Understanding Resilience and Family Carers

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Abstract

Background: Many family carers report suffering high levels of stress as a central part of the caregiver experience. Recently research has begun to examine the role of resilience in enhancing the capacity of individuals to 'bounce back', enabling them to continue to care. Resilience has been defined as 'the process of, capacity for, or outcome of successful adaptation despite challenging or threatening circumstances.' This study aimed to understand the nature and complexity of the caring task, identify the emotions and the quality of life outcomes family carers experience, explore their perception of resilience and how it applies to their caregiving roles by developing a carer definition and model of support for enhancing carer resilience. The study then undertook a scoping review to evaluate the effectiveness of two carers' centres to see if there is merit in further evaluative research.

Methods: A grounded theory study was undertaken, and situational analysis was used to provide a systematic way of interrogating the data and identifying themes. Focus groups were conducted with a range of family carers who were caring for a variety of adults and children with differing needs. The focus groups were recorded, transcribed and then analysed using grounded theory. The software package Nvivo was used to support the analysis. Two carers' centres participated in evaluative research to investigate both the cost and the worth of the services they provided. A logic model was used to create the evaluative research framework, quantitative data was collected using standardised measures and economic costings, qualitative data was collected using observations, surveys and interviews.

Results: Carers across care groups and across different relationships with the cared for define resilience in the same way. They define carer resilience as the ability to either continue caring or to move on, to continue navigating the changing relationship and to do this by adapting roles and behaviours throughout the carer journey. This includes adapting to the changing relationship with the care recipient; adapting one's identity; adapting one's behaviour to manage the symptoms and behaviour of the care recipient. *Carers want commissioned services aimed at building their resilience to focus on supporting the changing relationship between the carer and the cared for* and to better support the interplay between carers and the communities they live in.

Conclusions: Resilience (as defined by carers) would be a useful construct in helping professionals to understand that the key issue is the huge journey of change carers must move through. A common understanding of a social justice model of carer resilience might focus carer strategies on the different types of support carers require at different points in the carer journey to enable them to adapt to these massive changes. Translating policy into practice for carers will require a common understanding of carer resilience, an ability to measure it, a commitment to supporting carers across the carer journey and a more insightful understanding by policy makers of the challenges carers face. There needs to be an increase in studies that involve carers across care groups, across relationships and across the carer journey rather than studying carers in silos. There would be value in future research building on cost-analysis evaluation methods in attempting to gauge both the 'merit' and 'worth' of carer support services.

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Contents

Contents

1 Chapter 1: Context Setting 11
1.1 Introduction 11
1.2 Carers in Context 11
1.3 Carers' Centres in Context 13
1.4 Resilience in Context 15
1.5 The methodology in context 16
1.5.1 A qualitative approach 17
1.5.2 Grounded Theory 18
1.5.3 Narrative literature reviews 19
1.5.4 Focus groups 20
1.5.5 Scoping Review 21
1.5.6 NVivo 24
1.5.7 Situational analysis 25
1.6 The researcher in context 26
2 Chapter 2: What are the emotions and quality of life outcomes that carers experience? 28
2.1 Defining emotions 28
2.2 Defining quality of life outcomes? 29
2.3 Why explore the emotions and quality of life outcomes for carers? 32
2.4 The emotions and quality of life outcomes experienced by carers 33
2.4.1 Negative emotions and quality of life outcomes commonly experienced by carers across care groups and relationships 33
2.4.2 Positive emotions and quality of life outcomes commonly experienced by carers across care groups and relationships 37
2.5 Predicting the emotions and quality of life outcomes of carers – what are the differences between carers? 39
2.6 The Ethic of Care 49
2.7 Limitations of the previous research 50
3 Chapter 3: Methodology 51
3.1 Ethics 51
3.1.1 Ethics Application for Part One and Two 51
3.1.2 Ethics Application for Part Three 52
3.2 Quality of the research 54
3.2.1 Research Process 54

3.2.2 Empirical grounding of findings 71
3.3 Reflection and memo writing 74
4 Chapter 4: Part One – First Set of Focus Groups 75
4.1 Focus Groups 75
4.1.1 Participants 75
4.1.2 The Structure of the Focus Groups 76
4.1.3 Data Collection 76
4.2 Data Analysis 77
4.2.1 Situational map 77
4.2.2 Relational map 83
4.2.3 Social arena/world map 85
4.2.4 Positional mapping 89
4.3 Emerging themes 90
4.3.1 The scale of the caring role 91
4.3.2 THE skilled helper 92
4.3.3 Sense of loss 93
4.3.4 The Hidden World of the Carer 95
4.3.5 Resilience as the ability to keep caring 97
4.3.6 Identity 99
4.3.7 The Context 100
4.3.8 Experience of oppression and discrimination 101
4.4 Discussion 103
4.5 Limitations 105
4.5.1 Reliability 106
4.5.2 Validity 106
5 Chapter 5: Part One – Second Set of Focus Groups 107
5.1 Context 108
Negative emotions and subjective quality of life outcomes 108
5.1.1 108
5.1.2 Positive emotions and subjective quality of life outcomes 111
5.1.3 Oscillating and conflicting emotions and quality of life outcomes 112
5.2 Focus Groups 112
5.2.1 Participants 113
5.2.2 Structure of the focus groups 114
5.2.3 Data collection 114
5.3 Data Analysis 114
5.3.1 Situational map 114

5.3.2 Relational Mapping 119
5.3.3 Social arena/world map 121
5.3.4 Positional map 124
5.4 Emerging Themes 125
5.4.1 The Carer Journey 125
5.4.2 The hidden world of the carer 126
5.4.3 Carer as THE skilled helper 128
5.4.4 Sense of loss 128
5.4.5 Resilience as the ability to adapt through the carer journey 129
5.4.6 What makes it harder to be resilient? 131
5.4.7 What helps carers' to be resilient? 132
5.5 Discussion 132
5.6 Limitations 135
5.6.1 Reliability 136
5.6.2 Validity 136
6 Chapter 6: Part One – Third Set of Focus Groups 137
6.1 Context 137
6.2 Focus Groups 140
6.2.1 Participants 140
6.2.2 Structure of the focus group 141
6.2.3 Data collection 141
6.3 Data Analysis 141
6.3.1 Situational map 142
6.3.2 Relational Mapping 144
6.3.3 Social arena/world map 146
6.3.4 Positional map 149
6.4 Emerging Theory 150
6.4.1 Adapting to their changing relationship with the care recipient 150
6.4.2 Learning to manage the changing symptoms and behaviours of the care recipient 151
6.4.3 Adapting to their changing sense of self / identity 151
6.4.4 Good supportive relationships with other family and friends 152
6.4.5 Good supportive relationships with professionals and support agencies 152
6.4.6 Carer friendly communities 153
6.5 Discussion 153
6.6 Limitations 155
6.6.1 Reliability 156

6.6.2 Validity 156
7 Chapter 7: How do definitions, concepts and models of resilience relate to carers? 157
7.1 Why is resilience important in the context of carers? 157
7.2 Definitions of Resilience 157
7.3 Conceptualising resilience 158
7.3.1 Resilience as a personal characteristic 159
7.3.2 Resilience as a process 161
7.4 Resilience and Coping 161
7.5 Models of Resilience: How useful are they when applied to carers? 163
7.5.1 Metatheory of Resilience 164
7.5.2 Community Resilience 166
7.5.3 Range of Response to Loss Model 169
7.5.4 The developmental concept of resilience 171
7.6 Recent developments in the resilience literature 172
7.7 What are the limitations of previous research on resilience? 173
7.8 Reflective summary 174
8 Chapter 8: Developing the model of carer resilience 176
8.1 A Reminder about the Methodology 176
8.1.1 The research process 176
8.2 The workshops 178
8.2.1 Carer workshop 178
8.2.2 Carer Support Worker Workshop 180
8.3 Reflection on the workshops and memo writing 182
9 Chapter 9: Introduction, logic model and description of carers' centres 184
9.1 Introduction 184
9.1.1 A reminder about the research process 184
9.1.2 A reminder about the Logic Model 187
9.2 The Carers' Centres 189
9.2.1 Carers' Centre A 189
9.2.2 Carers' Centre B 191
10 Chapter 10: Scoping Review - the carer perspective 192
10.1 Carers' Centre Activities 192
10.1.1 Carers Centre A 192
10.1.2 Carers Centre B 195
10.2 Purpose and impact of the carers' centre 197
10.2.1 Carers centre A 197

10.2.2 Carers' Centre B 201
10.3 Wellbeing and resilience of carers 205
10.3.1 Carers' Centre A 205
10.3.2 Carers' Centre B 205
10.4 Discussion 205
10.5 Limitations 208
11 Scoping Review – The Carers' Centre perspective 210
11.1 Purpose of the carers' centre 210
11.1.1 Carers' Centre A 210
11.1.2 Carers' Centre B 211
11.2 Performance management data 212
11.2.1 Carers' Centre A 212
11.2.2 Carers' Centre B 214
11.3 Culture 216
11.3.1 Carers' Centre A 216
11.3.2 Carers' Centre B 218
11.4 Cost Analysis 221
11.4.1 Carers' Centre A 221
11.4.2 Carers' Centre B 222
11.5 Discussion 222
11.6 Limitations 224
12 Chapter 12: Reflections and final model of support for promoting carer resilience 226
12.1 What has the study revealed so far? How has it added to the previous research? 226
12.2 What new insights emerge from the final analysis? 227
12.3 Definition of Carer Resilience and Final Model of Support 229
12.4 Reflections on resilience and its relevance for carers 231
12.5 Implications for services 233
12.6 Limitations 235
12.7 Suggestions for future research 238
References 240
Appendix One: Carer Experience Commonalities and Differences 270
Appendix Two: Part One Ethics Application and Approval Letter 279
Appendix Three: Letter to Ethics Committee and approval letter 291
Appendix Four: Part Three Ethics Application and Approval Letter 293
Appendix Five: Letter to Ethics Committee and Approval Letter 315
Appendix Six: Initial Findings from the first set of focus groups 317

Appendix Seven: Example of line by line coding 321
Appendix Eight: Example Memos.....323
Appendix Nine: Audit Tool.....326
Appendix Ten: Short Well-being Scale (SWEMWBS).....330
Appendix Eleven: Brief Resilience Scale.....331
Appendix Twelve: Example of 'Day in the life of…' field notes.....332
Appendix Thirteen: Carer's Outcome Star 335
Appendix Fourteen: Unit Cost Calculation for Carers' Centre A.....339
Appendix Fifteen: Unit Cost Calculation for Carers' Centre B 340
Appendix Sixteen: Rationale for a SROI Evaluation of Carers' Centres.....341

Table of Tables

Table 1: Comparison of qualitative research methods..... 18
Table 2: Emotions and QoL Review search terms.....59
Table 3: Resilience Review search terms..... 60
Table 4: Template for ordered situational map..... 72
Table 5: Study 1 Demographic characteristics of participants..... 76
Table 6: Study 1 Ordered situational map..... 79
Table 7: Study 2 Demographic characteristics of participants.....113
Table 8: Study 2 Ordered situational map.....117
Table 9: Study 3 Demographic characteristics of participants.....140
Table 10: Definitions of resilience..... 158
Table 11: Demographic characteristics of participants (carers workshop)..... 178
Table 12: Demographic data on registered carers (carers' centre A)..... 189
Table 13: Demographic data on registered carers (carers' centre B)..... 191
Table 14: Demographic data on carer survey respondents (carers' centre A).....198
Table 15: Demographic data on carer survey respondents (carers' centre B).....202
Table 16: Carers' centre A performance data.....212
Table 17: Carers' centre B performance data.....215

Table of Charts

Chart 1: Impact score (carers' centre A).....199
Chart 2: Who carers were caring for (carers' centre A).....200
Chart 3: Number of hours carers were caring for (carers' centre A).....200
Chart 4: Impact score (carers' centre B).....203
Chart 5: Who carers were caring for (carers' centre B).....203
Chart 6: Number of hours carers were caring for (carers' centre B).....204

Table of Figures

Figure 1: Stress Process Model of Caring..... 41
Figure 2: The Double ABCX Model..... 42
Figure 3: Conceptual Model of Carer Adaptation..... 44
Figure 4: The Dual Process Model of Grief..... 45
Figure 5: Thesen's Model of Oppression..... 47
Figure 6: Thompson's PCS Model of Anti-Oppressive Practice..... 48

Figure 7: Research Process……57
Figure 8: Detailed Diagram of Scoping Review Process……58
Figure 9: Logic Model…… 64
Figure 10: Study 1 Situational Map……78
Figure 11: Study 1 Relational Map…… 84
Figure 12: Study 1 Social World Map…….. 86
Figure 13: Study 1 Positional Map…… 89
Figure 14: Study 2 Situational Map…….. 116
Figure 15: Study 2 Relational Map……120
Figure 16: Study 2 Social World Map……122
Figure 17: Study 2 Positional Map……124
Figure 18: Study 3 Situational Map……143
Figure 19: Study 3 Relational Map……145
Figure 20: Study 3 Social World Map……147
Figure 21: Study 3 Positional Map……149
Figure 22: Emerging model of carer resilience……155
Figure 23: Conceptual Model of Carer Adaptation……162
Figure 24: Metatheory of resilience……164
Figure 25: Adapted metatheory of resilience……165
Figure 26: Ungar's model of resilience……168
Figure 27: Range of response to loss model……...170
Figure 28: Leipold and Greve's Developmental Concept of Resilience…… 171
Figure 29: Part One and Two Research Process…….. 177
Figure 30: Carer model of support across the carer journey…… 180
Figure 31: Refined model of support for promoting carer resilience……181
Figure 32: Research Process……184
Figure 33: Detailed diagram of Scoping Review Process……186
Figure 34: Logic Model……..187
Figure 35: Carers' centre A activities……...192
Figure 36: Carers' centre B activities……196
Figure 37: Final Project Map……229
Figure 38: Final model of support for promoting carer resilience……230

Introduction

1 Chapter 1: Context Setting

1.1 Introduction

This thesis focuses on the concept of carers and resilience. The aim of this thesis is to explore the world of carers, their interpretation of resilience and to investigate whether there is value in further evaluative research to investigate whether carers' centres are effective in maintaining or improving the resilience of carers.

The thesis focuses on unpaid adult carers (those over the age of 18) caring for family or friends. Previous research has tended to focus on groups of carers, either by focusing on care groups (for example carers of people with learning disabilities, or dementia, or mental health issues, etc) or by focusing on the relationship between the carer and care recipient (for example parents, siblings, spouses). Previous research has demonstrated that the individual nuances are important in understanding the experience of carers. However, this study looks for commonalities across carer groups because the national strategy and policy for carers, the formal support network of carers' centres and campaign groups all refer to 'carers' as if they are one group. If policymakers legislate for carers as one group (as evidenced by the National Carers Strategy 2008, Carers Action Plan 2018-2020, The Care Act 2014, and the Children and Families Act 2014), and services are commissioned for carers as one group then it is important to understand whether there are commonalities, and indeed whether there is enough commonality that for the purposes of legislation and commissioning formal support we can think of carers as one group and develop a framework of resilience for all carers, within which individual nuances could be addressed.

The study attempts to answer the following five research questions:

1. What are the emotions and quality of life outcomes that carers experience? Are there commonalities across care groups and relationships?
2. How do carers across care groups and relationships define resilience?
3. How do current definitions, concepts and models of resilience relate to carers across care groups and relationships?
4. Is there a carer model of support that applies across care groups and relationships and that could lead to enhanced resilience?
5. Do two carers' centres promote the resilience of carers across care groups and relationships and would there be value in undertaking a more comprehensive evaluation of carers' centres?

1.2 Carers in Context

The Carers Action Plan 2018-2020 (DHSC) defines a carer as:

'A carer is considered to be anyone who spends time looking after or helping a friend, family member or neighbour who, because of their health and care needs, would find it difficult to cope without this help regardless of age or whether they identify as a Carer' (p7)

Recent polling published by Carers UK (2019b) has suggested there could now be as many as 8.8 million adult carers in the UK, compared to 6.3 million adult carers recorded in the 2011 Census. The number of people aged 65 years or over who are caring has grown from 1.4 million to potentially over 2 million. This is a 43% increase from 2011 to 2019. By 2030 it is estimated that the number of carers will increase by approximately 60% resulting in over 10 million carers (Carers UK, 2018).

The Office of National Statistics (ONS) calculate the output of informal adult care in the UK by multiplying the total hours of care by the wage rates of carers/nursing assistants. Gross value added (GVA), is then estimated by making an adjustment for the input of household housing services (inputs are purchases of goods and services, use of equipment and time/labour). The ONS (2016) estimated that the gross value added of informal adult care in the UK increased by 45.8% between 2005 and 2014, from £39.0 billion to £56.9 billion. The main data source used for this estimation is the Family Resource Survey (FRS) (commissioned by the Department for Work and Pensions, DWP) which collects information on the number of adults receiving care and whether this care is on a weekly, daily or continuous basis. The ONS state that FRS is currently the best data source available for the estimation of the household production of adult care, but it is known to underestimate the number of adults receiving care.

Buckner and Yeandle in their research (2015) estimated that the current economic value of the contribution made by carers in the UK is estimated to be £132bn a year, which is more than the annual cost of all aspects of the NHS.

In 2008 the government published a cross party National Strategy for carers (HM Government, 2008). The strategy stated that by 2018 (p16):

- Carers would be respected as expert care partners and have access to the integrated and personalised services they need to support them in their caring role
- Carers would be able to have a life of their own alongside their caring role
- Carers would be supported so that they were not forced into financial hardship by their caring role
- Carers would be supported to stay mentally and physically well and treated with dignity

Evidence that the aims of the strategy have not been fully achieved can be found by reading the 2018 State of Caring Report (Carers UK, 2018). Every year Carers UK carries out an annual survey of carers to understand the state of caring in the UK. In 2018 a total of 7,397 people shared their experience of what it's like to be a carer. Of respondents to the state of caring survey 47% were caring for 90 or more hours every week, while 16% cared for 50-89 hours, 24% for 20-49 hours and 5% cared for 1-19 hours a week. 63% of carers were aged 45-64; 78% identified as female and

20% identified as male; 38% were in paid work (Carers UK, 2018). Compared to the carer population as a whole, respondents to this survey were more likely to be female and caring for a high number of hours every week.

Other key findings from the survey (Carers UK, 2018) focus on the health implications of caring with 72% of carers stating they had suffered mental ill health because of caring and 61% of carers stating they had suffered physical ill-health because of caring. The financial implications of caring were also highlighted as 37% of carers described their financial situation as 'struggling to make ends meet' and 35% of carers reported that they had given up work to provide care. In summary, 50% of carers said they expected their quality of life to get worse in the next 12 months and only 43% said their ability and willingness to provide care was thoroughly considered and reflected in the support they receive.

In recognition that the 2008 Carers Strategy has not achieved all the aims the Government has recently published The Carers Action Plan 2018-2020 (DH, 2018). The action plan outlines the cross-government programme of work to support carers in England over the next two years and identifies four key themes in relation to adult carers:

- services and systems that work for and involve carers
- flexible working practices for carers
- recognising and supporting carers in the wider community and society
- building research and evidence to improve outcomes for carers

There is increasing recognition that a sustainable social care system for the future is not possible without focusing on how our society supports carers. The action plan puts a focus on current support for carers ahead of the forthcoming Green paper on social care which the Government states will put carers at the centre (Hunt, 2018).

Ultimately though government policy is only one part of the jigsaw required to support carers. There is a need for local communities to recognise and value the contribution carers make. In the 2015 Carers UK State of Caring report half of the carers said they felt society did not think about them at all. Exploring this hidden world of carers is one of the aims of this thesis (Carers UK, 2015).

1.3 Carers' Centres in Context

The birth of the welfare state and the 1948 National Assistance Act created a system of open-ended financial commitment and a population who were 'entitled' to support (Wanless, 2006, p11). The Act set out in broad terms the responsibilities of local authorities which focused on the provision of residential (institutional) provision. However, during the 1950s there was a move to support older people to remain in their own homes for as long as possible, driven in part by concerns to reduce financial pressures on state provision (Townsend 1964).

The Community Care reforms in the early 1990s built upon the need to reduce the pressure on state provision. The reforms changed the function of local authorities

from the ‘providers of care’ to the ‘co-ordinators of care’. The reforms meant that support was restricted to those most in need and as a result low level, preventative support was withdrawn and one of the consequences was an increase in care delivered not by paid and trained workers, but by family members and friends – those whom we now call carers (Wanless, 2006, p14; Carers Trust, 2019a). Furthermore, the reforms did not create any legal obligation for local authorities to assess the needs of informal carers alongside those in need of care. The Carers (Recognition and Services) Act which introduced the right for carers providing regular and substantial amounts of care to request an assessment of their needs was not enacted until 1995.

In 1991, to fill the gap in support for carers the Princess Royal Trust for Carers was established. The Trust acknowledged that all carers required information, support and recognition of their individual needs and they developed a model of service provision throughout the UK. This network of carers’ centres were funded for three years (one third by The Princess Royal Trust for Carers and two thirds by local statutory services who undertook to take over The Princess Royal Trust for Carers’ funding at the end of the three year period).

Most of these carers’ centres were established as independent charities. The management committee of each carers’ centre was comprised mainly of carers, although the manager and staff were largely professional care workers (Carers Trust, 2019a).

This network of carers' centres have continued to operate as independent local charities commissioned by local authorities across the UK. Carers’ centres tend to provide the following types of support (Carers Trust, 2019b):

- information and advice – on things like benefits, respite and support services, advocacy, carers' assessments, aids and adaptions
- emotional support – carers can talk with trained staff, volunteers and other carers who understand their situation
- community consultation – by giving carers a unified voice to have an impact on local, regional and national decision-making
- activities – including time out from caring, breaks, relaxation therapies, and the opportunity to enjoy their own social life

Carers' centres have also provided training on a range of subjects such as finding your way around the care system; dealing with challenging behaviour and financial planning. Some carers’ centres have also provided domiciliary care services aimed at supporting carers to have a break from caring.

Increasingly though statutory funding from local authorities has reduced. For most carers’ centres funding from local authorities has been their only (or at least main) source of income and reduced funding has left carers’ centres trying to fundraise to finance the level of support they have previously provided. With reduced funding many carers’ centres (including the ones involved in this research) report that they have needed to reduce the support they can offer to simply information and advice via their website or over the phone.

1.4 Resilience in Context

In recent years, a solution to reducing the demand on state funding has been an increasing focus by national and local government on developing the **personal resilience** of people in need of care and support and their carers. The Care Act (2014) Guidance has a section 'Developing resilience and promoting individual strength' that clearly states:

'Co-production is when an individual influences the support and services received, or when groups of people get together to influence the way that services are designed, commissioned and delivered. Such interventions can contribute to developing individual resilience and help promote self-reliance and independence…...' (Care Act (2014) Guidance, section 2.20)

Local authority Carers' Strategies often refer to developing the personal resilience of carers as one of their strategic aims:

'Our aims for carers are based on three outcomes we want for all carers:

- *Informed and empowered*
- *Individually resilient*
- *Providers of good quality care'*

(Barnsley Metropolitan Borough Council, 2017 p7)

'We need to support families to become better equipped to solve their own problems and address the challenges they face. We need to develop our role as a facilitator, so that more of what we do enables families to make positive changes themselves that ultimately make them stronger together and more resilient'. (Leeds City Council, 2015, p26)

Current policies infer that the problem lies with carers themselves and their lack of resilience. It is implied that carers could solve their own problems (and hence need less state funded support) if they were more resilient. The words 'resilience' and 'resilient' are frequently used but there is no agreed definition among government agencies and it appears there is a lack of informed understanding among policy makers that resilience does not only depend on individual attributes, but also on the socio-environmental context within which people exist. Much of the research on resilience has focused on identifying factors in the family, person and environment that either put people at risk, e.g. low income, or are protective factors, e.g. supportive families (Fraser and Pakenham 2008; Gilgun et al 2000; Masten 2001).

Masten, Best and Garmezy (1990) defined resilience as 'the process of, capacity for, or outcome of successful adaptation despite challenging or threatening circumstances (p426). Informal caring provided by carers is often viewed as a challenge and even a form of adversity (Cohen et al, 2011) with many carers reporting high levels of stress as a central part of the carer experience (Grant and Whittell 2000; Walden et al 2000; Emerson et al 2004). Maybe it is this

conceptualisation of caring that has led local authorities to the conclusion that the solution is to focus on increasing carer resilience.

Given that local authority carers' strategies often refer to enhancing the resilience of carers, and that the main support commissioned by local authorities to support carers are carers' centres there is an implied assumption that carers' centres improve the resilience of carers. Yet the systematic application of existing knowledge about resilience to carers' centres seems to be almost non-existent. Indeed there is a distinct tension between the assumptions implied by local authorities in their commissioning strategies and the role carers centres have traditionally played. The tension seems to spring from the tension between the concept of resilience as an individual characteristic versus a wider more situated context.

Literature on resilience-based interventions identify that the key aim is to enhance resilience either by identifying and using the resources available to the individual (Cohen at el, 2011; Li et al 2012), or by improving psychological wellbeing via emotion focused interventions (Bond and Bunce 2000; Karreman and Vingerhoets 2012). A look at prevention programs suggests that few are based on resilience theory or are specifically designed to increase the resilience of carers (Bartley et al 2012). Of the interventions that do attempt to do this, few have been evaluated in terms of the outcomes they achieve, the costs of implementing them (Emerson et al 2011) or the savings they make for the state. It seems therefore, that the assumption made by commissioners that reducing demand on state funding can be achieved by increasing the resilience of carers and that carers' centres as the main intervention will be achieving this is an assumption worth testing.

