched on demographic factors, or take into account any important differences that may exist between the two groups. There may also be differences attributable to the location itself, raising the risk that results may be wrongly interpreted.

In designing the current studies, the relative merits of different approaches were considered. A quasi-experimental design was chosen for Chapter 5, with participants being invited to specify whether they wanted to take part individually, in groups or in the control. Although groups tended to form at certain locations (such as carers' centres), some participants attending these centres elected to take part individually. Control participants were offered the intervention following the control period, although not all control participants wished to receive the intervention. The advantages of this approach included being able to accommodate participants' preferences about how and where to take part, and to make it easier for people to participate. However, the approach also meant that baseline differences between participants had to be taken into account in the analysis, and an attempt was made to use this information to understand factors which may make individuals more or less likely to access certain types of support.

7.2.2 The choice of outcome measures

A further problem with intervention studies is that they are difficult to compare because they use different outcomes, or different tools to measure comparable outcomes. This has been discussed as a difficulty in compiling reviews of caregiver interventions (for example, Hurley, Patterson & Cooley, 2014; Jensen et al., 2015; Cooke, McNally, Mulligan, Harrison & Newman, 2001; Gallagher-Thompson & Coon, 2007; Gallagher-Thompson et al., 2012). A related point is that intervention studies should use outcome measures which have a clear connection to the concepts targeted by the intervention (Zarit & Femia, 2008). There is no absolute consensus in this kind of study as to which measurement tools should be used, and different theoretical models may lead to the selection of different measures. However, it is important to try to reach some

consistency, and to measure outcomes which can offer some comparison with similar studies.

In Chapter 5, caregiver burden and depression were selected as measures of the outcomes of the caregiver stress process. There are well-documented reasons for being interested in these outcomes. Pearlin et al. (1981) discuss the relevance of measuring depression when we are looking at conditions which involve lasting, undesired and distressing circumstances which can lead to a diminishing of self-esteem and self-efficacy. Caregiver burden has also been used widely in caregiver research as an outcome measure, and burden has been found to be related to outcomes such as institutionalisation of the person with dementia (for example, Luppia et al., 2010; Gallagher et al., 2011; Spitznagel et al., 2006) and caregiver wellbeing (for example, Schulz et al., 1995). Some writers have questioned the utility of caregiver burden as a measurable entity; Black and Almeida (2004) argue that ‘burden’ is a broad term and that the clinical significance of caregiver studies could be improved by focussing on more specific phenomena such as depression. Additionally, ‘burden’ is currently a contested word and can be perceived as contributing to negative views of people with dementia (Dementia Engagement and Empowering Project, 2014), and this will be discussed later in this chapter.

Schulz et al. (2002) have suggested that there could be standard outcome measures used in caregiver studies, to make it easier to compare the results. They did not make specific proposals, but recommended a consensus-based approach to identify suitable measures. Although there is as yet no uniformity in the choice of tools to be used, the questionnaires selected for the study described in Chapter 5 have been used widely and shown to be reliable and valid measures. For example, the Centre for Epidemiological Studies – Depression (CESD; Radloff (1977)) scale is reported to be the most widely used measure of depression in dementia caregiver studies, and caregivers tend to have higher than normal scores on this scale (Schulz et al., 1995).

7.2.3 Interventions and attrition rate

As discussed in Chapter 2, interventions used in caregiver research have involved varying intensity and commitment from the participants. For example, the self-efficacy intervention used by Boise et al. (2005) lasted for six weeks and the authors reported that 28 per cent of participants did not complete the course, with completion considered

to be attendance at four or more sessions out of six. The authors of this study concluded that the length of the intervention may have contributed to the rate of attrition. In the study reported in Chapter 5, there was an attrition rate of 25 per cent (based on full attendance of the intervention or participating at pre- and post- stages for control participants). Most non-completing participants gave reasons for withdrawing from the study, and these appeared to be unavoidable reasons including family emergency and changes in circumstance regarding the person with dementia.

In their 2014 review of meditation interventions for caregivers, Hurley et al. considered attrition rate as an important factor, indicating the acceptability and feasibility of interventions for caregivers. Even the most rigorous RCT design can suffer when participants drop out of the study in high numbers due to the commitment required (Schulz et al., 2005). Zarit and Femia (2008), however, caution against making interventions so brief that they do not achieve an effect. Looking at previous literature on the durations of interventions and attrition rate, it appears that a balance needs to be struck between offering an intervention that will have sufficient content to produce an effect versus one that requires too large a time commitment from caregivers.

When designing the intervention for these studies, an effort was made to include techniques which had been used successfully in previous work, and which focussed on issues which had been identified as modifiable and relevant to the caregiving stress process. The sessions were designed to last no longer than two hours, and the intervention to require no more than three weeks' commitment from caregivers. The aim was that the intervention would offer content which would be helpful and which could also be delivered in a relatively short space of time, to minimise drop-out due to the commitment required. However, as discussed in Chapter 5, the unpredictable nature of caring for a person with dementia can mean that there is attrition from a study even when it has been planned to take these factors into account.

7.2.4 Conflicts between delivery of intervention and measuring of outcomes

A further issue that has been noted in some previous reviews (for example, Schulz et al., 2002) is that a single researcher can be responsible for delivering an intervention and carrying out the measurement of outcomes. This clearly carries with it certain risks: for example, participants may feel under pressure to rate an intervention positively if

outcome measures are taken in the presence of the person who designed and carried out the intervention.

This issue was considered carefully in the present work, which was carried out by a single person. As resources were not available to have a separate person deliver the intervention, I considered how to work with the issue of being the person who both delivered the intervention and measured its outcomes, and how to minimise the problems associated with this. Firstly, it was explained to participants that the outcome measures were not intended as a reflection of their enjoyment of the intervention. It was stressed that the questionnaires were there to track the participants' experiences at different points in time. To encourage participants to complete the outcome measures openly, they were asked to enter an individual code at the top of each questionnaire, rather than their names or other identifying information. Additionally, the inclusion of a measure of 'external stress', which was not targeted by the intervention and did not change significantly over the course of the intervention, helped to rule out the likelihood that participants were systematically reporting positive changes.

For Chapter 6, participants were interviewed about their experiences of taking part in the intervention study. This again clearly carried with it the risk that participants would feel obliged to give the intervention a favourable rating. To try to avoid this feeling of obligation, an interview schedule was devised, with open questions asking participants to consider different aspects of their experience, rather than asking participants to say whether they thought the intervention was 'good' or 'bad'. The interview schedule for Chapter 6 can be found in Appendix H. Additionally, the interviews for this study were conducted by telephone rather than face-to-face, in the hope that this might minimise any social pressure experienced by participants.

7.2.5 Treating caregivers as a homogenous group

Previous research has indicated that caregivers do not constitute a homogenous group, with the same needs applicable at all stages of the caregiving career. Schulz et al. (1995), in a review of caregiver risk factors, argue that the experience of caregiving is a complex one involving many factors, such as financial issues, social support, behavioural symptoms in the person with dementia, self-esteem and relationship to the person with dementia. Given the variability of these factors, it is unrealistic to think that one intervention given at one point in time could address the needs of all caregivers.

However, it is also difficult to design interventions which meet the need both to be replicable and sufficiently flexible to be useful to individuals.

Efforts to address this issue have been made with interventions being designed for use in a more person-centred way (for example, Zarit et al., 2013, and the REACH II project in the USA). With this in mind, the intervention for these studies was split over three individual sessions, targeting different types of caregiving stress and self-efficacy. It was hoped that the intervention would have the potential to be used either as a whole or split into separate sessions according to the needs of the individual at a given time, although for the purposes of the current work it was tested as a whole. Further, the demographic information reported in Chapter 5, as well as the interviews analysed for Chapter 6, were intended to contribute to an understanding of how aspects of an intervention might be useful to different groups of caregivers at different stages of caregiving.

7.2.6 Small sample sizes

A criticism (for example, Belle et al., 2006) of caregiver intervention studies is that sample sizes tend to be small, resulting in limited statistical power to draw reliable conclusions from the results. The nature of the current studies, with one person carrying out and evaluating the intervention, as well as challenges in recruiting participants (see Chapter 5), meant that a modest sample was planned, although this was comparable to similar intervention studies (for example, Gaugler et al., 2011, in a three-location study with two moderators at each location, recruited just over 60 person with dementia/caregiver dyads; Haley et al., 1987, recruited a total of 54 caregivers in a two-phase study; Kwok et al., 2013, recruited 38 caregivers; Zarit et al., 2013, used a sample of 35 caregivers). It was therefore important to consider steps that could be taken to make the research more robust.

The use of both quantitative and qualitative research methods allowed the intervention to be examined from more than one research perspective. As I will discuss later in this chapter, qualitative and quantitative methods carry different implications in terms of the knowledge that we can claim to get; however, the overall aim was to allow the results to inform and complement each other. Of course, a small sample size is less problematic for qualitative research than for quantitative, and this was kept in mind when reaching conclusions from the data.

7.3 Ethical Considerations

As with any research involving human participants, it was important to give full consideration to ethical concerns when designing the studies described in this thesis. Permission to conduct the studies was granted by the Ethics Committee within the School of Life Sciences, Heriot-Watt University. The British Psychological Society's Code of Ethics (2009) informed my consideration of ethical issues when designing the studies. The following issues were considered as particularly relevant to this work.

7.3.1 The wellbeing of participants

The intervention examined in Chapters 3, 5 and 6 was designed to increase feelings of self-efficacy and confidence, and it was anticipated at the outset that it would have a positive or neutral effect on participants' wellbeing, rather than a negative effect. However, it cannot be predicted that all participants in this type of study will find it to be a positive experience, and this concern may be heightened by the knowledge that caregivers of people with dementia are already at increased risk of depression, anxiety and other health-related issues (Ory et al., 1999; Mausbach et al., 2007). Similarly, the interview schedules used in Chapters 4 and 6 involved participants speaking about their experiences of caring for a close relative who had dementia, and it was anticipated that this could potentially be an emotionally distressing experience. Therefore, it was very important to ensure that participants' safety and wellbeing were prioritised.

Steps were taken to protect participants' wellbeing during these studies. For example, in the intervention study, participants were reminded that fictional case studies could be used in completing the exercises (these case studies were compiled ahead of the sessions), and that they should not feel under any pressure to talk about their own personal circumstances if this was too difficult.

Additionally, it was explained to participants at the start of the intervention sessions that the sessions would be run informally and that 'time out' could be taken at any time and for any reason. Participants were provided with information about agencies who could offer further support, and all participants were made aware that their participation was entirely voluntary and that they could choose to withdraw from the study at any time. I have experience of facilitating therapeutic group sessions which deal with sensitive

information, and drew on this experience to assess and respond to any perceived risk to participants that arose during the sessions (for example, moving the discussion on and offering ‘time out’ when a participant appeared to have difficulty in recounting an experience they had started talking about).

Similarly, participants in the interview studies were reminded that they could withdraw from the study, and were given signposting information about sources of support. Additionally, because an audio recording was made of the interviews, any signs of emotional upset were met with an offer to stop the recording and to take a break from the interview.

7.3.2 Confidentiality and anonymity

It was recognised that participation in these studies could involve the sharing of sensitive information. This could be information relating to the person with dementia (for example, during group discussions of caregivers’ experience of problematic behaviour) or relating to the caregiver (for example, asking them to complete the depression inventory). It was therefore important to consider both confidentiality and anonymity.

Confidentiality was considered in the context of the three group sessions comprising the intervention. Because of the way in which recruitment was carried out (such as involving groups of caregivers who attended particular carers’ centres) there was a strong possibility that some participants would already know each other and may already have some relationship outside of the centres. It was decided, therefore, to offer the option of working through the group exercises without relying on participants disclosing personal information, by offering case studies and examples.

Anonymity is closely related to confidentiality, and anonymization is used by researchers to guard against breaches of confidentiality (Wiles, Crow, Heath & Charles, 2008). In the interview studies reported in Chapters 4 and 6, which relied heavily on direct quotes from participants, anonymization was used to prevent the identification of individual participants from their quotes. This anonymization involved the use of pseudonyms, and the avoidance of using quotes in which participants revealed identifiable details such as locations, services attended or unusual personal circumstances.

For all studies, during an initial meeting with participants, basic demographic information was collected. Names of participants were essential in obtaining signed, informed consent to proceed with the research. Contact details were collected in order that any relevant follow-up could be conducted, including the collection of outcome data following the intervention. This information was stored securely, with the informed consent sheet and contact details being stored separately from the study data. Study data were anonymised: pseudonyms were used on the interview transcripts, and a coding system was used on outcome measure paperwork, with participants generating their own codes. Although there is always an element of risk to confidentiality with this type of study, in which people are recruited because of their specific experiences and examples of those experiences are reported, it was envisaged that these steps would help to ensure that individuals could not easily be identified in the reports.

7.4 Methodological implications of ‘mixed methods’ study design

When planning to use both quantitative and qualitative research across the three studies, consideration was given to the types of research question that could be asked and the specific knowledge claims that could be made using different types of research methodology. While quantitative research is often used to try to uncover underlying ‘truths’ or to state objectively that we have obtained evidence in favour of a particular theory, qualitative research is often used in a quite different way, offering an interpretation and carried out reflexively, with the researcher’s own beliefs and values taken into account during the analysis (Smith et al., 2009). In this section, I will consider some of the implications of using quantitative and qualitative research together in a body of research, before going on to look at how these approaches can be used to complement each other in enriching our understanding of the research topic.

7.4.1 Ontological and epistemological implications of using quantitative and qualitative approaches

Quantitative and qualitative research approaches can be seen to involve different ontological and epistemological positions: that is, different stances on what can be known and how we approach the gaining of knowledge. Broadly speaking, quantitative research usually follows a positivist position, in which it is assumed that we can uncover ‘truths’ about the world and that research can be carried out objectively.

Qualitative research lies closer to an interpretivist position, in which objective and subjective knowledge are linked (Della Porta & Keating, 2008). For example, qualitative analyses often include an acknowledgement of the researcher's interest in or prior experience of the topic being studied, as this is relevant to the particular analysis offered by the researcher.

For a body of research involving both quantitative and qualitative approaches, it is important to bear in mind these differences and the claims that can be made. For example, the study reported in Chapter 5 used an intervention to try to build self-efficacy in informal caregivers. The aim of this study was to test relationships between self-efficacy, stressors and outcome measures in an objective way, and to examine the extent to which the results supported existing theories. Using this approach, I was able to comment on whether or not the results supported particular hypotheses or relationships, based on statistical analysis.

In contrast, the studies carried out for Chapters 4 and 6 used a qualitative approach and were focussed on exploring aspects of caregivers' experiences; Chapter 4 focussed on experiences of caregiving stress while Chapter 6 looked more specifically at experiences of taking part in an intervention. In these studies, it was acknowledged that the knowledge gained constituted an interpretation, based very closely on the participants' own accounts but also influenced by my own focus and interpretation of the data.

These ontological and epistemological differences have implications for a body of research which contains both quantitative and qualitative research, in terms of the knowledge to be obtained and the degree to which we can state that results can be generalised. Qualitative work is not generally used to evaluate theories or models or to be used as 'evidence' in the way that quantitative research is often used. It is possible, however, to make connections between qualitative results and previous research while avoiding generalisations; this can be described as 'theoretical transferability' (Smith et al., 2009). For example, we can comment on results from a qualitative study and the degree to which they do or do not appear to fit with previous research, or how the individual experience does or does not appear to be as predicted by existing theory. In IPA, this type of research question would be considered a secondary one, with the primary research task being to explore or investigate the phenomena from the participants' perspectives (Smith et al., 2009).

7.4.2 Research aims, questions and methods

Quantitative and qualitative research approaches tend to use different methods and address different types of research question, based on the different theoretical backgrounds of the approaches. Looking back at the research aims identified towards the end of Chapter 3, there is a clear difference in the descriptions of the aims and the terminology used. Two of these aims referred to a quantitative approach:

- To examine the use of an intervention aimed at raising self-efficacy in three specific caregiving domains (Self-Efficacy for Obtaining Respite, Self-Efficacy for Responding to Disruptive Patient Behaviours and Self-Efficacy for Controlling Upsetting Thoughts About Caregiving, as defined by Steffen et al., 2002).
- To examine the role of self-efficacy, within an intervention study, in relation to objective stressors, caregiver depression and caregiver burden.

In these two aims, it was proposed to examine whether an intervention could raise self-efficacy in informal caregivers, and to gauge the role played by self-efficacy in relation to other variables within a model of caregiving stress. These aims clearly use the language of quantitative research; the study (Chapter 5) used an intervention and standardised outcome measures to test hypotheses, participants took part in one of three conditions (group, individual or control) and statistical methods were employed to test the hypotheses.

The following two research aims referred to the qualitative studies:

- To explore the experiences of informal caregivers of a person with dementia, with a particular focus on caregivers' experiences of stress, coping strategies and use of supportive resources.
- To explore the experiences of informal caregivers who participated in the intervention study.

These aims referred explicitly to qualitative research, with the focus being on participants' accounts of their own experiences. The transcripts of semi-structured interviews served as the data for these studies (Chapters 4 and 6), and the focus was on obtaining rich accounts from a small number of caregivers, and using the methods of

IPA rather than statistical analysis.

The different methods adopted for these studies illustrate typical differences in the ways in which quantitative and qualitative research are carried out. In the quantitative study (Chapter 5), for example, a larger number of participants was required, in order to study group differences between intervention and control participants.

In the qualitative studies (Chapters 4 and 6), smaller numbers of participants were required, and there was more of an idiographic focus, dependent on collecting in-depth data from each participant. A flexible interview schedule was used in each of these studies, and the analysis was an interpretative one, based closely on the participants' own words but involving my own interpretation of the meanings and themes arising from the interview data.

The decision to use both quantitative and qualitative approaches to the topic of caregiving stress, therefore, carried implications for the practical steps that were taken in carrying out the studies in this thesis, and affected every stage of the research process, including deciding the nature of the data to be captured, recruiting participants and conducting the analyses. When using quantitative and qualitative data together to illustrate a common theme, it is important to bear in mind the very different procedures that may have been used, and to consider the different strengths and weaknesses of each in the overall analysis.

7.4.3 Approaches to validity

A further area of difference between quantitative and qualitative research lies in the steps we can take to ensure that the research is valid. In quantitative research, validity can refer to a number of concepts which must be taken into account when considering whether or not the conclusions we draw from the research are sound. Internal validity in an experimental study refers to whether or not we can state with any degree of confidence that a change in the dependent variable was caused by our manipulation of the independent variable. Internal validity can be compromised by factors such as differential attrition rates between control and experimental groups, problems with sampling or problems with the measures used (for example, repeated application of

certain types of test can lead to improvement simply because participants are already familiar with the test (Corrigan & Salzer, 2003)). Construct validity also concerns the inferences we can make from manipulating an independent variable and observing changes in a dependent variable, but in this case the threats to validity would come from confounding factors, or things which change incidentally along with the independent variable (Shadish, Cook & Campbell, 2002).

Validity is also considered when appraising qualitative research. As quantitative definitions of validity are more difficult to apply to qualitative studies, some authors have proposed sets of guidelines for ensuring that the validity of qualitative studies can also be determined. For example, as discussed in Chapter 4, Elliot et al. (1999) proposed seven guidelines specifically aimed at ensuring that qualitative research was of a publishable standard:

1. 'Owning one's perspective': The researcher should give an account of his or her stance in relation to the topic being explored.
2. 'Situating the sample': Sufficient information about participants' backgrounds should be provided to allow the reader to judge the applicability of the findings.
3. 'Grounding in examples': Examples of data should allow the reader an insight into the analysis conducted and the conclusions formed.
4. 'Providing credibility checks': Attempts should be made to check the analysis being proposed by, for example, having a second analyst audit the analysis or checking interpretations with the interview participants.
5. 'Coherence': The analysis should be presented in a logical and coherent way to illustrate the ways in which findings fit together.
6. 'Accomplishing general vs. specific research tasks': General claims must be based on a suitable number of accounts, while specific claims must be backed up by evidence which is sufficiently in-depth. The limitations on generalisability must be made clear.
7. 'Resonating with readers': The findings must be presented in such a way that readers can engage with and understand the topic.

An alternative set of guidelines for qualitative research was proposed by Yardley (2000) and includes sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. The factors defined by Elliott et al. (1999) and Yardley (2000) have in common the fact that they are guidelines which provide a general sense

of how to achieve valid qualitative research, rather than step-by-step guides as to how this should be done; Smith et al. (2009) caution against more prescriptive approaches.