1.5 The methodology in context

This thesis is a grounded theory study made up of three parts. Part One of the study consists of a narrative literature review and three sets of focus groups to ascertain the experience of carers and develop a definition of resilience for carers. Part Two of the study uses a narrative literature review and workshop methodology to develop a model of support for carer resilience (as defined by carers). Part Three of the study undertakes a scoping review that evaluates the degree to which the services delivered by two carers' centres (both commissioned by their local authorities to improve the resilience of carers) fit the model of support carers said would help them to maintain or improve their resilience. Part Three explores whether the scoping review highlights the need for a more comprehensive evaluative research study and what might be involved in such a study.

- **Part One**
  - Chapter 2: Narrative review of the literature on the emotions and quality of life outcomes experienced by carers.
  - Chapter 3: Methodology for the first three studies is explained.
  - Chapter 4: First set of focus groups with carers living with their loved ones. The focus groups explored the emotions and quality of life outcomes of carers across all care groups and relationships and carers' views of resilience.

- Chapter 5: Second set of focus groups with carers whose loved ones had recently moved into a full-time care setting. The focus groups explored the emotions and quality of life outcomes of carers across all care groups and relationships and carers' views of resilience.
- Chapter 6: Third set of focus groups with a mixed group of carers including two former carers. The focus group tested for data saturation.

- **Part Two**
  - Chapter 7: Narrative literature review on how current definitions, concepts and models of resilience relate to carers.
  - Chapter 8: Empirical study to develop a model of support for carer resilience.
- **Part Three**
  - Chapter 9: Introduction to the scoping review and description of the two carers centres.
  - Chapter 10: Empirical study to evaluate the impact and cost of two carers' centres – the carer perspective.
  - Chapter 11: Empirical study to evaluate the impact and cost of two carers' centres – the carers' centre perspective.
  - Chapter 12: Final model of support for promoting carer resilience and reflections on whether a more comprehensive evaluation of carers' centres is required.

1.5.1 A qualitative approach

'Quantification' means to measure on some numerical basis. Counting things, quantifies them. Putting things into categories is a precursor to counting them. Quantitative research involves measuring things in a numerical way, counting or categorising them. In contrast qualitative research emphasises meanings and experiences (Coolican, 1999, p41). It often refers to research about people's lives, lived experiences, behaviours and emotions (Strauss and Corbin, 1990, p11). Qualitative research is a naturalistic, interpretative approach concerned with understanding people's social worlds (Bryman, 1988, p5).

The reason for choosing a largely qualitative approach is due to the nature of the research that aims to understand the social reality of carers and the way in which they interpret their reality. Understanding this requires the researcher to gather data on the lived experiences, behaviours and emotions of carers.

A second reason for choosing a largely qualitative approach is because the topic is a potentially sensitive area about which little is known. Exploring an unknown social reality that may prove sensitive lends itself to qualitative data collection techniques of focus groups and interviews and qualitative data analysis techniques such as grounded theory and situational analysis (Ritchie, 2003, p.37).

It should be noted that quantitative methods have been used where appropriate (e.g. around costings in part 3). This is described further in section 1.5.5.

1.5.2 Grounded Theory

The research method selected in any study should be driven by the research questions relevant to the topic and meet the needs and skills of the researcher (Maxwell, 2005, p229). There are a range of qualitative research designs the researcher could have chosen and the main aim of these designs are compared in the table below:

Table 1: Comparison of qualitative research methods

Narrative Research	**Phenomenology**	**Ethnography**	**Case study**	**Grounded Theory**
Needing to tell stories of individual experiences	Needing to describe the essence of a lived phenomenon	Describing and interpreting the shared patterns of culture of a group	Providing an in-depth understanding of a case or cases	Grounding a theory in the views of participants

(Creswell, 2014, p104).

Answering the research questions for this study required a research approach that didn't just describe the experiences of carers but produced a theory of carer resilience. The only qualitative research design that generates an actual theory is grounded theory and hence a grounded theory approach was the design best suited to this research.

The grounded theorist aims to enter the participants' lives to see it from inside which eventually illuminates the "unobtainable views" (Charmaz, 2006, p. 24). Grounded theory offers a practical and flexible approach to interpret complex social concepts (Charmaz, 2003, p250). It is a way of collecting rich data. The nature of grounded theory reflects the aim of the researcher and her attempt to understand the hidden world of being a carer. Grounded theory is therefore a relevant method for the topic and research aims.

Although grounded theory is "a member of the family of qualitative research approaches" (Glaser, 1998, p. 38), it differs from other qualitative research methods in that it does not only provide meaning, understanding and description of the concept under study, it also generates theory (Glaser 1978, p2). It is important to note that a theory is not an "absolute truth" but rather a statement regarding possible relationships among categories about a concept that facilitates the comprehension of a social world (El Hussein et al, 2014). Put simply, the fact that it explains or predicts something makes it a theory (Strauss and Corbin, 1990, p12). The theory evolves during the research process itself and is a product of continuous interplay between data collection and analysis of that data (Goulding, 2002, p.115). The results of a grounded theory study are expressed as a substantive theory, that is, as a set of concepts that are related to one another in a cohesive whole. As in most science, this theory is fallible, dependent on context and never completely final (Connor, 2012, p260).

Grounded theory meets the needs of this study because the study aims to discover whether there are any consistent themes for carers across all care groups and relationships, what a model of resilience for carers might be, and how carers' centres might improve or maintain the resilience of carers. These concepts have not previously been explored and hence there is potential for a new theory to emerge. Grounded theory encourages the researcher to avoid preconceived theories and instead to move through a process of discovery thus allowing for the emergence of original findings (Jones et al, 2005). The fact that grounded theory emphasises induction, means that there is a very open approach to the concept being studied which results in the emphasis of the study evolving as it becomes apparent to the researcher what is important to the participants.

Grounded theory was created from the 'constant comparative' method, developed by Glaser and Strauss, which alternated theory building with comparison of theory to the reality unveiled through data collection and analysis. One of the key strengths of grounded theory is its systematic approach to data analysis. This systematic approach of analysing data is beneficial in judging, generalising and comparing the results of grounded theory research (Strauss and Corbin, 1990, p13). This meant it was possible to compare the analysis across all three parts of this study and meant it was comparable with the data that had been collected in previous studies.

Theoretical sensitivity is an important skill, necessary for successfully using grounded theory. It allows the researcher to have insight into the data. It is this insight that enables the researcher to comprehend and interpret the data in a meaningful way without bias or forcing predetermined explanations. Theoretical sensitivity occurs through immersion in the data, the researcher's prior professional and personal knowledge and experiences and the researcher's ability to reflect (Strauss and Corbin, 1998, p278; Charmaz, 2006, p25). Being reflective keeps the researcher engaged and interacting with data and the emerging idea rather than taking a distanced view that can result in the researcher making assumptions that lead to forced conclusions (Charmaz, 2006, p26). In this case the researcher has theoretical sensitivity because she has conducted all the focus groups, read a wide range of studies, has worked in a professional capacity with many carers over the years and has engaged in the systematic process of open, axial and selective coding which requires reflective thinking and elicits theoretical sensitivity. Hence, grounded theory fits the skills of the researcher.

1.5.3 Narrative literature reviews

A literature review summarises published research on a topic by examining and critically analysing different sources of research. In this way a literature review provides a comprehensive overview of the topic. A literature review may be argumentative, integrative, historical, methodological, systematic, or theoretical, and these approaches may be adopted depending upon the methodology of the study.

The two types of literature review most commonly found are systematic and narrative reviews:

- A systematic literature review is a review of the evidence on a clearly formulated question that uses systematic and explicit methods to identify, select and critically appraise relevant primary research, and to extract and analyse data from the

studies that are included in the review. Systematic reviews list the types of databases and methodological approaches used to conduct the review and the evaluation criteria for inclusion of retrieved articles during database searches.

- A narrative literature review is a comprehensive, critical and objective analysis of the current knowledge on a topic. Narrative reviews are an essential part of a qualitative approach that helps to establish a focus or context for the research. A narrative review aims to identify patterns and gaps in the literature which results in a focused research question.

Systematic reviews provide specific answers to specific questions. Whilst robust and rigorous, the methodology is not aligned to a grounded theory study and for this reason the researcher undertook narrative reviews.

The timing of the literature review in grounded theory studies has been debated for decades, and traditionally grounded theory encourages the researcher to avoid preconceived theories and instead to move through a process of discovery thus allowing for the emergence of original findings (Jones et al, 2005). Glaser (1978) stressed the importance of avoiding preconceptions and remaining open-minded to what appears in the research field. He argued that a literature review should *not* be undertaken before the data collection. However, this is problematic as a literature review is usually requested when researchers apply for ethical permission to conduct a study. This was the case for the researcher on this occasion.

Fortunately, there is increasing evidence that suggests an initial literature review can enhance theoretical sensitivity and rigor and may lead to innovative insights (Giles et al, 2013). Giles argues that a narrative literature review at the start of a grounded theory study can enhance the research by ensuring that preconceptions are well grounded in evidence. This is in line with the view of Glaser (1998) when advocating that some preliminary reading before the study begins can be a useful way of putting the study into context. Any preconceptions must be subject to critical analysis throughout the study though and so the literature review must be used reflexively (Giles et al, 2013). In a constructivist grounded theory model, reflexivity does not aim to eliminate the researcher's subjectivity from the resulting theory, but to allow the data to be prioritized over the researcher's assumptions and previously acquired knowledge, including any reviewed literature (Charmaz, 1990). The idea is not to disregard existing knowledge, but to engage with it critically (Thornberg, 2012). It is for these reasons that a narrative review was undertaken at the beginning of Part One and Two on the two key topics of ‘Carers’ and ‘Resilience’ that this thesis explores. More information on how the narrative literature reviews were undertaken can be found in the methods chapter (chapter 3).

1.5.4 Focus groups

A focus group may be defined as ‘a group of individuals selected by researchers to discuss and comment on, from personal experience, the topic that has been a subject of the research’ (Powell and Single,1996 p. 499). Focus groups enable the researcher to study attitudes and experiences; to explore how opinion is constructed (Kitzinger, 1995) and to understand behaviours, values and feelings, (Patton, 2002, p477). The focus group method was therefore chosen for this study because it

allowed access to the views and experiences of the participants which helped the researcher understand the 'world of the carer'.

Focus groups allow the researcher to gather several perspectives on the same issue in a relatively short amount of time (Powell and Single,1996). The group setting enables the participants to build on the responses and ideas of the others, which increases the richness of the information gained. Instead of the group interview approach of asking each person to respond to a question in turn, in focus groups people are encouraged to talk to one another, ask each other questions, exchange stories and comment on each other's experiences and points of view.

Focus groups use the group interaction as part of the method which allows the researcher to gain insights that would not have occurred without the discussion taking place (Berg, 1998, p172). As the discussion progresses the individual responses of participants become honed and move to a deeper and more considered level. The overarching result of a collective discussion is that it can lead to a larger number of ideas or more sophisticated issues being raised and discussed (Finch and Lewis, 2003, p171). Such qualitative description is important when studying concepts that are unknown or have become stereotyped and is a useful way of exploring a topic in depth.

In a focus group the researcher acts as the facilitator. This is a demanding role and Gibbs (1997) identifies that facilitators will need to 'possess good interpersonal skills and personal qualities, be good listeners, non-judgmental and adaptable' (p5). The emergent nature of focus groups allows the researcher to probe issues as they arise. There is a risk that the group can exert pressure on individuals to 'agree' to the 'group' view or experience. The researcher must mitigate against this by asking questions such as 'who has a different experience?' The researcher can use the group process to encourage open, interactive discussion, but must also control it to prevent one view or person dominating the discussion. The skill of the facilitator is crucial in enabling the participants to engage in high quality dialogue centred on the topic. The researcher in this case is a trained facilitator and has almost fifteen years of experience of facilitating a wide variety of groups including focus groups for the purposes of research.

By their very nature focus groups provide the opportunity for peer support and when facilitated well, focus groups can create a safe space in which to discuss difficult issues. Bringing a homogeneous group together (in this case a group of carers) provides a stronger social context which offers an opportunity to see how ideas and language emerge in a more naturalistic setting than an in-depth interview (Bloor et al, 2001, p21).

1.5.5 Scoping Review

It was important that the knowledge of how resilience relates to carers was applied to carers' centres, as they are currently the main service commissioned by local authorities to support carers and as stated in many local authority Carers' Strategies one of the commissioning aims is to develop resilient carers. The scoping review in part three of this thesis aimed to test whether two carers' centres did improve or maintain the resilience of carers' using an evaluation tool developed by carers and carer support workers in part one and two of this study. The scoping review aimed to

undertake detailed evaluative research into whether the carers' centres, as they are currently commissioned, promoted resilience and whether the cost of the centres justifies the outcomes achieved. Memo writing and situational analysis was used throughout the evaluative research which helped to refine the theory further and enabled a discussion as to whether there was merit in undertaking a more comprehensive evaluation of carers' centres in the future.

Evaluative research emerged in the1960s and since then has become an increasingly legitimate methodology within social sciences (Stern, 2005, p3). The generic goal of most evaluative research is to provide "useful feedback" to a variety of stakeholders. Most often, feedback is perceived as "useful" if it aids in decision-making. At the service level, evaluative research allows service managers to: understand the nuances of a service, inform and make necessary changes, and communicate this information to stakeholders (Danseco, 2013; Suárez-Herrera et al, 2009; Roe and Roe, 2004).

At a more strategic level, one of the key functions of evaluative research is to build a stronger knowledge base for policy making (Olenjniczak, et al, 2016). In principle, evaluative research results should support a decision-making process by providing useful insight into public problems, possible change mechanisms and the fit with policy (Stern, 2002; Powell, 2006). In an environment of limited resources, evaluative research is an essential part of making informed decisions on funding (Carman, 2013). For this reason, commissioners of social care are using evaluative research more and more to aid them in deciding which services to invest in and which to cut.

Evaluative research activities are diverse, but have historically dealt with cost analysis, process evaluation, performance measurement, impact/outcomes assessment and organisational effectiveness (Ayob and Morell, 2016). Evaluative research sits at the intersection between research, evidence-based practice, the decision-making process and organisational change. It is a process of systematically collecting information in a manner that combines robust research methodology with sensitivity to political context and the points of view of multiple stakeholders (Trochim and Donnelly, 2001, p30). Rigor in evaluative research does not just reside in robust methodological design but also in matching an evaluation design to the knowledge needs of the decision-making stakeholders (Olenjniczak, et al, 2016).

The knowledge needs of the stakeholders in this scenario are:

- Carers need to know the support they are offered is good quality and will help
- Carers' centre managers need to know what impact their support has on carers
- Commissioners need to understand the costs and benefits of carers' centres so that they can decide whether to keep investing in them
- Policy makers need to know what works and how to deliver it effectively and efficiently.

The scoping review of two carers' centres contained within this thesis aimed to meet these knowledge needs and in so doing influence informed decision making. A useful definition of evaluation provided by Stufflebeam and Coryn (2014) states that:

'evaluation is the assessment of the merit and/or worth of a program or some other object' (p679). For Stufflebeam and Coryn 'merit' equates to 'outcomes' for people using the service and 'worth' is the cost effectiveness in meeting the needs of both the customers and the needs of the commissioners. A positive finding from an evaluation of a service should evidence that the service has excellent potential to meet the needs of the customers (in this case, carers) at a reasonable cost.

Evaluative research has some commonalities with grounded theory in that the process of evaluative research is dependent on the wisdom that the evaluative researcher brings based on their awareness and understanding of existing knowledge and their previous experience (Stufflebeam and Coryn, 2014, p8). This enables the evaluative researcher to draw out the learning and make recommendations.

Evaluative research provides a reliable, justified, logical basis for determining bad services or, conversely, expanding good services. Evaluative research is an important tool to assist organisations to test new ideas and learn what does and does not work (Norton et al, 2016). The production and appropriate use of rigorous evaluative research is a fundamental part of developing good quality services and societal progress. The evaluative research in this thesis therefore used a mixed methods approach which had several advantages (Creswell, 2014, p267):

- Collecting both qualitative alongside quantitative data ensured that the study findings were grounded in the voices of carers and their experiences.
- Integrating the qualitative and quantitative data provided insight into contradictions between quantitative results and qualitative findings.
- Using a mixed methods approach offered greater flexibility in terms of the research design and created opportunities to collect data using standardised measures and observations alongside interviews.

One of the primary audiences for this research are commissioners and policy makers. In times of austerity commissioners are asked to make increasingly difficult decisions about which services to fund and which to cut. Significant reductions to local authority funding has resulted in hard choices being an everyday reality for commissioners (Robertson et al, 2019). The context of austerity coupled with increasing need, inequality and poverty means that assessing return-on-investment is also a critical everyday occurrence for commissioners wanting to make informed decisions (New Economy, 2016). Furthermore, a change of approach to economic evaluation by NICE in recent times has placed more emphasis on cost–benefit analysis because it provides a single "currency" for measuring the impact of interventions on health and it allows comparisons of interventions in healthcare to allow the efficient allocation of resources (NICE, 2012).

For these reasons cost analysis was used to enhance the usefulness of the scoping review design for commissioners. However, a full cost-benefit analysis is a huge undertaking and not one the researcher had the resources to do. Therefore for the purposes of this scoping review the cost analysis involved a set of procedures that commissioners use and would find useful and which would help to ascertain the need

for a full cost-benefit analysis in the future. As with the rest of the scoping review (and any evaluative research) the cost analysis aimed to answer the questions of stakeholders. Firstly, carers want to know what economic investment local authorities are making in support for carers given the huge economic contribution carers make (Buckner and Yeandle, 2015)? This was explored by calculating the economic contribution of carers and comparing it to the investment made by the local authority.

Secondly commissioners want to know whether the intervention (in this case carers' centres) results in fiscal benefits i.e. savings to their budgets. This was explored by using the information contained in the 'Supporting public service transformation: cost benefit analysis guidance for local partnerships' (New Economy et al, 2014) and applying it to the number of carers who stated that they would be unable to continue caring without support from the carers' centre.

Finally, policy makers want to know what the investment achieved in terms of outcomes for carers and the broader economic and social benefits for society (Stufflebeam and Coryn, 2014, p152). To answer this question robustly would require a full cost-benefit analysis and this was not possible within this scoping review. However, the scoping review in part three of this thesis used the model of resilience that was developed with carers through the first two parts of the research, to evaluate carers' centres and the impact they had on carer resilience at what cost and to ascertain whether there was merit in undertaking a more comprehensive evaluative research study.

1.5.6 NVivo

Given the innovations in software technology, electronic techniques of data coding are gradually being employed in dealing with qualitative data. Using software in the data analysis process has been thought by some to add rigour to qualitative research (Richards and Richards, 1991, p40). The software package NVivo is relatively simple to use, is based on grounded theory approaches to data analysis and is seen by many as the best software package to use when analysing qualitative data (Hilal and Alabri, 2013).

Clearly, the use of electronic software greatly reduces manual tasks, for example the electronic coding process is much quicker compared to cutting and pasting pieces of text manually. It is argued that this efficiency gives the researcher more time to discover tendencies, recognise themes and derive conclusions from the data. It is possible that more coding will take place because it is quicker to do. Yet it is not necessarily the case that this additional coding contributes much to an understanding of the data. Instead there is a risk that it may make the researcher feel as though she is being more rigorous and transparent than would be the case using manual methods, and hence data are interpreted more confidently (Welsh, 2002).

Bazeley (2007,p6-15) mentions five important tasks through which NVivo eases the analysis of qualitative data. These include:

- Managing data: organizing several muddled data documents including: interview transcripts, surveys, notes of observations and published documents.

- Managing ideas: to understand the conceptual and theoretical issues generated during the study.
- Querying data: posing several questions of the data and utilizing the software in answering these queries. 'Results of queries are saved to allow further interrogation and so querying or searching becomes part of an ongoing enquiry process'.
- Modelling visually: creating graphs to demonstrate the relationships between the conceptual and theoretical data.
- Reporting: utilizing the data collected and the result found to formulate transcript reports about the study conducted.

NVivo is a good tool for organising data and helping the researcher to make sense of it during the process of analysis. In their study of qualitative researchers who had used data analysis software, Smith and Hesse-Biber (1996) found that it was used mainly as an organising tool. Research by Salmona and Kaczynski (2016) on the use of software in doctoral research identified that the use of software still requires a competent foundation in qualitative research. This adds weight to the idea that NVivo should be used as a data management tool, NOT a method of analysis and that it still requires the researcher to understand and apply valid and robust analysis techniques.

NVivo does speed up the process of coding and it may also limit researcher errors. However, for the researcher to succeed in generating a theory she needs to have an overview of what she is trying to produce (Welsh, 2002). For example, when it comes to interrogating text in detail Brown et al (1990) suggest that electronic searching techniques need to be coupled with manual scrutiny techniques so that the data are thoroughly interrogated and incidents where participants express similar ideas in completely different ways are identified.

Identifying themes across a data set requires the analysis of multiple codes. This can only really be done if the data is organised and sorted properly. The NVivo software makes the organisation of the data into themes and the retrieval of such data quicker and more efficient (Spencer et al, 2003, p. 209).

Based on the advantages of time and efficiency and the potential for seeing links across the data set, Nvivo was deemed a suitable and useful tool for this study.

1.5.7 Situational analysis

The situational analysis approach is a development from grounded theory, where the open coding process is recognised as a basis for constructing analytical situational maps that consider the complexity of the situation of enquiry (Clarke, 2005, p.84). Situational analysis moves reflective thinking beyond the focus of human interactions to the non-human. Situational analysis provides the methodological framework to reflect on the symbolic interactionism of the non-human objects in our world which have become increasingly significant in recent times (Clarke, 2005, p.87). Such objects include technologies, media, benefits, care homes, social services, etc. Given the links between resilience and the environment/context within which one exists the researcher felt it was important to enhance the grounded theory approach

by using the methodological framework of situational analysis to guide her reflection on the non-human elements of the carers' environments.

1.6 The researcher in context

The interpretive nature of grounded theory and situational analysis means that it is important that the researcher is aware of and mitigates against her own bias. Any bias will be a result of the researcher's previous experience and knowledge and so it is important to reflect upon this to bring to the surface any potential bias.

I started my career as a paid carer working with people with learning disabilities and autism in residential homes. In this context I had contact with many carers but at no point during this time did I receive any training or awareness raising of the emotional journey of parent carers and I realise now I had sympathy but not a lot of empathy. The mix of emotions that parent carers were probably feeling resulted in a variety of behaviours that ranged from parent carers who chose to have limited contact to others who were heavily involved and some who were heavily critical of the care their adult child was receiving. There was a culture of them (parent carers) and us (staff) in all the homes I worked in during that time.

There is a danger that I approach any support service having already decided that frontline staff lack a good understanding or empathy for carers and hence do not do a good job of supporting them. But my frontline paid carer experience was 20 years ago so it is possible that services have moved on. Furthermore, I did not work in a carers' centre and I cannot assume that the staff who do, do not receive training that raise awareness of the challenges that carers face.

For the past ten years my work has focused on the strategic level of commissioning. In this capacity I often support local authorities to engage with and preferably coproduce solutions with people using social care services and their families. As part of this work I have written several national guidance documents for Wales that include my work on carer resilience and the model described later in this thesis. Increasingly I find myself slightly jaded by the complex, bureaucratic and hugely underfunded council systems I work with. There is a danger that I could overemphasise the negative aspects of current arrangements between carers' centres and councils as a result. I am at risk of making assumptions and drawing subjective conclusions based on my experiences of working with policymakers, commissioners and service managers so it will be important to ensure that I view the data objectively.

In my private life I have observed and supported my sister through her journey as a parent carer to her eldest child who has physical and learning disabilities. I have also been on my own journey to understanding the complex relationship between wife and carer as my husband lives with anxiety and depression. There is a risk that I could overstate all the themes that resonate with my sister and I and underplay others. Added to this there is a risk that I explore factors that I'm interested in due to my circumstances or draw conclusions that work for my situation rather than staying objective and true to the data.

Mitigating these risks has required a robust methodology, careful coding and analysis, continuous reflection and critical feedback from others including my supervisors, stakeholders involved in the research and other academics in the research community.

Part One

2 Chapter 2: What are the emotions and quality of life outcomes that carers experience?

This chapter aims to build on previous literature by exploring whether there are commonalities across care groups and relationships. It could be argued that a lot is already known about the emotions and quality of life outcomes for carers. Research has tended to focus on groups of carers in silo and their differences. Little attention has been paid to whether there are commonalities even though the way that services are commissioned and policy is written assumes that there are. These assumptions about commonality across carers that have so heavily influenced commissioning and policy mean that if society is to take a positive step forward in carers' rights and if this is to be effectively translated in both policy and practice, there is a need to identify whether there are commonalities and how abundantly these commonalities manifest across care groups (e.g. MS, dementia, mental health illness, etc) and relationships (e.g. spouse, parent, sibling, etc).

In this chapter the concept of emotions and quality of life outcomes for carers across care groups and relationships are explored. Definitions, models and frameworks that have been used to describe emotions and quality of life outcomes are identified and discussed. The specific emotions and quality of life outcomes of carers are investigated across care groups and conclusions about the mixture of positive and negative emotions and quality of life outcomes are drawn. Factors that predict positive and negative emotions and outcomes are reviewed and models that illustrate coping mechanisms are outlined. Finally, attention to the usefulness of models of grief and oppression in understanding the emotions and outcomes for carers across care groups and relationships are highlighted.