Looking at the studies reported in this thesis, then, different issues had to be considered when trying to ensure that each study had validity. For example, in Chapter 5, it was important to look at issues such as demographic and baseline information, to account for any differences on which the results might have been based. In the qualitative studies (Chapters 4 and 6) it was important to take steps such as ensuring that any conclusions were supported by appropriate examples from the interview transcripts, and to account for ways in which my own values may have influenced the interpretations given.

7.4.4 Areas of overlap and the use of quantitative and qualitative approaches together

Quantitative and qualitative approaches to research, then, have important distinguishing features which must be taken into account when comparing research from each tradition. There are, however, areas of overlap between the research traditions. In practice, many quantitative research studies also collect some qualitative data, such as the inclusion of open-ended questions on questionnaires. These may not be subjected to any rigorous qualitative analysis but may be used to provide illustrative quotes to support the quantitative outcomes of the study. Similarly, looking at the IPA study which forms Chapter 4, although the analysis was conducted primarily with an idiographic focus, the second stage of the analysis involved looking for recurring themes which were present in the transcripts of most of the participants; there was therefore some attendance to the frequency with which certain themes arose.

The term 'reflexivity' is much more commonly used in connection with qualitative research than with quantitative, and refers to the researcher's consideration of his or her own part in the study. Reflexive practice may also have a place in quantitative research; Ryan and Golden (2006) examined their own values and experiences in relation to a quantitative study they had conducted, including experiences they shared with their participants and a consideration of all the information given to them informally by participants and not otherwise captured in quantitative outcome measures. A degree of reflexive practice was important in the quantitative study in Chapter 5, in which I acted both as the facilitator of the intervention and the person gathering the quantitative information from participants. As discussed earlier, Schulz et al. (2002) caution against

this use of a single person to both deliver an intervention and measure the outcomes; in the research reported in Chapter 5 it was therefore extremely important to take steps to account for and minimise the interpersonal effects that can come into play even when gathering quantitative data.

Similarly, although quantitative research tends to be associated with a positivist approach while qualitative research tends to align more closely with interpretivist beliefs, there can be areas of overlap. Westerman (2006) discusses ways in which quantitative research practices can be seen as interpretivist. For example, when designing an outcome questionnaire, researchers have to employ a degree of interpretation in choosing items or questions which seem to fit as indicators of the construct being measured. Similarly, to complete outcome measures, research participants need to make an interpretation of their own experiences, which may be mixed and extensive. It may therefore be misleading to state that quantitative research produces knowledge which is solely objective.

The studies included in this thesis were intended to take a ‘mixed methods’ approach to a single research topic, in this case the stress experienced by informal caregivers of a person with dementia. The use of quantitative and qualitative methods meant that a range of research questions could be asked and a range of research methods used in seeking answers to the research questions. It was anticipated that the combination of methods would provide slightly different angles and complementary datasets on a common topic. While it was important to bear in mind the different research traditions being employed and the different protocols involved, the overall aim was to create a cohesive piece of work and to shed light on the experiences of caregivers using a range of techniques.

7.5 Language and Representation in Dementia Caregiving Studies

The issue of language in dementia research is currently a contested area. While mainstream reporting and indeed much research focusses on the negative aspects of dementia, and terms such as ‘time bomb’ are often used to refer to the increasing prevalence of dementia (for example, Sheldrick, 2015; Till, 2015; Furness, 2012), there is a growing body of opposition to the use of such terminology, arguing that it can have negative repercussions for the experiences of those living with, and affected by, dementia (for example, Hare, 2014; Swaffer, 2014). A UK-based project, The Dementia

Engagement and Empowerment Project (DEEP), has recently produced a set of guidelines (DEEP, 2014), drawn up in conjunction with people who have a dementia diagnosis, with the aim of raising awareness and encouraging the use of more positive language when referring to the experiences of people affected by dementia. Words such as ‘suffering’ and ‘burden’, it is argued, do not represent the views and experience of all people with dementia or their friends and families, and over-use of these words can lead to negative stereotyping. Similarly, there has been a move towards using the phrase ‘person with dementia’, rather than ‘dementia patient’.

Language use can be considered alongside the issue of ensuring that people with dementia are included at all stages in research, publication and service development. In recent years, it has become common for people with a dementia diagnosis to present at international conferences (for example, Rohra, 2014; McAdam, 2014) and campaigning groups such as the Scottish Dementia Working Group (SDWG) are run by people with dementia. The presence of organisations like SDWG and DEEP illustrate some of the ways in which people with dementia can have a powerful influence on the language and representations of dementia that are used.

It was important to consider this argument and its implications for the current body of work, which focusses particularly on the stresses and challenges of being an informal caregiver; there is an inherent risk of over-use of ‘negative’ terminology in adopting such a focus. Indeed, one of the standard outcome measures used in Chapter 5 was the Zarit Burden Interview (Zarit et al., 1980), a questionnaire frequently used as a measure of ‘caregiver burden’, a well-established term which has been used throughout the caregiver literature as discussed in Chapters 1 and 2.

In thinking about language use as it applied to the current studies, I considered several issues, which will be discussed below in the context of the qualitative and quantitative research carried out. The wider issues of inclusion and representation were considered; given the nature of dementia and the effects on memory and other cognitive issues, it seems likely that representation and inclusion of people with more advanced dementia are particularly challenging areas. Similarly, when considering caregivers of a person with dementia, it is important to account for the fact that individuals may have different experiences, thoughts and feelings about dementia, and may indeed be affected by being at different stages in the caregiving ‘career’. A challenge for this research as a whole was to avoid the use of problematic language while focussing on caregiving stressors, allowing people to speak freely about their experiences and emotions.

7.5.1 Language and the qualitative studies

Language was considered when designing and carrying out the qualitative studies reported in Chapters 4 and 6. When conducting semi-structured interviews, it is vital that participants feel able to describe their experiences in terms that are personally meaningful. However, it was considered important for the interview schedule, and the terms used in asking the questions, to be balanced and neutral wherever possible. This is in line with good practice associated with semi-structured interviews, in which the questions should be open-ended and non-leading. In both written material given to participants, and in my introduction to the interviews, it was acknowledged that caregivers often have both positive and negative experiences and feelings connected with caring for a person with dementia. Questions were balanced in order to elicit both positive experiences and accounts of challenges.

Reflexivity was also used in conducting this research. My interest in carrying out the interviews lay in caregivers' experiences of stressful situations and in coping skills and resources that they found helpful in alleviating stress. It was therefore important to keep an awareness of this focus and to take measures to prevent the research questions from being leading. One way in which researchers can try to counter the possible bias from their own interests is in 'bracketing', or making an effort to set one's own interests and values aside, as discussed in Chapter 4 (Smith et al, 2009). Another, more appropriate to the use of IPA, is to use reflexive practices throughout the analysis, accounting for the part played by the researcher's own views and experiences in the interpretation offered ('Owning one's perspective', as proposed by Elliott et al., 1999).

The type of qualitative research used in this thesis, IPA, focusses very much on the participant's own experiences and meaning-making. When conducting interviews, therefore, although an interview schedule was used, this served as a guide rather than a rigid set of questions. So, for example, if a participant clearly indicated a wish to focus on either positive or negative feelings associated with caregiving, the interview was adapted to allow the participant to drive the content of the interview, with the interview schedule ensuring that the interview stayed within the overall research topic.

7.5.2 Language and the quantitative study

Language was also a consideration in carrying out the quantitative study reported in Chapter 5. In some ways, quantitative work can be seen as less flexible in terms of modifying language, unless the research is to be carried out using questionnaires and outcome measures which have been designed specifically for the study. For reasons discussed earlier, the work in Chapter 5 mainly made use of outcome measures which have been used in many different caregiver research studies, in order that the results here could meaningfully be compared with earlier research.

It was more challenging to adopt a neutral or balanced approach with the quantitative elements of the work. Existing questionnaires ask very clearly about the negative aspects of caregiving; for example, the Revised Memory and Behavior Problems Checklist (Teri et al., 1992) and the Zarit Burden Interview (Zarit et al., 1980) were used in the studies. The language used in these and other standard questionnaires represents a different type of use of ‘negative’ language, because it is being used to gauge participants’ scores on operationalised concepts such as ‘burden’, which are important in understanding the stress processes of caregiving.

As discussed earlier in this chapter, researchers have questioned the concept of caregiving ‘burden’ as a useful measure of caregiving experience (Black & Almeida, 2004). Given that there is increasing controversy about the use of terms which can be seen to frame dementia in a solely negative light, it may well be that the language used in outcome measures will evolve or that newer measures will be devised to replace existing ones. However, for the purposes of the study described in Chapter 5, in which the focus was on the caregiving stress process and the role of self-efficacy in response to caregiving stressors, it was important to use established measures which captured this aspect of the caregiving experience.

The studies in this thesis were conducted at an interesting point in the debate about language use in dementia research, and a point at which the interests of researchers sometimes seem to come into conflict with the requests from campaigning groups and people with dementia to use more moderate language. With presentations from these two groups of people often scheduled side-by-side at international conferences, it seems likely that this debate about language use and representation will continue to evolve. For the purposes of this thesis, a balance had to be struck between using respectful and

non-prejudicial language and accurately capturing and representing the experiences of the research participants.

In this reflective chapter, I have accounted for some of the issues and considerations underpinning the decisions made in planning and carrying out the studies reported in Chapters 4, 5 and 6. Many of these decisions involved thinking about complex issues and attempting to strengthen the design of the studies, while recognising that certain limitations remained. These limitations will be discussed further in Chapter 8, in which I will revisit the studies in the context of the original research questions and aims, looking at how the work fits within the current field of caregiving research.

Chapter 8: Discussion and Conclusions

8.1 Introduction

As discussed in Chapter 3, the work reported in this thesis was an attempt to answer some unanswered questions from the field of caregiver research concerning informal caregivers of a person with dementia. To recap, the research aims and objectives identified were:

Aims:

1. To explore the experiences of informal caregivers of a person with dementia, with a particular focus on caregivers' experiences of stress, coping strategies and use of supportive resources.
2. To examine the use of an intervention aimed at raising self-efficacy in three specific caregiving domains (Self-Efficacy for Obtaining Respite, Self-Efficacy for Responding to Disruptive Patient Behaviours and Self-Efficacy for Controlling Upsetting Thoughts About Caregiving, as defined by Steffen et al., 2002).
3. To examine the role of self-efficacy, within an intervention study, in relation to objective stressors, caregiver depression and caregiver burden.
4. To explore the experiences of informal caregivers who participated in the intervention study.

Objectives:

1. To carry out semi-structured interviews with informal caregivers of people who have dementia, exploring experiences of caregiver stress and coping, and to use Interpretative Phenomenological Analysis (IPA) to identify relevant themes.
2. To carry out a controlled intervention study, using an intervention aimed at increasing self-efficacy in informal caregivers of people with dementia, and to carry out pre- and post-test measures to explore the possible effects of using this intervention.
3. To conduct semi-structured interviews with caregivers who participated in the intervention study, and to use IPA to identify experiential themes.

To approach the topic of stress, coping and supportive interventions for informal caregivers, three studies were conducted, using a combination of qualitative research (Interpretative Phenomenological Analysis) to explore aims 1 and 4 (and objectives 1 and 3) above, and quantitative methods to examine aims 2 and 3 (and objective 2). The main findings from each of the three research projects in this thesis have already been reported in their individual chapters (Chapters 4-6). The present chapter will look at the contribution of these studies to the field, and will include an evaluation of the studies in the light of the original research aims and objectives, a discussion of limitations of the work, and some ideas about how the research might best be taken forward in the form of further studies, research priorities and implications for practice.

8.2 Main outcomes and contribution to the field

The research aims, defined above, provide a useful framework for evaluating the present research and its ability to contribute new information to the field of dementia caregiver research. In this section, I will revisit each of the aims in turn, discussing how the aims of the research were or were not addressed by the studies conducted. I will then discuss the implications of the results of these studies in relation to existing theory and previous research into caregiving stress.

Aim 1

The first aim, concerning the experiences of informal caregivers, was addressed in Chapter 4 using Interpretative Phenomenological Analysis, and the themes emerging from this research provided new information relating to caregivers' experiences of stress, challenges and coping. For example, although it has often been reported that much caregiver stress can be related to the symptoms and behaviours associated with dementia (Ory et al., 1999), the caregivers' accounts in this study did not feature these symptoms in any central way. Rather, there was attention given to the changing nature of dementia, and the ways in which participants experienced loss. These results supported an account of caregiving stress which prioritises experiences such as loss of a loved one, or the stress of coping with uncontrollable or unpredictable change. Although these factors had been considered previously as possibilities (Ory et al., 1999;

Schulz et al., 2002), they have not been central to quantitative work on caregiving stress.

Another theme identified in Chapter 4 concerned caregivers' perceptions of their own skills and characters in relation to the demands of caregiving. Although there has been a focus in the caregiving literature on 'caregiving burden', this has tended to be measured as it relates to the needs of the cared-for person (for example, Zarit et al., 1980). The results obtained in Chapter 4 would seem to point to a different kind of 'burden', relating to a perceived gap between the challenges of caregiving and whether or not an individual feels equipped to meet these challenges. This result would support the use of interventions focussing on concepts such as self-efficacy (for example, Bandura, 1994) or appraisal, in which attention is paid to how able caregivers feel to undertake the work of caregiving.

Additionally, the analysis presented a complex picture of the roles played by other people, including friends, family and professionals, and the ways in which each of these groups could contribute to caregiving stress as well as alleviating it. Previous qualitative studies have highlighted potential issues with family relationships in a caregiving situation (for example, Stokes et al. (2014) found that isolation from friends and family could occur). Although the stress and coping caregiving model proposed by Pearlin et al. (1990) allows for the fact that family and friends may play more than one role in regulating stress, the results reported in Chapter 4 would support an increased focus on these relationships as a potential contributor to stress.

Caregivers' accounts of using support services were not straightforward, and tended to involve both positive experiences and relationships, and more challenging ones. This factor has not been included in stress and coping models such as the ones proposed by Haley et al. (1987) and Pearlin et al. (1990). As the 'care system' was prioritised by many of the participants in the study reported in Chapter 4, this would suggest that greater focus needs to be given to relationships between caregivers and the services they can access, and to systems which may be experienced as confusing, difficult to access and unhelpful in meeting needs.

Reflecting on the study reported in Chapter 4, it appears that more work needs to be done on establishing the most appropriate settings in which interventions can be delivered, the optimal conditions for professional helping relationships and the ways in which services can work in partnership with service users, reducing the feeling of a

power imbalance. These contextual issues should be considered alongside the content of future interventions.

Aim 2

The second of the four aims concerned the use of the self-efficacy intervention in relation to caregiving outcomes, as reported in Chapter 5. The following two research questions were related to this research aim:

1. Were there observable improvements in caregiver outcomes immediately after the third intervention session, in participants who took part in the intervention versus controls? Improvements would be indicated by reductions in depression, burden and reaction to stressor scores, and by increases in self-efficacy scores.
2. Were there observable improvements three months after the third intervention session in the same outcomes, in participants who took part in the intervention versus controls?

In answer to the first research question, the intervention was observed to have positive effects in terms of reducing caregiver burden and reducing the stress responses of caregivers to behavioural and memory problems of the person with dementia. These effects were significant for the intervention participants when compared to a control, but not for the individual participants as a sub-group, perhaps due to the small number of individual participants and subsequent lack of statistical power (an issue also discussed by Gaugler et al., 2011). The intervention had no statistically significant effect on depression or self-efficacy scores, when comparing intervention and control groups.

One contribution of the current work is that this new intervention, which was written with the aim of being relatively undemanding of caregivers' time and professional input, has been demonstrated to have positive effects on caregiving outcomes. It is anticipated that the intervention could easily be disseminated in a community setting, with the addition of brief training notes to enable workers to facilitate the sessions. There is a need for interventions to be cost-effective as well as effective (Gallagher-Thompson et al., 2012) and one of the ideas underpinning this research was about reducing the time commitment required of individuals accessing an intervention. As previously outlined, although it has been suggested that brief interventions (short interventions which can be used to help individuals at particular points of difficulty)

may be appropriate for use with caregivers (Parker, 2007) these have tended not to be explored in dementia caregiving literature.

No benefit of the intervention was observed at the three-month follow-up, addressing the second research question here. This finding may again reflect the low participant numbers and lack of statistical power at this stage. Alternatively, it may reflect the shorter nature of the intervention, which could be most suited for use to address specific needs at specific times, as described above.

Aim 3

The third research aim concerned the role of self-efficacy in the intervention study, and a specific research question was written to address this aim in Chapter 5:

3. What role, if any, was played by self-efficacy in the results?

This question could not be answered fully, as no significant differences in self-efficacy were observed between intervention and control participants. The observed pattern of results differed from previous studies (for example, Au et al., 2009; Gallagher et al., 2011), which found self-efficacy to be a mediating factor between caregiving stressors and negative outcomes, although these studies were cross-sectional in nature. The study discussed in Chapter 5 was in part an attempt to look at whether the mediating relationship held in an intervention context, and there was no evidence to suggest that it did. Because of issues identified in the current work with the measurement of self-efficacy (such as the tendency for participants to find some of the self-efficacy questions irrelevant to their own situations, meaning that a questionnaire tailored to the intervention may have been more suitable), the exploration of self-efficacy in an intervention setting would warrant further research. One approach would be to develop a new self-efficacy questionnaire for a future intervention study.

Relating the results of the intervention study to stress and coping models (such as Pearlin et al., 1990), the gauge of objective stressors used in this study (behavioural and memory problems associated with the person with dementia, as measured using the Revised Scale for Memory and Behavior Problems Checklist (Teri et al., 1992)) did not change significantly from pre- to post-test. However, the outcomes of caregiver burden and caregiver reaction to the above stressors did change significantly with the intervention. These results would support the hypothesis that the intervention was

effective in protecting against the negative outcomes of caregiving stress. However, the results did not suggest that the intervention was working by way of increasing self-efficacy, which had been proposed as a mediating factor. This may mean that some other factor was involved as a mediator (for example, appraisal or control, discussed in Chapter 2 as similar concepts to self-efficacy). Alternatively, the results here may be attributable to some issue with the study itself, such as the issues discussed above with the use of the Steffen et al. (2002) Revised Scale for Caregiving Self-Efficacy.

Aim 4

The final research aim, concerning participants' experiences of the intervention, was addressed by using Interpretative Phenomenological Analysis and discussed in Chapter 6. The use of IPA alongside an intervention is a relatively underused application of IPA (Smith et al., 2009) and the study reported here adds to this small body of research. The information gained in this qualitative study formed a counterpart to the quantitative data on the intervention, and highlighted possible reasons for caregivers choosing to take part in a group or individual intervention. For example, participants in this study appeared to be considering their own stages of caring and perceived needs in relation to whether a group or individual support setting was going to be more helpful.

In some instances, participants' accounts in this IPA study appeared to be relevant to self-efficacy theory (for example, two-directional learning between peers was discussed, similar to modelling as described by Bandura (1994)) and on the role of peers in appraising one's own situation (with appraisals featuring in stress and coping models of caregiving, such as Haley et al. (1987)). The work in Chapter 6 should therefore be considered alongside the quantitative results in Chapter 5 in understanding the benefits of the intervention. Although the results reported in Chapter 5 did not support the idea that the intervention was working by raising self-efficacy, the benefits reported by participants in the Chapter 6 study appeared to share some similarities with self-efficacy theory.

Contributions made by the studies collectively

Looking at the studies collectively, it is possible to see how the current research sits within the field of caregiving intervention research. The inclusion of two IPA studies

give the research a focus on rich, exploratory, qualitative data, and the intervention study focussed on looking at the ‘real world’ application of an intervention, rather than one delivered to clinical standards; there was an overall aim to capture and reflect the authentic experiences of caregivers. This focus for the research was chosen to align with the identified need for practical, cost-effective interventions (Gallagher-Thompson et al., 2012) and a decision to prioritise community context and external validity (Green et al., 2009).

The field of caregiver intervention research has tended to focus on RCT study designs, as reviewed by Schulz et al. (2002), Godwin et al. (2013) and Jensen et al. (2015). Following discussion that the RCT design may not be an optimal way in which to offer caregiver interventions (Zarit & Femia, 2008), the intervention study here represented an aim to take a different approach, in which participants were invited to select the participation mode they felt was most suitable. The demographic information reported in Chapter 5 offers an insight into the different groups of carers who may be more suited to individual or group interventions (for example, older, spousal caregivers were most likely to request individual interventions). The qualitative follow-up reported in Chapter 6 reinforced these findings, by exploring the ways in which participants considered their own needs and stages of caring.

A further contribution from using mixed methodology was that the issue of ‘external stressors’ – stressors including practical caregiving issues as well as relationships with services – was highlighted, both in the IPA study reported in Chapter 4 and in the piloting of a questionnaire in the intervention study to gauge the presence of these external stressors in caregivers’ experiences. This approach pays attention not only to the psychosocial elements of caregiving which have traditionally been considered modifiable and targeted in interventions, but to external factors which should also be taken into account when considering how and why people experience stress. It is important to attend not simply to factors concerning the individual who experiences stress, but to the context in which the individual is striving to cope. Recent work in the self-help field by Barker (2015) takes a similar approach, arguing that context must be taken into account along with individual factors when designing self-help interventions. By paying attention to external sources of stress, it should be easier to gauge more clearly the role that can be played by psychosocial interventions, the results that can realistically be expected and other changes (such as improved access to services) which may help to reduce caregiving stress.

8.3 Implications for theory

Models of caregiver stress and coping (Haley et al., 1987; Pearlin et al., 1990) were introduced in Chapter 2 and were used to guide the intervention study in this research. There is a need for interventions to align with theory, so that we can gain an understanding of how and why interventions may work (Gallagher-Thompson et al., 2012). The work here was also informed by previous cross-sectional research which had suggested that self-efficacy may be a mediating factor in stress and coping experiences, and may therefore be a suitable target for psychosocial interventions (Au et al., 2009; Gallagher et al., 2011).

Although the results of the intervention study supported the use of the intervention in reducing the negative outcomes detailed in stress and coping models (in this case, caregiver burden and caregiver reactions to the symptoms of the person with dementia), the results did not support self-efficacy as the mediating mechanism by which this happened. Issues concerning the measurement of self-efficacy in this study have been discussed above and in Chapter 5; however, the current work would suggest that further research is needed to determine the effects of self-efficacy within longitudinal or intervention study designs.

The qualitative studies (Chapters 4 and 6) also have some relevance for stress and coping models and the application of these models in intervention research. For example, the experiences of participants reported in Chapter 4 suggest that more focus should be given to a range of potential stressors, including losses associated with dementia and relationships which may contribute to stress. Although the Pearlin et al. (1990) model is fairly complex and includes factors such as family tensions as secondary stressors, research based on stress and coping models has tended to focus on the symptoms of dementia as a stressor.

Additionally, the qualitative studies here suggest that more focus should be given to the role of services, and that these should not be seen simply in terms of being supportive resources. Caregivers' experiences of formal support tended to be complex and to include themes relating to power, relationships with workers, gatekeeping and so on. Stress and coping models have included programme provision as a positive resource (Pearlin et al., 1990). As the aim is for interventions ultimately to be offered in a

community setting following research, it is important to be aware of the complexity of factors which may affect caregivers' experiences of services.

8.4 Implications for practice

The work contained in this thesis has relevant points for different groups of people involved in dementia caregiving. In terms of future research, several recommendations arise from these studies, and these will be discussed below.

Looking at service provision for caregivers of people with dementia, the current research would support certain recommendations. The qualitative studies reported in Chapters 4 and 6, and the demographic patterns observed in Chapter 5, would support offering services in a variety of ways to address caregivers' needs and preferences (for example, offering the choice between individual and group support).

Taking into account the caregivers' experiences reported in Chapter 4, and the range of experiences of accessing services, it would seem prudent for service providers to focus on relationship building and partnership working practices with caregivers. As reported by participants here, there are many examples of good practice in this respect; however, the mixed experiences suggest that certain processes could be made clearer and more accessible. It is acknowledged that service constraints and resources are a probable factor in some of the experiences discussed here by caregivers. Woolrych and Sixsmith (2013), focussing on dementia care, highlighted further priorities for services to enable professional carers to adopt relationship-focussed working practices; these included training for formal carers, appropriate rewards and a working culture which fosters a sense of autonomy. Although this study examined care for the person with dementia, these priorities are also relevant to service provision for carers of people with dementia.

In addition to maintaining a focus on relationships between caregivers and service providers, there is a requirement for on-going assessment of needs, as indicated by the evolving challenges facing participants in these studies. For example, at different times, caregivers may need support of various kinds including specific skills training, respite or emotional support, and even something as basic as the provision of information may be perceived as helpful or stressful by an individual at a given time. As discussed in Chapter 4, caregivers in this study did not focus particularly on the symptoms of dementia when describing their stressors (but focussed on related issues, including change and loss), suggesting that support for caregivers should not focus solely on the

management of behaviours and situations but should take into account the emotional experiences of caregivers.

It may be prudent for services to offer, where feasible, a named worker with a primary working relationship with the caregiver, who can assess the appropriateness of different interventions at different times. In addition to prioritising the helping relationship, a named worker system should help to reduce the incidence of caregivers feeling confused or overwhelmed by trying to navigate a complex system of support. In 2013, the Scottish Government committed to offering a year's support from a named Link Worker to each person diagnosed with dementia (Alzheimer Scotland, 2017). A similar scheme aimed at informal caregivers (and ideally not time-limited) may prove beneficial. Given that the stage of diagnosis appeared to be a particularly overwhelming time for participants (Chapter 4), the supportive relationship should begin at this early stage in caregiving.

For this type of support to be available, of course, there needs to be a commitment in terms of funding and availability of services for caregivers. Alzheimer Scotland (2012) published a model for community support comprising of eight 'pillars'; one of these pillars relates to support for caregivers, and an evaluation of this model is being considered by The Scottish Government (2016) as part of their proposal for 2016-19 dementia strategy. The results of the studies included here would indicate that the needs of caregivers evolve and are present throughout the process of caring for a person with dementia, with support being required at all stages of caregiving.

8.5 Limitations of the work

Some of the limitations of this body of research have already been touched upon in individual data chapters, along with research decisions taken and attempts to minimise the negative impacts on the individual studies. For example, the interview schedule and the nature of the interviews conducted for Chapter 6 were restricted by the interviews being conducted by the same person who had carried out the intervention study; optimally, these interviews would have been conducted by a second person and could have been a lot more probing about the intervention itself.

To sum up the limitations of the studies here as a whole, many of these related to the practicalities of conducting research involving one person and a limited time scale. This meant that the recruitment for the intervention study was bounded by time as well as limited access to carers' organisations, and yielded a modest sample, although this was comparable to other intervention research in the same field (for example, Haley et al., 1987). As discussed in Chapter 5, recruitment involved challenges such as approaching busy carers' services (some of which were already involved in research or had previous negative experience of research recruitment), working with the busy schedules and changing situations of informal caregivers, and accommodating the different preferences of individuals in terms of how, when and where to meet. These difficulties are not restricted to single-researcher studies, but can affect even studies with multiple locations and personnel (Gaugler et al., 2011).

Conversely, the sample used in the IPA study for Chapter 4 was a relatively large sample for this type of study (Smith et al., 2009). Using IPA, there is a balance to be struck between being able to analyse data to a sufficient depth and being able to find recurring themes. While this study generated many recurring themes, the body of data generated meant that a quantity of data was ultimately not used in the final analysis. Each of the interviews used in Chapter 4 would have generated a thorough case study; however, decisions had to be made about data to be used when incorporating twelve participants in one analysis.

To make the best use of the time available, the Interview study reported in Chapter 4 and the intervention study reported in Chapter 5 had to run concurrently. Ideally, the intervention study would have been conducted following the IPA study, which would have allowed the intervention to be informed by the outcomes of Chapter 4 (for example, more focus may have been given to the issues of caregivers' relationships with services, as this emerged clearly in Chapter 4 as a theme relating to caregiver stress). However, to keep the work within the appropriate timescale, the timing of these studies overlapped.

Other limitations are linked to the methods used in conducting the studies reported in this thesis. For example, IPA, as used in Chapters 4 and 6, necessarily uses small, homogenous samples (Smith et al., 2009) and offers an interpretation of the data. This raises obvious questions about the generalisability of results and whether or not to base recommendations on these outcomes. However, as a secondary research aim in IPA, comparisons can be made between the outcomes of an IPA study and previous research

and theories (Smith et al., 2009), and this process was followed when considering the findings and applicability of the qualitative studies.

As previously discussed in Chapter 5 and earlier in this chapter, the quantitative intervention study prioritised external over internal validity (Green et al., 2009). This approach carried with it certain limitations; the presence of baseline differences between groups of participants meant that confounding factors could not be ruled out. For example, group participants were also more likely to be children rather than spouses of the person with dementia, so it is impossible to say with certainty which factor accounted for the results.

8.6 Suggestions for further research

As well as addressing the research questions and making several contributions to existing caregiving literature, the studies reported here give rise to further questions and avenues to be explored in future research. Some of these ideas for future projects will be discussed below.

8.6.1 Replication/extension of the intervention study

As identified in Chapter 5 and in the ‘Limitations’ section of this chapter, the intervention study reported in this thesis was dependent on modest numbers of participants. One way forward for the self-efficacy intervention might, therefore, be to conduct a larger-scale study; this may strengthen the conclusions that could be made about the effectiveness of the intervention, as well as providing a clearer answer about the use of the intervention with individual participants. One way to approach a larger study might be to use a team approach, possibly involving existing practitioners from the field of caregiving support, and involving a division of labour between intervention delivery and data collection, which was not possible in the present work. Another option would be to conduct the study at more than one location (such as running simultaneous studies in Scottish and English locations). The timing of outcome measures could also be re-considered; it may be that an optimal time to measure self-efficacy would be one or two weeks after the intervention, rather than immediately at the end of the final session, to allow new information to be put into practice.

The issue of whether or not to follow a randomised, controlled design would have to be considered in any further trial of the intervention. As discussed, the present work took an ‘effectiveness study’ approach to looking at the intervention; an RCT design would provide ‘efficacy’ information on the intervention (Singal et al., 2014); that is, it would show the potential of the intervention as used under carefully controlled conditions.

8.6.2 Use of the intervention to meet assessed needs

One area of interest for future research would be to explore more fully the usefulness of the intervention as a tool to be used to meet specific needs. Chapter 5 identified that the group intervention appeared to be more desirable or feasible for children of a person with dementia, and caregivers living separately from the person with dementia, while individual interventions were more likely to be requested by older, spousal caregivers living with the person with dementia.

As discussed in Chapter 2, there has already been some research into how to make interventions more suitable or tailored to sub-groups of dementia caregivers, rather than treating caregivers as a homogenous group (Kim et al., 2012). An idea for a future study would be to examine the use of the intervention in response to assessed need. For example, since the intervention appeared to offer a reduction in caregiver burden (measured using the Zarit Burden Interview (Zarit et al., 1980)), a study could be conducted comparing the effectiveness of the intervention with groups of caregivers whose baseline ZBI scores indicated higher or lower levels of perceived burden. This may allow the intervention to be disseminated in a responsive way according to assessed need, one of the priorities identified in Chapter 2 (for example, Gallagher-Thomson et al., 2012). This approach would also allow for an exploration of whether a shorter intervention could be useful as part of a ‘toolkit’ for responding to identified needs, moving this area of caregiving interventions closer to the ‘brief intervention’ applications used in other fields in which people are subject to unpredictable, changeable stressors, or allowing more tailored, flexible interventions to be developed.

8.6.3 Train-the-trainer study

An early version of the proposal for the current work proposed a train-the-trainer study with informal caregivers. A train-the-trainer approach is one in which training is given

to individuals, who then go on to provide training to others, and so on. This approach has been used both in cascading training among professionals and in providing lay people with the skills and experience to provide training or interventions to their peers. In the current work, the train-the-trainer approach was not pursued because information from the pilot test of the intervention suggested that a qualitative approach was prudent in order to capture important contextual information about the range of needs of caregivers. However, a train-the-trainer study would be proposed as a next stage in exploring how the intervention used in this work might be disseminated.

Pearce et al. (2012) carried out a review of train-the-trainer literature involving different professional groups, including studies looking at training in such diverse skills as Motivational Interviewing (Martino et al., 2011), dissemination of HIV information (Wu et al., 2002) and cancer prevention screenings in GP surgeries (Tziraki et al., 2000). The review of these studies was broadly in support of the use of train-the-trainer techniques, and suggested that mixed-method, interactive training sessions may be beneficial.

There are examples of peer-led interventions in the caregiving literature. Chiu, Wei, Lee, Choovanichvong and Wong (2011) evaluated the Family Link Educational Program, in which family members of people with mental health diagnoses were trained to deliver interventions aimed at empowering fellow caregivers. Family caregivers in this study were trained to deliver a manual-based intervention, and they also received training in counselling skills and group dynamics before going on to deliver the intervention.

Similarly, Pickett-Schenk, Lippincott, Bennett and Steigman (2008) found that a family-led mental health education programme was effective in decreasing families' need for information, an effect still visible six months after the intervention. The authors noted the importance of credible role models in the success of this type of intervention. Dixon et al. (2004) used a train-the-trainer approach in their study of the Family to Family Education Programme, also aimed at families of people with mental illness. This study found certain benefits of the approach (for example, a reduction in caregiver burden and an increase in knowledge of mental health issues).

The study by Boise et al. (2005), described in the section on self-efficacy in Chapter 2, also used a train-the-trainer approach. In this case, both professional and volunteer trainers were trained using the *Powerful Tools for Caregiving* manual to provide

workshops for caregivers. One of the principles underpinning this study was that people who have personal experience of caregiving can in turn lead groups of caregivers in disseminating useful techniques.

The literature on train-the-trainer or cascade training has obvious implications for service provision and cost-effective support: if this type of intervention proves effective in supporting caregivers, it could potentially improve the reach of certain types of support in areas in which little is provided due to financial or other constraints. One proposal for future research would be to study the effectiveness of the intervention when applied in a train-the-trainer way; this would involve creating a trainers' guide for the intervention manual, providing training and support to caregivers who would then carry out small groups with fellow caregivers, and monitoring outcomes for both trainers and group attendees. It is worth noting that the time constraints on informal caregivers might pose considerable challenges to testing an intervention in this way, and the fact that the Chiu et al. (2011) study was relatively resource-intensive, due to the training provided to caregivers.

8.6.4 Further examination of external stressors

When piloting the intervention used in the current work, it became immediately clear that caregivers experienced stress in connection with 'external' factors; that is, stress not directly connected to caregiving tasks or to the needs of the cared-for person. Although some sources of external stress are accounted for in the model of stress and coping devised by Pearlin et al. (1990), the caregiving intervention literature has tended to focus on exploring or modifying the stress attributable to the demands of caregiving itself, based on research identifying stress in relation to behavioural problems of the person with dementia (for example, Ory et al., 1999).

The current work, particularly the IPA study reported in Chapter 4, identified that external sources of stress appear to be salient for caregivers of people with dementia. In the interviews conducted with caregivers for this study, the care 'system' itself emerged in the accounts of all twelve participants when recounting their stressful or challenging experiences; there were accounts of unhelpful systems and power imbalances between

services and caregivers, as well as accounts of positive relationships with workers.

The Caregiver External Stress Scale was written following the pilot study reported in Chapter 3. A future study could take this idea further, perhaps with a study aimed at developing and validating the CESS. This could be a cross-sectional study, looking at caregivers' responses to the questionnaire and how their scores related to those on other outcome measures. Additionally, a future roll-out of the intervention could incorporate one or more sessions looking specifically at addressing externally-related stress: information on local services, caregivers' entitlements and the subject of how to navigate the care 'system' are possible topics of interest. It is likely that this type of session would be subject to local variation, and could possibly involve delivery of specific sessions by existing providers of support to caregivers.

8.6.5 Further exploration of the effects of professional relationship quality on outcomes

One of the most striking themes to emerge from the IPA study reported in Chapter 4 concerned the relationships between service providers and caregivers. An idea for further research would be to explore the quality of relationships between caregivers and service providers and the outcomes experienced by caregivers. This could be done by exploring caregivers' use of existing services, perhaps using qualitative methods to explore issues around professional supporting relationships. Alternatively, it could involve a variation of the intervention study in which the intervention was delivered by professionals known to the participants, with the relationship quality gauged at baseline to explore whether this affects any benefits observed.

8.7 Conclusion

The intervention study used in this research has been demonstrated to have positive benefits for caregivers of a person with dementia, in terms of protecting against caregiving burden and caregivers' stress responses to the behavioural changes associated with dementia. This intervention was designed to be relatively short, and recommendations have been made to carry out further tests of its effectiveness for possible use as a flexible tool to be used in response to identified need, or in a 'train-the-trainer' capacity. While including proposals for cost-effective methods to meet some of the needs of informal caregivers of people with dementia, the work in this

thesis should not be interpreted as advocating for any reduction in resources allocated to supporting caregivers; rather, the work is offered in the spirit of increasing the reach of such supportive interventions.

The qualitative studies reported here support dynamic, complex models of caregiving stress (for example, Pearlin et al., 1990) but point to the importance of professional relationship quality in supporting informal caregivers. Previous research, and the intervention study (Chapter 5) indicate that certain aspects of caregiving stress and distress are amenable to psychosocial interventions, including caregiver burden and reactions to behavioural stressors. However, the work here would recommend adopting a wider view of the context in which interventions are received by caregivers, and providing supportive approaches which also account for sources of stress external to the caregiver-person with dementia dyad.

Considered as a whole, the results of the current studies would suggest the viewing of psychosocial interventions as one element in supporting informal caregivers, to be accompanied by efforts to make helping systems more easily understood and accessed by caregivers, on-going assessment of the needs of individuals and a focus on developing positive partnership approaches to supporting caregivers.

References

- Aguero-Torres, H., von Strauss, E., Viitanen, M., Winblad, B., Fratiglioni, L. (2001). Institutionalization in the elderly: The role of chronic diseases and dementia. Cross-sectional and longitudinal data from a population-based study. *Journal of Clinical Epidemiology*, 54(8), 795-801.
- Alzheimer Scotland. (2012). *Delivering Integrated Dementia Care: The 8 Pillars Model of Community Support*. Edinburgh.
- Alzheimer Scotland. (2013). *About Dementia: Some facts and figures*. Edinburgh.
- Alzheimer Scotland. (2017). *Dementia Link Workers: Post-Diagnostic Support*. Retrieved March 20, 2017, from <https://vimeo.com/203791995>
- Alzheimer's Society. (2007). *Dementia UK*. London.
- Alzheimer's Society. (2014). *Dementia UK Update*. London.
- Aneshensel, C.S., Pearlin, L.I., Levy-Storms, L. and Schuler, R.H. (2000). The transition from home to nursing home mortality among people with dementia. *Journal of Gerontology: Social Sciences*, 55B:3, 152-162.
- Au, A., Lai, M-K., Lau, K-M., Pan, P-C., Lam, L., Thompson, L. and Gallagher-Thompson, D. (2009). Social support and well-being in dementia family caregivers: The mediating role of self-efficacy. *Aging and Mental Health*, 13:5, 761-768.
- Bandura, A. (1977). Self-Efficacy: Towards a unifying theory of behavioural change. *Psychological Review*, 84:2, 191-215.
- Bandura, A. (1994). Self-Efficacy. In V. S. Ramachaudran (Ed.), *Encyclopedia of Human Behavior* (Vol. 4, pp.71-81). New York: Academic Press. (Reprinted in H. Friedman (Ed.), *Encyclopedia of Mental Health*. San Diego: Academic Press, 1998).
- Barker, M-J. (2015). *Doing self-help differently*. Retrieved February 14, 2017, from <http://www.open.ac.uk/ccig/blogs/methods-in-motion-blog-6-meg-john-barker-on-doing-self-help-differently>
- Baron, R.M. and Kenny, D.A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, 51:6, 1173-1182.

- Bass, D.M., Judge, K.S., Snow, A.L., Wilson, N.L., Morgan, R., Looman, W.J., McCarthy, C.A., Maslow, K., Moye, J.A., Randazzo, R., Garcia-Maldonado, M., Elbein, R., Odenheimer, G. and Kunik, M.E. (2013). Caregiver outcomes of Partners in Dementia Care: Effect of a care coordination program for veterans with dementia and their family members and friends. *Journal of the American Geriatrics Society*, 61, 1377-1386.
- Bekhet, A.K. (2013). Effects of positive cognitions and resourcefulness on caregiver burden among caregivers of persons with dementia. *International Journal of Mental Health Nursing*, 22, 340–346.
- Belle, S.H., Burgio, L., Burns, R., Coon, D., Cjaza, S.J., Gallagher-Thompson, D., Gitlin, L.N., Klinger, J., Koepke, K.M., Lee, C.C., Martindale-Adams, J., Nichols, L., Schulz, R., Stahl, S., Stevens, A., Winter, L. and Zhang, S. (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups, *Annals of Internal Medicine*, 145, 727-738.
- Black, W. and Almeida, O.P. (2004). A systematic review of the association between the behavioral and psychological symptoms of dementia and burden of care. *International Psychogeriatrics*, 16:3, 295-315.
- Blom, M.M., Bosmans, J.E., Cuijpers, P., Zarit, S.H. and Pot, A.M. (2013). Effectiveness and cost-effectiveness of an internet intervention for family caregivers of people with dementia: Design of a randomized controlled trial. *BMC Psychiatry*, 13:17. Retrieved from <http://www.biomedcentral.com/1471-244X/13/17>
- Bodenheimer, T., Lorig, K., Holman, H. and Grumbach, K. (2002). Patient self-management of chronic disease in primary care, *Journal of the American Medical Association*, 288:19, 2469-2475.
- Boise, L., Congleton, L. and Shannon, K. (2005). Empowering family caregivers: The Powerful Tools for Caregiving Program, *Educational Gerontology*, 31, 573-586.
- Boots, L.M.M., de Vugt, M.E., van Knippenberg, R.J.M., Kempen, G.I.J.M. and Verhey, F.R.J. (2014). A systematic review of internet-based supportive interventions for caregivers of people with dementia. *International Journal of Geriatric Psychiatry*, 29, 331-344.
- Boots, L.M.M., Wolfs, C.A., Verhey, F.R.J., Kempen, G.I.J.M. and de Vugt, M.E. (2015). Qualitative study on needs and wishes of early-stage dementia caregivers: The

paradox between needing and accepting help. *International Psychogeriatrics*, 27:6, 927-936.