2.1 Defining emotions

Currently, the research literature does not present a consensus on a definition of the word "emotion," and the present data suggest that it is not easily defined as a unitary concept (Izard, 2010). Kleinginna and Kleinginna (1981) describe emotion as a result of multifaceted interactions between subjective and objective feedback, interceded by hormones.

Most contemporary approaches consider emotions to consist of multiple components (Kuppens et al, 2009). The idea that emotions are fixed, innate entities within the person that switch on, last for a while unaltered, and then switch off again (Ekman 1985) has largely been replaced with theories that suggest emotions are highly changeable, vary over time, over situations, and across people (Barrett, 2009).

Williams and Penman (2011) define emotions as being:

'.....like a background colour that's created when your mind fuses together all of your thoughts, feelings, impulses and bodily sensations to conjure up an overall guiding theme or state of mind' (Williams and Penman, 2011 p.19).

Psychologically speaking, emotions are a large part of what makes a person unique. People have different genetic qualities and are exposed to different experiences, relationships, and life events. Research suggests that emotional variability exists due to differences in social factors, underlying cognitive and physiological processes and differences in how individuals appraise situations (Larsen et al, 2009).

Our individual history results in each of us experiencing a unique emotional life (Kuppens et al, 2009). Very few people would deny the variety in emotional life (Barrett, 2009) for example the sadness a person might experience when leaving a job is unlikely to be the same as the sadness they would feel if they lost a child. The sadness they would feel might not be experienced in the same way by the other parent, and some people will never experience these feelings of sadness at all. Morris (1992) argued that emotions provide information about environmental challenges (e.g., sadness signals the loss of something important, anxiety signals an impending threat) and moods provide information about our resources for meeting those challenges (e.g. tiredness and fatigue signal a lack of energy to meet challenges).

It is clear from the research that "emotion" influences thinking, decision-making, actions, social relationships, wellbeing, and physical and mental health (Izard, 2010). Understanding the range of emotions carers experience and the uniqueness of their emotional lives is important when trying to identify approaches that might increase the resources and resilience carers must have to meet the challenges they face. Understanding whether these emotions differ across care groups or relationships or whether there are commonalities is also important when it comes to thinking of carers as 'one group' for the purposes of policy setting and commissioning services.

2.2 Defining quality of life outcomes?

There is broad acceptance that quality of life (QoL) is a universal, multidimensional concept. Definitions of health-related QoL overlap with those of broader health status, and include physical and mental health/wellbeing. Broader QoL incorporates more than physical and mental health; it is more multidimensional than health-related or disease-specific QoL, and is relevant when examining the whole person, and also in evaluating interventions or conditions that can affect one's whole life (Bowling, 2005).

In general, there is a lack of consensus among researchers regarding a universal definition of QoL (Carr et al. 1996; Schalock 2000; Haraldstad et al, 2019) but there is considerable common ground amongst authors on the domains used to categorise aspects of people's QoL. Felce (1997) describes six QoL domains:

- Physical Wellbeing: health, nutrition, mobility, fitness, safety, etc.
- Material Wellbeing: housing, environment, wealth, transport, etc.
- Social Wellbeing: interpersonal relationships, community involvement, social roles, etc.
- Productive Wellbeing: personal development, competence, self-determination, constructive activity, etc.
- Emotional Wellbeing: happiness, self-esteem, contentment, sexuality, spirituality etc.

- Civic Wellbeing: privacy, protection under the law, civic duties etc.

There is also agreement amongst authors that there are two types of QoL: objective and subjective (Cummins 1997; Diener & Suh 1997). Objective QoL is determined by measures such as income, housing quality, physical health, etc. Subjective QoL is determined by asking how satisfied with their life in relation to the various QoL domains an individual is. It is this subjective measure of QoL that has gained increasing importance in recent years. According to the World Health Organization, QoL is defined as: *'an individual's unique perspective of their position in life, in relation to their culture and value structures, aspirations and expectations'* (The WHO QOL Group,1997, p1).

QoL frameworks have been a useful concept for policy and service development. In the past the key objectives outlined in policy and service specifications were about services, procedures, funding and agency responsibilities rather than consequences for people (Qureshi et al, 1998). In recent years there has been a move towards identifying the consequences for people and a focus on the individual's aspirations for their QoL (Dowling et al, 2006). This focus has resulted in a transformation in health and social care services that aims to put the person receiving support at the centre of service design and delivery (DH, 2007). It was quickly recognised that if the aim was to support people to reach their QoL aspirations then there was a need to measure the outcomes people who received support experienced. Policy documents and guidance tend to use the phrase 'outcomes' to mean 'QoL'. The audience for this thesis includes commissioners, policy makers and other researchers. To ensure that all audiences understand what is being referred to the term 'quality of life outcomes' is used.

Several outcome frameworks, based on QoL domains have been developed (DH, 2008; DH, 2012; CQC, 2010) and are used to articulate the vision for services and to measure the quality of service provision. One such framework specific to carers is the one outlined in The National Carers Strategy (2008). Five key QoL outcomes were identified:

- I am recognised and supported as an expert care partner
- I am enjoying a life outside caring
- I am not financially disadvantaged
- I am mentally and physically well and treated with dignity

And that:

- Children are thriving and protected from inappropriate caring roles

Recent social care policy has focused on supporting both carers and those they care for to achieve QoL outcomes which it has articulated as wellbeing. The Care Act (2014) uses the following categories to define wellbeing:

- personal dignity (including treatment of the individual with respect);
- physical and mental health and emotional wellbeing;
- protection from abuse and neglect;

- control by the individual over day-to-day life (including over care and support provided and the way it is provided);
- participation in work, education, training or recreation;
- social and economic wellbeing;
- domestic, family and personal relationships;
- suitability of living accommodation;
- the individual's contribution to society.

The Care Act (2014) gives carers the right to an assessment that aims to identify and facilitate access to the support carers feel they need to achieve a sense of wellbeing.

Whilst the wellbeing framework used in current policy does have commonalities with the QoL frameworks in the broader literature, there are also some tensions. The policy wellbeing framework may be a useful tool for encouraging local authorities to have a more holistic, person-centred conversation that is broader than 'what needs do you have, this is the service we can provide to meet those needs' the framework does not provide a way of measuring wellbeing. This is important because if the aim is to improve wellbeing then there needs to be an agreed, valid and robust way of measuring whether wellbeing has been improved both subjectively and objectively.

Recently some research has been undertaken on conceptualising and measuring the QoL of family carers. Daley et al (2018) found that for carers of people with dementia, the QoL construct included condition-specific domains which were not routinely considered in generic assessments of QoL. The resulting QoL framework included carers' perceptions of their relationship with and changes in the person with dementia, the caring situation, and the extent to which external factors outside the caring relationship were helpful or unhelpful. Brown et al (2019) built upon this research and developed an instrument to measure the QoL of family carers of people with dementia called the C-DEMQOL. The C-DEMQOL measures overall QoL and five subdomains: 'meeting personal needs'; 'carer wellbeing'; 'carer-patient relationship'; 'confidence in the future' and 'feeling supported'.

As with many commonly used measures of QoL, the C-DEMQOL focuses on the areas of life directly influenced by the situation and condition which in this case is caring and dementia. The instrument quantifies the carer's subjective perceptions about their experiences which is again a commonly used approach for measuring QoL. Subjective perceptions are of value, as overall QoL may be perceived differently by different people. However, the current lack of consensus on best measurement, and the diversity of approaches used, can be problematic for attempts to evaluate service outcomes and cost-effectiveness of interventions (Bowling et al, 2015).

The Adult Social Care Outcomes Framework (ASCOF) (DHSC, 2019) was designed to measure how well care and support services achieve the outcomes that matter most to people. The measures are grouped into four domains (quality of life, delaying and reducing the need for support (prevention), satisfaction with services, and safeguarding of vulnerable adults) which are typically reviewed in terms of movement over time. It is an attempt to evaluate the difference 'social care interventions' make to the lives of users and carers rather than capturing QoL more broadly.

This type of outcome assessment is important for commissioning cost-effective health and social care support services and pathways. However, where a condition can affect life overall, broader QoL measurement is required (Bowling et al, 2015). QoL is a subjective concept, and thus measures require the participation of the population concerned in their development. Few researchers have developed their measures truly 'bottom-up' with the population of interest, and tend to focus on 'expert opinions'. Thus, most measures have unknown social relevance, and there is no certainty about whether they are measuring the right things (Bowling et al, 2015).

2.3 Why explore the emotions and quality of life outcomes for carers?

Coming to terms with the caring role can reportedly be a long and painful process that is a huge emotional drain and requires a huge emotional adjustment (Gray et al, 2009). Yet the actual emotions and the QoL outcomes that carers experience remain, surprisingly relatively undocumented. There is an obvious connection between emotions and QoL when we consider that research on QoL describe it as a subjective concept. Subjectivity is based on or influenced by personal feelings and feelings are an expression of a person's emotional state.

Research that has explored the QoL outcomes and emotions that carers experience has tended to focus on carers caring for people with specific conditions. For example, research on carers caring for a loved one with multiple sclerosis or carers caring for a loved one with an eating disorder or carers caring for a loved one with dementia. Previously, there has been a focus on researching carers in silos because it has been believed that carers experience specific emotions, outcomes, and challenges related to the conditions of the people they care for. Yet, the assumption both in practice and in policy is that carers experience similar emotions, QoL outcomes, and challenges no matter the condition of the person they care for or the nature of their relationship with the person they care for. Therefore, it seems pertinent that research explores whether there are common themes across carers in relation to the emotions and QoL outcomes experienced.

It is known that providing support to carers and lowering their distress can empower them, enabling the family to serve as an important resource in treatment (Kyriacou et al 2008). To develop interventions aimed at decreasing carer distress the factors that are part of the caring experience, and that are possible to change must first be identified (Kyriacou et al, 2008). Taking a holistic approach to identifying factors that can be modified across care groups and relationships will result in interventions that are efficient, effective and produce sustainable, good QoL outcomes.

A holistic approach needs to consider not just the objective, visible QoL outcomes e.g. changes in physical health, financial status etc., and the subjective QoL perspective e.g. satisfaction with life outside of caring etc., but it must also consider the emotional dimensions of care (Seedhouse, 2000) which by their very nature are inextricably linked to QoL outcomes. The emotional dimensions of carers' lives must be considered within the context that research suggests many carers experience positive emotions as well as negative emotions in relation to their carer role (Pakenham, 2005a; Ulstein et al, 2008; Arksey, 2003). Experiencing a range of

emotions is human nature and carers often experience a mixture of emotions at any one time.

The ways in which professionals manage the varying, complex and sometimes conflicting emotions, presented by carers remains relatively unexplored (Gray et al, 2009). As does the link between emotions, QoL outcomes and resilience. This is important because resilience is something that policy documents suggest can be improved. As a result, one of the key commissioning aims of carers' centres is to improve resilience yet there seems to be little understanding of the links between resilience, QoL outcomes and the emotional and practical experience of caring.

2.4 The emotions and quality of life outcomes experienced by carers

Previous research has focused on the differences in the emotions and QoL outcomes experienced by carers. This is due to the fact that research on carers has tended to be undertaken in silos e.g. carers of people with MS, older carers, spousal carers, parent carers of disabled children, etc. Such studies have emphasised the specific issues that are relevant and common to the group being studied. Some of these studies do compare carers with non-carers but there are a lack of studies that compare different carer groups.
In reviewing the literature on the emotions and QoL outcomes experienced by carers for this thesis, studies across care groups and relationships were actively sought and the findings compared. The researcher compared both the differences and the commonalities across care groups and relationships. The comparison of studies identified a surprising multitude of commonality in the emotions and quality of life outcomes experienced. These commonalities are summarised in section 2.4.1 and 2.4.2. (Appendix One provides a sample of the comparison of studies in a table format). Whilst the comparison of studies identified surprising commonality on WHAT carers felt and the QoL consequences of being a carer; the comparison also identified nuances and variability between carers in the level of emotion they experienced and degree to which their QoL was impacted upon. These differences related to their personal circumstances, coping styles and the behaviour and symptoms of the person they cared for due to the condition they had. These differences are explored in section 2.5.

2.4.1 Negative emotions and quality of life outcomes commonly experienced by carers across care groups and relationships

The literature has often portrayed care-giving as burdensome. Carer burden refers to:
'..... the observable consequences of an illness (or disability) resulting from the provision of economic, instrumental and emotional support to the care recipient (objective burden) and the emotional responses of the carer to this role (subjective burden)' (Dimitropoulos et al, 2008, p740).

Examples of objective burden might be financial strain, disruptions to family life, limitations on social life and employment opportunities. Examples of subjective burden might include feelings of loss, fear, or anxiety.

Gray et al (2009, p127) stated that the negative feelings that carers of adults with mental health problems reportedly experience include:
'guilt, grief, helplessness, anger, sadness, despair, frustration, hatred, isolation, anxiety, disempowerment, worry, loneliness, shame, depression, desperation, denial, stress and believing they have no future'.

This list of emotions seems to be reflected in the literature across the various care groups. For example, carers of people with eating disorders report experiencing anxiety, loss, anger, grief, and helplessness at the *'relentless, controlling and all-encompassing grip of the illness'* (Kyriacou et al, 2008, p37). Caring for a partner with fronto-temporal dementia increases psychological distress and may lead to the development of disorders such as depression or anxiety (Bristow et al, 2008; Martin-Cook et al, 2003; Hammar et al, 2019). As the dementia progresses carers play an increasingly important role for the person suffering from the disease but at the same time carers must deal with loss and sorrow (Ulstein et al 2008). Carers who are caring for people with Multiple Sclerosis (MS) report feelings of tiredness, worry and pessimism about the future (Chipchase & Lincoln, 2001). Han and Haley (1999) identified that carers of stroke survivors also have elevated levels of depression and Greenwood et al (2008, p1329) stated that: *'Providing informal care for victims of stroke often has a negative impact on carers with increased psychological morbidity and reduced quality of life'.*

This short summary of the literature on the negative emotions experienced by carers makes apparent that there are common themes emerging and that carers experience similar negative emotions regardless of the condition the person they care for has.

A review of the literature across a wide range of care groups and relationships indicates other similarities. An example is the initial emotional responses experienced by carers. Initial reactions of parents to the knowledge that their child has a developmental disability include shock, disbelief, anger, denial and guilt (Quine and Pahl, 1987). These emotions are reflected in the initial reactions of families to the knowledge that a loved one has been diagnosed with a long-term chronic condition or terminal illness (Grbich et al, 2001).

These feelings have been described as manifestations of grieving (Wilson, 2014, p.33). For parents of a disabled child it is often the loss of the anticipated normal child (Cameron et al 1992; Whittingham 2013), for carers of people with dementia, MS, mental health conditions or survivors of stroke it is often the loss of the person they once knew, loss of the person's potential, loss of the shared relationship or lifestyle they previously had (Shim et al, 2012; Barrowclough et al, 2001; Hoskins et al, 2005; Bland and Darlington, 2002; Lou et al 2017). Across all care groups and relationships, the literature also describes a loss of the meaning in life due in part to the disconnection between how they expected and wanted life to be versus how it has turned out (Zuckerberg, 2006; Hoskins et al, 2005; Servaes et al, 1999). This fits with the assumptive world theory model of grief that suggests we each have a life narrative, a personal world. Grieving can turn our personal world and assumptions of what would be in the future, upside down (Parkes, 2006, p.30).

This grieving process may be experienced as cyclic with symptoms of grief being reactivated with specific triggers and at key moments. For parents of a disabled child

this may occur at key transition points in their child's life as the parent re-experiences the disparity between their actual parenting experience and their idealized one (Whittingham, 2013). The concept of ongoing grieving is something found in the literature for other care groups and relationships. For example, Aoun et al (2011, p845) describe the experience of family caring for a person with Motor Neurone Disease as: '*a series of losses'.* Pakenham (2005b) states that the distress experienced by carers of people with MS can be described as 'chronic sorrow'. 'Chronic Sorrow' is defined as: *'the periodic recurrence of grief-related emotions associated with an ongoing disparity between desired and current reality due to a loss experience'* (Eakes et al, 1998, p180). Olshansky (1962) put forth the view that chronic sorrow in families of disabled children should be viewed as a normal response to a tragic fact. It is possible that this view translates to other care groups and relationships.

Another similarity across care groups and relationships is the experience of feeling isolated and lonely. Parents (especially mothers) of disabled children repeatedly describe feeling alone and isolated from friends and family. Mothers describe friends and family as not fully understanding and therefore not always supportive (Cameron et al 1992). These feelings are reflected in the literature on eating disorders where parents reportedly experience shame and self-blame for the development of the illness and may feel stigmatised and isolated because of social misperceptions of eating disorders (Kyriacou et al, 2008; Blondin et al, 2019). Carers of older people with dementia often experience a reduced social life and degrees of social isolation (Draper et al ,1992) and carers of people with serious mental health conditions are vulnerable to isolation due to social stigma (Ostman and Kjellin, 2002; Lavoie, 2018).

Anger and frustration associated with specific situations related to the family's lifestyle and activities of daily living is another similarity found across care groups and relationships (Aggar et al, 2011; Bruce and Paterson, 2000). The daily experiences of caring for a disabled or chronically ill person are often frustrating as they lose or indeed in the case of disabled children, sometimes never reach, the ability to perform daily living skills such as wash, dress, eat or move unaided.

A second source of anger and frustration reflected in the literature across care groups and relationships is related to community services. Carers often experience high levels of frustration with gaining access to services leaving them with a sense of powerlessness (Langridge, 2002; Bruce and Paterson, 2000; Thompson and Briggs, 2000; Bhopti et al, 2019). One of the most common problems reported by carers of stroke survivors are problems with services and transfer of care (Greenwood et al, 2008). Carers of people with Anorexia Nervosa face difficulties accessing services and often feel: *'excluded, misunderstood, or blamed by professionals'*, and report unmet needs for: *'information on treatment, prognosis, and coping strategies, as well as a lack of social and professional support'* (Kyriacou et al, 2008, p37).

It is not just accessing services that seems to be the problem. Wilkins (2015) refers to the power imbalance often experienced by carers. The professionals' view of themselves as the expert and not treating carers as equal partners in decision making and problem solving, leaves many carers feeling de-valued and oppressed (Roen et al, 2018). Alvarez and Leeuwen (2015, p1) state that:

'*Helping relationships are inherently unequal…..with the provider of help being depicted as competent and powerful while the recipient is cast in a dependent and incompetent role.*'

Wilkins (2015) describes how the act of asking social services for help is often a last resort for carers and therefore it does not feel like a choice to them. This lack of choice is rarely recognised by social care professionals who often perceive carers as asking for too much or inappropriate help. Wilkins (2015) illustrates that the social care system has placed too much emphasis on assessing need, providing services and gatekeeping access to resources. As Kam (2014, p734) points out such a system *'makes it easy to pathologize the client'*. Being seen as 'problem bearers' rather than as equal partners leaves many carers feeling oppressed, angry and frustrated. Again, the experience of oppression, anger and frustration occurs regardless of the condition of the person you care for or of the nature of your relationship with that person.

Anger and frustration can end up resulting in resentment. Caring can often result in a range of changes and sacrifices. If the carer feels that their caring role is out of their control and they have no choice but to look after the care recipient it can lead to feelings of resentment (Williamson et al, 1998). Resentment in caring has been associated with prior poor interpersonal relationships (Williamson & Shaffer, 2001) and occurrence of behavioural symptoms (Martin-Cook et al, 2003). Feelings of resentment have been, for the most part, overlooked as a reaction to caring or as a component of carer burden. However, if caring is an unchosen role, anger and resentment can impact on the total caring situation (Aggar et al, 2011).

There are also similarities across care groups and relationships at the end of the caring role. According to Nolan et al (1996b, p131) the end of the caring role involves a process of letting go of caring, moving on and reclaiming a new life. Various studies report that carers receive minimal assistance at this difficult period and are generally left to get on with their 'new life'. Yet many carers are left with a legacy of guilt and continued stress (Gray et al, 2009; Wingrove et al, 2019; Nolan et al, 1996b; Kelly et al, 1999).

It is not surprising then that the sometimes-burdensome nature of caring and the resulting negative emotions it evokes, often results in poor QoL outcomes for carers in comparison to non-carers (Aubeeluck et al, 2012; Bruvik et al, 2012; Bosboom et al, 2012; Kenny et al, 2010; Walden et al, 2000). A study comparing carers of older people with non-carers found that carers are more likely to report higher levels of stress, higher use of psychotropic and other prescribed medication, poor self-care and physical symptoms such as elevated blood pressure (Burns and Rabins, 2000). Those caring for someone with dementia have poorer physical and psychological health than people without such tasks (Ulstein et al, 2007). This is like parents of disabled children who reportedly experience greater parental stress than parents of non-disabled children (Walden et al, 2000) and carers of people with Anorexia Nervosa who showed significantly higher levels of anxiety and depression than the parents of healthy controls (Kyriacou et al, 2008). Research has demonstrated that carers of stroke survivors often experience low satisfaction with their social life, sexual life and partner relationship (Forsberg-Warleby et al, 2004; Lou et al, 2017). This is reflected in carers of people with MS (O'Connor and McCabe, 2011) and in

carers of people with Huntington's disease (O'Connor et al, 2008) who also report increasing dissatisfaction with marital relationships. Carers of people with mental health conditions report insecurity and ambivalence in the relationship with the care recipient, changes regarding intimacy and familiarity, shifts in role distribution, lack of opportunity for relaxing activities, sorrow and fears regarding the further course of the illness, impairment of health and financial strains (Jungbauer et al, 2004; Lavoie, 2018). Importantly reviewing the research across care groups and relationships demonstrates that these issues are common themes that occur regardless of the condition of the person you care for or the nature of your relationship with them.

Whilst the finding that carers are more distressed than non-carers is not unexpected, what is interesting is the variability in distress between carers (Bristow et al, 2008; Walden et al, 2000; Li et al, 2012; Chipchase and Lincoln, 2001). As a group, carers are more stressed than non-carers, but they have a wide distribution of scores that does not correlate with the condition the care recipient or the relationship between the care recipient and the carer (e.g. parent, spouse, etc) and this requires further investigation. There are several models and theories that attempt to explain this, and these will be explored in section 2.5.

2.4.2 Positive emotions and quality of life outcomes commonly experienced by carers across care groups and relationships

Until recently, caring was thought to result in negative emotions only. The emotional, physical, practical, and social costs of caring for people with chronic illnesses or disabilities have been well established. However, recent research has started to recognise that caring is not only associated with negative consequences, but that carers also experience positive gains and emotions. (Kulhara et al, 2012; Lyons et al, 2007; Grant and Nolan, 1993; Bhopti et al, 2019).

Recognition of positive experiences in caring initially surfaced from anecdotes by carers who suggested that caring increased their feelings of pride in their ability to meet challenges, improved their sense of self-worth, led to greater closeness in relationships, and provided an enhanced sense of meaning, warmth and pleasure (Kramer, 1997). Morrison (1999) concluded that the available evidence suggested that caring has different effects on different people and that not all caring is intrinsically 'burdensome'. Kramer (1997) stated that: *'Lack of attention to the positive dimensions of caring seriously skews perceptions of the caring experience and limits our ability to enhance theory of carer adaptation'* (Kramer, 1997, p218).

Recently, positive aspects of caring have secured an important place in the research literature. It is becoming increasingly apparent that there is much to be gained by examination of the positive dimensions of caring (Zarit, 2012). Pakenham and Cox (2008, p584) state that: *'it is likely to be the benefits of caring that sustain carers over the long haul of caring for a loved one with chronic illness.'*

The caring benefits/gains described in the literature are similar across care groups and include feeling more useful, feeling valued, experiencing gratitude, feeling needed and important, learning new skills, adding meaning to one's sense of self, gaining a sense of fulfilment, feeling responsible and enjoyment derived from expressing love through caring or from finding a sense of companionship and

meaning within the relationship (Kulhara et al, 2012; Cohen et al, 2002; Farran et al, 1991; Shim et al 2012; Bacon et al, 2009).

Tarlow et al (2004, p437) reported that most carers of people with dementia felt that: *'caring enabled them to appreciate life more, to develop a more positive attitude toward life, and strengthened their relationships with others'.* Blacher & Baker (2007) examined mothers and fathers with preschool-aged children with disabilities and found a positive impact on families in their sample as did Grant et al. (1998). Carers of people with mental health problems also report experiencing satisfaction and emotional reward, particularly in sustaining a comfortable, loving and caring relationship (Gray et al, 2009). Chen and Greenberg (2004) found that many carers of people with mental health issues felt they had become a better, more understanding, and patient person because of coping with their relative's illness. It is a similar picture for carers of stroke survivors who report increased self-esteem, feeling appreciated, feelings of pleasure, and pride/satisfaction in the prevention of further deterioration in the person being cared for (Bacon et al, 2009; Lou et al, 2017). No matter the condition of the person you care for or the nature of your relationship with them, it seems there are common themes across care groups and relationships in terms of the positive emotions and QoL outcomes experienced by carers.

Various authors have attempted to define carer gain. Chen and Greenburg (2004, p424) have defined carer gains as *'the caregiver's perceived personal growth and enhanced interpersonal relationships.'* Lawton et al. (1989) distinguishes uplifts from caring satisfactions. Uplifts are described as events of short duration that evoke pleasure or joy in the carer and satisfaction is a more stable state and is the accumulation of daily uplifts (Shim et al, 2012). Pakenham (2005b) describes seven benefit finding themes including: greater insights into illness and hardship, caring gains, personal growth, the strengthening of relationships, increased appreciation of life, health gains, and a change in life priorities and personal goals. Kramer makes a distinction between gain that is specific to the caring role, and psychological wellbeing that may be influenced by, but is potentially independent of, the caring experience (Kramer, 1997).