Bowen, D.J., Kreuter, M., Spring, B., Cofta-Woerpel, L., Linnan, L., Weiner, D., Bakken, S., Kaplan, C.P., Squiers, L., Fabrizio, C. and Fernandez, M. (2009). How we design feasibility studies. *American Journal of Preventive Medicine*, 36:5, 452-457.

Braun, V. and Clarke, V. (2006). Using Thematic Analysis in psychology. *Qualitative Research in Psychology*, 3:2, 77-101.

The British Psychological Society. (2009). *Code of ethics and conduct*. Retrieved from http://www.bps.org.uk/system/files/Public%20files/bps_code_of_ethics_2009.pdf

Brocki, J.M. and Weardon, A.J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology & Health*, 21:1, 87-108.

Brodaty, H., Green, A. and Koschera, A. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society*, 51, 657-664.

Brodaty, H., Thomson, C., Thompson, C. and Fine, M. (2005). Why caregivers of people with dementia and memory loss don't use services. *International Journal of Geriatric Psychiatry*, 20, 537-546.

Bunn, F., Goodman, C., Sworn, K., Rait, G., Brayne, C., Robinson, L., McNeilly, E. and Iliffe, S. (2012). Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: A systematic review of qualitative studies. *PLoS Medicine*, 9:10, e1001331. doi:10.1371/journal.pmed.1001331

Burgio, L., Stevens, A., Guy, D., Roth, D.L. and Haley, W.E. (2003). Impact of two psychosocial interventions on white and African American family caregivers of individuals with dementia, *The Gerontologist*, 43:4, 568-579.

Cabote, C.J., Bramble, M. and McCann, D. (2015). Family caregivers' experiences of caring for a relative with younger onset dementia: A qualitative systematic review. *Journal of Family Nursing*, 21:3, 443-468.

Canham, S.L., Battersby, L., Fang, M.L., Sixsmith, J., Woolrych, R. and Sixsmith, A. (2016). From familiar faces to family: Staff and resident relationships in long-term care. *Journal of Aging and Health*, 1-16. doi: 10.1177/0898264316645550

Carbonneau, H., Caron, C.D. and Desrosiers, J. (2011). Effects of an adapted leisure education program as a means of support for caregivers of people with dementia. *Archives of Gerontology and Geriatrics*, 53, 31-39.

The Caregiver Helpbook: Powerful Tools for Caregivers (2006), USA: Legacy Health Systems.

Charmaz, K. (1996). The Search for Meanings – Grounded Theory. In J.A. Smith, R. Harré and L. Van Langenhove (Eds.), *Rethinking Methods in Psychology* (pp. 27-49). London: Sage Publications.

Chiu, M.Y.L., Wei, G.F.W., Lee, S., Choovanichvong, S. and Wong, F.H.T. (2011). Empowering caregivers: Impact analysis of FamilyLink Education Programme (FLEP) in Hong Kong, Taipei and Bangkok, *International Journal of Social Psychiatry*, 59, 28-39.

Chiu, T.M.L. and Eysenbach, G. (2011). Theorizing the health service usage behavior of family caregivers: A qualitative study of an internet-based intervention. *International Journal of Medical Informatics*, 80, 754-764.

Chiu, T.M.L., Marziali, E., Tang, M., Colantonio, A. and Carswell, A. (2010). Client-centred concepts in a personalized e-mail support intervention designed for Chinese caregivers of family members with dementia: A qualitative study. *Hong Kong Journal of Occupational Therapy*, 20:2, 87-93.

Collins, C., Liken, M., King, S. and Kokinakis, C. (1993). Loss and grief among family caregivers of relatives with dementia. *Qualitative Health Research*, 3:2, 236-253.

Cooke, D.D., McNally, L., Mulligan, K.T., Harrison, M.J.G. and Newman, S.P. (2001). Psychosocial interventions for caregivers of people with dementia: A systematic review. *Aging & Mental Health*, 5:2, 120-135.

Coon, D.W., Thompson, L., Steffen, A., Sorocco, K. and Gallagher-Thompson, D. (2003). Anger and depression management: Psychoeducational skill training interventions for women caregivers of a relative with dementia, *The Gerontologist*, 43:5, 678-689.

Cooper, C., Balamurali, T.B.S., Selwood, A. and Livingston, G. (2007). A systematic review of intervention studies about anxiety in caregivers of people with dementia, *International Journal of Geriatric Psychiatry*, 22, 181-188.

- Corrigan, P.W. and Salzer, M.S. (2003). The conflict between random assignment and treatment preference: Implications for internal validity. *Evaluation and Program Planning*, 26, 109-121.
- Crellin, N., Charlesworth, G. and Orrell, M. (2014). Managing family caregiver efficacy for managing behavioural and psychological symptoms in dementia: A psychometric evaluation, *International Psychogeriatrics*, 26:1, 93-103.
- Cummings, J.L., Mega, M., Gray, K., Rosenberg-Thompson, S., Carusi, D.A. and Gornbein, J. (1994). The Neuropsychiatric Inventory. *Neurology*, 44:12, 2308-2308.
- Cummings, S.M., Long, J.K., Peterson-Hazan, S. and Harrison, J. (1998). The efficacy of a group treatment model in helping spouses meet the emotional and practical challenges of early stage caregiving. *Clinical Gerontologist*, 20:1, 29-45.
- Czaja, S.J., Gitlin, L.N., Schulz, R., Zhang, S., Burgio, L.D., Stevens, A.B., Nichols, L.O. and Gallagher-Thompson, D. (2009). Development of the Risk Appraisal Measure: A brief screen to identify risk areas and guide interventions for dementia caregivers, *Journal of the American Geriatrics Society*, 57, 1064-1072.
- Dam, A.E.H., de Vugt, M.E., Klinkenberg, I.P.M., Verhey, F.R.J. and van Boxtel, M.P.J. (2016). A systematic review of social support interventions for caregivers of people with dementia: Are they doing what they promise? *Maturitas*, 85, 117-130.
- Dancyger, C., Smith, J.A., Jacobs, C., Wallace, M. and Michie, S. (2010). Comparing family members' motivations and attitudes towards genetic testing for hereditary breast and ovarian cancer: A qualitative analysis. *European Journal of Human Genetics*, 18, 1289-1295.
- Della Porta, D. and Keating, M. (Eds.). (2008). *Approaches and methodologies in the social sciences: A pluralist perspective*. Cambridge: University Press.
- Dementia Engagement and Empowerment Project. (2014), *Dementia words matter: Guidelines on language about dementia*. Retrieved from <http://dementivoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf>
- Dixon, L., Lucksted, A., Stewart, B., Burland, J., Brown, C.H., Postrado, L., McGuire, C. and Hoffman, M. (2004). Outcomes of the peer-taught 12-week Family-to-Family Education Program for severe mental illness, *Acta Psychiatrica Scandinavica*, 109, 207-215.

- D'Onofrio, G. and Degutis, L.C. (2002). Preventive care in the emergency department: Screening and brief intervention for alcohol problems in the emergency department: A systematic review. *Academic Emergency Medicine*, 9:6, 627-638.
- Ducharme, F., Beaudet, L., Legault, A., Kergoat, M-J., Lévesque, L. and Caron, C. (2009). Development of an intervention program for Alzheimer's family caregivers following diagnostic disclosure, *Clinical Nursing Research*, 18:1, 44-67.
- Ducharme, F.C., Lévesque, L.L., Lachance, L.M., Kergoat, M-J., Legault, A.J., Beaudet, L.M. and Zarit, S.H. (2011). 'Learning to become a family caregiver': Efficacy of an intervention program for caregivers following diagnosis of dementia in a relative, *The Gerontologist*, 51:4, 484-494.
- Dunne, E.A. and Quayle, E. (2001). The impact of iatrogenically acquired Hepatitis C infection on the well-being and relationships of a group of Irish women. *Journal of Health Psychology*, 6, 679-692.
- Dura, J.R. and Kiecolt-Glaser, J.K. (1990). Sample bias in caregiving research. *Journal of Gerontology: Psychological Sciences*, 45:5, 200-204.
- Ecker, J. (2017). A reflexive enquiry on the effect of place on research interviews conducted with homeless and vulnerably housed individuals, *Forum: Qualitative Social Research*, 18:1.
- Edley, N. (2001). Analysing masculinity: Interpretative repertoires, ideological dilemmas and subject positions. In M. Wetherell, S.Taylor and S.J. Yates (Eds.), *Discourse as data: A guide for analysis* (pp189-228). London: Sage.
- Elliott, A.F., Burgio, L.D. and DeCoster, J. (2010). Enhancing caregiver health: Findings from the Resources for Enhancing Alzheimer's Caregiver Health II Intervention, *Journal of the American Geriatrics Society*, 58, 30-37.
- Elliott, R., Fischer, C.T., & Rennie, D.L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229.
- Elvish, R., Lever, S-J., Johnstone, J., Cawley, R. and Keady, J. (2013). Psychological interventions for carers of people with dementia: A systematic review of quantitative and qualitative evidence. *Counselling and Psychotherapy Research*, 13:2, 106-125.

- Elwood, S.A. and Martin, D.G. (2000). 'Placing' interviews: Location and scales of power in qualitative research. *Professional Geographer*, 52:4, 649-657.
- Enosh, G. and Ben-Ari, A. (2016). Reflexivity: The creation of liminal spaces – researchers, participants, and research encounters. *Qualitative Health Research*, 26:4, 578-584.
- Etters, L., Goodall, D. and Harrison, B.E. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of the American Academy of Nurse Practitioners*, 20, 423-428.
- Finlay, L. (2002). 'Outing' the researcher: The provenance, process, and practice of reflexivity. *Qualitative Health Research*, 12:4, 531-545.
- Fortinsky, R.H., Kercher, K. and Burant, C.J. (2002). Measurement and correlates of family caregiver self-efficacy for managing dementia. *Aging and Mental Health*, 6:2, 153-160.
- Franzmann, J., Krause, K., Haberstroh, J. and Pantel, J. (2014). Assessment of self perceived social competencies of caregivers in dementia care. *GeroPsych: The Journal of Gerontopsychology and Geriatric Psychiatry*, 27:2, 67-73.
- Fulkerson, C.C.F., Hawkins, D.M. and Alden, A.R. (1981). Psychotherapy groups of insufficient size. *International Journal of Group Psychotherapy*, 31, 73-81.
- Furness, H. (2012, March 7). Dementia is 'next global health time bomb'. *The Telegraph*. Retrieved from www.telegraph.co.uk.
- Gallagher, D., Ni Mhaolain, A., Crosby, L., Ryan, D., Lacey, L., Coen, R.F., Walsh, C., Coakley, D., Walsh, J.B., Cunningham, C. and Lawlor, B.A. (2011). Self-efficacy for managing dementia may protect against burden and depression in Alzheimer's caregivers, *Aging and Mental Health*, 15:6, 663-670.
- Gallagher-Thompson, D. and Coon, D.W. (2007). Evidence-based psychological treatments for distress in family caregivers of older adults. *Psychology and Aging*, 22:1, 37-51.
- Gallagher-Thompson, D., Tzuang, Y.M., Au, A., Brodaty, H., Charlesworth, G., Gupta, R., Lee, S.E., Losada, A. and Shyu, Y-I. (2012). International perspectives on

nonpharmacological best practices for dementia family caregivers: A review. *Clinical Gerontologist*, 35, 316-355.

Gaugler, J.E., Gallagher-Winker, K., Kehrberg, K., Lunde, A.M., Marsolek, C.M., Ringham, K., Thompson, G. and Barclay, M. (2011). The Memory Club: Providing support to persons with early-stage dementia and their care partners, *American Journal of Alzheimer's Disease and Other Dementias*, 26:3, 218-226.

Gaugler, J.E., Roth, D.L., Haley, W.E. and Mittelman, M.S. (2008). Can counseling and support reduce burden and depressive symptoms in caregivers of people with Alzheimer's Disease during the transition to institutionalization? Results from the New York University Caregiver Intervention Study. *Journal of the American Geriatrics Society*, 56, 421-428.

Gitlin, L.N., Corcoran, M., Winter, L., Boyce, A. and Hauck, W.W. (2001). A randomized, controlled trial of a home environmental intervention: Effect on upset and efficacy in caregivers and on daily function of persons with dementia. *The Gerontologist*, 41:1, 4-14.

Green, L.W., Glasgow, R.E., Atkins, D. and Stange, K. (2009). Making evidence from research more relevant, useful, and actionable in policy, program planning, and practice. *American Journal of Preventive Medicine*, 37, S187-S191.

Gilliam, C.M. and Steffen, A.M. (2006). The relationship between caregiving self-efficacy and depressive symptoms in dementia family caregivers, *Aging and Mental Health*, 10:2, 79-86.

Godwin, K.M., Mills, W.L., Anderson, J.A. and Kunik, M.E. (2013). Technology-driven interventions for caregivers of persons with dementia: A systematic review, *American Journal of Alzheimer's Disease and Other Dementias*, 28:3, 216-222.

Gonyea, J.G., O'Connor, M., Carruth, A. and Boyle, P.A. (2005). Subjective appraisal of Alzheimer's Disease caregiving: The role of self-efficacy and depressive symptoms in the experience of burden. *American Journal of Alzheimer's Disease and Other Dementias*, 20:5, 273-280.

Haley, W.E., Brown, S.L. and Levine, E.G. (1987). Experimental evaluation of the effectiveness of group intervention for dementia caregivers. *The Gerontologist*, 27:3, 376-382.

- Haley, W.E., Levine, E.G., Brown, S.L. and Bartolucci, A.A. (1987). Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychology and Aging*, 2:4, 323–330.
- Hall, L. and Skelton, D.A. (2012). Occupational therapy for caregivers of people with dementia: A review of the United Kingdom literature. *British Journal of Occupational Therapy*, 75:6, 281-288.
- Hare, P. (2014). *Time bombs and tsunamis: The impact of negative language and images on people with dementia*. Paper presented at the meeting of Alzheimer Europe, Glasgow, UK.
- Harmell, A.L., Mausbach, B.T., Roepke, S.K., Moore, R.C., von Känel, R., Patterson, T.L., Dimsdale, J.E., Mills, P.J., Ziegler, M.J., Allison, M.A., Ancoli-Israel, S. and Grant, I. (2011). The relationship between self-efficacy and resting blood pressure in spousal Alzheimer's caregivers. *British Journal of Health Psychology*, 16, 317-328.
- Harvey, K., Langman, A., Winfield, H., Catty, J., Clement, S., White, S., Burns, E. and Burns, T. (2005). *Measuring outcomes for carers for people with mental health problems*. London: NCCSDO.
- Hébert, R., Bravo, G. and Prévile, M. (2000). Reliability, validity, and reference values of the Zarit Burden Interview for assessing informal caregivers of community-dwelling older persons with dementia. *Canadian Journal on Aging*, 19, 494-507.
- Hébert, R., Dubois, M-F., Wolfson, C., Chambers, L. and Cohen, C. (2001). Factors associated with long-term institutionalization of older people with dementia: Data from the Canadian Study of Health and Aging. *Journal of Gerontology*, 56A:11, 693-699.
- Hellawell, D. (2006). Inside-out: Analysis of the insider-outsider concept as a heuristic device to develop reflexivity in students doing qualitative research. *Teaching in Higher Education*, 11:4, 483-494.
- Hollon, S.D. and Shaw, B.F. (1979). Group Cognitive Therapy for Depressed Patients. In A.T.Beck, A. J. Rush, B. F. Shaw and G. Emery (Eds.), *Cognitive Therapy of Depression* (pp. 328-353). New York: Guilford Press.
- Hoppes, S., Bryce, H., Hellman, C. and Finlay, E. (2012). The effects of brief mindfulness training on caregivers' well-being. *Activities, Adaptation & Aging*, 36:2, 147-166.

- Huang, H.-L., Shyu, Y.-I.L., Chen, M.-C., Chen, S.-T. and Lin, L.-C. (2003). A pilot study on a home-based caregiver training program for improving caregiver self-efficacy and decreasing the behavioral problems of elders with dementia in Taiwan. *International Journal of Geriatric Psychiatry*, 18, 337–345.
- Hurley, R.V.C. Patterson, T.G. and Cooley, S.J. (2014). Meditation-based interventions for family caregivers of people with dementia: A review of the empirical literature. *Aging & Mental Health*, 18:3, 281-288.
- Husserl, E. (1982) [1913]. *Ideas Pertaining to a Pure Phenomenology and to a Phenomenological Philosophy*. Trans. F. Kersten. The Hague: Nijhoff.
- Jensen, M., Agbata, I.N., Canavan, M. and McCarthy, G. (2015). Effectiveness of educational interventions for informal caregivers of individuals with dementia residing in the community: Systematic review and meta-analysis of randomised controlled trials. *International Journal of Geriatric Psychiatry*, 30:2, 130-143.
- Karlsson, S., Bleijlevens, M., Roe, B., Saks, K., Martin, M.S., Stephan, A., Suhonen, R., Zabalegui, A. and Hallberg, I.R. (2015). Dementia care in European countries, from the perspective of people with dementia and their caregivers. *Journal of Advanced Nursing*, 71:6, 1405-1416.
- Kempenaar, L.E. (2006). *Caring for a relative with dementia: individual differences in coping and distress* (Doctoral dissertation). Retrieved from ETHOS database (uk.bl.ethos.443171)
- Kim, K., Zarit, S.H., Femia, E.E. and Savla, J. (2012). Kin relationship of caregivers and people with dementia: Stress and response to intervention. *International Journal of Geriatric Psychiatry*, 27, 59-66.
- Krause, N. (1994). Stressors in salient social roles and well-being in later life. *Journal of Gerontology*, 49:3, 137-148.
- Kwok, T., Wong, B., Ip, I., Chui, K., Young, D. and Ho, F. (2013). Telephone-delivered psychoeducational intervention for Hong Kong Chinese dementia caregivers: a single-blinded randomized controlled trial. *Clinical Interventions in Aging*, 2013:8, 1191-1197.
- Kwok, T., Au, A., Wong, B., Ip, I., Mak, V. and Ho, F. (2014). Effectiveness of online cognitive behavioural therapy on family caregivers of people with dementia. *Clinical Interventions in Aging*, 2014:9, 631-636.

- Kurz, A., Wagenpfeil, S., Hallauer, J., Schneider-Schelte, H. and Jansen, S. (2010). Evaluation of a brief educational program for dementia carers: The AENEAS Study. *International Journal of Geriatric Psychiatry*, 25, 861-869.
- Laakkonen, M.L., Hölttä, E.H., Savikko, N., Strandberg, T.E., Suominen, M. and Pitkälä, K.H. (2012). Psychosocial group intervention to enhance self-management skills of people with dementia and their caregivers: Study protocol for a randomized controlled trial. *Trials*, 13:133.
- Landmark, B.T., Aasgaard, H.S. and Fagerström, L. (2013). “To be stuck in it - I can’t just leave”: A qualitative study of relatives’ experiences of dementia sufferers living at home and need for support. *Home Health Care Management & Practice*, 25:5, 217-223.
- Larkin, M., Flowers, P. and Shaw, R. (2015). The use of multiple perspective designs in experiential qualitative psychology research. Retrieved February 15, 2017, from https://prezi.com/k_r3m4250j1d/the-use-of-multiple-perspective-designs-in-experiential-qualitative-psychology-research/
- Larkin, M. and Griffiths, M.D. (2004). Dangerous sports and recreational drug-use: Rationalizing and contextualizing risk. *Journal of Community & Applied Social Psychology*, 14, 215-232.
- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in Interpretative Phenomenological Analysis. *Qualitative research in psychology*, 3, 102-120.
- Lavoie, J-P., Ducharme, F., Lévesque, L., Hébert, R., Vézina, J., Gendron, C., Préville, M., St-Laurent, C. & Voyer, L. (2005). Understanding the outcomes of a psycho-educational group intervention for caregivers of persons with dementia living at home: A process evaluation. *Aging & Mental Health*, 9:1, 25-34.
- Lazarus, R.S. and Folkman, S. (1987). Transactional theory and research on emotions and coping. *European Journal of Personality*, 1, 141-169.
- Lee, E. (2015). Do technology-based support groups reduce care burden among dementia caregivers? A review. *Journal of Evidence-Informed Social Work*, 12, 474-487.
- Lee, Y. and Smith, L. (2012). Qualitative research on Korean American dementia caregivers’ perception of caregiving: Heterogeneity between spouse caregivers and child caregivers. *Journal of Human Behavior in the Social Environment*, 22:2, 115-129.

- Lockeridge, S., & Simpson, J. (2013). The experience of caring for a partner with young onset dementia: How younger carers cope. *Dementia*, 12:5, 635-651.
- Losada, A., Márquez-González, M. and Romero-Moreno, R. (2011). Mechanisms of action of a psychological intervention for dementia caregivers: Effects of behavioral activation and modification of dysfunctional thoughts. *International Journal of Geriatric Psychiatry*, 26, 1119-1127.
- Losada, A., Montorio, I., Knight, B.G., Márquez, M. and Izal, M. (2006). Explanation of caregivers distress from the cognitive model: The role of dysfunctional thoughts. *Psicologia Conductual*, 14:1, 115-128.
- Livingston, G., Barber, J., Rapaport, P., Knapp, M., Griffin, M., King, D., Livingston, D., Mummery, C., Walker, Z., Hoe, J., Sampson, E.L. and Cooper, C. (2013). Clinical effectiveness of a manual based coping strategy programme (START, STRategies for RelaTives) in promoting the mental health of carers of family members with dementia: Pragmatic randomised controlled trial. *BMJ: British Medical Journal*, 347, doi: 10.1136/bmj.f6276
- Luppa, M., Luck, T., Weyerer, S., König, H-H., Brähler, E. and Riedel-Heller, S.G. (2010). Prediction of institutionalization in the elderly. A systematic review. *Age and Ageing*, 39, 31-38.
- Mackenzie, C.S. and Peragine, G. (2003). Measuring and enhancing self-efficacy among professional caregivers of individuals with dementia. *American Journal of Alzheimer's Disease and Other Dementias*, 18:5, 291-298.
- Martino, S., Ball, S.A., Nich, C., Canning-Ball, M., Rounsaville, B.J. and Carroll, K.M. (2011). Teaching community program clinicians motivational interviewing using expert and train-the-trainer strategies. *Addiction*, 106, 428-441.
- Marziali, E., McCleary, L. and Streiner, D.L. (2010). Evaluation of an assessment battery for estimating dementia caregiver needs for health and social care services. *American Journal of Alzheimer's Disease and Other Dementias*, 25:5, 446-454.
- Mausbach, B.T., Patterson, T.L., Von Känel, R., Mills, P.J., Dimsdale, J.E., Ancoli-Israel, S. and Grant, I. (2007). The attenuating effect of personal mastery on the relations between stress and Alzheimer caregiver health: A five-year longitudinal analysis. *Aging and Mental Health*, 11:6, 637-644.

- Mausbach, B.T., Roepke, S.K., Chattillion, E.A., Harmell, A.L., Moore, R., Romero-Moreno, R., Bowie, C.R. and Grant, I. (2012). Multiple mediators of the relations between caregiving stress and depressive symptoms. *Aging and Mental Health, 16:1*, 27-38.
- Mausbach, B.T., Roepke, S.K., Depp, C.A., Moore, R., Patterson, T.L. and Grant, I. (2011). Integration of the Pleasant Events and Activity Restriction models: Development and validation of “PEAR” model of negative outcomes in Alzheimer's caregivers. *Behavior Therapy, 42*, 78-88.
- McAdam, N. (2014). *Nancy— A purposeful life with dementia*. Paper presented at the meeting of Alzheimer Europe, Glasgow, UK.
- McFadyen, J. and Rankin, J. (2016). The role of gatekeepers in research: Learning from reflexivity and reflection. *Journal of Nursing and Health Care, 4:1*, 82-88.
- Mcintyre, A. and Reynolds, F. (2012). There's no apprenticeship for Alzheimer's: The caring relationship when an older person experiencing dementia falls. *Ageing and Society, 32:5*, 873-896.
- Milders, M., Bell, S., Lorimer, A., MacEwan, T. and McBain, A. (2013). Cognitive stimulation by caregivers for people with dementia. *Geriatric Nursing, 34:4*, 267-273.
- Mittelman, M.S., Ferris, S.H., Steinberg, G., Shulman, E., Mackell, J.A., Ambinder, A. and Cohen, J. (1993). An intervention that delays institutionalization of Alzheimer's Disease patients: Treatment of spouse-caregivers. *The Gerontologist, 33:6*, 730-740.
- Mittelman, M.S., Roth, D.L., Haley, W.E. and Zarit, S.H. (2004). Effects of a caregiver intervention on negative caregiver appraisals of behavior problems in patients with Alzheimer's Disease: Results of a randomized trial. *Journal of Gerontology, 59B:1*, 27-34.
- Moran, D. (2000). *Introduction to Phenomenology*. London: Routledge.
- Moore, R.C., Chattillion, E.A., Ceglowski, J., Ho, J., von Känel, R., Mills, P.J., Ziegler, M.G., Patterson, T.L., Grant, I. and Mausbach, B.T. (2013). A randomized clinical trial of Behavioral Activation (BA) therapy for improving psychological and physical health in dementia caregivers: Results of the Pleasant Events Program (PEP). *Behaviour Research and Therapy, 51*, 623-632.

- Mountain, G.A. and Craig, C.L. (2012). What should be in a self-management programme for people with early dementia? *Aging and Mental Health*, 16:5, 576-583.
- Mullin, J., Simpson, J. and Froggatt, K. (2013). Experiences of spouses of people with dementia in long-term care. *Dementia*, 12:2, 177-191.
- Murray, C. D. and Harrison, B. (2004). The meaning and experience of being a stroke survivor: An interpretative phenomenological analysis. *Disability and Rehabilitation*, 26, 808–816.
- Murray, C.D. and Rhodes, K. (2005). Nobody likes damaged goods: The experience of adult visible acne. *British Journal of Health Psychology*, 10:2, 183-202.
- Myren, G.E.S., Enmarker, I., Saur, E. and Hellzen, O. (2013). Relatives' experiences of everyday life when receiving day care services for persons with dementia living at home. *Health*, 5:8, 1227-1235.
- Newton, E., Larkin, M., Melhuish, R., & Wykes, T. (2007). More than just a place to talk: Young people's experiences of group psychological therapy as an early intervention for auditory hallucinations. *Psychology and Psychotherapy: Theory, Research and Practice*, 80:1, 127-149.
- O'Donnell, A., Anderson, P., Newbury-Birch, D., Schulte, B., Schmidt, C., Reimer, J. and Kaner, E. (2014). The impact of brief alcohol interventions in primary healthcare: A systematic review of reviews. *Alcohol and Alcoholism*, 49:1, 66-78.
- O'Shea, E. and O'Reilly, S. (2000). The economic and social cost of dementia in Ireland. *International Journal of Geriatric Psychiatry*, 15, 208-218.
- Olazarán, J., Reisberg, B., Clare, L., Cruz, I., Peña-Casanova, J., del Ser, T., Woods, B., Beck, C., Auer, S., Lai, C., Spector, A., Fazio, S., Bond, J., Kivipelto, M., Brodaty, H., Rojo, J.M., Collins, H., Teri, L., Mittelman, M., Orrell, M., Feldman, H.H. and Muñoz, R. (2010). Nonpharmacological therapies in Alzheimer's Disease: A systematic review of efficacy. *Dementia and Geriatric Cognitive Disorders*, 30, 161-178.
- Oltmann, S.M. (2016). Qualitative interviews: A methodological discussion of the interviewer and respondent contexts. *Forum: Qualitative Social Research*, 17:2. Retrieved from <http://www.qualitative-research.net/index.php/fqs/article/view/2551/3998>

- Ory, M.G., Hoffman, R.R., Yee, J.L., Tennstedt, S. and Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. *The Gerontologist*, 39:2, 177-185.
- Parker, J. (2007). Crisis intervention: A practice model for people who have dementia and their carers. *Practice*, 19:2, 115-126.
- Pearce, J., Mann, M.K., Jones, C., Van Buschbach, S., Olf, M. and Bisson, J.I. (2012). The most effective way of delivering a train-the-trainers program: A systematic review. *Journal of Continuing Education in the Health Professions*, 32:3, 215-226.
- Pearlin, L.I., Menaghan, E.G., Lieberman, M.A. and Mullan, J.T. (1981). The stress process. *Journal of Health and Social Behavior*, 22:4, 337-356.
- Pearlin, L.I., Mullan, J.T., Semple, S.J. and Skaff, M.M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30:5, 583-594.
- Pickett-Schenk, S.A., Bennett, C., Cook, J.A., Steigman, P., Lippincott, R., Villagrancia, I. and Grey, D. (2006). Changes in caregiving satisfaction and information needs among relatives of adults with mental illness: Results of a randomized evaluation of a family-led education intervention. *American Journal of Orthopsychiatry*, 76:4, 545-553.
- Pickett-Schenk, S.A., Lippincott, R.C., Bennett, C. and Steigman, P.J. (2008). Improving knowledge about mental illness through family-led education: The Journey of Hope. *Psychiatric Services*, 59:1, 49-56.
- Pinquart, M. and Sörensen, S. (2006). Helping caregivers of persons with dementia: Which interventions work and how large are their effects? *International Psychogeriatrics*, 18:4, 577-595.
- Pioli, M.F. (2010). Global and caregiving mastery as moderators in the caregiving stress process. *Aging and Mental Health*, 14:5, 603-612.
- Pot, A.M., Deeg, D.J.H. and van Dyck, R. (1997). Psychological well-being of informal caregivers of elderly people with dementia: Changes over time. *Aging and Mental Health*, 1:3, 261-268.
- Pot, A.M., Deeg, D.J.H. and van Dyck, R. (2000). Psychological distress of caregivers: Moderator effects of caregiver resources? *Patient Education and Counseling*, 41, 235-240.

- Pot, A.M., Deeg, D.J.H., van Dyck, R. and Jonker, C. (1998). Psychological distress of caregivers: The mediator effect of caregiving appraisal. *Patient Education and Counseling*, 34, 43-51.
- Pozzebon, M., Douglas, J. and Ames, D. (2016). Spouses' experience of living with a partner diagnosed with a dementia: A synthesis of the qualitative research. *International Psychogeriatrics*, 28:4, 537-556.
- Pusey, H. and Richards, D. (2001). A systematic review of the effectiveness of psychosocial interventions for carers of people with dementia. *Aging and Mental Health*, 5:2, 107-119.
- Quinn, C., Clare, L., McGuinness, T. and Woods, R.T. (2013). Negotiating the balance: The triadic relationship between spousal caregivers, people with dementia and Admiral Nurses. *Dementia*, 12:5, 588-605.
- Quinn, C., Clare, L., Pearce, A. and van Dijkhuizen, M. (2008). The experience of providing care in the early stages of dementia: An Interpretative Phenomenological Analysis. *Aging and Mental Health*, 12:6, 769-778.
- Rabinowitz, Y.G., Mausbach, B.T., Thompson, L.W. and Gallagher-Thompson, D. (2007). The relationship between self-efficacy and cumulative health risk associated with health behaviour patterns in female caregivers of elderly relatives with Alzheimer's Dementia. *Journal of Aging and Health*, 19:6, 946-964.
- Radloff, L.S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1:3, 385-401.
- Riedel, O., Klotsche, J. and Wittchen, H-U. (2016). Overlooking informal dementia caregivers' burden. *Research in Gerontological Nursing*, 9:4, 167-174.
- Rohra, H. (2014). *People with dementia as advocates for change*. Paper presented at the meeting of Alzheimer Europe, Glasgow, UK.
- Romero-Moreno, R., Losada, A., Mausbach, B. T., Márquez-González, M., Patterson, T. L. and López, J. (2011). Analysis of the moderating effect of self-efficacy domains in different points of the dementia caregiving process. *Aging and Mental Health*. 15:2, 221-231.

- Romero-Moreno, R., Márquez-González, M., Mausbach, B.T. and Losada, A. (2012). Variables modulating depression in dementia caregivers: A longitudinal study. *International Psychogeriatrics* 24:8, 1316-1324.
- Rosenberg, E. and Gouge, N. (2007). 'Powerful Tools for Caregivers': Teaching skills that reduce stress and increase self-confidence. *Age in Action*, 22:2, 1-5.
- Rostill-Brookes, H., Larkin, M., Toms, A. and Churchman, C. (2011). A shared experience of fragmentation: Making sense of foster placement breakdown. *Clinical Child Psychology and Psychiatry*, 16:1, 103-127.
- Ryan, L. and Golden, A. (2006). 'Tick the box please': a reflexive approach to doing quantitative social research. *Sociology*, 40:6, 1191-1200.
- Samia, L.W., Hepburn, K. and Nichols, L. (2012). 'Flying by the seat of our pants': What dementia family caregivers want in an advanced caregiver training program. *Research in Nursing and Health*, 35, 598-609.
- Salfi, J., Ploeg, J. and Black, M.E. (2005). Seeking to understand telephone support for dementia caregivers. *Western Journal of Nursing Research*, 27:6, 701-721.
- Savundranayagam, M.Y. and Brintnall-Peterson, M. (2010). Testing self-efficacy as a pathway that supports self-care among family caregivers in a psychoeducational intervention. *Journal of Family Social Work*, 13:2, 149-162.
- Savundranayagam, M.Y., Montgomery, R.J.V., Kosloski, K. and Little, T.D. (2011). Impact of a psychoeducational program on three types of caregiver burden among spouses. *International Journal of Geriatric Psychiatry*, 26, 388-396.
- Schulz, R., Beach, S.R., Cook, T.B., Martire, L.M., Tomlinson, J.M. and Monin, J.K. (2012). Predictors and consequences of perceived lack of choice in becoming an informal caregiver. *Aging and Mental Health*, 16:6, 712-721.
- Schulz, R., O'Brien, A.T., Bookwala, J. and Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *The Gerontologist*, 35:6, 771-791.

Schulz, R., O'Brien, A., Czaja, S., Ory, M., Norris, R., Martire, L.M., Belle, S.H., Burgio, L., Gitlin, L., Coon, D., Burns, R., Gallagher-Thompson, D. and Stevens, A. (2002). Dementia caregiver intervention research: In search of clinical significance. *The Gerontologist*, 42:5, 589-602.

The Scottish Government (2016). *Proposal for Scotland's national dementia strategy 2016-2019*. Retrieved from <http://www.gov.scot/Topics/Health/Services/Mental-Health/Dementia/March>

Selwood, A., Johnston, K., Katona, C., Lyketsos, C. and Livingston, G. (2007). Systematic review of the effect of psychological interventions on family caregivers of people with dementia. *Journal of Affective Disorders*, 101, 75-89.

Semiatin, A.M. and O'Connor, M.K. (2012). The relationship between self-efficacy and positive aspects of caregiving in Alzheimer's Disease caregivers. *Aging and Mental Health*, 16:6, 683-688.

Shadish, W.R., Cook, T.D. and Campbell, D.T. (2002). *Experimental and quasi-experimental designs for generalized causal inference*. Boston: Houghton Mifflin Company.

Shaw, W.S., Patterson, T.L., Ziegler, M.J., Dimsdale, J.E., Semple, S.J. and Grant, I. (1999). Accelerated risk of hypertensive blood pressure recordings among Alzheimer caregivers. *Journal of Psychosomatic Research*, 46:3, 215-227.

Sheldrick, G. (2015, July 21). Dementia crisis as £26bn 'time bomb' threatens to sink the NHS. *Express*. Retrieved from www.express.co.uk.

Singal, A.G., Higgins, P.D.R. and Waljee, A.K. (2014). A primer on effectiveness and efficacy trials. *Clinical and Translational Gastroenterology*, 5:45. Doi: 10.1038/ctg.2013.13

Sixsmith, J., Boneham, M. and Goldring, J.E. (2003). Accessing the community: Gaining insider perspectives from the outside. *Qualitative Health Research*, 13:4, 578-589

Smith, J.A. (1996). Beyond the divide between cognition and discourse. *Psychology and Health*, 11, 261-271.

- Smith, J. A. (1999). Towards a relational self: Social engagement during pregnancy and psychological preparation for motherhood. *British Journal of Social Psychology*, 38, 409–426.
- Smith, J. A. (2004). Reflecting on the development of Interpretative Phenomenological Analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1:1, 39-54.
- Smith, J.A., Flowers, P. and Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage.
- Son, J., Erno, A., Shea, D.G., Femia, E.E., Zarit, S.H. and Stephens, M.A.P. (2007). The caregiver stress process and health outcomes. *Journal of Aging and Health*, 19:6, 871-887.
- Sörensen, S., Pinquart, M. and Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist*, 43:3, 356-372.
- Sørensen, L. V., Waldorff, F. B. and Waldemar, G. (2008). Early counselling and support for patients with mild Alzheimer's disease and their caregivers: A qualitative study on outcome. *Aging and Mental Health*, 12:4, 444-450.
- Spitznagel, M.B., Tremont, G., Duncan Davis, J. and Foster, S.M. (2006). Psychosocial predictors of dementia caregiver desire to institutionalize: Caregiver, care recipient and family relationship factors. *Journal of Geriatric Psychiatry and Neurology*, 19, 16-20.
- Steffen, A.M. and Mangum, K.R. (2012). Predicting attendance at dementia family support groups. *American Journal of Alzheimer's Disease and Other Dementias*, 27:8, 633-639.
- Steffen, A.M., McKibbin, C., Zeiss, A.M., Gallagher-Thompson, D. and Bandura, A. (2002). The Revised Scale for Caregiving Self-Efficacy: Reliability and validity studies. *Journal of Gerontology: Psychological Sciences*, 57B:1, 74–86.
- Stokes, L.A., Combes, H. and Stokes, G. (2014). Understanding the dementia diagnosis: The impact on the caregiving experience. *Dementia*, 13:1, 59-78.
- Strauss, A.L. (1987). *Qualitative Analysis for Social Scientists*. Cambridge: University Press.

- Sutcliffe, C.L., Roe, B., Jasper, R., Jolley, D. and Challis, D.J. (2015). People with dementia and carers' experiences of dementia care and services: Outcomes of a focus group study. *Dementia*, 14:6, 769-787.
- Swaffer, K. (2014). Dementia: stigma, language, and dementia-friendly. *Dementia*, 13:6, 709-16.
- Tang, W.K. and Chan, C.Y.J. (2015). Effects of psychosocial interventions on self-efficacy of dementia caregivers: A literature review. *International Journal of Geriatric Psychiatry*. Doi: 10.1002/gps.4352
- Teri, L., McCurry, S.M., Logsdon, R. and Gibbons, L.E. (2005). Training community consultants to help family members improve dementia care: A randomized controlled trial. *The Gerontologist*, 45:6, 802-811.
- Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S. and Vitaliano, P.P. (1992). Assessment of behavioral problems in dementia: The Revised Memory and Behavior Problems Checklist. *Psychology and Aging*, 7:4, 622-631.
- Till, T. (2015, September 24). Scotland faces dementia time bomb. *The Scotsman*. Retrieved from www.scotsman.com.
- Tomkins, L. and Eatough, V. (2015). Meanings and manifestations of care: A celebration of hermeneutic multiplicity in Heidegger. *The Humanistic Psychologist*, 41:1, 4-24.
- Toms, G.R., Quinn, C., Anderson, D.E. and Clare, L. (2015). Help yourself: Perspectives on self-management from people with dementia and their caregivers. *Qualitative Health Research*, 25:1, 87-98.
- Tuckman, B. W. (1965). Developmental sequence in small groups. *Psychological Bulletin*, 63:6, 384-399.
- Tuomola, J., Soon, J., Fisher, P. and Yap, P. (2016). Lived experience of caregivers of persons with dementia and the impact on their sense of self: A qualitative study in Singapore. *Journal of Cross-Cultural Gerontology*, 31:2, 157-172.
- Turner, A., Barlow, J. and Ilbery, B. (2002). Play hurt, live hurt: Living with and managing osteoarthritis from the perspective of ex-professional footballers. *Journal of Health Psychology*, 7, 285-301.