There is evidence across care groups to suggest that many carers feel a mix of emotions at any one time and live through positive and negative experiences on a regular basis. Shim et al (2012, p225) state: *'It was not that they did not grieve the loss of the individual or relationship they once had, their focus had simply moved from thinking of what was lost, to cherishing what remained'.* Cameron et al (1992, p.100) reports that: *'Despite feelings of anger and frustration some mothers did feel satisfied with their ability to parent their child.'*

Further studies also suggest that the positive impact of a disabled child on family members occurs concurrently with, and is independent of, any negative impact (e.g. Hastings & Taunt 2002; Blacher & Baker 2007) (Griffith et al, 2011). Pakenham and Cox (2008) report that the strength or intensity of carer gains for carers of people with MS may fluctuate in some areas and that carers report a wide range of gains despite also experiencing 'chronic sorrow' (Pakenham, 2005b; Bacon et al, 2009). This fits with Lois Tonkin's (2007) Circles Model of grief. Her model of grief suggests that the grief does not always diminish, that it can stay the same forever. The loss becomes

part of who the person is, but they also grow round their grief, finding new strength of character, understanding and self-esteem (Attig, 2001, p.43).

Evidence across all care groups and relationships indicates that, like negative emotions, there is variability in the type and intensity of positive emotions experienced by carers. Chen and Greenberg (2004) reported that although most carers could identify caring gains, there was considerable diversity in their experiences. As mentioned in the previous section there are several models and theories that attempt to explain this variability, and these are explored in the following section. This is where the nuances between conditions, how they manifest, the coping styles of carers and their personal circumstances become important.

2.5 Predicting the emotions and quality of life outcomes of carers – what are the differences between carers?

Specific factors which have been cited as predicting negative emotions and outcomes include aspects of the care recipient's condition, such as cognitive impairment, degree of difficulty with activities of daily living, extent of personality change and the presence of psychiatric symptoms and behavioural disturbances (Bristow et al, 2008; Chipchase and Lincoln, 2001; Tooth et al, 2007; Calder et al, 1991; Hammar, 2019). Other predictors of high stress levels include being female, the amount of informal and formal care available, the carer's physical and mental state, their personality and coping style (Walden et al, 2000; Weinberg and Huxley, 2000; Rosness et al, 2011). Carer strain and perceived uncertainty of how the condition will progress have also been reported to predict carer general health, mood & life satisfaction (Dimitropoulos et al, 2008; Blondin et al, 2019; Hsieh et al, 2013). Other factors that seem to affect carer burden include satisfaction with coping, family composition, life span and perceived social support satisfaction (Greenwood et al, 2008; Grant and Whittell, 2000; Minnes et al, 2007). Expressed emotion, attributional style and marital intimacy have also been related to carer burden (Burns & Rabins, 2000; Kyriacou et al, 2008; Blondin et al, 2019; Raune et al, 2004; Dossetor et al, 1994; Lam et al, 2003). It is possible that this is where the nuances between the nature of the relationship (e.g. spouse, parent, sibling, etc) become important.

Comparing previous studies of carers identified the commonality in emotions and outcomes carers experienced; reviewing the variables that predicted the emotions and QoL outcomes of carers highlighted that 'exactly why' carers felt anxious, sad, depressed or happy depended upon differences between them.

Much of the research that has examined what predicts emotions and QoL outcomes for carers has been guided by Lazarus and Folkman's (1984) stress and coping theory. This multidimensional model is considered one of the most comprehensive caring frameworks (Bainbridge et al, 2009). The stress process model offers researchers an overarching conceptual framework to consider the range of factors that interact with and build upon each other resulting in carer stress and poor QoL outcomes (Pearlin et al, 1990). Although there are slight variations to the stress process model of caring across care groups (e.g. Hill, 1958; Pearlin et al, 1990; Dimitripoulos et al, 2008) all the models consist of five interrelated domains: Background/Context, primary and secondary variables, coping resources (mediators), and the emotions and QoL outcomes for carers. Figure 1 below

illustrates the Stress Process Model. Examples of variables are given from studies conducted across care groups.

Figure 1: Stress Process Model of Caring

Background/Context	Primary Variables	Secondary Variables	Coping Resources (Mediators)	Emotions & Quality of Life Outcomes
Characteristics of the carer. The context of the caring situation and the prior quality of the relationship Characteristics of the carer e.g: ■ Gender ■ Age ■ Health ■ Employment status Context e.g: ■ Other dependents ■ Living environment / housing Prior relationship e.g: ■ Loving ■ Respectful ■ Antagonistic ■ controlling	***Stem directly from the needs of the care recipient and the nature and magnitude of the care demanded by these needs.*** Characteristics of the illness/disability of the care recipient e.g: ■ Behaviour ■ Daily Living Skills ■ Cognitive impairment	***Products of and reactions to the primary variables e.g:*** ■ Stigma ■ Increased family conflict over the seriousness of the illness or how to respond to it ■ Grief/Chronic Sorrow ■ Oppression ■ Episodes of chronic stress	***Things that help the carer to cope and mediate against stress*** ■ Social support ■ Appraisal ■ Problem-solving skills ■ Financial resources ■ Specific knowledge and skills e.g. positive behaviour support	***Emotions (negative & positive)*** ■ Sadness ■ Anger ■ Pride ■ Fulfilment ***Quality of life outcomes (negative & positive)*** ■ Life satisfaction ■ Social network ■ Financial status ■ Physical and mental wellbeing

Within the context of differences between carers, reviewing the variables that predict emotions and QoL outcomes across carer studies once again identified surprisingly more commonalities than differences. For example, whether caring for a child with learning disabilities, a spouse with MS or a parent with dementia it is the behaviour displayed by those in need of care and support that may test a carer's ability to cope. Whilst the behaviour displayed might be quite different, the commonality here is that the carer in each situation is faced with behaviour that is challenging to cope with. Furthermore, in each situation the carer's social network and financial status may vary but for all these carer groups these were coping resources that were cited as likely to mediate the effect of the primary and secondary variables.

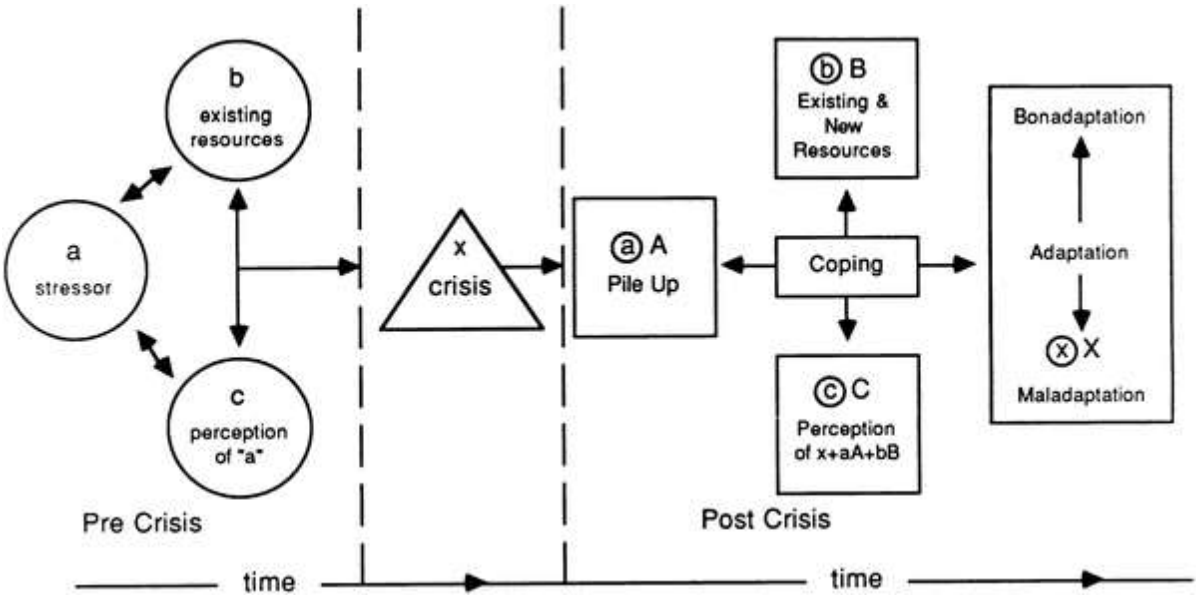
Indeed the key principle that underpins the model is that the process of coping either increases or decreases the effects of the primary and secondary variables on a carer's wellbeing i.e. emotions and QoL outcomes (Lazarus and Folkman, 1987). Coping attempts are employed either with the intention of managing the problem that is causing the distress or aimed at the regulation of the emotions associated with a variable (Folkman, 1984).

Pearlin et al, (1990) describes coping as having three possible functions:

- management of the situation giving rise to stress;
- management of the meaning of the situation such that its threat is reduced;
- management of the stress symptoms that result from the situation.

Hill's (1958) ABCX Model of family stress and McCubbin and Patterson's (1983) expanded version The Double ABCX Model have similar connotations as seen below.

Figure 2: The Double ABCX Model



The traditional stress process model has been useful in identifying predictors of negative outcomes and emotions, but it has been less helpful in identifying predictors

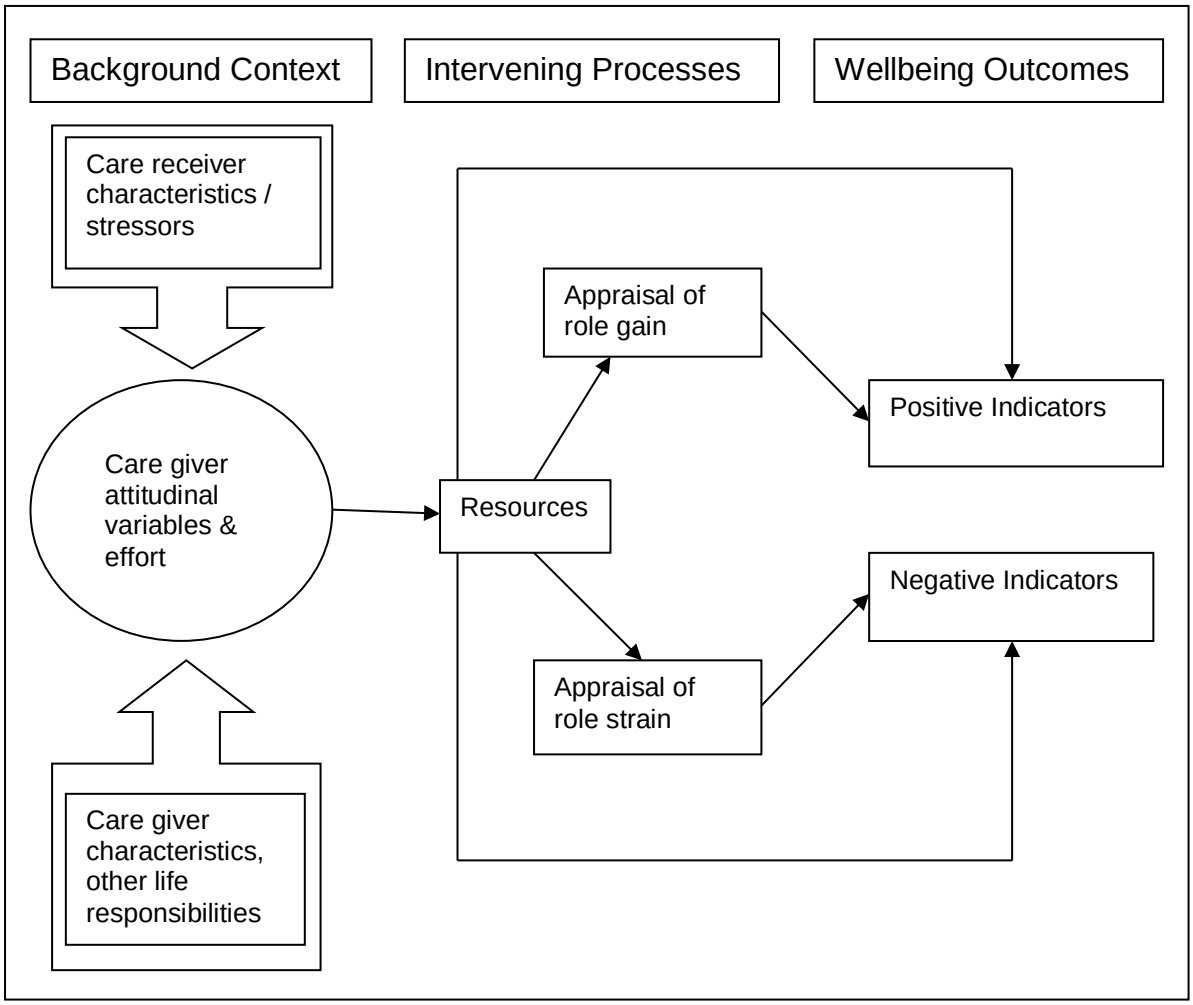
of positive outcomes and emotions. There is some recognition that the stress-process model relies too heavily on coping strategies and social support to predict carer outcomes and emotions and tends to pay less attention to other factors that might help to explain the variety of carer reactions including carer gain. Farran (1997) suggests that taking an existential perspective can help us to understand why some carers do so well in such difficult circumstances. Farran (1997) identified that finding meaning in caring is what helps some carers to remain positive and experience good outcomes. Frankl (1963) suggests that values play a major role in determining how people deal with difficult life circumstances. It can be argued that Pearlin et al, (1990) includes this concept in his model and badges it as a positive mediating or resource variable which he names 'managing meaning'.

Noonan and Tennstedt (1997) also examined the relationship between meaning in caring and psychological wellbeing and placed it in the context of the Stress Process Model of coping. They controlled for demographic and stressor variables and found that the carer's sense that they had found meaning in caring was negatively associated with depressive symptoms and positively associated with self-esteem. Their study also found that meaning in caring was not related to the extent of care performed, frequency of care, the care recipient's cognitive impairment or problem behaviours. Other studies have found that for positive experiences to occur, a perception of the potential for improvement or control is important (Bacon et al, 2009).

Carer studies have identified hopefulness in the carer as a crucial part of the coping process for carers of people with mental health conditions (Wasow, 1995). Hope theorists consistently define hope as being grounded in an achievable reality. Its capacity to be achieved distinguishes it from wishful thinking (Bland and Darlington, 2002). Research has suggested that not having hope threatens emotional, physical, and spiritual health and may be a predictor of suicide. How hopeful a person can be is reportedly determined by their perceived mastery of the future, purpose in life, anticipated support from others and self-esteem (Nunn, 1996). Hope for a brighter future is often held in opposition to the grief for what has been lost. Bland and Darlington (2002) identified three main sources of hope: family and friends, professionals and religious beliefs. Maintaining hope seems to play a vital role in the complex process of adjusting to the caring role, maintaining the ability to cope and achieving a sense of wellbeing (Holtslander and Duggleby, 2008). Feeling connected to friends and family and having faith are two factors that Holtslander and Duggleby (2008) suggest predict hope. Once again it seems that there is commonality across care groups and relationships as 'being hopeful' did not appear to be tied to any one carer group in the comparison of studies in Appendix One.

Duggleby and Wright (2005) state that positive reappraisal is one way in which carers 'hang on to hope'. In her critical review of studies on carer gain, Kramer (1997) found three studies that drew links between attitudinal variables and gain. She developed a conceptual model of carer adaptation that takes such attitudinal variables as hope and positive appraisal into account.

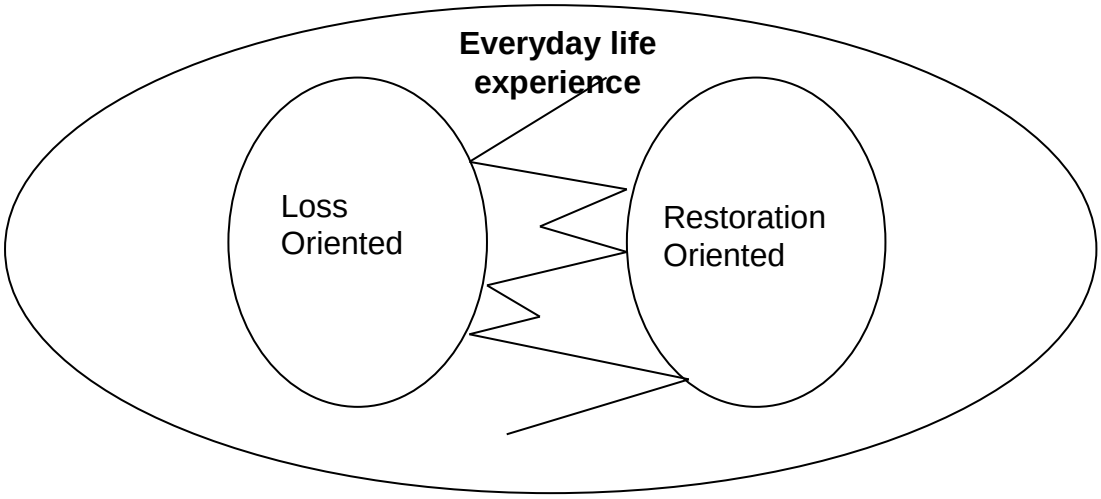
Figure 3: Conceptual Model of Carer Adaptation (Kramer, 1997)



Other studies have also established that positive emotions and carer gains have been found to be related to more positive appraisal and less escape-avoidance coping strategies (Lam et al 2003; Bacon et al, 2009). Appraisal is an evaluative process that reflects the person's subjective interpretation of the event. If a carer appraises a caring-related event as exceeding their coping resources they will experience negative emotions and/or QoL outcomes (Pakenham, 2005a). Avoidance is when certain ideas, feelings, thoughts, activities and situations are consciously avoided.

Avoidance may be looked upon as an attempt to control the feelings and restore emotional equilibrium (Ulstein et al, 2007). Experiential avoidance is a significant unique predictor of parental psychological symptoms, parenting burden and chronic sorrow symptoms (Whittingham et al, 2013). The usefulness of avoidance as a coping technique is a concept that can be found in some models of grief. Strobe and Schut (1999) built on the work of Lazarus and Folkman (1987) and developed the dual process model of grief.

Figure 4: The Dual Process Model of Grief (Strobe and Schut, 1999, p.213)



The big outside oval symbolises the individual's daily life. The two smaller ovals symbolise two possible grieving styles: 'loss oriented' (intrusion of grief, denial, avoidance) and 'restoration oriented (doing new things, new attitudes, new roles). People who make the most successful adaptations to their loss are those who spend some time in each grieving style (Wilson, 2014, p.121).

The concept of oscillation fits with the literature that suggests carers across care groups and relationships often feel a mix of emotions at any one time. The Dual Process Model of Grief takes this a stage further and suggests that feeling a mix of emotions and oscillating between positive and negative emotions is necessary if successful adaptation to the loss is to be achieved. Yet emotional support features only lightly in the stress process model of coping which conceptualises emotions as outcomes rather than part of the process of successful adaptation.

Lois Tonkin's (2007) Circles Model of grief builds on the theory of mixed emotions and oscillation with the concept that people can 'grow around their grief'. This implies that the negative emotions are not something that ever go away but that the positive emotions related to personal growth are something that can be enhanced. Personal growth is a benefit to caring that various studies have identified (Kelso et al, 2005; Chen and Greenberg, 2004; Pakenham, 2005b). The implication of these two models of grief is that successful adaptation to the caring role and hence ability to sustain it requires an ability to oscillate. The literature on carers suggests that the ability to oscillate varies across carers from all care groups and relationships.

The concept of ambiguous loss (Boss and Yeates, 2014) must also be reflected upon in relation to carers. Boss and Yeates describe two types of ambiguous loss 'Leaving without goodbye' (their examples include deployment to war, suicide, miscarriage) and 'goodbye without leaving' (their examples include dementia, mental illness, drug addiction, autism). Ambiguous loss is therefore, a loss that occurs without closure and thus complicates the process of grieving. Boss and Yeates argue that bereavement and loss literature has tended to focus on the pathology of ambiguous loss and complicated grief. However, they say the focus should instead be on resilience and have created the 'Six guidelines for resilience with ambiguous loss' (p67):

- Finding Meaning: 'What does the situation mean to you?'
- Tempering mastery: 'How do I let go of what I cannot control?'
- Reconstructing identity: 'Who I am now?'
- Normalising ambivalence: 'What do I do with my conflicted feelings?'
- Revising attachment: 'How do I both let go and still remember?'
- Discovering hope: 'How do I find hope in a situation that has no closure?'

The recognition that chronic sorrow, loss and the negative emotions related to them are not things that can be annihilated for carers suggests that there is a need to consider how carers are supported emotionally and how responsive and emphatic carers' support services are to oscillating emotions, and avoidant versus problem-solving coping behaviours. The ability to cope in the long-term also requires personal growth and it is possible that the strength that comes from such growth enables carers to continue in the most difficult of circumstances.

Some studies suggest that carers experience barriers to self-development and growth. Marin (2014) maintains that 'the need to be flexible' is fundamental to the caring role and that it is this aspect of caring that makes it difficult for carers to engage in activities that are important for their own self-development. This is because of the constraints 'being flexible' places on opportunities for self-development. These constraints are not limited to the simple logistics of ensuring someone else is present to provide care. Carers spend time meeting the needs of someone else, which means that they have less time and energy for developing their own skills. Carers must be ready for and anticipate new or unpredictable care needs which makes planning their own activities difficult and puts further obstacles in the way of their own self-development. These barriers can be found across all care groups and relationships. Marin (2014) links these constraints to self-development to Young's (2004) definition of oppression.

Young (2004, p53) states that powerlessness is the strongest form of oppression and she describes constrained opportunity for self-development, lack of decision-making power and exposure to disrespectful treatment as being central to the experiences of inequality suffered by oppressed groups. The concept that oppression always involves a dictator employing cruelty as a means of controlling groups of people is inaccurate. In many cases, oppression is the result of well-meaning decision makers developing policies that create 'a normal way of doing things.' These norms are rarely questioned and can become the barriers which prevent a group of people from accessing the same opportunities or attaining the same QoL outcomes. Oppression can be defined as systematic and widespread social inequity that occurs due to the misuse of power (Case and Hunter, 2012; Deutsch, 2006; Watts et al, 1999).

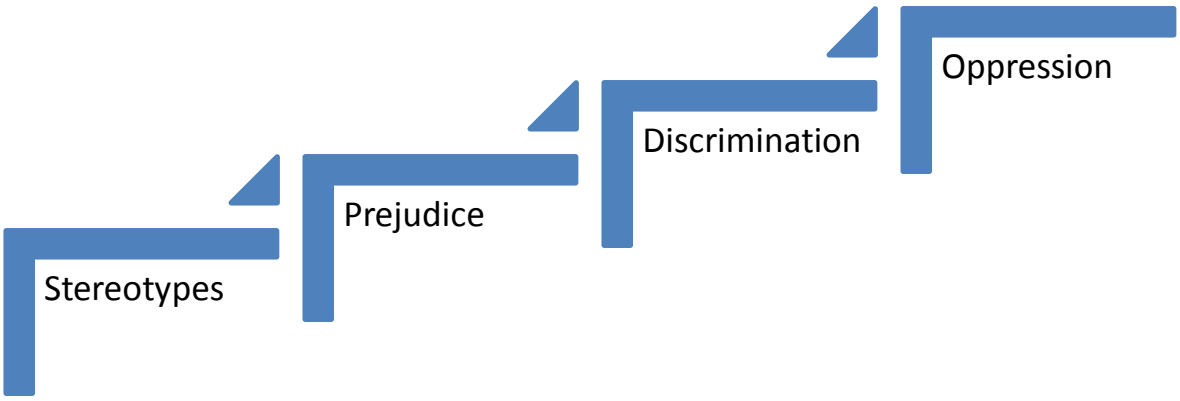
Young (2004) goes on to explain that powerlessness is the strongest form of oppression because '*it allows people to oppress themselves and others*.' (p53). One example of this is clearly articulated in a famous quote from Harriet Tubman, an American Activist born in 1820: '*I freed a thousand slaves, I could have freed a thousand more if only they had known they were slaves*.' Nevertheless, to suggest that all carers are oppressed is inaccurate and overstated. Environmental and individual factors are likely to affect one's experience of oppression (Perez and Soto, 2011). For example, the degree to which carers are unable to engage in activities for

their own self-development depends, in part, on the flexibility of the support they receive from their social network, the help they get from services and their financial situation. However, it does not appear to be tied to the condition of the person they care for or the type of relationship they have (e.g. spouse, sibling, parent, etc).

Some studies have linked the experience of being oppressed to decreased QoL and poor sense of wellbeing (Case and Hunter, 2012). Oppression involves depriving a person or group of people of something that is needed, wanted or helpful and in doing so it threatens the person's mental or physical wellbeing or ability to cope (Hanna et al, 2000). Many carers across care groups and relationships report incidents of not receiving the help they need and as a result experiencing negative emotions and poor QoL outcomes (Langridge, 2002; Bruce and Paterson, 2000; Thompson and Briggs, 2000).

There is also evidence to suggest that repeated individual or group experiences of oppression result in low self-esteem and a sense of not being valued or heard by society. The Carers UK survey in 2015 found that half of carers said they feel society does not think about them at all. Lago (2011) points out oppressive groups don't always understand or acknowledge their privilege and hence much of their oppressive behaviour is unconscious. Thesen's (2005) model of oppression helps to explain how people in 'helping' professions e.g. doctors, social workers etc can and do engage in behaviours that are oppressive.