- Tziraki, C., Graubard, B.I., Manley, M., Kosary, C., Moler, J.E. and Edwards, B.K. (2000). Effect of training on adoption of cancer prevention nutrition-related activities by primary care practices: Results of a randomized, controlled study, *Journal of General Internal Medicine*, 15, 155-162.
- van der Lee, J., Bakker, T.J.E.M., Duivenvoorden, H.J. and Dröes, R-M. (2014). Multivariate models of subjective caregiver burden in dementia: A systematic review. *Ageing Research Reviews*, 15, 76-93.
- Van Mierlo, L.D., Meiland, F.J.M., Van der Roest, H.G. and Dröes, R-M. (2011). Personalised caregiver support: Effectiveness of psychosocial interventions in subgroups of caregivers of people with dementia. *International Journal of Geriatric Psychiatry*, 27, 1-14.
- Van't Leven, N., Prick, A-E.J.C., Groenewoud, J.G., Roelofs, P.D.D.M., de Lange, J. and Pot, A.M. (2013). Dyadic interventions for community-dwelling people with dementia and their family caregivers: A systematic review. *International Psychogeriatrics*, 25:10, 1581-1603.
- Vernooij-Dassen, M., Joling, K., van Hout, H. and Mittelman, M.S. (2010). The process of family-centered counseling for caregivers of persons with dementia: Barriers, facilitators and benefits. *International Psychogeriatrics*, 22:5, 769-777.
- Vitaliano, P.P., Russo, J., Young, H.M, Teri, L. and Maiuro, R.D. (1991). Predictors of burden in spouse caregivers of individuals with Alzheimer's Disease. *Psychology and Aging*, 6:3, 392-402.
- Vitaliano, P.P., Zhang, J. and Scanlan, J.M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin*, 129:6, 946-972.
- Wagstaff, C., Jeong, H., Nolan, M., Wilson, T., Tweedlie, J., Phillips, E., Senu, H. and Holland, F., (2014). The accordion and the deep bowl of spaghetti: Eight researchers' experiences of using IPA as a methodology. *The Qualitative Report*, 19:47, 1-15.
- Wawrziczny, E., Pasquier, F., Ducharme, F., Kergoat, M-J. and Antoine, P. (2015). From 'needing to know' to 'needing not to know more': An Interpretative Phenomenological Analysis of couples' experiences with early-onset Alzheimer's disease. *Scandinavian Journal of Caring Sciences*. Doi: 10.1111/scs.12290
- Westerman, M.A. (2006). Quantitative research as an interpretive enterprise: The mostly unacknowledged role of interpretation in research efforts and suggestions for

- explicitly interpretive quantitative investigations. *New Ideas in Psychology*, 24:3, 189-211.
- Wiles, R., Crow, G., Heath, S. and Charles, V. (2008). The management of confidentiality and anonymity in social research. *International Journal of Social Research Methodology*, 11:5, 417-428.
- Williams, K.L., Morrison, V. and Robinson, C.A. (2014). Exploring caregiving experiences: Caregiver coping and making sense of illness. *Aging and Mental Health*, 18:5, 600-609.
- Williamson, G.M. and Schulz, R. (1993). Coping with specific stressors in Alzheimer's Disease caregiving. *The Gerontologist*, 33:6, 747-755.
- Winters, K.C., Lee, S., Botzet, A., Fahnhorst, T. and Nicholson, A. (2014). One-year outcomes and mediators of a brief intervention for drug abusing adolescents. *Psychology of Addictive Behaviors*, 28:2, 464-474.
- Wolverson, E.L., Clarke, C. and Moniz-Cook, E. (2010). Remaining hopeful in early-stage dementia: A qualitative study. *Aging & Mental Health*, 14:4, 450-460.
- Wooffitt, R. (2001). Researching psychic practitioners: Conversation Analysis. In M. Wetherell, S. Taylor and S.J. Yates (Eds.), *Discourse as Data: A Guide for Analysis* (pp 49-92). London: Sage.
- Woolrych, R. and Sixsmith, J. (2013). Toward integrated services for dementia: A formal carer perspective. *Journal of Integrated Care*, 21:4, 208-220.
- World Alzheimer Report. (2013). *Journey of Caring: An analysis of long-term care for dementia*. London: Alzheimer's Disease International (ADI).
- Wu, Z., Detels, R., Ji, G., Xu, C., Rou, K., Ding, H. and Li, V. (2002). Diffusion of HIV/AIDS knowledge, positive attitudes, and behaviors through training of health professionals in China. *AIDS Education and Prevention*, 14:5, 379-390.
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and health*, 15:2, 215-228.
- Yee, J.L. and Schulz, R. (2000). Gender differences in psychiatric morbidity among family caregivers: A review and analysis. *The Gerontologist*, 40:2, 147-164.

- Zarit, S.H. (2012). Positive aspects of caregiving: More than looking on the bright side. *Aging and Mental Health, 16:6*, 673-674.
- Zarit, S.H., Anthony, C.R. and Boutselis, M. (1987). Interventions with care givers of dementia patients: Comparison of two approaches. *Psychology and Aging, 2:3*, 225-232.
- Zarit, S.H. and Femia, E.E. (2008). A future for family care and dementia intervention research? Challenges and strategies. *Aging and Mental Health, 12:1*, 5-13.
- Zarit, S.H., Lee, J.E., Barrineau, M.J., Whitlatch, C.J. and Femia, E.E. (2013). Fidelity and acceptability of an adaptive intervention for caregivers: An exploratory study. *Aging and Mental Health, 17:2*, 197-206.
- Zarit S.H., Reever, K.E. and Bach-Peterson J. (1980) Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist, 20:6*, 649–655.
- Zarit, S.H., Todd, P.A. and Zarit, J.M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. *The Gerontologist, 26:3*, 260-266.
- Zarit, S.H. and Zarit, J.M. (1982). Families under stress: Interventions for caregivers of senile dementia patients. *Psychotherapy: Theory, Research and Practice, 19:4*, 461-471.
- Zhang, S., Edwards, H., Yates, P., Guo, Q. and Li, C. (2013). Partial mediation role of self-efficacy between positive social interaction and mental health in family caregivers for dementia patients in Shanghai. *Plos One, 8:12*. Doi: 10.1371/journal.pone.0083326

Appendix A

Information Sheets for Participants

Information Sheet – Carer Confidence and Coping Study

About the Study

This research is about looking at how people cope with caring for someone who has dementia. The study will focus on things which can make us feel more confident about coping with difficult tasks, or more in control of difficult situations. The more confident or in control we feel, the more likely it is that we will persist until we have successfully completed a task or faced a challenge.

About Participating in the Study

As a participant in this study, you will be invited to do several things. Participation is voluntary and you may withdraw from the study at any time.

In the first stage, you will be asked to give answers to several questionnaires. These will ask you about things like how you are feeling, how you feel about being a carer and how well you feel able to cope with being a carer.

You will be invited to attend three short sessions (around an hour and a half each) in which we will work through some exercises looking at various aspects of caring: coping with behavioural aspects of dementia, coping with difficult feelings and taking breaks as a carer. These sessions can be arranged as small groups with other carers present, but if you would prefer not to take part in a group or would find it difficult to attend three sessions, they can be carried out individually between you and the researcher.

You will be given a copy of all the exercises we work through and the information we discuss, and this is yours to keep. The exercises have been designed so that you can continue to use them at home if you find them helpful.

Following the three sessions, you will be asked to complete the questionnaires again.

Three months after the sessions, you will be asked to complete the questionnaires once more. We will contact you at the right time to ask you to do this.

I am also looking for volunteers who would like to complete the questionnaires only, so if you have a small amount of free time and would be interested in doing this, your help would be very valuable.

Your participation in the study and your answers to the questionnaires will be stored securely and will be anonymised (for example, your name will not be included on the questionnaires).

If you have any questions or concerns about participating in the study, please approach the researcher, Lorraine Douglas, for further information (email ld126@hw.ac.uk or telephone 07946 230897).

Should you wish to get further support or to talk about any issues raised while you are participating in this study, the Alzheimer Scotland Dementia Helpline can provide support. You can call them on 0808 808 3000. You can also approach your GP for support.

Information Sheet – Interview Study

About the Study

This research is about looking at how people cope with caring for someone who has dementia. Although people report that being a caregiver involves many positive experiences, it is also known that caregivers are often at risk of stress. The study will focus on your experiences of being a caregiver, including some of the challenges you may have had. It will also look at the resources and skills you use in coping with the stressful aspects of caring for someone.

About Participating in the Study

As a participant in this study, you will be invited to take part in an interview. Participation is voluntary and you may withdraw from the study at any time.

The interview should last no longer than an hour and you will be asked questions including whether you have experienced stress as a caregiver, and what you do to alleviate or cope with stress. The interview will be carried out by the researcher, Lorraine Douglas, who has a lot of experience in speaking to people who may be facing challenges.

The interview between you and the researcher will be recorded with your permission, and will be stored securely, and any analysis of the discussion will be anonymised so that you cannot be identified.

If you have any questions or concerns about participating in the study, please approach the researcher, Lorraine Douglas, for further information (email ld126@hw.ac.uk, telephone 07946 230897 or contact by post at Room 2.65, David Brewster Building, School of Life Sciences, Heriot Watt University, Edinburgh EH14 4AS).

Should you wish to get further support or to talk about any issues raised while you are participating in this study, the Alzheimer Scotland Dementia Helpline can provide support. You can call them on 0808 808 3000. You can also approach your GP for support.

Appendix B

Consent Form

Caregiver Confidence and Coping Study

Please initial within each box

I confirm that I have read and understood the information sheet for the above study.

I understand that participation in this study is entirely voluntary and that I can withdraw from the study at any time without giving a reason, retrospectively.

I understand that I am free to ask any questions at any time. I am free to withdraw without providing a reason, or to discuss my concerns with the experimenter.

I consent to participate in the study titled Caregiver Confidence and Coping.

Name:

Signed:

Date:

Researcher:

Signed:

Date:

Consent Form

Caregiver Stress and Coping Study

Please initial within each box

I confirm that I have read and understood the information sheet for the above study.

I understand that participation in this study is entirely voluntary and that I can withdraw from the study at any time without giving a reason, retrospectively.

I understand that I am free to ask any questions at any time. I am free to withdraw without providing a reason, or to discuss my concerns with the experimenter.

I consent to participate in the study titled Caregiver Stress and Coping.

Name:

Signed:

Date:

Researcher:

Signed:

Date:

Appendix C

Caregiver Intervention Manual

Introduction

Caring for someone with dementia can be complicated and challenging. It is well-known that caring can affect the lives of carers in many different ways.

Some of these changes can be very positive and rewarding. For example, you might have found new ways to enjoy spending quality time with the person you care for, and have very fulfilling contact with friends and family. However, it is known that people who care for someone with dementia are also more prone to certain stresses and difficulties.

You may have experienced some of these difficulties as a result of your caregiving:

- Stress and anxiety
- Loss of contact with other people
- Fatigue
- Difficulty in attending to your own needs (e.g. keeping medical appointments)
- Feelings of being unable to cope
- Feelings of guilt

In this workbook, we will look at some techniques which may help you to feel more able to deal with the pressures associated with caring for someone who has dementia. By increasing your confidence in coping with challenges, and by paying attention to your own emotional health, it is likely that you will feel able to provide care for longer. Put simply, in order to be strong enough to care for someone else, it is essential to look after your own health and happiness.

The workbook is divided into three sections: **Coping with Behavioural Aspects of Dementia**, **Coping with Difficult Feelings** and **Taking a Break**. In each section, there will be practical tips and exercises to help improve your confidence in responding to the different challenges of caring for someone who has dementia.

Section 1: Coping with Behavioural Aspects of Dementia

One of the most difficult aspects of caring for someone with dementia is that dementia can lead to the person behaving in ways that are difficult to understand, or ways in which the person would not have acted before having dementia. There are several reasons why the behaviour of a person with dementia might change.

The dementia itself, and the changes in the brain, might be responsible for behavioural changes. Emotional factors can also lead to behaviour change – for example, the person may be expressing distress at no longer being able to do certain things, or may be showing frustration at not being able to communicate easily.

Behavioural changes can vary between different people who have dementia. Here are some of the behavioural changes which can be associated with dementia:

- Walking or wandering
- Agitation
- Loss of inhibitions – for example, swearing or making inappropriate comments
- Aggression
- Repetitive questioning

As a caregiver, your responses to these behaviours are very important. As we will see in the following activities, there are things we can do to feel more in control when these behaviours happen. It can be very distressing to see someone you care for behaving in ways that appear to be out-of-character, but by learning more about the reasons behind these behaviours, we can start to make beneficial changes.

Before we begin looking at the activities, it is important to say that some behavioural changes can indicate an underlying health concern. For example, sometimes increased confusion can be related to a problem such as a urinary infection. If you are concerned about any changes in behaviour or routine in the person with dementia, you should seek advice from the person's GP.

Understanding why behavioural changes happen

All behaviour happens for a reason. When someone has dementia, it can be more difficult for others to understand the reasons behind certain behaviours, but the reasons will still be there for the person with dementia.

To make it easier to cope when someone starts to display new or out-of-character behaviour, it can help to try to understand what that behaviour might mean for the person with dementia.

Here are some of the possible causes for behaviour that you may find challenging:

- Difficulty communicating something like hunger, pain or distress
- Memory problems
- Boredom or loneliness
- Confusion about something, e.g. time of day
- Frustration

The first thing to remember with this type of behaviour is that you should not take it personally. There are many reasons why your relative may be acting in this way. We will look at some of the possible reasons for certain types of behaviour that you might find challenging.

Walking or wandering

Quite often, people who have dementia will display walking or wandering behaviour. There can be different reasons why this happens. Perhaps the person has a lot of energy, or has always enjoyed walking. He or she might not be aware of time or other things to do with safety, and might walk at times or in places that you do not consider to be safe.

It is possible that your relative is responding to something he or she has seen, such as a jacket over the back of a chair or a bunch of keys, making them think about going for a walk. Perhaps their routine has slipped a bit and they have been sleeping during the day, resulting in a burst of energy in the evening.

Agitation

If the person you care for becomes very agitated, it can be hard not to take this personally and to become distressed by it, but it is worth thinking about why the behaviour is happening – the chances are that the person is not intending to 'take it out on you'.

Agitated behaviour can have a number of causes. The person with dementia may be having difficulty in communicating something like distress or discomfort, and may be feeling very frustrated as a result. It is possible that your relative may be upset at no longer being able to do something independently.

Agitation can also sometimes be the result of confusion. Your relative may believe, for example, that an item has been stolen because he or she cannot find it.

Loss of inhibitions and aggression

Loss of inhibitions can be a very difficult and upsetting thing to experience, and it may seem as if your relative is acting completely out of character. This type of behaviour can sometimes be the result of the person misinterpreting something that another person has said or done – for example, if the person with dementia thinks that someone else is an intruder, and responds with verbal aggression. Loss of inhibitions may also directly be a result of changes in the brain as a result of the dementia.

Frustration can also be the cause of behaviour such as verbal aggression. The person with dementia may be finding it difficult to cope with not being able to do things independently. Feeling unwell or in pain can sometimes also explain this type of behaviour.

Repetitive questioning

Repetitive questioning can occur when the person with dementia forgets some information they've already been given. They may also forget that they have already asked the question. For example, someone may repeatedly ask when lunch is. This kind of question may also indicate that the person is feeling hungry or thirsty – there may be some physical reason why the person's attention keeps returning to the same topic.

To know how to respond to a difficult behaviour, it is important to try to think about what might be the reason for the behaviour. If you think your relative is in pain or discomfort, then the solution might be to ask for a review of medication or to get an appointment with the GP. If the behaviour seems to be resulting from confusion or memory problems, then it may be that the situation can be resolved, for example, by showing your relative that an object has not been lost or stolen.

☀ Activity 1: Identifying and understanding behaviours

Try to think of a behaviour that you find personally challenging. Remember that different people find different things to be challenging, so there are no right or wrong answers here. What we want to do is to look at something which you find difficult to deal with, and to ask certain questions to try to get a deeper understanding of why this behaviour might occur.

Describe the behaviour that you find challenging or difficult to deal with.

When does this behaviour tend to occur? Is there anything else which is happening at the same time?

Is your relative trying to communicate something – for example, discomfort, frustration, boredom, hunger or thirst?

Has something frightened or upset your relative - for example, not knowing who someone is, not being able to find something?

By asking this type of question about behaviour that challenges us, we can start to get an insight into the reason why the behaviour is occurring, and what it might mean for

the person with dementia. Remember that certain changes, such as changes in toilet routine or increased confusion, can sometimes be the result of underlying health problems such as infections, so you should consult your GP for advice if you believe your relative may be showing any symptoms of being unwell.

Looking at the things we can and cannot change

To feel more able to cope with behaviour that challenges, it can help to break a situation down and to look at parts of the situation that we can and cannot control.

For example, in the case of a person with dementia who walks late at night, we cannot directly control the fact that the person decides to walk. We can never directly control another person's behaviour. However, the things we do before and after the behaviour occurs can make a big difference to the situation.

Say, for example, that the person with dementia is confused about the time of day when he or she starts to walk. Perhaps there is something about the environment that makes him or her think that it is an appropriate time for a walk – the curtains might still be open, for example, or the person's outdoor jacket might be kept in the living room, acting as a cue for the person to want to go for a walk. Perhaps your relative has a lot of leftover energy at night, and enjoys going for a walk.

It is worth being aware of simple cues in the environment that could be making the person think about going for a walk. In this case, by doing things like closing the curtains for the night and putting outdoor coats and shoes out of sight, we can help to give the person cues that it is time to unwind for the evening. If you think the person is walking at night because of excess energy, it may help to plan some activity earlier in the day, such as an afternoon walk.

These are things we can do *before* the walking behaviour occurs, to try to reduce the chance that the person will want to go for a walk. The other thing we can try to alter is our own reaction in the event of the person wanting to go for a walk. For example, if our normal reaction is to try to persuade the person not to go for a walk, and this leads to the person becoming agitated, it may be time to try a different approach.

There is no absolute right or wrong in this, and how we respond will depend on the individual situation. However, here are some approaches that may be helpful in this kind of situation:

- Consider whether the person is walking in a safe area and at a safe time. If there are no safety concerns, then it may be best just to allow the walk to take place. Some carers choose to walk along with the person, and if this is feasible then it may also be a good idea.
- Try to offer another activity to divert the person's attention. This can just be a simple household task or other short activity to hold the person's attention instead of walking.
- If the walking is happening late at night, when you are trying to get to sleep, try gently reminding your relative that it is night time, and encourage him or her to try to get some rest.

☀ Activity 2

In the space below, note a behaviour that you find challenging to deal with. Try to think about things you could do before the behaviour happens (such as changes to the environment, planned activities and so on) and ways in which you might respond to the behaviour when it happens.

Description of the behaviour that you find challenging
(for example, walking at night, repetitive questioning)

Is there anything that happens before this behaviour occurs, or anything that might prompt your relative to carry out this behaviour? If so, are there changes you could make to the environment?
(for example, putting away a bunch of keys)

How could you respond to this behaviour when it happens?
(for example, providing reassurance and explaining who someone is, gently encouraging your relative to try to sleep)

How confident do you feel about being able to carry out these responses?

As well as looking at things we can and cannot change, it can help to identify those things which are most important to work on. For example, if a person with dementia regularly walks out of the house late at night, this can clearly cause risks compared with, for example, the person becoming confused about a meal time. There is no right or wrong here and there is individual variation in which type of behaviour we find most worrying. However, it can help to sort out which behaviour we are most concerned about from things which don't cause any direct harm, or that we can live with.

Are there any behaviours which cause you more concern than others?

Are there behaviours which are less harmful, or less important to try to manage?

Communicating with someone with memory problems

One of the most difficult things about dementia is that it changes the ways in which someone is able to communicate. Communication can be seriously affected by the symptoms of dementia. Memory problems, confusion and frustration can all make it more difficult for the person with dementia to take part in conversations with you, and you may need to make adjustments to the ways in which you communicate. This can take a lot of getting used to. Here are some tips which may help make it a little easier to talk to your relative.

Remove all unnecessary distractions. Try turning off the TV or radio when you want to talk. Any unnecessary background noise or distraction will make it more difficult for the person with dementia to focus on the conversation.

Keep words, sentences and explanations short. Talk to the person with dementia as an adult, but try to avoid using overly long sentences or explanations.

Ask yes/no questions. Questions like, 'Would you like a cup of tea?' are easier for the person with dementia to answer than open-ended questions such as 'What would you like to drink?'

Give straightforward options. When asking your relative to give a preference for something, it is best to express this as a simple choice – for example, 'Would you like this cake or that one?', while showing the person the options.

Use names and eye contact. To help make communication easier, it is best to face the person when talking, and to use his or her name in conversation. If the person is not sure who you are, mention your own name and relationship.

Avoid correcting the person with dementia. If your relative asks the same thing several times, it is best to try to distract them from this rather than to correct or draw attention to the repetition.

Remember non-verbal behaviour. When we communicate, a lot of what the other person understands is our non-verbal behaviour, and this is very important for people with dementia. Be aware of how you may be coming across emotionally, and try to pay attention to how the person with dementia is feeling as well as listening to what he or she is saying. Good-natured humour can be very useful in a conversation.

Setting goals around behaviour that challenges

In this section we will look at how we can plan to make changes around behaviour that challenges us. Setting goals can be a good way of setting out clearly the changes we plan to make, as well as a good way of knowing whether or not we are making progress.

Here are some tips to help you set goals that are achievable.

Clearly define the behaviour or other problem. Before setting a goal, have a think about exactly what it is that you want to change. Be as specific as you can. For example, a goal of 'helping my relative to feel less agitated' can encompass a huge range of things (including things you probably can't control), whereas 'knowing what to do when my relative thinks she has lost money' is more specific. The smaller and more specific your goals, the better the chance that you will achieve them.

Remember the things you can and cannot change. As we discussed earlier, we can't set goals that are directly about someone else's behaviour, since this is something we can't control. We can, however, look at the things that go before and after the behaviour, and can make changes to encourage the person with dementia to act differently.

Be realistic. You may be trying to make small changes to a behaviour that has been challenging you for some time. Remember that you can't change everything all at once, and that some challenging situations may be very persistent. The aim here is to try to feel a little more confident and in control than before, and to value any improvement you can make. Remember to reward yourself for any improvement you make, such as an improved routine, an enjoyable afternoon spent with your relative, a new way of dealing with difficult conversations, and so on.

☀ **Activity 3: Setting a Goal**

Try to identify a specific behaviour you find challenging, or a specific small change you want to make (such as a change in routine, to help your relative to sleep at night and use up any excess energy during the day). Use the following steps to plan how you will work towards the goal.

What is the goal or behaviour that you would like to improve?

(remember to be as specific as possible – a small and specific goal is easier to achieve than a larger, long-term one)

List the different possible things you could do to help you achieve this goal.

(asking friends and family for ideas can help at this stage – list as many possible approaches as you can, and don't worry at this stage if some are more realistic than others.)

Which of the above ideas do you think is worth trying first?

Make a plan:

What I am going to do:

When I am going to do it:

How often am I going to do it:

How will I know if my plan is working?

(for example, positive changes in your relative's sleep routine, feeling more able to cope with repeated questioning)

How confident do I feel about following this plan? (on a scale of 1-10)

If my score is less than 7, what can I do to make the plan easier to achieve?

Try following the steps on your plan, and be aware of any changes you see. Remember that changes may be small or may not be visible for a while – for example, it can take a few weeks of applying a new routine before you start to see the benefits.

If you feel that the plan is not working, remember to go back to your original list of ideas, and try another one instead.

Summary

In this section, we have looked at behaviour associated with dementia, and possible reasons behind this type of behaviour. We have looked at some of the things we can do to feel a bit more in control when this type of behaviour occurs, including:

- Asking questions about why this behaviour may be happening
- Looking at the parts of a situation that we can and cannot control
- Setting goals for coping with behaviour that challenges us

In the next section, we will look at techniques for helping us feel more in control of difficult feelings we may have about caregiving.

Section 2: Coping with Difficult Feelings

It is well-known that caring for someone with dementia can have a profound effect on the carer's emotional health. For example, carers are at increased risk of suffering from stress, anxiety and depression, all of which make it much more difficult to go on coping with the daily challenges of caring for someone.

It is sometimes difficult to recognise that we are becoming stressed by a situation. When we deal with something every day, there can be a gradual build-up of stress and we might not necessarily see ourselves as being stressed. Here are a few of the signs that you may be suffering from stress:

- You feel tired a lot of the time
- Even simple tasks seem to be more difficult than usual
- You find it more difficult to concentrate or make decisions
- Your sleep pattern has changed (either sleeping too much or too little)
- You feel more irritable
- It is difficult to stop thinking about the negative side of situations

Another feeling often experienced by carers is guilt. Carers often feel that they are letting their loved one down in some way by not being there every hour of the day, or by not responding perfectly to every situation.

It is not unusual for carers to feel angry or resentful about their situation. You may feel that your life has completely changed out of control, or ask questions like, 'Why me?'

Caring for someone with dementia is undeniably a stressful, difficult job at times, and yet it is possible to do things to reduce the extent to which we feel things like stress, anxiety and guilt. This section will include some techniques for managing difficult emotions. As in the previous section, we will see that there are some things we cannot control (for example, the situation that we find stressful) but that we can take steps to improve our coping strategies so that we feel much less stressed or worried.

We will look at various ways in which to minimise or control difficult feelings, including simple exercises to help you to reduce stress levels, and ways in which we can replace negative thoughts or beliefs with more positive ones.

☀ Activity 1: Relaxing Breathing Exercise

This is a simple technique for helping you to relax, and it can be practised even when you have only a short period of time to spare.

Practise deep breathing regularly and in a quiet place where you won't be disturbed. Try to wear comfortable clothing and remove shoes and jackets.

Sit in a comfortable chair, or lie on the floor or a bed. Place your arms on the chair arms, or flat on the floor or bed, slightly away from your body. If you're lying down, keep your legs hip-width apart, and if you're sitting, make sure your legs aren't crossed.

Once you are comfortable, start to focus on your breathing. Breathe in and out slowly,

trying to keep to a regular rhythm.

- Gently fill up the whole of your lungs with air, picturing them filling from the bottom.
- Breathe in through your nose and out through your mouth.
- Breathe in slowly and regularly counting from one to five (if a count of five is too difficult, reduce this).
- Breathe out slowly, counting the breath as it leaves.
- Repeat this until you start to feel more calm.

Practise this relaxed breathing for a few minutes, whenever you are feeling stressed.

By practising a simple breathing technique such as this one, you can help to take control of the overall level of stress you are experiencing. By taking time to relax your mind and body, you are giving yourself the best chance to cope with stressful thoughts and situations when they arise.

Unhelpful thoughts

Feelings and thoughts can be closely connected. Sometimes, difficult feelings come about because of unhelpful thoughts. For example, if you frequently have the thought, 'I'm not a good enough carer', this can worsen feelings of anxiety and depression. Negative thoughts can also mean that we approach a situation in a negative way, and they can affect the way a situation turns out.

Of course, it's natural to have less positive thoughts sometimes when you are providing care for someone. However, if you are having these thoughts all the time then they can start to cause problems.

There are things you can do to become more aware of unhelpful thoughts, and to challenge these thoughts before they become a problem. The first step is to be aware of any negative thoughts you may have around the issue of caring. These might include things like:

- Nothing I ever do is good enough
- My relative is taking it out on me when he/she becomes agitated
- Family members are never around to give me any help

Do you have any recurring negative thoughts about caregiving?

☀ Activity 2: Changing Perspective

Sometimes negative thoughts can come about because of a particular perspective we have on a situation. For example, 'My relative is always taking it out on me' is one perspective, which involves us thinking that the person with dementia is annoyed with us and deliberately doing something to get back at us.

A different perspective might be to believe that the dementia itself is causing the person

to behave in an agitated way (which is a much more likely explanation), and that the person is not frustrated with us at all. He or she might be trying to express something completely different.

It's not easy to change your perspective, especially in 'the heat of the moment' when you're dealing with a difficult situation. It can be worth taking a moment or two to reflect, though, and to think about different ways of looking at what is happening.

Can you think of different perspectives which might help counteract these negative beliefs?

- Nothing I ever do is good enough

- Family members don't give me enough help

- I'm letting my relative down if I have to ask services for support

- What did I/we do to deserve this?

Self-Talk

Self-talk is another important aspect of how well we manage difficult thoughts and feelings. Self-talk is what we say to ourselves, usually not out loud but silently.

If we have a running commentary of negative things going on inside our minds, then this makes it more difficult to see situations in a positive light. This in turn can mean that we feel more stressed or depressed by things, and it can also affect how things turn out – if you don't believe you are 'good enough', this can affect how you approach situations and what kind of result you get.

It makes sense, then, to try to practice positive self-talk. This can be difficult and can take practice, as we may have been thinking negative thoughts about ourselves for years.

Typical examples of negative self-talk would be statements beginning with:

- I can't
- I should have
- I shouldn't have
- I'm not good enough

Challenging negative self-talk involves trying to replace these thoughts with more positive ones about ourselves, often called affirmations. Positive affirmations involve focussing on the things we *can* do, our strengths, our successes and our good qualities.

☀ **Activity 3: Using Positive Self-Talk**

Look at the examples of negative self-talk below, and try to think of positive alternatives.

I can't cook the things Mum likes – she never finishes anything I make

Positive self-talk: I always do my best and cook nutritious food for Mum

I should be able to go on without a break – that's twice this week I've had to ask family to help

Positive self-talk:

I shouldn't have taken Jane to the shops – I should have known she would become distressed

Positive self-talk:

Now try to think of examples of negative self-talk that you use, and positive self-statements you could try instead.

Negative self-talk:

Positive self-talk:

Negative self-talk:

Positive self-talk:

Tips

- If you are struggling to think of positive affirmations, try to imagine what you would say to reassure a friend who was expressing negative thoughts. Often it is easier to be kind to others than to ourselves!

- It can also help to ask a friend to describe you in your role as a carer. People often see the positives in us that we can't see.
- Some people find that it helps to write out positive affirmations and to leave them around the house as reminders to ourselves – for example, writing affirmations on sticky notes and putting them on the fridge door.

Guilt

Guilt can be a very strong emotion for carers. You may feel that by putting your own health first, you are somehow letting down the person you care for. It isn't unusual for carers to say that they feel they should just be able to keep going. Yet as we have seen above, becoming 'burnt out' is not good for the person with dementia or for the person who is the carer.

Learning how not to feel guilty can take time – the chances are you have been putting pressure on yourself for a while now! To start challenging guilty feelings in ourselves, we can use one of the methods we saw earlier in this section. Guilt is another type of 'difficult feeling' and it often comes with a lot of negative self-talk, such as, 'I'm not doing enough' or 'I should be able to cope with this'. To reduce guilt, we need to look again at the kind of negative self-talk that is making us feel guilty, and try to re-frame things in a more positive way.

Activity 4: Challenging Guilt

Below are some examples of the kind of negative self-talk that comes along with feelings of guilt. Try to find statements to replace the negative ones below. Feel free to add in any negative thoughts you may have had, and to find more positive things to say to yourself.

Negative Self-Statement

'I never seem to cook anything my relative likes'

'I should be there for my relative round-the-clock'

'I shouldn't be feeling tired'

'I'm not the one who deserves help'

Positive Self-Statement

'I always do my best'

Summary

In this section, we have looked at some techniques for reducing the impact of difficult feelings we might have about caregiving.

These include:

Relaxed breathing to help us manage stress

Being aware of unhelpful thoughts and looking at changes in perspective

Using positive self-talk or affirmations

Challenging guilt

In the next section we will look at the importance of taking breaks from caregiving.

Section 3: Taking a Break

Respite, or time for yourself, is an important part of caring for someone. There are a number of reasons why carers can find it difficult to take time out from being a caregiver. These can include practicalities (for example, not knowing who to approach for help, lack of local amenities) and emotional reasons (for example, feeling guilty or feeling that you are not doing a good job as a carer if you take breaks).

However, by making sure that you have breaks and time to attend to your own needs, it is likely that you will be able to go on caring for your family member for longer. Respite can help you to feel refreshed and to feel that you have the energy to go on being a carer. It can also help you to feel more in control and able to cope with things, meaning that you may be less likely to feel overwhelmed by behavioural changes, or by your own feelings of stress.

Respite, or a break from caring, can mean more than one thing. It may be a formal period of respite, with a service supporting the person who has dementia to allow you to have a holiday, or it may simply mean asking a friend or relative to sit with the person who has dementia for half an hour to allow you to attend to something.

In this section, we will look at identifying options you may have for taking a break, as well as addressing some of the difficulties you may face when doing this.

How do you see your role as a carer?

One difficulty often experienced by carers is that they can feel isolated. If you see yourself as the main or even the only person involved in providing care for someone, then it is very difficult to step back and take some time out.

However, it is possible to see your role as a carer in a different light. Being a carer doesn't mean that you need to take responsibility for doing everything yourself; it can also mean, for example, that you're the co-ordinator in a team of different people. It's likely that the person you care for has a GP and possibly other professional sources of support (for example, nurse, occupational therapist, psychiatrist, Alzheimer Scotland worker), as well as people who can provide informal support, such as friends, family and neighbours.

☀ Activity 1: Completing the team

The table below can be used to identify some of the other people who can help with different aspects of caregiving. Some of these people will have a very specific role (for example, GP and psychiatrist will oversee things like medication and hospital appointments), while others will be able to provide different types of support (for example, a neighbour who is willing to help may be able to sit with the person you care for, to let you attend to something else).

Name	Role or Relationship (eg GP, friend, neighbour)	Type of help they can provide (eg sitting with your relative, health care)

You may wish to consider some of these groups of people in your table:

Healthcare providers such as GP, psychiatrist, nurse

Respite providers such as residential respite or support workers who will come to your home. You may also have a care manager who can access these services.

Advice providers such as welfare rights officers or Citizens Advice, who can give advice about things like money.

Day centre support or local groups which could include any centres that you or your relative can access for support, meetings or information.

Informal support including friends, family or neighbours who may be able to help.

Why should you take breaks?

For many carers, the decision to take more breaks (whether those are short breaks or longer periods of respite) is not an easy decision. You may feel that it is your job to be with your relative all the time, or that you will be letting him or her down if you have a break. Feelings of guilt are all too common when carers think about prioritising their own needs.

However, there is another way of looking at it. Being a carer for someone who has dementia is a very demanding role, as we have discussed earlier. Carers are subject to an increased risk of things like stress and depression – this risk is greater for carers of people with dementia than it is for carers of people with other long-term health problems.

By not taking breaks, carers run the risk of becoming more and more stressed, and a feeling of being 'burned out' can develop, meaning that carers feel constantly exhausted. This can actually mean that the carer becomes less and less able to give the care that is

needed, because his or her health starts to suffer and everyday tasks become more and more difficult to manage.

Imagine the jobs done by people like nurses and care workers, who often work long hours looking after people. These jobs have a lot in common with being a carer – they can involve all the different aspects of supporting someone, such as providing physical help with self-care or providing emotional support to people. This work is demanding, and the law states that workers need to have proper breaks when they are on shift, as well as breaks between one shift and the next, and days off work. The reason for these breaks is that the work would be impossible to do otherwise.

Now, imagine your role as a carer. You have a lot of the same tasks and responsibilities as nurses or care workers, but your role is much more intense, because you have a personal relationship to the person you care for, and perhaps share your life with that person. Most carers recognise that there is a very positive side to being a carer, but the fact remains that it is also a very challenging role to have.

Taking breaks from being a carer is not selfish, nor is it something you should feel guilty about. A break can leave you feeling refreshed and having the energy to go on, and it can also mean that you get the chance to catch up on other important aspects of your life – it is all too easy to neglect parts of your life when you are providing round-the-clock care to someone. Just as a worker feels more able to go on shift and provide good care after having a rest, so does caregiving benefit if you feel rested and refreshed.

☀ **Activity 2 – What will be different if I start taking breaks?**

In the spaces below, list the ways in which your life would be different if you took regular breaks from caregiving. It doesn't matter whether these changes in your life are positive or negative – just list any changes that occur to you.

If I start taking breaks, these changes are likely to happen:

(some examples of positive things might be, 'I will have more energy', 'I will find it easier to cope when my relative asks repeated questions' or 'I will be looking after my own health'. Negative things might be, 'I will feel as if I am not being a good enough carer')

Looking at your list above, do you feel more or less confident about taking breaks?

Using Assertive Communication to ask for Help

It is one thing to reach the decision that you need to take more breaks from caregiving, but another to ensure that you have enough help and support from others to allow you to do this. Assertive communication can greatly increase your chances of getting the help you need.

Assertive communication involves telling people in a straightforward way what you want or need, or how you feel or think about something. Being assertive isn't always easy, especially if you were brought up to believe that you shouldn't directly ask for help, but should wait for it to be offered.

To understand more about what assertive communication involves, let's look at three different types of communication: passive, assertive and aggressive.

Passive communication means avoiding saying things directly. For example, if someone assumes we can take on an extra task, a passive response would be to say, 'Yes, that's ok,' when in fact it wasn't ok to take on this task. Passive communication means not expressing yourself directly, and it can mean that other people don't realise when we are becoming stressed or overloaded. People who use passive communication sometimes become frustrated when no-one offers to help, believing that people should know how we are feeling and should offer the help without being asked.

Assertive communication means stating things directly but calmly, in a way that lets the other person know about our thoughts, feelings, needs or wishes. An assertive style also recognises that the other person's point of view is important, and that we might not always get exactly the solution we want. People who use assertive communication often use 'I' statements to make it clear that they are expressing their own opinions or feelings. Examples of this would be, 'I need someone to help me on Thursday for an hour', 'I am feeling under a lot of pressure just now and would be glad of some help' or 'I have to go to an appointment on Monday. Would you be able to sit with Mum for an hour?'

Aggressive communication also involves telling someone else what we think, but in this case it is done in an unhelpful way. Aggressive communication can be when we say something through anger, or without listening to the other person's point of view. An example might be, 'I'm sick and tired of you not helping with Mum – I'm at the end of my tether with your laziness!' Aggressive communication rarely gets the outcome we need, and often ends up with the other person feeling defensive and arguing back.

☀ Activity 3 : Using assertive communication

In the examples below, say which style of communication (passive, assertive or aggressive) is being used. What could the person say instead, to increase the chances of getting a positive result?

Mary has been caring for her mother, who has Alzheimers Disease. Mary has a brother, Steve, who visits once a week and takes their mother out for a coffee. Mary feels that she does all the day-to-day caring and that Steve just comes along once a week and does something enjoyable with their mother. Finally, one day she has had enough and says,

'You never do any of the hard work. I'm sick and tired of taking Mum to all her appointments, doing all the housework, helping her with everything and never having any time for myself. It's time you stopped being so useless.'

What type of communication is Mary using?

How do you think Steve is likely to respond?

What could Mary say instead, to get the results she wants (more help from Steve)?

John's wife, Linda, has dementia. John often feels isolated and stressed. Linda has a care manager, Irene, who comes round to the house every month to see how things are going. At the end of one appointment, Irene says to John, 'It looks like you have everything under control. I'll see you again next month', to which John replies, 'Yes, that's fine.'

What type of communication is John using?

What kind of result is John likely to get?

What else could John have said instead?

Now think about your own communications with various people: the person you care for, family and friends, professional helpers. What style of communication are you likely to use with each of these? How confident do you feel about using assertive communication and 'I' statements?

Assertive communication is a good way of letting people know exactly what you think, how you feel or what you need, in a way that still respects their right to say 'no' or to have different opinions. It's important to judge when to use assertive communication. For example, it might be very helpful when letting people know that you would really appreciate some extra help, to let you take a break. On the other hand, there are certain situations, such as talking to someone who is already very upset, or when it is more important to 'keep the peace' than to express some opinion, when assertive

communication might not be the best way to go about something. Try to think about when it is suitable to assert yourself, and when it is preferable just to let something pass.

Tips for asking for help

When you are asking someone to help you, there are things you can do to make it more likely that the person will feel able to help. It's worth considering these ideas before you ask someone for help.

- What kind of activity is the helper most interested in? For example, if someone really likes shopping, then it's more likely that they won't consider it too much of a chore if you ask for help with shopping.
- Try to avoid asking the same person for help all the time. Of course, it always feels easier to ask someone who is obliging than someone who makes it a little more difficult, but try to avoid asking the same person all the time, to avoid that person feeling burnt out.
- Consider the person's daily routine. If someone works from 9-5, for example, they're probably going to be feeling tired and hungry at 5pm, and may not be in the best frame of mind to consider your request for help.
- Be specific about the time involved. If you ask someone to help 'on Sunday' it may sound like you are asking them to help for the whole day. Your request may be more successful if you specify that you need them to help you with something for an hour on Sunday.
- Consider making a list of things that need doing, and inviting friends or family members to choose something from the list that they can do. This can mean that people know their help is valued even if they are only able to do a small chore.