Figure 5: Thesen's Model of Oppression



Thesen maintains that oppression starts by objectifying people i.e. seeing a person only in terms of a label. An example would be seeing an individual only as a woman. Once you objectify a person it's easy to make the next step of applying stereotypes e.g. all women are more emotional than men. This makes it easier to apply prejudice e.g. unlike men, women are too emotional to do Board Room level jobs. The next step is discriminatory behaviour e.g. not interviewing any women for Board Room Level jobs. Ultimately a whole group of people (in this case women) are denied something they want or need, and it affects their wellbeing and self-esteem. They do not have the 'privilege' of being male, they have not been given equal opportunities

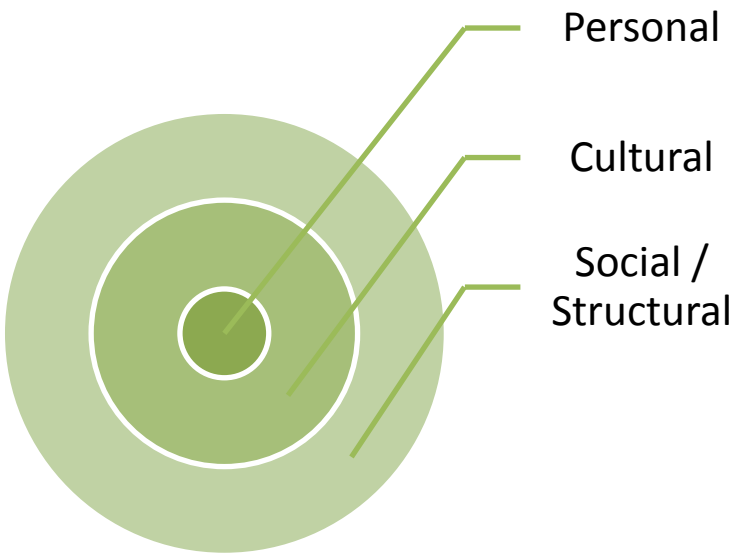
to get the top jobs and are powerless to change it because no one is listening. They are oppressed. If the woman was seen by men as the person she is and not just as a woman they would have seen her as a skilled, capable, company leader. When people see the person, they are less likely to apply stereotypes and it is easier to go down the track of empowerment rather than oppression.

One of the problems for carers is that their role and skill as a carer is vastly undervalued and often not seen at all. Their caring role is due in part to the fact that they have a relationship with the person they are caring for and it is only this relationship that is seen and responded to. For example, seeing Mrs X only as a mother of a disabled child; applying the stereotype that compared to other mothers, all mothers of disabled children are a bit emotional and neurotic; that all the care she provides is simply part of what she should do as a mother; therefore the extra childcare she is asking for so that she can go to work is inappropriate because other mothers don't get that help. The difference could be that other mothers can use traditional childcare, but her son's needs cannot be met by traditional childcare so without the help she is asking for she can no longer work. In being denied the help she is denied the ability to work which is something she needs and wants. As a result, her self-esteem and wellbeing are affected. She does not have the 'privilege' of having a non-disabled son and she is denied the same opportunities to access work, she is powerless to change it because no one is listening, she is oppressed.

Achieving a sense of wellbeing in the face of such oppression requires a variety of psychological and behavioural strategies. Jones (2003) concludes that adaptive responding and a sense of wellbeing occurs when both strategies of self-protection and self-enhancement are employed. Whilst self-protection strategies will often occur at an individual level, self-enhancement strategies often need to be facilitated at a community level (Jones, 2005, p161).

Thompson (1997) sees anti-oppressive practice as occurring on three levels: personal, cultural and societal.

Figure 6: Thompson's PCS Model of Anti-Oppressive Practice



The personal level (P) involves relationships, feelings, attitudes, beliefs, perceptions and interactions between individuals. The personal is embedded within the cultural context (C) where the person's culture establishes norms and rules that shape how the individual feels about themselves, others around them and interactions between people and the environment. Both the personal and cultural levels are then embedded within the societal framework (S), which sets the structures, norms, rules and order within society.

The PCS model illustrates that anti-discriminatory practice does not only take place on the personal level, but also takes place on the cultural and societal / structural levels as these levels are each embedded within one another. This means that if successful adaptation to the caring role and ability to sustain it requires an ability to oscillate between coping and avoidant behaviours, if learning to do this requires personal growth and if we agree that carers face oppression due to the barriers they face in regards to opportunities for self-development; then the solution must be based on anti-discriminatory practice and hence be something that takes place at a personal, cultural and societal / structural level. It is also apparent that the argument is the same across care groups and relationships and hence it is appropriate to refer to carers as one group in the context of policy setting and commissioning carers' centres.

2.6 The Ethic of Care

Barnes (2012) in her book *Care in Everyday Life states that:*

'Care is fundamental to the human condition and necessary both to survival and flourishing. While in the UK official discourse has sought to marginalise care within social care practice, in people's everyday lives care is an essential part of how they relate to others'. (p1)

Kittay et al (2005) argued that if it was acknowledged that everyone was at times vulnerable and reliant on others the carer would not be invisible.

However, Kittay et al (2005) emphasised that differences in ability, race, gender, sexuality, religion, culture, and geography orient us differently towards "inevitable dependencies," making questions concerning the giving and receiving of dependency care a matter of social, moral and political importance. The concept that care is common to us all and is of political importance led to a theory that:

'The ethic of care provides not only a basis for understanding relationships of care at the micro level but also a potent form of political ethics, relevant to the development of welfare services'. (Lloyd (2010) p188).

Lloyd (2010) argued that if, in principle society agreed that, at some point in our lives, we all need care then people should be empowered to both give and receive care by legislation that enshrines such rights in law (p191). Yet neoliberalism creates the context for care being a private matter where citizens use their own resources to take care of themselves; where privatisation, free markets, profit and autonomy are the cultural norm (Nguyen et al, 2017). Tronto (2013) brings these concepts together through the insistence that care is an on-going social process, and thus takes into account the different levels of 'caring for the self', 'caring for the others' and 'caring

for the world'. Whilst our dependence upon each other is most obvious when we are babies, seriously ill, disabled or very frail as humans we value social relationships throughout our lives. Indeed the quality of our lives is impacted upon by how connected to others we feel; the way others treat us and we treat them. Barnes states that:

'Care ethics prompts us to give attention to ways in which such connections can be supported to improve the well-being of all….' (p15).

Although individual nuances between care groups and relationships remain important, the fact that caring is a common experience and part of the human condition is at the centre of why this thesis places importance on understanding the commonalities as it is through this understanding that effective policy and practice will be developed.

2.7 Limitations of the previous research

There are several limitations to previous research. These range from the properties of terms such as 'carer stress' not always being clearly defined; to small sample sizes or low response rates. Not all the studies used standardised assessment scales. In some cases where standardised scales were used, they were instruments that had not previously been used with carers.

Some studies suffered from issues of responder bias due to self-report data. Participants can overestimate or fail to report issues which affects the accuracy of self-report data. The participants in the studies are also unlikely to be representative of all carers as in many cases the samples were English speaking and in touch with services. It is plausible that those who were not coping were less likely to have engaged and this literature review did not include studies on people who had stopped caring or reduced their caring role.

The cross-sectional design of the studies makes it impossible to infer causal effects. Only a longitudinal design will make it possible to assess the true predictive value of the factors identified. However, longitudinal designs are problematic when you consider that carers are not a static population. The UK Carers Survey (2014) stated that every year over 2.1 million adults in the UK become carers and almost as many people find that their caring responsibilities change or come to an end.

However, the main limitation of previous studies is that the majority focus on a specific care group or relationship such as carers for people with MS or carers for people who have suffered a stroke or parent carers of disabled children. Reviewing the literature across care groups and relationships has however identified that there are common themes and that the prediction or maintenance of QoL outcomes is not dependent solely on the condition of the cared for person or the relationship between the carer and the care recipient.

3 Chapter 3: Methodology

This section aims to describe the methodology for the study, describing in detail how the research was undertaken.

3.1 Ethics

Two Ethics Applications were made. The first for Part One and Two of the Study and the Second for Part Three. For both applications the researcher strictly adhered to all procedures and regulations prescribed by the Tizard Centre and the University of Kent at Canterbury. The Ethics Application summarised the background literature and outlined the research questions. It described the methodology and explored the ethical considerations. The application was approved by the researcher's supervisors prior to submission to the Tizard Ethics Committee. The researcher gained the approval of the Ethics Committee (the application and approval letter for part one and two can be found in appendix two and three; the application and approval letter for part three can be found in appendix four and five) and then submitted the application and approval letter to the University of Kent research governance framework. Once the researcher had received approval from the University research governance framework the research began. Local Government Research Governance was not needed because the research was not being conducted with local authority staff or service users in local authority care provision.

3.1.1 Ethics Application for Part One and Two

All participants were able to give informed consent. Information sheets, consent forms and complaint forms were provided to participants before each focus group began to establish informed consent. No one was excluded based on culture, religion or beliefs. Any steps required to increase accessibility to people whose first language was not English were taken although on this occasion the use of an interpreter was not required.

As in any ethical study, the researcher ensured that participation was voluntary, that participants could withdraw at any time, and that confidentiality was protected. Two facilitators were present at each group (the researcher and a carer support worker known to the participants). The focus groups were recorded using an audio recorder and transcribed verbatim. All responses were anonymised before analysis, by using code numbers for participants, and care was taken not to reveal potentially identifying details. Data were kept in accordance with the Data Protection Act (1998). All focus group material was kept in locked cabinets and records stored via NVivo software on the researcher's laptop were password protected. In terms of confidentiality amongst the group, ground rules (including confidentiality) were discussed at the beginning of each focus group. At the end of the research the audio recordings will be destroyed.

At no point did any participants become upset but if they had done so at any time the focus group would have been paused. The participant would have been encouraged to have a conversation with the assistant facilitator outside the room and support would have been offered. If the participant chose to withdraw at that point, their choice would have been respected. The rest of the focus group would have been asked if they wished to continue. In the event, this was not needed in any of the

three studies. All participants were provided with information and advice as to how they could access ongoing support via their carer network.

It was possible that some carers could have experienced a power imbalance between themselves and the researcher that might have made it difficult for participants to refuse participation initially. This was partly overcome by contacting potential participants via the carers' centres rather than the researcher contacting people directly. There was also some potential for people to feel like they could not withdraw once the focus group had started. Having an assistant facilitator present who was a known and trusted carer support worker to the participants was crucial in trying to ensure that participants felt able and supported to withdraw at any time.

It had been planned that the carers' centres would write to carers and send them the information sheet and consent letters, with the aim that people would come along to the focus group having completed a consent form. Unfortunately, the carers' centres were very stretched and so their capacity to do this was limited. Instead, carers' centres suggested sending out invites to potential participants via their carers' centre Facebook Page or adding the focus group on as an optional session at the end of one of their drop-in sessions. According to the carers' centres this had been a successful strategy in the past in terms of advertising and successfully recruiting carers to participate in focus groups. However, it did mean that the signing of consent forms had to be dealt with face to face at the beginning of the focus group. The researcher was conscious that in this situation some carers might feel unable to say that they no longer wished to participate. Therefore, the researcher explained the purpose of the study, the use of the audio recorder, talked through the information sheet, and described how their responses would remain confidential. The researcher then passed out consent forms after which she left the room for a short period. This gave the carer support worker a chance to double check with carers that they truly were comfortable and were giving informed consent.

Approval for this change in procedure was sought from the Tizard Ethics Committee. The researcher wrote to the ethics committee to explain the situation and waited for approval before continuing with the research. Both the letter to the Ethics Committee and the confirmation of approval can be found in appendix three.

3.1.2 Ethics Application for Part Three

All participants were able to give informed consent. Information sheets, consent forms and complaint forms were provided to participants to establish informed consent. Participants were reassured that they were free to decline without risk to their employment (if they were staff) or their support (if they were carers).

For the online survey the information sheets were part of the invitation to participate that was emailed out to family carers via the carer networks. Those who wanted to participate clicked on a link to the survey. The first few questions of the survey focused on consent. At the end of the survey (and at any point that the participant withdrew from the survey) a link to the complaint form appeared.

For the interviews the information sheets were part of the invitation to participate that was sent out to staff and governors. Those who wished to participate contacted the

researcher directly. Prior to the interview consent forms and complaint forms were given to the participant.

The peer support sessions the researcher observed via the ethnographic observations were arranged in partnership with the carers' centre who consulted with carers first (using the research information sheet) to check whether carers would be comfortable with the researcher's presence. Then directly before the beginning of the session, informed consent was sought from the carers using the consent form and with support from the carer support worker.

All the carer support workers were invited to participate in the ethnographic observations and provided information sheets and consent forms via email. All carer support workers were reassured that if they chose not to participate it would not affect their employment. All carer support workers were also reassured that they could choose to withdraw at any time. At this point any observations would have been stopped and further support offered via their line manager.

Carer support workers received training on the resilience scale and wellbeing questionnaire. During the initial conversation with new referrals carer support workers talked through the information sheet and asked several questions focused on consent. If the carer wished to participate they were asked to complete both scales and were reminded that they could withdraw at any time and that it would not affect their support. At the end carers were asked if they would like to be contacted in six weeks to repeat the measures. When those who had given consent were contacted six weeks later, the information sheets and consent questions were repeated prior to the measures being repeated.

As in any ethical study, the researcher ensured that confidentiality was protected. The carers' centres removed identifying details from the surveys, resilience scale and wellbeing questionnaires and replaced them with code numbers for participants before passing them on to the researcher. The staff interviews were recorded on an audio recorder and transcribed verbatim. All responses were anonymised before analysis, by using code numbers for participants, and care was taken not to reveal potentially identifying details. Data were kept in accordance with the Data Protection Act (1998). All material was kept in locked cabinets and records stored via NVivo and SPSS software on the researcher's laptop were password protected. At the end of the research the audio recordings will be destroyed.

At no point did any participants become upset but if they had done so at any time during the interviews, workshops or ethnographic observations the activity would have been paused. The participant would have been encouraged to have a conversation with the facilitator and support would have been offered. If the participant chose to withdraw at that point, their choice would have been respected. All participants were provided with information and advice as to how they could access ongoing support via their carer network (if they were carers) or their line manager (if they were staff).

It was possible that some participants could experience a power imbalance between themselves and the researcher that might make it difficult for participants to refuse participation initially. This was partly overcome by contacting potential participants

via emails from the carers' centres rather than the researcher contacting people directly. There was also some potential for people to feel like they could not withdraw once the research activity had started. Reassuring participants that they could withdraw at any time was crucial.

The original ethics application stated that:

All new referrals for a period of 2 months will be asked to complete the wellbeing questionnaire and to rate on a 5 point scale the degree to which they feel able to continue caring. The measures will be repeated 12 weeks later.

The methodology had been discussed with the carers' centres and originally, they felt it would be fine. However, due to their reducing resources and hence capacity there was a need to shorten the period from 2 months to 2 weeks and to repeat the measures after 6 weeks not 12 as 6 weeks is when they do their usual follow-up calls and so it did not require extra resource.

Secondly, when the carers' centres started using the wellbeing checklist they had a lot of negative reactions from carers in relation to a couple of the questions. Furthermore, the 5 point 'able to continue caring' scale did not seem to work well either. The short wellbeing questionnaire (SWEMWBS) (NHS Health Scotland et al, 2008) and the brief resilience scale (Smith et al, 2008) were therefore piloted with a carer support worker and a few carers. The response was very positive and so the researcher wrote to the ethics committee asking to replace the original scales with these and to change the timescales. The ethics committee approved the changes and the approval letter can be found in appendix five.

3.2 Quality of the research

The quality of research is often judged based on the reliability, validity and generalisability of the data and findings. Qualitative researchers have argued that the traditional, quantitative approach to judging the quality of research does not 'fit' when it comes to judging the quality of qualitative research. Strauss and Corbin (1998, p298) identified two sets of criteria that were important for assessing the quality of grounded theory research. The two sets of criteria were:

- Research process
- Empirical grounding of findings

3.2.1 Research Process

An essential feature of grounded theory research is the continuous cycle of collecting and analysing data. The researcher started analysing data as soon as it was collected and then moved on to compare the analysis of one set of data with another. The researcher started by collecting data on carers living with the person they cared for, this data was then compared with data collected from carers whose loved ones had moved into full-time care settings. Finally, this data was compared to data collected from a mixed group of carers that also included two former carers.

Coding is the key process in grounded theory (Strauss and Corbin 1990, p12). According to Charmaz (2006, p46), *'coding is the pivotal link between collecting data and developing an emergent theory to explain these data.'* Coding occurs in stages. Initial coding begins in the early stages of data collection where the researcher generates as many ideas as possible inductively from the data. One way in which the researcher did this was by always writing a memo immediately after a focus group. The memo aimed to capture all her thoughts. The researcher then analysed the transcripts line-by-line and allocated labels, otherwise known as codes to the text. The codes represented concepts that later became part of the theory. In Grounded Theory the codes themselves provide meaning to the text and may be created by the researcher or may be taken from the text itself. These codes were then clustered into descriptive categories.

As the research progressed, the researcher continued to review the categories as further new data was collected, to ensure that data was not being forced into the categories but rather that the categories represented the data. This dynamic relationship between data collection and analysis enabled the researcher to check if preliminary findings remained constant when further data was collected.

Next came focused coding where the researcher pursued a selected set of descriptive categories throughout the entire dataset and the study. This required decisions about which initial codes were most prevalent or important, and which contributed most to the analysis. Situational analysis aided this process because it enabled the researcher to follow a structured process that on the one hand ensured all ideas were captured and coded and secondly provided a framework for surfacing the most important themes through the creation of the various situational maps and writing reflective memos throughout the process.

Categories are merely descriptions of the data, so they must be further developed to form the theory. In this study, once data saturation was reached, the categories were re-evaluated for their interrelationships and were gradually subsumed into higher-order categories via the situational analysis. This resulted in the identification of a set of 'core' categories around which the theory was built. The core categories were central in that all other categories related to them and they appeared frequently in the data. These core categories became a set of concepts that were related to one another in a cohesive whole and facilitated the understanding of a social world, thus suggesting an emergent theory (Sbaraini et al, 2011; O'Connor, 2012).

Grounded theory generates concepts by utilizing the logic of constant comparison and frequent memo writing (Glaser, 1978). The researcher used a process of writing memos throughout as a way of analysing the data and recording her thinking as it developed (Myers, 2009, p110). Theoretical sampling is informed by this process of coding comparison and memo writing. Analysis raises questions, suggests relationships, highlights gaps in the existing data and reveals what the researchers do not yet know. By carefully selecting participants and by modifying the questions asked in data collection (i.e. Theoretical Sampling), the researcher filled gaps, clarified uncertainties, tested her interpretation, and built an emerging theory (Charmaz, 2006, p24). The process of data collection and conceptualisation continued until categories and relationships were 'saturated', that is new data did not add to the developing theory (Glaser and Strauss, 1967; Strauss and Corbin, 1998).

An important feature of grounded theory is that it does not require checking whether participants agree with the researcher's interpretation of data. The process of theoretical sampling and constant comparative analysis requires that the researcher moves on to involve other groups who have different experiences to see if the findings hold as new data are collected (Seale, 1999, p92) Taken together, constant comparative analysis and data collection offer the researcher an opportunity of generating research findings that represent accurately the phenomena being studied (Strauss and Corbin, 1998, p297). This is the approach the researcher took in that she did not go back to the same participants to see if they agreed with the emerging themes. Instead the researcher shared emerging themes with new participants and facilitated a discussion that built on them.

Charmaz (2009, p139) argues that the aim of the grounded theorist is to gain an "*interpretive understanding of the empirical phenomenon*" so that the theory constructed will be credible, original, useful, and above all resonates and is relative to the "historical moment". This challenges the assumptions of generating a general abstract theory and instead suggests that the insight gained provides a one off picture of current relationships, social customs and power dynamics (El Hussein et al, 2014). This is an important point to keep in mind when reflecting on the findings from this study given how heavily the caring role is influenced by the social context, (e.g. family dynamics) within which it takes place and that it is possible that this context will change over time, (e.g. as the relationship between the carer and care recipient changes or as adult children leave the family home).

Below is a summary of the research process for this study. The blue squares relate to part one of the study, the green squares relate to part two of the study and the pink squares relate to part three of the study. A second diagram follows the first and provides a detailed summary of the Scoping Review process:

Figure 7: Research Process

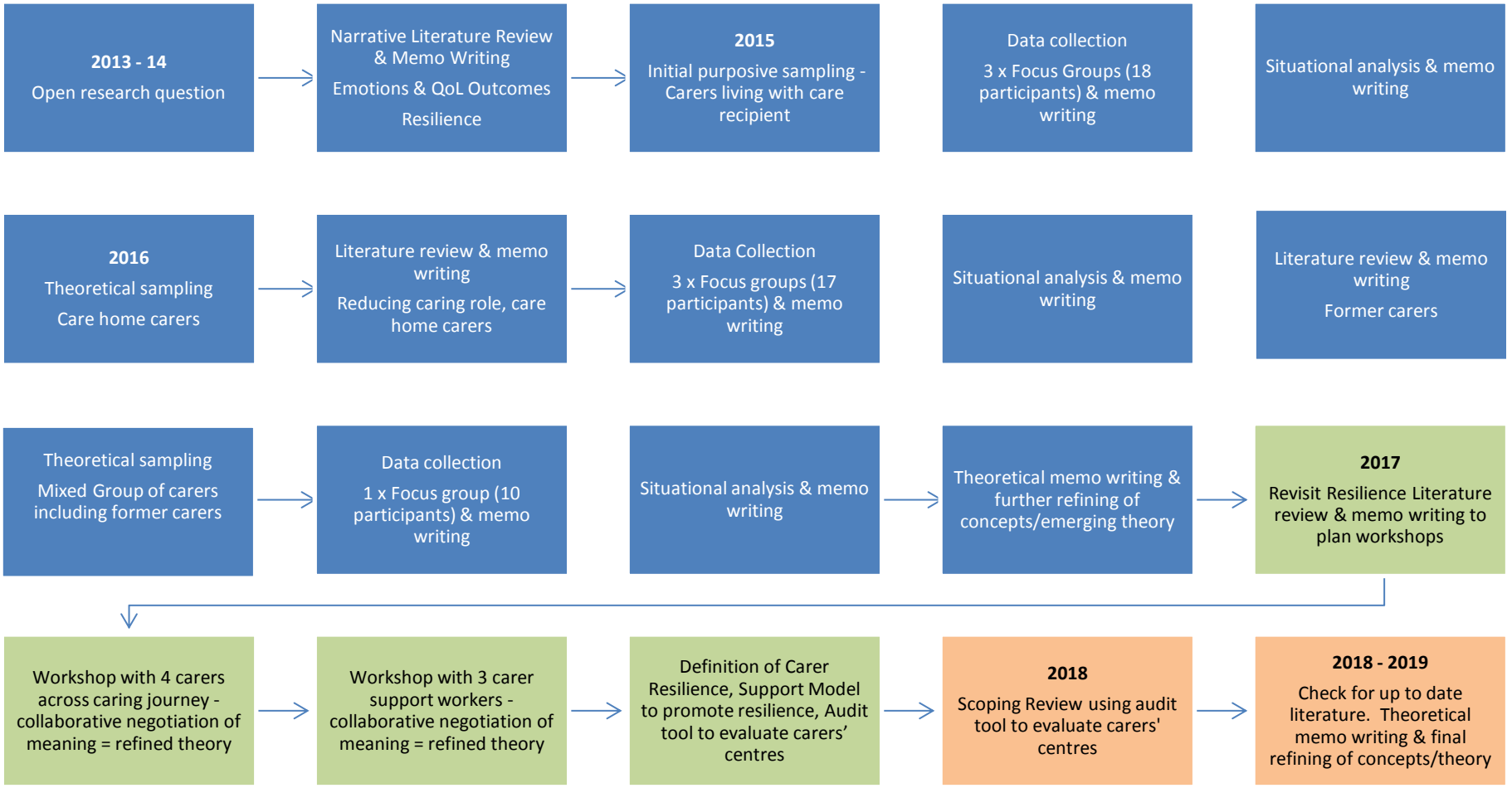
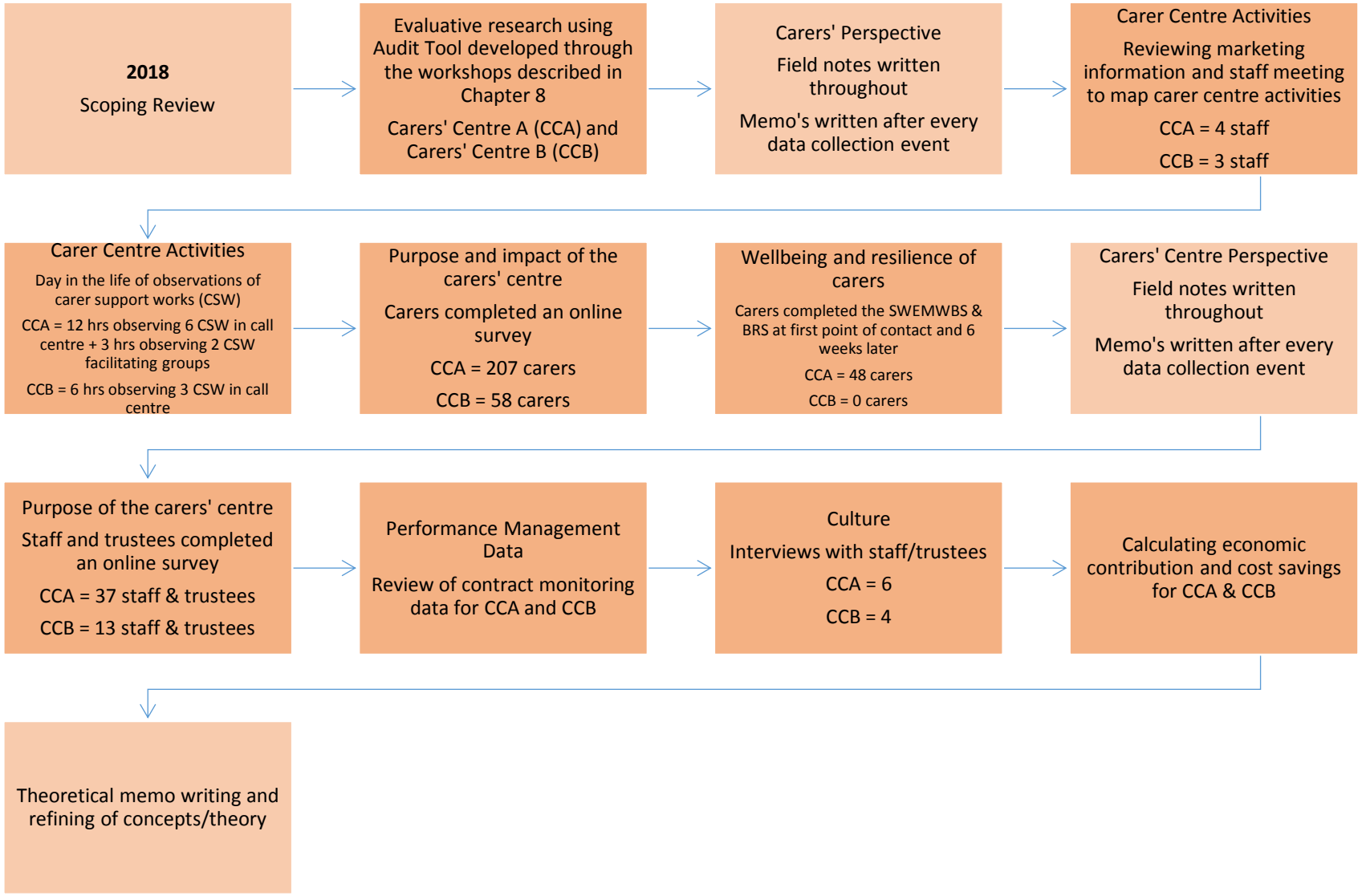


Figure 8 : Detailed Diagram of Scoping Review Process



3.2.1.1. Narrative Review Methodology

As with all narrative reviews, the narrative reviews in this thesis aimed to identify the gaps in the literature and helped to formulate the research questions. In a grounded theory study the narrative review is used to help the researcher reflect on the current context and the unanswered questions and this is how the narrative reviews were used in this research too. Narrative reviews are a more iterative process than either systematic or even meta-analysis reviews as the researcher searches for literature to 'fill in the gaps'. The gaps and the search criteria were identified using the grounded theory approach of reflecting on the literature using memos. The iterative nature of the literature review meant that when reviewing an article, the researcher identified cited references that might potentially 'fill in a gap'. These articles were obtained and reviewed and again if cited references that might fill in further gaps were identified in these articles, these too were obtained and reviewed. The researcher wrote reflective memos throughout which were later analysed and coded along with the rest of the data that was collected as part of the thesis.

Emotions and quality of life narrative review

Using the psycINFO, pubmed, web of science and google scholar databases the researcher searched for articles on the emotions and quality of life outcomes experienced by family carers. In the search for primary studies the researcher agreed the following combinations of search criteria with her supervisors:

Table 2: Emotions and QoL Review Search Terms

Date	Title	Keyword
1980 – 2013*	Carers	Quality of Life
1980 - 2013	Carers	Outcomes
1980 -2013	Carers	Emotions
1980 - 2013	Carers	Stress
1980 - 2013	Carers	Coping
1980 - 2013	Parents	Quality of Life
1980 - 2013	Parents	Outcomes
1980 -2013	Parents	Emotions
1980 - 2013	Parents	Stress
1980 - 2013	Parents	Coping

*2013 was the year the literature review was conducted.

The original searches looked for articles (peer reviewed journal articles and book chapters) from 2000 to 2013 but the low number of articles resulted in extending the year back to 1980. Non-English Language articles were excluded as were articles that were not available or could not be obtained. Titles and abstracts were read and articles were selected. Other reasons for exclusion included articles that focused on evaluating the effectiveness of interventions; or articles that did have carers or parents in the title but the focus on QoL, outcomes, emotions, stress or coping was minimal; or articles that were about these things but the subject was paid carers (not family carers) or parents of children who were not ill or disabled, or the focus was on

the experience of the care recipient not the carer. The researcher wrote reflective memos throughout the literature review as this was a key element of the data extraction process and analysis.

When the thesis was in its final stages six years later the researcher repeated the process to identify any recent literature. The same exclusion criteria were used. Memos were again written and reflected upon. The literature was incorporated into the narrative literature review.

At this point a further search was also done to specifically identify any research on carers as a whole group rather than silos of carers e.g. carers of people with dementia, MS, etc or parent carers, spousal carers etc. A summary of and reflection on this literature can be found in chapter 12.

Resilience narrative review

Using the psycINFO, pubmed, web of science and google scholar databases the researcher searched for empirical articles on resilience. In the search for primary studies the researcher agreed the following combinations of search criteria with her supervisors:

Table 3: Resilience Review Search Terms

Date	Title	Title
1980 – 2014*	Resilience	Model
1980 – 2014	Resilience	Concept
1980 -2014	Resilience	Definition
1980 – 2014	Resilience	Theory
1980 – 2014	Resilience	Framework

*2014 was the year the literature review was conducted.

Non-English Language articles were excluded as were articles that were not available or could not be obtained. Titles and abstracts were read and articles were selected. Other reasons for exclusion included articles that focused on evaluating the effectiveness of interventions on resilience; or articles that focused on developing measures for resilience; or articles that were focused on resilience in a science context. When the thesis was in its final stages six years later the researcher repeated the process to identify any recent literature on resilience. A summary of three key papers that built on earlier concepts was incorporated into the end of the narrative literature review and reflected upon in chapter 12. The researcher wrote reflective memos throughout the as this was a key element of the data extraction process and analysis.

3.2.1.2. Focus Groups Methodology

As mentioned in chapter 1, focus groups were the method of choice instead of interviews because bringing a homogeneous group together (in this case a group of carers) provides a stronger social context which offers an opportunity to see how ideas and language emerge in a more naturalistic setting than an in-depth interview (Bloor et al, 2001, p21). Whilst an interview can result in more detailed insight the

interactions between participants is important data in itself and cannot be collected in an interview. The need to understand the commonalities across carers and the fact that the range of different carers are rarely, if ever, brought together to discuss their experiences (as peer support groups are often constructed in silos e.g. parent carers, older carers, etc) made it even more important to capture the interactions between them. Focus groups enabled the researcher to test the level or lack of consensus in a way that individual interviews would not have done (Smithson, 2000). Far more insight into the commonalities across carers emerged because carers listened and responded to each other. This process resulted in very rich data about commonalities the extent of which was a surprise to the researcher, the carers and even the carer support workers who were present throughout.

For all the focus groups data were collected via audio-recording which ran the full length of the focus groups. The recordings were then transcribed.

After the consent forms were completed the researcher asked carers to introduce themselves and to tell the group who they cared for or had cared for (i.e. spouse, adult child, sibling, parent,etc) and the condition the person had that resulted in them needing care.

First set of focus groups – those living at home with the care recipient
Three focus groups were conducted. The researcher asked the groups three questions aimed at answering the first research question: *What are the current, common, lived experiences of carers across care groups & relationships?*

1) What tasks do you do as part of your caring role?
2) What roles do you play as part of your caring role?
3) What skills do you need / have you learnt as part of your caring role?

The researcher then asked the groups two further questions aimed at answering the second research question: *What are the specific emotions and quality of life outcomes that are common to carers across care groups & relationships?*

4) How does your caring role leave you feeling? What emotions do you experience?
5) What is the impact of your caring role on your life? What are the consequences for you?

The researcher then asked the groups two final questions aimed at answering the third research question: *How do carers across care groups & relationships describe resilience?*

6) What does resilience mean to you in relation to your caring role?
7) What does or would help you to be resilient?

Second set of focus groups – carers whose loved ones were living in full-time care settings

Three focus groups were conducted aimed at building on the emerging themes by involving carers in a different caring position to the carers in the first set of focus groups. The following questions were asked at each focus group:

- How would you describe resilience? What does it mean to be a resilient carer?
- On a scale of 1-10 how resilient are you? Why?
- Has your ability to be resilient changed since your caring role changed? Why? Why not?
- What factors played a part in the decision for your loved one to move into a full-time care setting.
- How were you left feeling? What were the outcomes for you?
- Do you wish anything could have been done differently? What and why?
- In what ways would it have impacted on your resilience then and now?

Third set of focus groups – Mixed Group

The purpose of the third set of focus groups was to test the emerging themes with a mixed group of carers who had not previously been involved with the research. In the end the researcher could only recruit enough participants for one focus group in this third set. The focus group explored whether the themes that had been identified resonated with carers still living with their loved ones, carers whose loved ones had moved into full-time care settings and former carers whose loved ones had died. The rational for a mixed group of carers centred on the desire to test whether data saturation had been reached. The following questions were asked at the focus group:

- How would you describe resilience? How does a resilient carer behave?
- Do you consider yourselves to be resilient? Can you give an example?
- How has your resilience changed throughout your carer journey?
- Researcher to summarise the theme 'THE skilled helper' – does this theme resonate with you? How does being THE skilled helper affect your ability to be resilient?
- Researcher to summarise the theme 'Hidden world' - does this theme resonate with you? How does the hidden world of the carer affect your ability to be resilient?
- Researcher to summarise the theme 'sense of loss' - does this theme resonate with you? How does your sense of loss affect your ability to be resilient?
- What helps you to be resilient?
- What reduces your resilience? What happens to your resilience when your loved one passes away?

As expected with focus group research, the questions for all focus groups were refined by the research process and were built upon based on responses from the participants. Open-ended questions were used to solicit the views and experiences of the participants. The discussion on each question continued until it seemed all discussion had been exhausted. At the end the researcher summarised the comments that had been made. This provided an opportunity for the researcher to

check that her interpretation of the comments was correct and to clarify anything that was unclear. The researcher then thanked the participants and discussed contact information and the intention to share the completed research with them.

3.2.1.3. Workshop Methodology

Whilst focus groups result in the generation of new ideas they do not usually aim to produce a specific outcome or product unlike a workshop. The workshop provides a context within which participants can negotiate to develop a collaborative understanding or meaning (Ørngreen and Levinsen, 2017).

Workshops are conducted by people with experience within the domain, and they promote genuine participation. By describing scenarios and discussing them in a structured way, the group dynamics can work productively to open up the issues. The participant group is kept small to allow everyone personal attention and the chance to be heard (Ørngreen and Levinsen, 2017).

Cornwall, and Jewkes (1995) distinguished four participation modes:

- contractual, whereby people are contracted by the researchers to participate in inquiries and experiments;
- consultative, whereby people are consulted regarding their opinions before interventions are made;
- collaborative, whereby researchers and participants work together, but with the researchers in control; and
- collegiate, whereby researchers and participants contribute in a mutual process controlled by the participants.

For the purposes of this research the collaborative mode was used enabling meaning to be negotiated. In this case the negotiated meaning focused on three interconnected products:

- Definition of carer resilience
- The model of support to sustain and/or promote carer resilience
- The audit tool for evaluating carers' centres

The workshops provided an opportunity to identify new factors at play and the relationships between them, which neither the participants nor the researcher had been aware of prior to the workshop.

3.2.1.4. Scoping Review Methodology

This was an exploratory, mixed methods, evaluative research scoping review. The resilience audit tool was used to evaluate the degree to which two carer's centres were geared towards promoting the resilience of carers and was used as the framework for the scoping review study. The scoping review aimed to answer the following research questions:

- What support aimed at promoting resilience does the carers' centre provide?
- Does the carers' centre improve and/or maintain the resilience of carers?
- Does the carers' centre improve and/or maintain wellbeing of carers?

- What cost savings does the carers' centre intervention result in?
- Is a more comprehensive evaluation of carers' centres required?

Carer Centre A was from the East-Midlands and Carer Centre B was from the West-Midlands. Both carers' centres had been involved in parts one and two of the research.

The logic model

Logic models have been used for at least thirty years and were recommended in official evaluation guidance (HM Treasury, 2011) as a method to support robust evaluation. Kaplan and Garrett (2005) described a logic model as a visual map of the relationship between the purpose of the service, it's resources, activities and intended results. McLaughlin and Jordan (1999) stated the benefits of using a logic model included:

- Helps to identify key metrics and data required to measure 'worth' and 'cost'
- Enables a standardised but flexible approach to evaluation
- Enables a shared understanding and supports communication between researchers and staff
- Supports formative evaluation by highlighting what is and isn't working
- Helps to identify what features of the service contributed to outcomes for customers (who in this case are carers)

The audit tool provided a framework upon which to build the logic model. The logic model below illustrates how the carer's centres were evaluated to explore whether the purpose of carers' centres was to promote resilience and how this related to the activities the carers' centres undertook, their resources and the outcomes they achieved for carers. The logic model outlines the data collection and analysis methods used to answer the research questions. The connection between the logic model and the audit tool is illustrated in appendix nine.

Figure 9: Logic Model

PURPOSE OR MISSION What is the purpose of the carer's centre?
Data Collection A Survey that asks 'What is the purpose of the carer's centre?' The survey collected data from: • The Governance Board • The senior management team • Carer support workers • Commissioners and other funders • Carers
Data Analysis Thematic analysis to explore what people thought the purpose of the carers' centre was and to identify the degree to which people thought the purpose was about maintaining or improving resilience using the carer definition of resilience = 'ability to continue caring or to move on by adapting roles and behaviours throughout the carer journey'.

INPUTS	ACTIVITIES	OUTPUTS	OUTCOMES
What were the resources used by the centre? E.g. • Finance • Staff • Buildings • Partnerships • Volunteers • etc	How did the centre use the resources? What information, advice and support did the centre offer to carers?	What evidence was there that the activities were performed?	What were the outcomes for carers? Was their resilience maintained or improved? What were the cost savings to the state?
Data Collection Workshop with the senior management team to map the resources.	**Data Collection** Workshop with the senior management team and carer support workers to map the activities. Review of the marketing information on the services available. Ethnographic 'day in the life of' observation of carer support workers.	**Data collection** Collating the data the carers' centre already collected e.g. number of referrals, demographics of carers, number of carers that access different types of support, complaints and compliments, annual carer survey, contract monitoring information.	**Data Collection** All new referrals for a period of 2 weeks were asked to complete the brief resilience scale and the short wellbeing questionnaire. The measures were repeated 6 weeks later. Online survey for carers asking about the impact the carers' centre had on them. Cost information collected from accounts and discussions with finance staff.
Data Analysis Summarised the inputs. Calculated the Unit Cost of the carers' centre.	**Data Analysis** Mapped the activities against the resilience audit tool. Content analysis on the marketing information and mapped it against	**Data Analysis** Benchmarked the reach (i.e number & demographics of carers) against the estimated prevalence of carers locally. Mapped the data the carers centre	**Data Analysis** Statistical analysis using SPSS for the resilience scale and wellbeing questionnaire. Thematic analysis of the online survey to identify

	the resilience audit tool. Thematic analysis on the notes from the carer support worker ethnographic observations and mapped it against the resilience audit tool.	already collected against the resilience audit tool.	the impact carers said the centre had on them. Financial calculations on economic contribution and savings to the state.
CONTEXT What is the context and culture (attitudes and beliefs) within which the carer's centre operates? **Data Collection** Used the resilience audit tool to structure interviews with the Chair of the Board, The CEO, 2 senior managers, 3 carer support works, 1 administrator.			
Data Analysis Thematic analysis mapped against the resilience audit tool.			

Field notes and memos were written throughout the scoping review. Situational analysis and theoretical memo writing was then undertaken at the end of the scoping review to refine the final theory and ascertain whether there was merit in undertaking a more comprehensive evaluation of carers' centres.

Data collection methods – The Carers' Perspective

There are a number of quality of life measures for carers that the researcher could have chosen to use including the Adult Social Care Outcomes Tool which has a section for carers (Rand et al, 2017). However, the focus of the research meant it was important to collect data specifically on resilience. Alongside resilience it was important to collect data on wellbeing not just because of the relationship between the two concepts which is discussed later in the thesis, but also because the central social care policy that directs both commissioning and frontline social care work for adults - The Care Act (2014) – puts wellbeing at its heart. The policy enshrines in law that the commissioning of services has to improve or maintain wellbeing for the population of concern and assessments for carers and care recipients are also based upon the person's current wellbeing and how to improve or maintain it. It therefore felt important to collect data specifically on wellbeing rather than quality of life more broadly. Although the researcher would have liked to have collected data on carer quality of life too but she needed to be mindful of the limited time and resources carer support workers had and the fact that they already collected data via their assessment process using the Carers Star. For this reason data on carers' quality of life using a standardised measure was not undertaken.

Quantitative data was collected to measure differences in the resilience and wellbeing of carers between the first point of contact and review 6 weeks later.

Short Wellbeing Questionnaire

A review of the literature highlighted a lack of standardised wellbeing measures for adults. The main one that surfaced was the Warwick Edinburgh Mental Well-Being Scale (WEMWBS) (NHS Health Scotland et al, 2006). It comprises of 14 positively phrased Likert-style items and was developed to measure changes in mental wellbeing when evaluating mental wellbeing interventions, something which government, services and researchers have become increasingly interested in. Usefully this measure had been incorporated in government health and social care outcomes frameworks (DH, 2013), so demonstrating effectiveness with this measure carried added value (Stewart-Brown, 2015). However, after piloting it was found to be too long and impractical for carer support workers to administer at the first point of contact with carers who were often distressed and in crisis.

The WEMWBS scale has since been developed into a shorter 7 item scale called the Short Warwick Edinburgh Mental Wellbeing Scale (SWEMWBS) (NHS Health Scotland et al, 2008) (see appendix ten). It has proved to be valid and reliable in measuring the overall wellbeing of a person (Stewart-Brown et al, 2009), although it does focus more on the positive psychological functioning, good relationships and self-realisation/acceptance than on factors of happiness and life satisfaction. On piloting this scale received a positive response by carer support workers and so it was used for the study.

Brief Resilience Scale

To decide which resilience measure to use the researcher reviewed the measures available. This process began by identifying potentially suitable measures using Windle et al's (2011) systematic review of 15 resilience measures. Windle et al's review identified 6 resilience measures that could be used with adults however 5 of them measured resilience as a personal characteristic. Only one, The Resilience Scale for Adults (Friborg et al, 2003) measured resilience as a dynamic process although it still didn't truly fit the carer definition of resilience. However, the multi-level nature of the measure that covered family support and cohesion, external support systems and dispositional attitudes and behaviours meant it was the most appropriate one to use. When it was piloted with the carer support workers though it was found to be too long and impractical to use at the first point of contact with carers for the same reasons as the wellbeing measure. Reviewing all the adult measures again resulted in the identification of the Brief Resilience Scale (BRS) (Smith et al, 2008) as it only had 6 questions instead of the 37 in the Resilience Scale for Adults. Whilst it did not cover all the domains of the RSA it was an outcome measure rather than purely a measure of personal characteristics. This was important as the key information the researcher wanted to collect was whether input from the carer's centre improved the outcomes for carers. During piloting the BRS gained a more positive response from the carer support staff and so was used instead.

The Brief Resilience Scale (BRS) (Smith et al, 2008) is a 6 item self-report questionnaire designed as an outcome measure to assess the ability to recover from stress (see appendix eleven). It has been proven to be valid and reliable in terms of measuring this aspect of resilience, but it focuses on the outcomes for individuals' rather than the availability of resources from the family and community which we know are also important factors when we conceptualise resilience as a dynamic process of adaptation to adversity (Windle, 2011). Within the carer model of

resilience there is an element of personal coping skills/attributes and ability to recover from stress which meant that the BRS was a relevant measure to use even though it was not all encompassing.

Purpose and impact of the carers' centre
An online survey was used to collect data from carers on their perspective of the purpose of the carers' centre and the impact the support from the carers' centre had on their resilience. Surveymonkey was used by both carers' centres to create the survey.

A link to the survey was sent out by the carers' centre to carers registered with the centre via their email addresses. The survey asked four key questions:

- What do you think the purpose of the carers' centre is?
- What impact has support from the centre had on your ability to keep caring?
- What has the centre been able to help you with?
- What has the centre been unable to help you with?

Data Collection Methods – The Carers' Centre Perspective
Mapping the carers' centre activities
The following methods were used to collect data on the carers' centre activities.

- Review of marketing information and staff meeting to map activities

All the marketing information published by the carers' centre was collated and reviewed to identify the activities advertised. The website was also reviewed, and activities advertised were cross-checked with the marketing information. The researcher then met with staff from the adult carer team to map out all the activities they engaged in. Again, this was cross-checked with the review of the website and marketing information.

- 'Day in the life of' (ethnographic) observations of carer support workers

Direct observation of the carer support workers was used to collect the data. (More information is provided about the observations for each carers' centre in the results section). To enhance objectivity, and to overcome the bias of the researcher's personal perspectives, the researcher was clear and transparent about her role and perspectives with all those she observed. The only other people in the environment when the observations took place were the carers seeking support or advice. The carers were always asked whether they were happy for me to observe the carer support worker and reassured that I could stop observing at any time if they wanted me to. Furthermore, to ensure that the data collected was as in-depth as possible the researcher was careful to record everything she could including body language and what was happening in the background (Fusch et al, 2017). Field notes were used as a way of recording the data in situ (see appendix twelve). After the observations, memos were written that reflected upon the field notes and were used to help identify themes and patterns. The questions driving the observations centred around the first domain of the audit tool 'Relationship with the care recipient' and looked at how well the carer support workers supported carers to navigate their changing relationship with the care recipient, how well carers were supported to manage any feelings of loss, guilt or shame and how well carers were supported to understand their caring role and the impact it had or might have on their quality of life

now and in the future. The details of the observations for each carer centre are outlined below:

- Carer Centre A - The 'day in the life' observations of carer support workers involved observing six carer support workers undertaking their main activity which was answering the phones to carers calling in for advice or ringing carers in response to a referral. The carer support workers were observed for four hours on three separate occasions. Two facilitated, peer support groups were also observed. The support groups were facilitated by two different carer support workers.
- Carer Centre B - The researcher undertook 'day in the life observations' for three hours on two separate occasions. On both occasions the three carer support workers were mostly sat at their desks working on their computers. Conversations with them and the CEO revealed that since the cut in funding and the restructure of the service, carer support workers no longer facilitated the peer support groups or did 1:1 face to face visits with carers. Furthermore, there had also been a reduction in the number of calls coming into the office (on the observation days only a handful of calls were received) and a reduction in the number of carers popping into the centre.

Purpose of the carers' centre

An online survey was used to ascertain what staff felt the purpose of the carers' centre was and how this compared to the concept that carers' centres should aim to increase or maintain carer resilience (as defined by carers). The online survey was sent to the trustees, senior managers and carer support workers. Originally it had been agreed that the survey would also be sent to the commissioner but due to tensions around funding for both carers' centres it was agreed that this perspective would be gathered by examining the contracts with the councils.

Participants were asked to answer the following questions:

- In your opinion, what is the purpose of the carers' centre?
- What should the carers' centre achieve for carers?
- What should the carers' centre achieve for funders?

Performance management data

Data were collected on the business aspects of the carers' centres using the contract monitoring information required by the councils. The data were collected by the carers' centre and shared with the researcher. The data included information on the number of registered carers, new referrals and the number of times the carers' centre provided information, support or an activity to carers.

Culture

Open-ended question interviews were conducted with Trustees and staff with the aim of gaining insight into perceptions of the current and desired context and culture. The researcher used the same set of questions for each interview although these were expanded upon when exploring the answers provided.

Data were collected via audio recording which ran the full length of the interviews. The interviews were then transcribed. For the purposes of the evaluation the transcriptions were first coded and analysed using thematic analysis.

An email was sent out to staff and trustees inviting them to participate in the interviews. The email contained the information sheet and instructions on how to get involved. The carers' centres scheduled the interviews. At the start of each interview the researcher talked through the information sheet and the consent form being careful to explain that the participant could withdraw at any time without fear of repercussions. If the participant was happy to proceed they signed the consent form and the researcher turned on the audio recording equipment. The researcher then asked the following questions during each interview:

- What is the aim of the carers' centre?
- To what degree do you think the carers' centre currently achieves that aim?
- If you had all the resources you needed, what would be your vision going forward?
- What would need to be different for that to happen?
- (Having shown the interviewee the model and audit tool ask) What activities does the carers' centre currently do in each of these areas? Are there any barriers?
- Do you have any other comments?

Cost Analysis
The cost analysis aimed to answer the following questions:

- What economic investment are local authorities making in support for carers given the huge economic contribution carers make?
- Do carers' centres result in fiscal benefits i.e. savings to commissioners' budgets?