Making Time for Pleasant Activities

Pleasant activities are simply any activities that you find enjoyable or relaxing. In this section we will look at things you enjoy doing, as well as things your relative enjoys. It doesn't matter whether these pleasant activities are things you do yourself or with the person you care for – all that matters is that you enjoy them and make time for them. All too often, we fail to prioritise pleasant activities, yet these are extremely important in order to feel refreshed and relaxed.

When you lead a busy life, you can sometimes become disconnected from the things you used to enjoy doing, so it may help to start by making a list of activities and interests you enjoy.

☀ Activity 4: Identifying Pleasant Activities

Here are some suggestions for activities you may enjoy doing. Feel free to note any of these that you find personally enjoyable, or add your own suggestions. Think about which of these activities you enjoy doing, and which ones your relative enjoys.

Activity	I enjoy this	My relative enjoys this
Going for a coffee		
Seeing a movie at the cinema		
Reading a book or magazine		
Watching the news		
Going for a walk		
Going to a friend's for lunch		
Watching a TV programme		
Doing a crossword		
Having your hair cut		
Shopping		
Chatting on the phone		
Listening to music		
Keeping fit		
Watching a comedy show		
Going to the theatre		

Some of these activities are things you can enjoy on your own, and some may be things you can do along with the person you care for. The important thing is to identify pleasant activities and make time for these. All too often, when we are busy we forget about doing things for fun.

Making Time for Pleasant Activities

It may seem strange to think about making a plan for pleasant activities. As a carer for someone, however, it can be all too easy to neglect the things you enjoy doing, because you're always so busy or something else always seems more important.

Pleasant activities are vital if you're to go on having the energy you need to be a carer. For this reason, it can be a good idea to make plans to do the things you find enjoyable.

The important thing here is to make sure you can set aside the time to unwind and enjoy yourself, not to feel like you are under more pressure than ever. It's best to set small goals that you know you can achieve. For example, if you enjoy keeping fit and want to make sure you set aside more time for this, it might be an idea to set a goal like, 'Go for a 20 minute walk three times a week', or whatever you think is reasonable. Try not to set a goal that will seem unachievable (like saying you'll do something every day – we all know there are some days when nothing seems to go to plan, so don't put this kind of pressure on yourself).

Activity 5

Choose a few of the pleasant activities you identified, and set a goal about doing these. Remember that this is not intended to put any pressure on you, but is just there as a reminder, so that you set aside time to relax and do something enjoyable.

Pleasant activity:
(e.g. going for a walk)

When I will do this:
(e.g. on Tuesday afternoons when someone can sit with my relative)

How often will I do this:
(e.g. once a week)

Pleasant activity:

When I will do this:

How often will I do this:

Pleasant activity:

When I will do this:

How often will I do this:

How confident do you feel that you can make time for pleasant activities?
It might help to go back over the list of pleasant activities you made in Activity 4 from time to time, to remind yourself of the range of things you can do to unwind. Sometimes when we are stressed, it is difficult to think of the things that help us feel better.

Summary

In this section we have looked at some of the reasons for taking breaks and the benefits of doing this, both for the carer and the person who has dementia.

We have also looked at some activities to help make it easier to take breaks:

- Identifying the other people in the 'team' who can help
- Using assertive communication to ask for help
- Being aware of pleasant activities and their importance in making us feel rested
- Making time for pleasant activities

Appendix D

Interview Schedule

Can you please tell me a bit about your caring situation?

Prompts: Who is the person you care for? How long have you been caring for this person?

Have you found positive aspects of caring for a person who has dementia?

Prompts: Can you tell me a bit more?

Have you experienced challenges in your caring role?

Prompts: What are some of the challenges you have faced? Can you tell me a bit more?

Would you say you were able to cope with those challenges?

What helped you to cope with the challenges you have told me about?

Prompts: Was anything particularly helpful to you?

Is there anything that you think would have made it easier for you to provide this care?

Prompts: Can you tell me a bit more?

If you could give advice to a new carer, what would it be?

Is there anything else you would like to tell me about that we have not covered?

Appendix E

Worked IPA Example

Ideas for Emerging Themes	Transcript	Initial notes (including notable words/expressions, summaries and interrogative remarks)
<p>Time and stages</p> <p>Medical treatment of dementia</p> <p>Loss of certainty</p> <p>Ongoing challenges</p> <p>Help and timing</p> <p>Stages of caring</p>	<p>L: Uh huh, just about your experience of caring.</p> <p>C: Well, what you try desperately to do four years on, and Bill is at home, we don't have any help erm [clears throat] you think in the beginning you try to be extremely positive because you think well, erm his score is not bad, erm he goes on to Aricept and so you you start off incredibly optimistic cause you think, this is the way to do it, right, more or less like this. Erm and then the realisation dawns that actually this is not a fight erm it all it is is a series of challenges one after the other. Erm you deal with one challenge, the shoulders go down and another one comes along. Erm I read a book called Contented Dementia at the beginning and couldn't cope with it and threw it across the room when it said go to your, find, the moment you get a diagnosis of dementia go to your, look at care homes because eventually that's what will happen and that was too early for me and I thought 'oh, that's a terrible thing'. In</p>	<p>'desperately' – struggle</p> <p>Time period – 4 years</p> <p>Initial positivity (declines later?)</p> <p>'start off' – process</p> <p>Hope</p> <p>Initial confidence</p> <p>Fight then acceptance/giving up fight</p> <p>One challenge after another/can't relax</p> <p>Frustration at advice/clash between book and early hopes?</p> <p>Timing/stages and needs</p> <p>Importance of info matched to stages</p>

Process of acceptance	fact I now realise that that was probably quite a sensible thing to say, it didn't go down well at that stage but it was probably a very sensible thing to say. Because what you realise is you're trying to anticipate crises which you know will come [L: okay] and that's the awful thing, you you realise that you have to live always ahead of the game which is terribly exhausting.	Stages of caring/dementia Trying to anticipate crises (impossible task?) Exhaustion
Impact of caring		
Controlling or anticipating events	L: and how do you do that, living ahead of the game? C: Erm living ahead of the game means that you are always on the alert, always keyed up, ready to stop the glass of wine being knocked over, going over on the red light or always anticipating disa- now, this is not what everybody would do, this happens to be my erm nature and it's a very difficult one to know to know that you want, I want Bill to keep his independence as long as possible. What is safe, what is, you know that that and if you are an anxious person of course you chip away at the independence because you couldn't bear anything to happen if you felt that you had allowed something that you thought was perhaps unsafe. My GP, this is where the GP was wonderful, she said she said two or three very wise things and and she said at your age, cause I'm nearly 79, she said at your age first of all you must accept that you may not feel 78 or look 78 but your body is [L: okay] so you have to accept that and say,	Trying to beat something? Always on alert Own nature – sees self as anxious Uncertainty
Self and own nature		
Uncertainty		
Self vs needs of PWD		Anxious person vs independence of PWD (own input as negative?) 'allowing' bad things to happen 'wonderful' GP – good advice Own ageing
Responsibility for PWD		
Authority of professional		
Ageing		
Acceptance		Accepting things as they are Instruction from GP
Authority of professional		

<p>Power over PWD Change in relationship Own needs</p>	<p>here I am in this situation, now she said with Bill let's divide the day into three parts, morning afternoon and evening, you really should not be with him for more than two out of the three parts now I know that sounds very simple but it actually gave me permission to think right, after lunch I can say it, I felt as if I was banishing him but I was given permission to say, you go upstairs to your study, I need to sit down and have a rest it gave you that period of [sighs].</p>	<p>'Permission' from professional Need for someone else to take charge? Time for self</p>
--	---	---

Appendix F

Themes Emerging from a Single Transcript

Note: For each transcript, a table was created, with a list of the emergent themes in the left-hand column. In the right-hand column, initial groupings of these themes were made, with suggested names for superordinate themes. The table below shows an example of the emergent and proposed superordinate themes for one transcript, and is not a complete list.

Emergent Themes	Proposed Superordinate Themes
Anticipating crises Time to diagnosis Lack of confidence Financial response to dementia Changes to friendships Responsibility for PWD Carers' power over PWD Anxiety about future Self as observer in professional presence Comfort of authority Lack of family support Coping with disappointment Loss of hope Preparing for disaster Self-doubt Respite Lack of support Anger/resentment Disappointment Protecting PWD Loss of PWD Fear of illness Need own space Emotional detachment Awareness of ageing Stigma of social care Bureaucracy of dementia Process of acceptance Depressing services Hopelessness Uncertainty Series of challenges Responsibility for PWD Importance of social life Self-talk Time for self Need for worthwhile activity Timing aspect of help Practical challenges	Stressors Time to diagnosis Coping with disappointment Loss of hope Lack of support Anger/resentment Disappointment Hopelessness Uncertainty Series of challenges Anticipating crises Caring is exhausting Responsibility for PWD Lack of confidence Awareness of ageing Loss of PWD Fear of illness Practical challenges Anxiety about future Self-doubt Bureaucracy of dementia Grief Loss of relationship Expecting bad outcome Coping mechanisms Self-talk Protecting self against disappointment Process of acceptance Avoidance of disappointment Protecting PWD Feeling fortunate Preparing for disaster Learning process/changes in carer Emotional detachment Safe environment Needs of carer Time for self

<p>Lack of support Learning process/changes in carer Protecting self against disappointment Grief Feeling fortunate Professional authority Expecting bad outcome Negative experiences (services) Avoidance of disappointment Delays in support ‘Passport’ for help Dementia affects social life Dementia causes social unease Need time alone Gatekeepers Fighting with services Emotional needs of carer Not taken seriously by services False hopes Medical response to dementia Loss of relationship Carer sidelined by professionals Bureaucracy of dementia Safe environment Uncertainty about entitlement Private sector services Reluctance to depend on others Dementia vs normality Importance of social standing Misleading services Advice from others Lack of info at diagnosis Not person centred Misleading info from services Comparison between dementia and other conditions Loss of abilities in PWD Appearance vs reality in PWD Reluctance to depend on others Family advice Temporary solutions Others don’t understand Reluctance to ask for informal help Importance of others Stages of caring Comparison with others – self as more fortunate Importance of social standing Other carers’ stories Everyone is different Dementia causes loss of skills</p>	<p>Respite Need for worthwhile activity Need time alone Need own space Emotional needs of carer</p> <p>Formal services Not taken seriously by services Negative experiences (services) Lack of support False hopes Financial response to dementia Medical response to dementia Timing aspect of help Professional authority Depressing services Self as observer in professional presence Comfort of authority Carer sidelined by professionals Stigma of social care Delays in support ‘Passport’ for help Bureaucracy of dementia Uncertainty about entitlement Private sector services Misleading services Gatekeepers Fighting with services Advice from others Lack of info at diagnosis Not person centred Misleading info from services</p> <p>Informal support Reluctance to depend on others Family advice Lack of family support Temporary solutions Reluctance to ask for informal help Importance of others</p> <p>Relationships with others Comparison with others – self as more fortunate Importance of social standing Others don’t understand Reluctance to depend on others Other carers’ stories Dementia affects social life</p>
---	--

<p> Process of dementia Dementia down to chance Caring is exhausting Dementia changes relationships Loss of PWD Dilemma of PWD still being there Normality – keeping up appearances Everyone is different </p>	<p> Importance of social life Changes to friendships Dementia causes social unease Everyone is different </p> <p> Beliefs about dementia and caring Process of dementia Comparison between dementia and other conditions Dementia down to chance Stages of caring Responsibility for PWD Carers’ power over PWD Dementia changes relationships Loss of PWD Dilemma of PWD still being there Dementia vs normality Importance of social standing Loss of abilities in PWD Appearance vs reality in PWD Dementia causes loss of skills Normality – keeping up appearances Everyone is different </p>
---	--

Appendix G

Outcome Measures

Caregiver External Stressors Scale

For each of the following items, please answer yes/no to indicate whether you have experienced problems with these issues, in relation to caring for someone who has dementia, in the last 3 months.

For any issue which you have answered 'yes', please indicate using the following scale how stressful or bothersome you found this.

0 = not stressful or bothersome

1 = slightly stressful or bothersome

2 = moderately stressful or bothersome

3 = very stressful or bothersome

4 = extremely stressful or bothersome

Issue or Problem	Experienced in last 3 months (Yes or No)	If yes, how stressful was this? (rate 0 to 4)
Problems with finances/benefits (for example, being unsure about entitlements or not knowing how benefits can be accessed/used)		
Legal problems (for example, issues around arranging power of attorney)		
Not knowing where to get help (for example, lack of information about local services, not knowing where to access respite care)		
Family issues (for example, lack of help or loss of contact with family members, family relationship issues)		
Problems with professional care (for example, changes in staff, issues around timing of care or difficulties in contacting professionals)		
Issues around contact with social worker/care manager (for example, appointments being cancelled or changed, difficulty getting an appointment)		

Revised Memory and Behavior Problems Checklist (Teri et al., 1992)

Instructions: The following is a list of problems patients sometimes have. Please indicate if any of these problems have occurred during the past week. If so, how much has this bothered or upset you when it happened. Use the following scale for your reaction. Please read the description of the ratings carefully.

Has it occurred in the past week:

0 = No

1 = Yes

Reaction ratings:

0 = Not at all

1 = A little

2 = Moderately

3 = Very much

4 = Extremely

Please answer all the questions for both frequency and reaction.

Problem

Has it occurred?

Reaction

(in last week)

(how much it
bothered you)

Problem	Has it occurred? (in last week)	Reaction (how much it bothered you)
1. Asking the same question over and over	No	Yes
2. Trouble remembering recent events (ie items in newspaper or TV)	No	Yes
3. Trouble remembering significant past events	No	Yes
4. Losing or misplacing things	No	Yes
5. Forgetting what day it is	No	Yes
6. Starting, but not finishing, things	No	Yes
7. Difficulty concentrating on a task	No	Yes
8. Destroying property	No	Yes
9. Doing things that embarrass you	No	Yes
10. Waking you or other family members up at night	No	Yes
11. Talking loudly and rapidly	No	Yes
12. Appears anxious or worried	No	Yes
13. Engaging in behavior that is potentially dangerous to self or others	No	Yes
14. Threats to hurt oneself	No	Yes
15. Threats to hurt others	No	Yes
16. Aggressive to others verbally	No	Yes
17. Appears sad or depressed	No	Yes
18. Expressing feelings or hopelessness or sadness about the future	No	Yes
19. Crying and tearfulness	No	Yes
20. Commenting about death of self or others	No	Yes
21. Talking about feeling lonely	No	Yes
22. Comments about feeling worthless or being a burden to others	No	Yes
23. Comments about feeling like a failure, or about not having any worthwhile accomplishments in life	No	Yes
24. Arguing, irritability, and/or complaining	No	Yes

Center for Epidemiologic Studies Depression Scale (Radloff, 1977)

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

	During the Past Week			
	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
1. I was bothered by things that usually don't bother me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I did not feel like eating; my appetite was poor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I felt that I could not shake off the blues even with help from my family or friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I felt I was just as good as other people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I had trouble keeping my mind on what I was doing.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I felt depressed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I felt that everything I did was an effort.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I felt hopeful about the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I thought my life had been a failure.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I felt fearful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. My sleep was restless.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I was happy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I talked less than usual.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I felt lonely.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. People were unfriendly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I enjoyed life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I had crying spells.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I felt sad.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. I felt that people dislike me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. I could not get "going."	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Revised Scale for Caregiving Self-Efficacy (Steffen et al., 2002)

“For this part, we are interested in how confident you are that you can keep up your own activities and also respond to caregiving situations. Please think about the questions I am going to read to you carefully, and be as frank and honest as you can about what you really think you can do. I will read items which cover activities and thoughts that could come up for you as a caregiver. Please think about each one and tell me how confident you are that you could do each item. Rate your degree of confidence from 0 to 100 where a 0% confidence means that you cannot do it at all, a 50% confidence means that if you gave it your best effort, chances are about 50-50 that you could perform the activity, and a 100% confidence means you are certain you can do it. You can use any score between 0 and 100 (10, 20, 30, etc.) to express your confidence. For example, a rating of 20% confidence means that it is unlikely, but not totally out of the question for you to be able to perform the activity.

0	10	20	30	40	50	60	70	80	90	100
Cannot do					Moderately					Certain
at all					certain can do					can do

Please make all your ratings based on what you could do Today, as the person you are NOW rather than on the person you used to be, or the person you would like to be. Just rate how you think you would do as you are right Now. Do you have any questions? We are going to do a quick practice rating to make sure everything makes sense. If you were asked to lift objects of different weights right now, how confident are you that you can :

PHYSICAL STRENGTH	CONFIDENCE (0-100)
1. Lift a 10 pound object	_____
2. Lift a 20 pound object	_____
3. Lift a 50 pound object	_____
4. Lift a 100 pound object	_____

“Great. Let’s go on. How confident are you that you can do the following activities?” (If necessary, say “If this is absolutely not applicable to your situation, let me know.” Then put N/A).

Self-Efficacy for Obtaining Respite

____ 1. How confident are you that you can ask a friend/family member to stay with ____ for a day when you need to see the doctor yourself?

____ 2. How confident are you that you can ask a friend/family member to stay with ____ for a day when you have errands to be done?

____ 3. How confident are you that you can ask a friend or family member to do errands for you?

____ 4. How confident are you that you can ask a friend/family member to stay with ____ for a day when you feel the need for a break?

___ 5. How confident are you that you can ask a friend/family member to stay with ___ for a week when you need the time for yourself?

Self-Efficacy for Responding to Disruptive Patient Behaviors

___ 6. When ___ forgets your daily routine and asks when lunch is right after you've eaten, how confident are you that you can answer him/her without raising your voice? (Clarify that "answer" can be direct or a distraction.)

___ 7. When you get angry because ___ repeats the same question over and over, how confident are you that you can say things to yourself that calm you down?

___ 8. When ___ complains to you about how you're treating him/her, how confident are you that you can respond without arguing back? (e.g., reassure or distract him/her?)

___ 9. When ___ asks you 4 times in the first one hour after lunch when lunch is, how confident are you that you can answer him/her without raising your voice?

___ 10. When ___ interrupts you for the fourth time while you're making dinner, how confident are you that you can respond without raising your voice?

"All caregivers sometimes have negative thoughts about their situation. Some thoughts may be brief and easy to get rid of. Other times, thoughts may be hard to put out of your mind, just like a silly tune is sometimes hard to get out of your mind. We would like to know how well you can turn off any of the following thoughts. Use the same confidence rating. Don't be concerned about how often the thoughts come up. We want you to rank your confidence that you can turn off or get rid of each type of thought when it does come up." (Administrator: When caregivers state that they have absolutely never had the thoughts in one of the items, put "N/A" (not applicable) on the line for rating confidence.)

Self-Efficacy for Controlling Upsetting Thoughts about Caregiving

___ 11. How confident are you that you can control thinking about unpleasant aspects of taking care of ___?

___ 12. How confident are you that you can control thinking how unfair it is that you have to put up with this situation (taking care of ___)?

___ 13. How confident are you that you can control thinking about what a good life you had before ___'s illness and how much you've lost?

___ 14. How confident are you that you can control thinking about what you are missing or giving up because of ___?

___ 15. How confident are you that you can control worrying about future problems that might come up with ___?

Zarit Burden Interview (Zarit et al., 1980)

THE ZARIT BURDEN INTERVIEW

Please circle the response that best describes how you feel.	Never	Rarely	Sometimes	Quite Frequently	Nearly Always	Score
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4	
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4	
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4	
4. Do you feel embarrassed over your relative's behaviour?	0	1	2	3	4	
5. Do you feel angry when you are around your relative?	0	1	2	3	4	
6. Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0	1	2	3	4	

7. Are you afraid what the future holds for your relative?	0	1	2	3	4	
8. Do you feel your relative is dependent on you?	0	1	2	3	4	
9. Do you feel strained when you are around your relative?	0	1	2	3	4	
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4	
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4	
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4	
13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4	
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4	
15. Do you feel that you don't have enough money to take care of your relative in	0	1	2	3	4	

addition to the rest of your expenses?						
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4	
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4	
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4	
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4	
20. Do you feel you should be doing more for your relative?	0	1	2	3	4	
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4	
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4	
Total Score (out of 88)						

Appendix H

Interview schedule for Chapter 6

Can you tell me about your experience of attending the three sessions?

Prompts: How did it feel to talk with other carers/ about your own experiences? Can you tell me more about how you felt about taking part?

Was there anything in the three sessions that you didn't already know about?

How did these sessions fit with your own experiences of caring for someone?

What about taking part in a group/individually – what was helpful or unhelpful about this? Prompt: How did you feel about taking part in this way?

Can you tell me about any part of the sessions you have used again since, or anything you do differently now?

Can you remember how you felt after completing the sessions?

Is there anything else you would like to say about your experience of taking part?