The first question was explored by calculating the economic contribution made by carers using Buckner and Yeandle's (2015) methodology and comparing it to the investment commissioner's made in the main intervention for carers i.e. the carers' centre. Quantifying the economic value of carers' support is critical. It serves as an economic measure which, if it fluctuates, has significant implications for what the state may have to provide. Buckner and Yeandle (2015) calculated the economic contribution of carer populations across each council footprint using carer prevalence rates (based on 2011 census data) to estimate the number of 'caring hours' and multiplied it by the average hourly rate for homecare.

(Note: this is phrased as economic contribution rather than savings to the council because even if family carers were not providing care, some care recipients would not receive council funded services as an assessment of their finances would place them above the financial threshold and they would have to pay for their own care).

The second question was then explored by first ascertaining whether, if the carers' centre did not exist and carers were not supported would some carers be likely to stop caring? A survey was used to calculate the number of carers who were likely to stop caring if the carers' centre could no longer support them. Then, the information

contained in the 'Supporting public service transformation: cost benefit analysis guidance for local partnerships' (New Economy et al, 2014) on the fiscal benefits for reducing admission to residential care was applied to the number of carers who stated that they would be unable to continue caring without support from the carers' centre. New Economy et al (2014) calculated the fiscal benefits i.e. savings to the council for a variety of outcomes that might be achieved by an intervention. These outcomes included things such as a reduction in alcohol dependency, a reduction in children in care, a reduction in hospital admissions, etc. One of the outcomes they calculated the fiscal benefits for was a reduction in admission to residential care. They calculated that on average 67% of the costs of residential care fall to the local authority and 33% of the costs fall to the individuals themselves or their families. The majority of carers' who participated in the survey were caring for over 50 hours a week and this level of care meant it was reasonable to assume that the care recipients would need residential care. Furthermore, New Economy et al (2014) have not made any calculations for the fiscal benefits for reducing home care so this calculation was not an option.

Data analysis methods

Qualitative data analysis
Initial thematic analysis was used to analyse the data including the researcher's field notes and memos. Chapters 10 and 11 summarise the findings from the initial thematic analysis. The data was then combined with the data collection from parts one and two and situational analysis was undertaken in keeping with the grounded theory nature of this research. The results of the situational analysis are presented and reflected upon in the final chapter (chapter 12) where a final project map, a final model of support for promoting carer resilience and a discussion on the merit of a more comprehensive evaluation of carers' centres are presented.

Quantitative data analysis
Statistical analysis (using SPSS) was used to analyse the data collected via the SWEMWBS and the BRS. Wilcoxon Signed Rank Test was used to test changes in resilience between initial contact and review. Pearson's Correlation was used to test the relationship between resilience and wellbeing.

3.2.2 Empirical grounding of findings

In situational analysis there is a focus on understanding how discourse within the situation of inquiry produces power, control and ideologies that shape, influence and construct the individuals/groups within the situation of inquiry. In Clarke's method of situational analysis diagrams are radically transformed, into maps that are the basis for higher-level analysis (Clarke 2005, p85). Situational analysis provides a systematic approach to analysing the data from the focus groups. This approach adds academic rigour by providing validity in terms of traceability from initial data coding to final theory.

The transcripts for all focus groups in part one were coded line by line producing initial codes (see Appendix seven for an example). The data was then analysed using situational analysis to produce a situational map. The situational map identifies which human (individuals, communities, organisations) and non-human elements (discourses, debates, objects, structures) informed the research enquiry: "Who and

what are in the situation? Who and what matters in this situation? What elements 'make a difference'?" (Clark 2005, p. 87). Both situational analysis and grounded theory use memos as a way of surfacing emerging themes. Using situational analysis within a grounded theory approach for this thesis meant that during the coding and analytical process, memos were made to capture thoughts, ideas and to reflect on links with the literature review which in turn led to new codes (see Appendix eight for an example).

In situational analysis, the situation is the unit of analysis; in this case, carers lived experience of the caring role and the correlations with their description of resilience. The situational map identifies the major elements of concern in the research. This initial map is exploratory in nature and aims to capture the messy complexity of the situation, and relationships between key human and nonhuman agents (Clarke, 2003, p539). An example of a situational map can be found in section 4.3.1.

Following Clarke's method (2005) the next step was to create an abstract, ordered version of the map, using organising categories (Clarke, 2005, p90). These categories signify general orders, i.e. orders that can be used in other research projects that may generate new elements and are another way of thoroughly examining the situation of enquiry. The categories are illustrated in the table below:

Table 4: Template for ordered map

Individual human elements/actors (e.g. key individuals and significant people in the situation)	**Nonhuman elements/actants** (e.g. technologies, materials, knowledge, infrastructure)
Collectives human elements/actors (e.g. particular groups, specific organisations)	**Discursive constructions of individual and/or collective human actors**
Key events in the situation	**Implicated/silent actors/actants**
Political/economic elements (e.g. the state, particular industries, political parties)	**Discursive constructions of nonhuman actants**
Temporal elements (e.g. historical, seasonal, crisis and/or trajectory aspects)	**Socio-cultural/symbolic elements** (e.g. religion, race, sexuality, gender, ethnicity, nationality)
Major issues/debates (usually contested)	**Related discourses (historical narrative, and/or visual)** (e.g. normative expectations, moral/ethical elements, mass media, popular cultural discourses)
Other kinds of elements	**Spatial elements** (e.g. spaces in the situation, geographical aspects)

Sticking to the process of grounded theory and situational analysis, memos were used throughout the process of creating the ordered map as a way of capturing commonalities between codes. Clarke (2005, p89) clearly states that there is no need to have all categories from the messy situational map in the ordered situational map because what appears in the ordered situational map should be based on the researcher's situation of enquiry. Furthermore, the ordered situational map should

undergo several iterations throughout the life of the research. Some codes will move among categories and some codes will appear in more than one category.

Following Clarke's (2005) method the next step was relational analysis. Codes were reviewed to decide on the most important codes to retain and to further cluster them by commonality thus producing emerging themes. The relational analysis goes on to identify the connections between the emerging themes. An example of a relational analysis map can be found in section 4.3.2.

The next step was to create social arena/world map(s). These maps aim to identify the social worlds that exist within the arena of concern. Analysis of social worlds recognises that people do not exist in a vacuum, but are shaped by their social worlds and the social discourses that prevail. The maps themselves allow social worlds to be identified and the connections and activities between social constructions and social groups surface. Once the social worlds become visible they can be analysed via memos (Clarke, 2005 p110). Social worlds are actor defined and the connections and activities between them are due to their interdependence.

The collective and individual human actor sections in the structured map were used to create a list of social arenas. A memo was written on each of the arenas that outlined what the focus of the arena was, the social worlds present and not present, the hot issues/contested topics and any gaps/silences. A memo was then written on each social world that described what the work of the world was, how the world presented itself, what actions the social world undertook, how the work of furthering that social world's agenda was organised and the technologies used (Clarke, 2005, p110). An example of a social world map can be found in section 4.3.3.

Positional maps were then used to explore the different positions taken in discourses across social worlds. Positions are not correlated with groups of people or organisations which is a useful way of avoiding bias and stereotypes. An example of a positional map can be found in section 4.3.4. The significant discourses that emerged were identified on the structured map. Reviewing field notes and memos enabled the researcher to identify for these significant discourses, the different opinions that had been voiced. These different opinions were then mapped using positional mapping.

The various maps were continually added to and refined throughout the life of the research project. In the final chapter of this thesis, when the maps were fully saturated, they were pulled together into a final project map that summarised the main findings. Clarke (2005, p137) states that final project maps draw upon the other three kinds of maps but no longer further the analysis. Instead they are maps tailored to illuminate aspects of the project to intended audiences. The project map should provide an analytical account and supply audiences with an accessible big picture into which individual aspects can be placed. The final project map for this thesis can be found in section 12.2.

3.3 Reflection and memo writing

As mentioned above reflection is a central theme in grounded theory. Situational analysis provided the framework for integrating the data and reflecting on the various discourses within the situation of inquiry. Memo writing is a core aspect of grounded theory and hence situational analysis. Memo writing requires the researcher to reflect and so a model for reflection was used to do this. There are a wide variety of models and they all have strengths and weaknesses resulting in contexts where they are best applied.

For the purposes of this study the Rolfe et al (2001) Framework for Reflexive Learning was used. The framework is based on the three "What? So what? Now what?" questions, but repeats these questions at three levels, with increasingly deeper reflection at each level. The levels are descriptive, theoretical and action-orientated and therefore provided a useful way of structuring the memos for this research.

Theoretical sensitivity is an important skill, necessary for successfully using grounded theory. Using the Rolfe et al, (2001) reflective framework helped to provide the researcher with a structured approached to memo writing which in turn helped her to interact with the data and the emerging ideas rather than taking a distanced view that could have resulted in the researcher making assumptions based upon her own bias.

Mitigating the risk of bias also required careful coding and analysis, and critical feedback from others including supervisors, stakeholders involved in the research and other academics in the research community which the researcher did build in time for.

4 Chapter 4: Part One – First Set of Focus Groups

The purpose of the first set of focus groups was to build upon the themes identified from the review of literature on the emotions and QoL outcomes of carers by collecting data on the current, lived experience of carers across care groups and relationships. The aim was to explore the nature of the caring task and to investigate the emotions and outcomes carers experience. Moreover, to do this by bringing together a range of carers who differed in age, gender, ethnicity, the relationship they had with the person they cared for and the nature of the condition of the care recipient. Within the context of the grounded theory approach the study aimed to use focus groups and situational analysis to answer the following research questions:

- What are the current, common, lived experiences of carers across care groups & relationships?
- What are the specific emotions and QoL outcomes that are common to carers across care groups & relationships?
- How do carers across care groups & relationships describe resilience?

4.1 Focus Groups

Three focus groups were conducted. Data were collected via audio-recording which ran the full length of the focus groups. The recordings were then transcribed.

4.1.1 Participants

For the three focus groups conducted, the aim was to recruit between six and ten participants for each group. The only criterion for participation was that participants were adult carers living with the person they cared for.

Participants were recruited by reaching out to local carer support organisations and using referral sampling whereby the carer support organisations recruited participants from among the carers they knew. This was an appropriate method for recruiting participants for this study because it helped the researcher gain access to a population that can otherwise be hard to reach.

A total of 18 participants, including 15 women and 3 men participated in the three focus groups. All participants were White British, reflecting the area of the country. The participants ranged in age from 38 to 81 years old (with an average age of 55 years). Participants were either caring for their adult children, their parents or for their spouses. The conditions of the care recipients that participants were caring for included learning disabilities, mental health conditions, dementia, multiple sclerosis, physical disabilities, autism, Parkinson's and cancer. Comparing the demographics to those of the respondents to the Carer UK (2018) State of Caring Survey (see Introduction to thesis) suggests that the participants involved in the focus groups were a representative sample of carers.

Table 5: Demographic Characteristics of Participants

Participant Number	Gender	Age range	Who they cared for	Condition requiring care
1	Female	41 - 65	First son Second son	Downs Syndrome Autism
2	Male	66 - 75	Wife	Multiple sclerosis
3	Female	41 - 65	Son	Autism
4	Female	66 - 75	Husband Father-in-law	Alzheimer's Alzheimer's
5	Female	41 - 65	Son	Autism
6	Female	41 - 65	Son	Autism
7	Male	≥ 75	Wife	Cancer
8	Male	≥ 75	Wife	Dementia
9	Female	66 - 75	Husband	Parkinson's
10	Female	41 - 65	Daughter	Learning Disability
11	Female	≥ 75	Son	Schizophrenia
12	Female	41 - 65	Son	Schizophrenia
13	Female	≤ 40	Husband	Chronic fatigue Syndrome & post-traumatic stress-disorder
14	Female	41 - 65	Husband Daughter	Quadruple amputee Bi-polar disorder
15	Female	≤ 40	Son	Learning disability
16	Female	41 - 65	Daughter	Leiber's Congenital Amourosis
17	Female	41 - 65	Son	Cerebral palsy, learning disability, blind, quadriplegic
18	Female	66 - 75	Husband	Kidney failure

4.1.2 The Structure of the Focus Groups

The first focus group had 10 participants, three men and seven women and was held at a carers' centre in a market town in the West-Midlands. The participants ranged in age from 46 to 81 years of age. The second group had 4 participants, all women and was conducted at a carers' centre in a large town in the East-Midlands. The participants ranged in age from 40 to 72 years old. The third focus group had 4 participants, again all women and was conducted in the home of one of the participants in the South-west. The participants ranged in age from 38 to 62 years old. Each focus group was scheduled for two hours.

4.1.3 Data Collection

After the consent forms were completed the researcher asked carers to introduce themselves and to tell the group who they cared for (i.e. wife, adult daughter, husband, etc) and the condition of the person they cared for, which resulted in them needing care.

The researcher then asked the group the questions outlined in section 3.2.1.1. A summary of the answers to each question can be found in appendix six.

4.2 Data Analysis

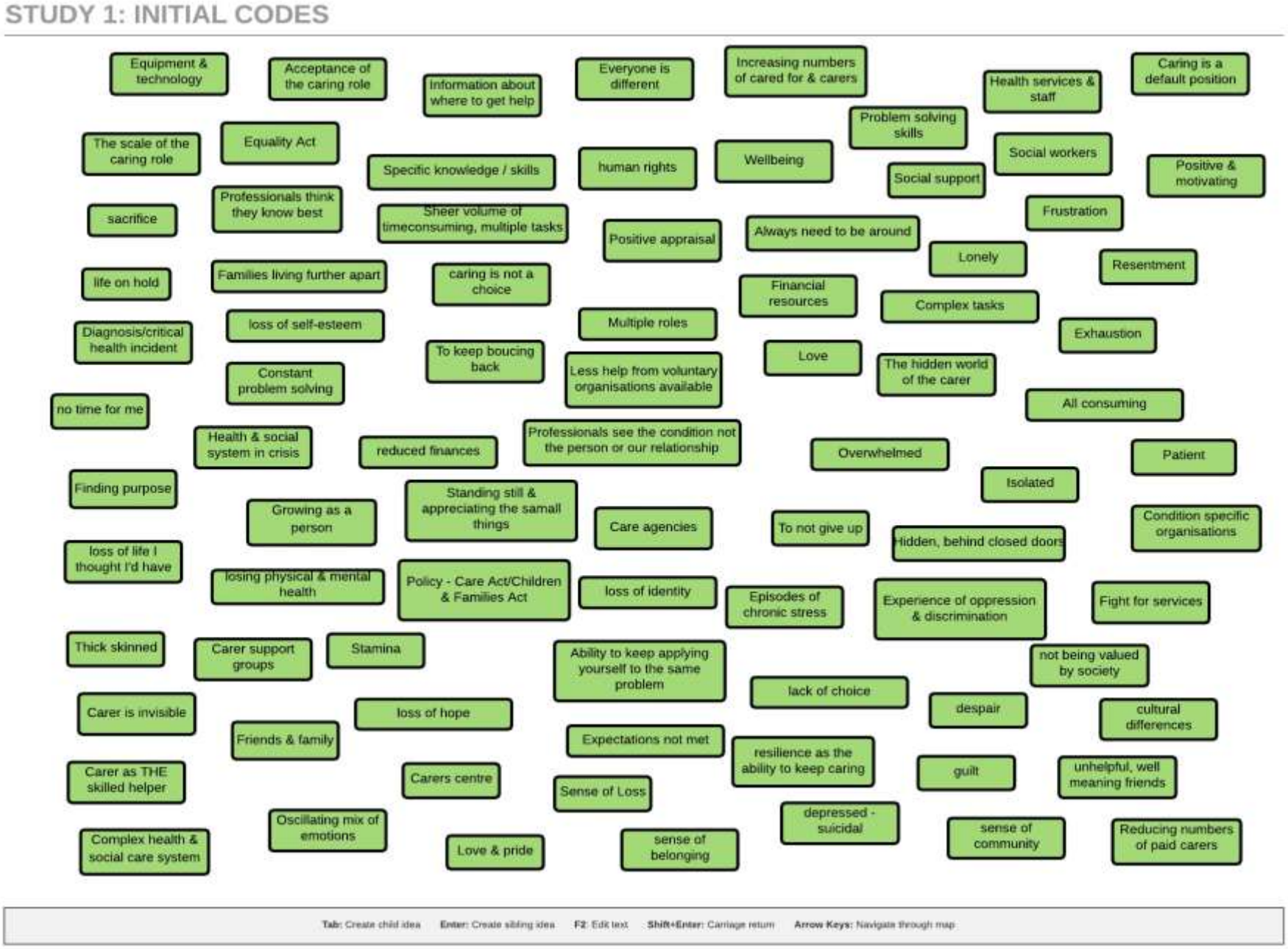
Situational analysis was used to surface emerging themes. The transcripts were coded line by line producing initial codes.

4.2.1 Situational map

The first step of the situational analysis produced a situational map that identified "Who and what were in the situation? Who and what mattered in this situation? What elements 'made a difference'?" (Clarke 2005, p. 87). Using situational analysis within a grounded theory approach meant that during the coding and analytical process, memos were made to capture thoughts, ideas and links with the literature review which in turn led to new codes.

Figure 10 shows the early 'saturated' situational map; many different versions have preceded this one and its production was therefore a re-iterative process.

Figure 10: First set of focus groups - Situational Map



Following Clarke's method (2005) the next step was to create an abstract, ordered version of the map, using organising categories from Clarke (2005, p90). Taking the elements in the early map, an ordered version of it is presented in Table 6 below.

Table 6: Ordered Situational Map

Individual human elements/actors (e.g. key individuals and significant people in the situation) ▪ Carer ▪ family member cared for	Nonhuman elements/actants (e.g. technologies, materials, knowledge, infrastructure) ▪ equipment and technology ▪ condition specific knowledge/skills ▪ information about where to get help from ▪ complex health and social care system ▪ carers' centres
Collectives human elements/actors (e.g. particular groups, specific organisations) ▪ family ▪ friends ▪ carer support groups/organisations ▪ care agencies ▪ health services and staff – GPs, community nurses, hospital staff ▪ social workers ▪ condition specific organisations e.g. Alzheimer's society	Discursive constructions of individual and/or collective human actors i.e. discussions about people ▪ carer is invisible ▪ professionals think they know best ▪ professionals see the condition not the person or the relationship between carer and cared for ▪ everybody is different ▪ a person does not choose to be a carer, it is a default position ▪ volume and complexity of tasks ▪ multiple roles of the carer ▪ carer as THE skilled helper
Key events in the situation ▪ critical health incident e.g. stroke ▪ diagnosis ▪ start of the caring role ▪ acceptance of the caring role ▪ changing the caring role	Implicated/silent actors/actants ▪ silent voices of carers ▪ hidden world of the carer ▪ sacrifice ▪ life on hold ▪ loneliness ▪ isolation ▪ despair ▪ depressed – suicidal ▪ resentment ▪ Well-meaning but unhelpful friends/family
Political/economic elements	Discursive constructions of nonhuman actants i.e. discussions about concepts

(e.g. the state, particular industries, political parties) ■ financial resources ■ new policy e.g. Care Act/Children and Families Act ■ human rights and equality act ■ less help from voluntary organisations available	■ resilience as the ability to keep caring ■ coping and episodes of chronic stress ■ sense of loss ■ love ■ oppression and discrimination ■ loss of self-esteem ■ ability to bounce back ■ ability to keep applying oneself to the same problem – perseverance ■ ability to be positive and motivating towards the cared for person ■ constant problem solving ■ scale of the caring role
Temporal elements (e.g. historical, seasonal, crisis and/or trajectory aspects) ■ increasing numbers of people needing care ■ increasing numbers of carers ■ reducing numbers of paid carers (Brexit) ■ health and social care system in crisis ■ no time for me ■ life on hold/loss of life I thought I'd have ■ oscillating mix of emotions ■ loss of hope over time ■ continuing and not giving up ■ standing still and appreciating the small things ■ finding purpose and growing as a person ■ losing physical and mental health	Socio-cultural/symbolic elements (e.g. religion, race, sexuality, gender, ethnicity, nationality) ■ families living further apart ■ changing expectations about caring responsibilities towards parents, spouses, etc ■ sense of community ■ sense of belonging ■ sense of identity ■ cultural differences related to expectations about caring responsibilities ■ social support
Major issues/debates (usually contested) ■ carers not being valued by society ■ carers not being involved in discussions about care ■ importance of wellbeing ■ building the personal resilience of carers is the solution	Related discourses (historical narrative, and/or visual) (e.g. normative expectations, moral/ethical elements, mass media, popular cultural discourses) ■ Discourses on relationships ■ Discourses on caring as a choice

▪ where does the relationship end, and the caring role begin e.g. the line between being spouse or carer, parent or carer, daughter or carer? ▪ Fight for services ▪ Lack of choice for support/services	▪ discourses on social care as the place of last resort ▪ discourses on lifestyle ▪ discourses on wellbeing ▪ discourses on resilience ▪ discourses on coping and positive appraisal ▪ discourses of person-centred care ▪ discourses on oppression and discrimination
Other kinds of elements ▪ personal attitudes and emotions ▪ guilt ▪ loss ▪ resentment ▪ Love and pride ▪ growing as a person ▪ exhaustion ▪ frustration ▪ overwhelming ▪ expectations not met ▪ stamina ▪ thick skinned ▪ patience	Spatial elements (e.g. spaces in the situation, geographical aspects) ▪ accessible communities ▪ carer friendly employers ▪ caring happens out of sight, in people's homes, behind closed doors ▪ the gap between expectations of how life was going to be and the reality of how life has turned out ▪ discussion is missing on the impact the caring role has on the original relationship between the carer and the cared for ▪ always need to be around/available to the care recipient ▪ all consuming

Sticking to the process of grounded theory, memos were used throughout the process of creating the ordered map as a way of capturing commonalities between codes.

4.2.1.1. Reflections on the situational mapping and memo writing

What did the situational mapping reveal?

The situational mapping identified several initial codes that seemed important. These included:

- The carer is invisible
- Professionals think they know best
- Professionals see the condition of the care recipient, not the person or the relationship between carer and care recipient
- A person does not choose to be a carer, it is a default position
- Carers perform a huge number of tasks with a wide range of complexity

- Carers perform multiple roles for the care recipient
- The carer's world is hidden

Within this hidden world carers sacrificed, put their life on hold, experienced loneliness and isolation, felt despair and depressed, experienced resentment and often unhelpful support from well-meaning friends and family.

Carers said resilience was the ability to keep caring. Things that impacted on their ability to keep caring included:

- Coping with episodes of chronic stress
- Dealing with a sense of loss
- Their ability to continue to love
- Experiences of oppression and discrimination
- The loss of self esteem
- Their ability to bounce back and to keep applying themselves to the same problem i.e. their perseverance
- Their ability to motivate the care recipient
- Their problem-solving skills
- The impact the sheer scale of the caring role has on them

Carers described an oscillating mix of emotions coupled with the loss of hope over time and yet an ability to continue and not give up whilst often losing both their physical and their mental health.

The invisibility of carers left them not feeling valued by society and not always being involved in discussions about the care of the person they cared for. Carers consistently recounted stories of fighting for services and a lack of choice in the services or support they got.

Carers reported that caring was often seen by professionals as a choice but by carers as part of their duty due to the nature of the relationship they had with the care recipient e.g. spouse, parent, etc.

There seemed to be blurred lines about the differences between resilience, coping and wellbeing. Carers seemed to relate coping to individual situations and resilience to the ability to keep caring in the longer term. Carers described an ability to keep caring and hence be resilient whilst also experiencing a loss in their sense of wellbeing.

There seemed to be a gap between expectations of how life was going to be and the reality of how life had turned out that resulted in a sense of loss for the carer. There seemed little opportunity for carers to discuss the impact the caring role had on their original relationship with the person they cared for. There were blurred lines between where the relationship ended, and the caring role began.

For many the caring role was all consuming and required carers to be constantly available to meet the needs of the person they cared for at a moment's notice.

What new understanding surfaced through the situational mapping?

It became increasingly clear throughout the analysis that the hidden emotional and practical life of carers was a strong theme and one that had a huge impact on the way carers perceived themselves and were perceived by society. The invisibility led to a tendency by professionals to dismiss or ignore the role they played and the sacrifices they made.

This lack of insight by professionals seemed to result in a very simplistic view of the tasks carers engaged in and the support they needed due to the impact the caring role had on their lives and their relationships. The fact that these consequences seemed to be common across care groups and relationships is new insight that has not previously surfaced.

There was a strong theme emerging around identity, changing identity and loss of identity. Again, the impact that the caring role had on the carers' sense of identity across care groups and relationships has not been previously examined. Yet it was clear from the analysis here that the carers' sense of identity was strongly connected to the degree to which they felt overwhelmed or out-of-control and their ability to keep caring.

The situational analysis also allowed themes to surface around the need for carer-friendly communities, workplaces and services. The analysis clearly highlighted that no matter how good at problem solving and staying positive a carer was, if the community around them was not carer friendly then their ability to continue caring over time was compromised.

The theme of oppression and discrimination due to the lack of equal opportunities and flexible services surfaced through the data analysis. It was clear that carers did not experience the ability to access the things they enjoy and need if those things cannot afford them maximum flexibility because the caring role demanded maximum flexibility.

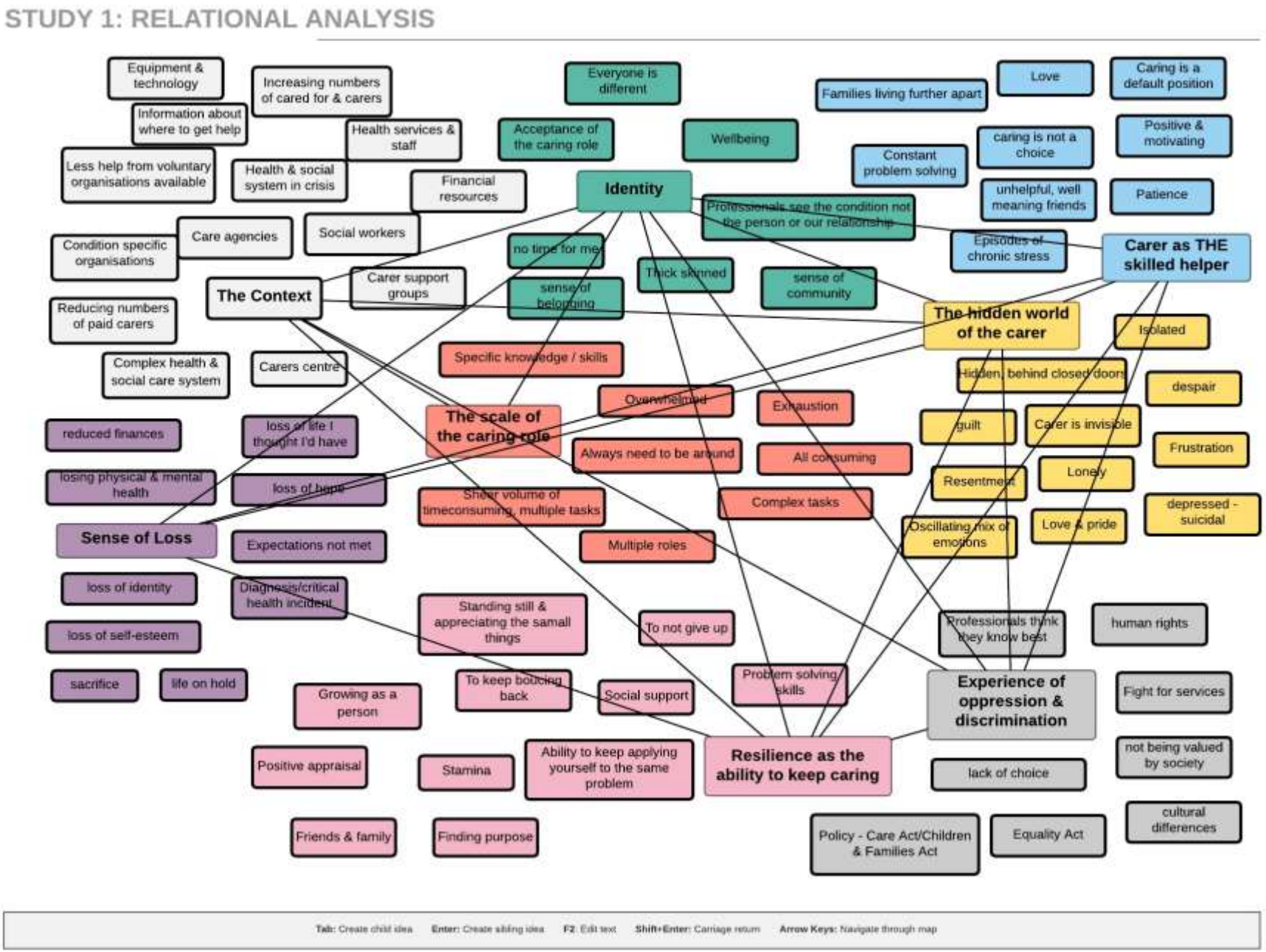
4.2.2 Relational map

Following Clarke's (2005) method the next step was relational analysis. Codes were reviewed to decide on the most important codes to retain and to further cluster them by commonality thus producing emerging themes:

▪ **The context** ▪ **Identity** ▪ **Carer as the Skilled Helper** ▪ **The Hidden World of the Carer** ▪ **The Scale of the Caring Role**	▪ **Sense of loss** ▪ **Experience of discrimination and oppression** ▪ **Resilience as the ability to keep caring**

The emerging themes and the link back to the initial codes are illustrated on the map below using a different colour for each emerging theme. The relational analysis goes on to identify the connections between the emerging themes. This is illustrated by using lines to connect the emerging themes (see Figure 11).

Figure 11: First set of focus groups - Relational Map



4.2.2.1. Reflections on the relational mapping and memo writing

What did the relational mapping reveal?
The relational map identified eight emerging themes:

- The scale of the caring role
- The skilled helper
- Sense of loss
- The hidden world of the carer
- Resilience as the ability to keep caring
- Identity
- The context
- Experience of oppression and discrimination

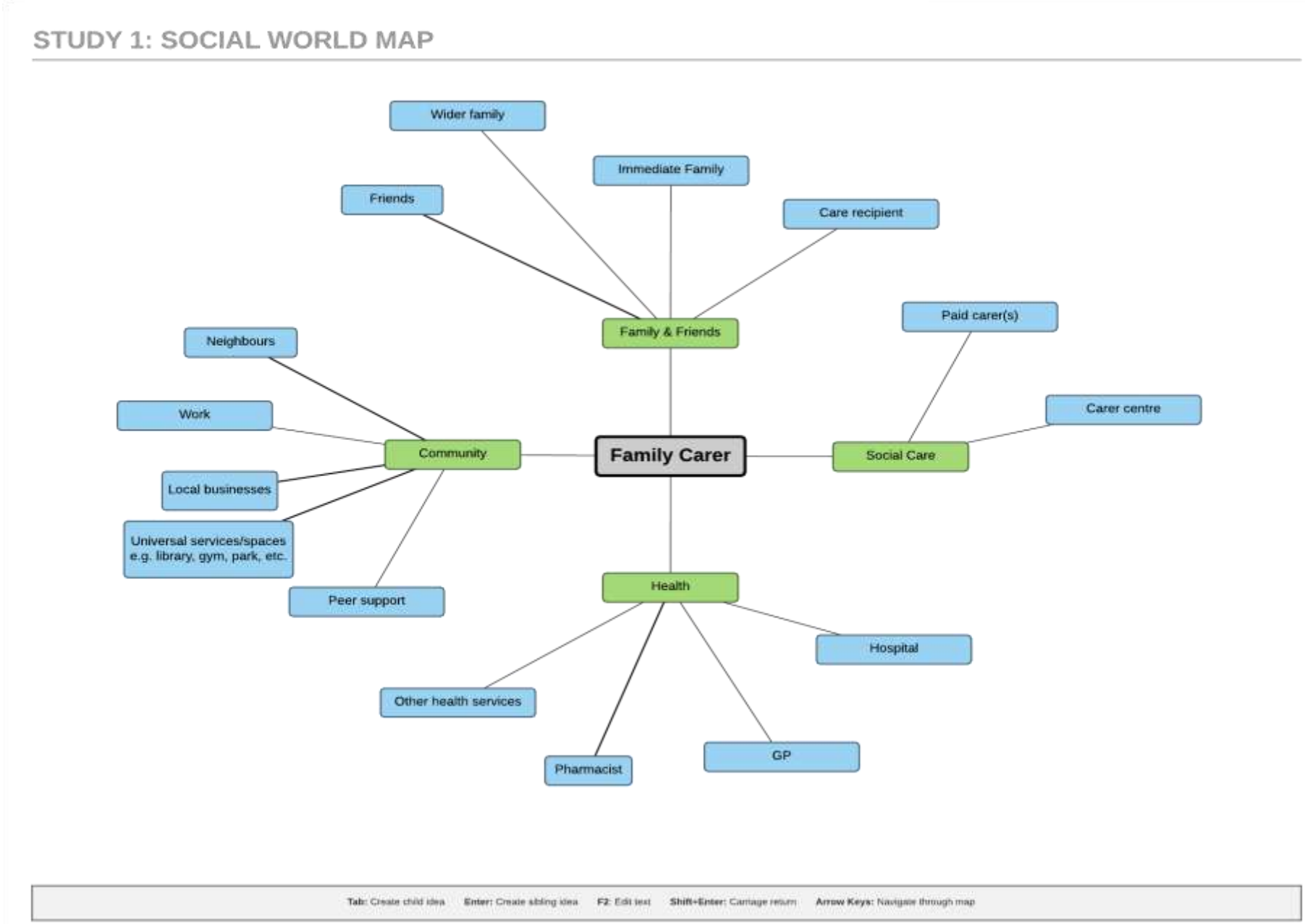
What new understanding surfaced through the relational mapping?
The range of common themes across carers (i.e. across care groups and relationships) were surprising given the lack of attention to this in previous literature. It seemed that there was a journey that all carers went on and that many of their challenges and experiences were similar regardless of how they were related to the person they cared for or the condition the care recipient had.

The analysis implied that it was possible to think of carers as one group for the purposes of policy and commissioning services. However, given that many of the themes identified have not been previously explored in any detail there is a need to explore them further in the context of this research.

4.2.3 Social arena/world map

This map (Figure 12) aimed to identify the social worlds that existed within the arena of carers.

Figure 12: First set of focus groups - Social World Map



A memo was then written on each social world that described what the work of the world was, how the world presented itself what actions the social world undertook, how the work of furthering that social world's agenda was organised and the technologies used (Clarke, 2005). These were then reflected upon further and a memo was written on the arena of the carer that outlined the social worlds present and not present, the hot issues/contested topics and the gaps/silences. This was reflected upon against the backdrop of emerging themes from the relational analysis.

4.2.3.1. Reflections on the social world/arena mapping and memo writing

What did the social world/arena mapping reveal?

The arena focused on the social world of the carer. There were four key components to the social world:

- Family and friends
- Social care
- Health
- Community

Within these social worlds there were distinct gaps or shrinking parts:

- Within the family and friend's world the friends circle tended to shrink and there were gaps in terms of harnessing the assets of family and friends in supporting both the carer and the care recipient.

- Within the social care world there was a current gap in the analysis around care homes and this is something for further investigation.

- The world of health was often an increasingly big and unwieldy world that carers were left to navigate. It was a world that was often poorly coordinated and difficult for the carer to access as quite often health professionals would only work with the care recipient. So, whilst the world of health increased (particularly if the care recipient's health deteriorated) it often ignored or dismissed the carer.

- The world of the community could also shrink if there was a lack of accessible services and spaces. The world of community could also shrink if the carer was unable to secure enough flexibility in relation to their employment that allowed them to juggle both work and their caring responsibilities. For many carers with a significant caring role the ability to juggle both became impossible so the carer ended up giving up work once again shrinking their worlds.

In terms of the hot issues there were tensions around:

- The assets family and friends could bring to the table but the reluctance of carers to ask.
- The lack of family and friends that truly listened and understood the perspective of the carer and hence provided the targeted support the carer required.

- The tension between paid carers and family carers often caused by a lack of sensitivity, empathy and appreciation by paid carers of the practical and emotional life of family carers. This was exacerbated by the fact that paid carers were commissioned to focus on the care recipient and as a result rarely considered the whole family dynamic.
- Carers' centres seemed to be the one organisation that focused solely on carers however there was a tension in a time of austerity that due to a lack of funding many services provided by carers' centres were being cut.
- The tension within the world of health was again that carers were often invisible to health staff. They saw carers first and foremost within the context of the relationship with the care recipient. This meant they were often blind to the fact that the parent, spouse, sibling was also a carer. Because they were slow to identify carers they were also slow to recognise the challenges carers faced. Few reasonable adjustments were made to support the care recipient or the carer. Hospitals rarely recognised that this was where many carers started their journey and the instant a loved one was discharged from hospital they were instantly turned into a carer.
- The tensions within the world of community sat largely with work and universal services. The issue with work was usually around flexibility or lack of it and hence the inability for carers to juggle both a job and their caring responsibilities when those caring responsibilities were significant. The tension with universal services was around reasonable adjustments, lack of accessibility and lack of implementation of the Equality Act.

The main surprising silence was simply how the social worlds were so unaware of carers and the challenges they faced. Carers were a hidden population and most of their work was carried out behind closed doors and never seen. As a result, the social worlds carers moved between knew very little about their reality.

What new understanding surfaced through the social world mapping?

The social world mapping increased the identified individual human elements from simply the carer and care recipient which the situational mapping identified, to the wider human elements of family and friends, paid carers, health professionals, carer support workers and the variety of people within their community spanning from neighbours to work colleagues.

A key insight the social world mapping surfaced was the invisibility of carers and the issues they faced across all their social worlds. As a result, social worlds lacked empathy and did not make reasonable adjustments that would reduce the social isolation and stress that carers faced. There were also links with the experience of oppression and discrimination due to the lack of equal opportunities and implementation of the Equality Act.

Another key insight was how important these social worlds were to the ability of the carer to continue caring. If the social worlds disappeared or were hard to access their ability to continue caring was reduced.

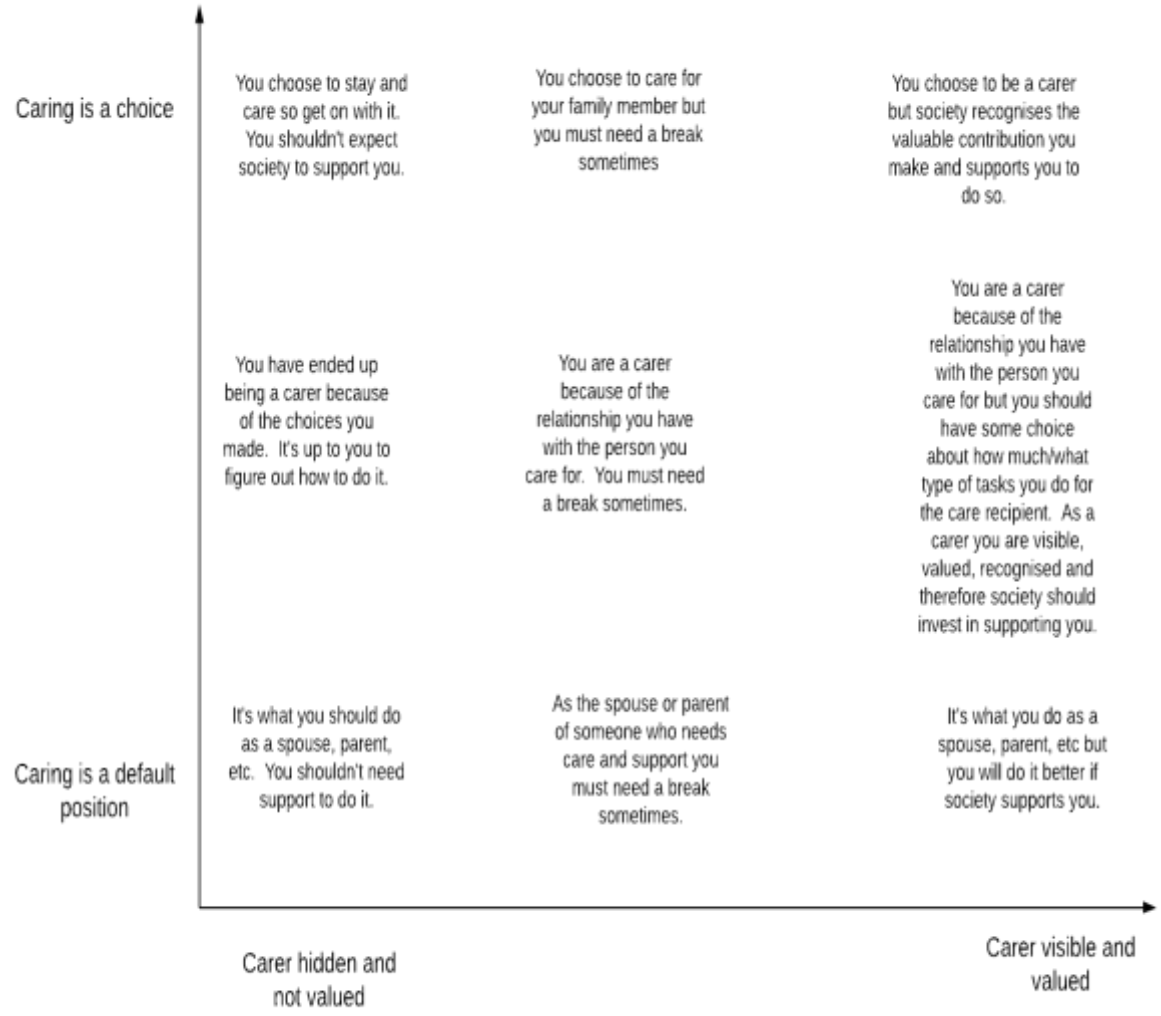
The last key insight related to identity. As social worlds shrank or were focused on the care recipient, so the carer lost bits of themselves and their sense of identity. But

often their carer status was also not recognised, and they were simply the wife, dad, sister of the care recipient.

4.2.4 Positional mapping

Two key themes that surfaced from the analysis were the degree to which being a carer was a choice or default position and the degree to which carers were visible and valued or hidden and not valued. The positional map below aimed to map the positions taken in relation to this discourse. The positions do not correlate with specific groups as people within any group will have a range of opinions.

Figure 13 First set of focus groups: Positional Map



4.2.4.1. Reflections on the positional mapping and memo writing

What did the positional mapping reveal?

This positional map outlined the discourses related to the fact that being a carer was either a default position due to the relationship with the care recipient, or a choice the

carer had made; and the carer being hidden and not valued versus visible and highly valued.

What new insights surfaced through the positional mapping?
Analysing the various positions allowed some other themes to surface around commitment to invest in carer support services or not and whether being able to continue to care was simply down to personal skills, attitudes and knowledge or whether community support played a part.

Other themes that ran through the discourses were linked to emotions. Positions where the caring role was not recognised, and the focus was on the relationship there was a sense of expectation that it was one's duty (as a parent, spouse, etc) to undertake the caring role. That looking after their loved one was something they should want to do and should do with little support. This seemed to lead to carers experiencing feelings of guilt, shame, a sense of duty and resentment.

Where the role of carer was recognised but the relationship with the care recipient was not acknowledged, there was again a sense of expectation that because they had chosen to do this they should be able to do it well and with little support. Therefore, some carers tended to feel it was impossible to admit that they were struggling, and they had no sense of who to ask for help. Again, this seemed to lead to carers feeling despair as they felt there was no light at the end of the tunnel. This position left carers who were struggling, fighting to maintain their self-esteem.

In positions where both the relationship and the caring role were recognised there was still a sense of blame if the caring role was not valued (i.e. you've ended up being a carer because of the choices you've made). The impact on carers of this position seemed to be a mixture of anger, frustration, despair, and low self-esteem.

The position in the centre of the map alluded to the need for some investment in carer support services but there was still a tendency to oversimplify the support that was required. That said the recognition of both the relationship and the carer role seemed to help carers access support when they needed it.

The position that seemed to have the most positive impact on the carer was the position that provided recognition of both the relationship and the carer role but crucially also recognised that there should be some choice involved and that carers should have some options around how much care they provided and the nature of that care. This position alluded to the need for investment in carer support and an investment in services for the care recipient. This position seemed to leave carers feeling in control and positive. It seemed to enable them to juggle other commitments and interests beyond their caring role and in so doing maintained their self-esteem and sense of identity.

4.3 Emerging themes

This section describes the themes that emerged from the analysis above. (Some quotes do contain names. These names have been changed to protect the anonymity of participants and those they care for).

4.3.1 The scale of the caring role

The first theme that emerged from analysing the data was *The Scale of the Caring Role.* It was clear from the vast range of tasks each carer was engaging in that the things they did with or for the person they cared for covered every aspect of daily living. It was also clear that for many of the carers there wasn't much they didn't do either with or for the family member they cared for:

'Where do you start?'

'Perhaps it's easier to say what we don't do.'

Tied to this were the various skills that carers had learnt to enable them to undertake the range of tasks that were part of their caring role. In some cases, the skills carers had acquired were complex and required specialist training:

'It's quite complicated, I had to undergo special training at the hospital'.

The range of tasks and their complexity meant that all the carers performed multiple roles for the care recipient:

'And you have so many hats, don't you? You know, one minute you're the carer and the next minute you're, you know, the financial advisor then you're sort of the transport person then you're co-ordinator, I mean there are so many hats that you have to wear in order to be a carer that, you know, you're multitasking all the time and then you tend to forget about yourself.'

For some carers there was an element of being forced to take on roles they didn't want and that fundamentally changed the nature of their relationship with the person they cared for:

'……if you've got somebody that becomes unwell particularly in the mental health context, it kind of immediately forces you into a parent role whether you want to be one or not and if that's your partner then.…'

The shift in roles and the impact it had on people's relationships meant that 'being a carer' affected every aspect of their lives. The scale of the caring role isn't just the number of tasks carers are doing or the number of hours they care for. The scale of the caring role is related to the range of roles a carer ends up playing for the cared for person and the impact this has on the relationship:

'I was just thinking, with me, it tends to be, I mean, I do all the cooking now whereas we used to take it in turns, dealing with common household stuff really, he just can't deal with handling any kind of paperwork, anything official, any phone calls, anything like that he's just all, like, he just can't, he just can't cope with any of it."

Across all the focus groups carers agreed that the hardest role to manage was the role of co-ordinator. Some carers described it as the personal assistant role they had to play to ensure that the person they were caring for got their needs met.

'We are often the only people who have the overall view of what's going on as in, we worked out, my wife and I, that we are in contact with twenty different agencies. But everybody, all these agencies, they're all in those boxes, aren't they?
… and there's nobody that's got the overall picture or handle on anything.'

Then there is the emotional toll all these roles take. Carers reported that quite often the person they were caring for started to feel like they were not in control and were being bossed about:

'he does say to me will you stop going on at me, he tells me to stop going on, I'm not a child, yeah… I'm, I'm not a child.'

The enormity of the caring role, the complexity of the tasks involved and the emotional toll of wearing so many hats is seemingly made harder by the onslaught of crisis after crisis, a system that is at breaking point and doesn't successfully involve carers:

'You're sort of then picking up the pieces all the time…'

'….the health service works sort of but it creaks, it creaks so badly and, um, how can carers be trained, um, you know, with sort of, um, well I mean, with sort of reasonably well educated but, I mean, if you weren't, well, if you weren't prepared to pick up the telephone and keep on the line until you actually got on to the consultant, um, you know, how, how, how do you, how do you cope?'

4.3.2 THE skilled helper

The scale of the caring role for family carers must be considered alongside the second theme to emerge from the analysis, that of 'THE skilled helper'. The nature of the relationship between the carer and care recipient, meant that the carer naturally became THE default carer. When they looked around there was no one to hand the caring baton on to because they were the only person who lived with the cared for person or they were the person's husband, wife, parent, or adult child and there was an expectation that they would care for their loved one. Whilst many carers loved the person they were caring for and so wanted to protect and look after them, taking on the caring role was less of a choice and more of a default position they found themselves in. The burden of the caring role was not just a result of it being so vast but due to the lack of choice about undertaking it.

'I had said to my local authority that, okay I'm not willing to look after my son anymore, he's an adult, he's no longer my responsibility. They said well yeah that's fine, you can dump him on our doorstep, we'll just take him down to the police station and he'll spend a few nights there and then he will spend a night in these horrible, um, lodging places, etc., etc. so in the end because you still care just about enough for the person you continue to care for them'.

Not only did family members find themselves as THE default carer, they became THE skilled helper. This was not least because they tended to be the person who knew the care recipient best. As a husband, wife, parent or adult child they knew the

care recipient's likes, dislikes, what was important to them, how they liked to do things, etc. The knowledge they had about the person they cared for made them very skilled carers and so they became THE skilled helper. Quite often in the eyes of the care recipient and professionals THE skilled helper was the preferred care option.

'They don't want other people intruding into their life'.

'…..people have an idea that you should be behaving and conducting yourself in a certain role because that's what is expected of you so there's that added pressure of, of what you want for yourself and what people expect of you.'

Becoming THE skilled helper is all consuming…..

'… that's all you can think, eat and sleep and talk about.'

'Everything in your head is consumed with the care of that person.'

In summary becoming THE Skilled Helper was less of a choice and more of a default position.

4.3.3 Sense of loss

The role of THE skilled helper took over from everything else resulting in a loss of identity

'You're having to constantly, um, adjust, you know, your identity loses out in favour of the, the needs of the person…'

'The thing is though you lose your self-identity, you don't know who you are anymore, you don't know who you've morphed yourself into.'

This loss of self meant that carers didn't always attend to their own needs, and at times put themselves at risk.

'… you're, you're always in the back of the queue, you know, you think okay I'll do that for myself tomorrow or I'll go to the gym tomorrow or do whatever.'

'I needed to go to hospital, but I was trying to time it to be in between his dialysis. And that just sums our lives up actually doesn't it. Whoever we're caring for is our absolute priority and nothing can get in the way of that….. I was in my hospital bed ordering pills for my husband'.

And it didn't stop there. Being THE skilled helper demanded availability at a moment's notice. The flexibility to be constantly available resulted in an inability to sustain employment.

'I struggle to fit work in with caring, you know, it, it cuts down on what I can actually do.'

'I'm practically doing nothing because the school term's only thirty-nine weeks of a year and what you do with your special needs child for the other, because no one gets that much holiday, do they.'

Being unable to sustain work had a knock-on effect in terms of financial loss:

'… I took a carer break for a year because I couldn't cope with it… But I wished I'd known then, instead of taking a carer break, I should have gone to the doctors for stress and he'd of put me off but because I took a carer break my money stopped.'

'There's also the financial loss, erm, in a lot of people because you can't have the job you would maybe have or maybe might not even have a job because the caring role is so great.'

For many carers becoming THE skilled helper meant that they were very restricted in what they could do and when they could do it. Many reported feeling like their life was on hold whilst they tended to the needs of the care recipient:

'You definitely put your life on hold, I mean, you have aspirations and things you want to do and you just never get round to doing them because you haven't the time or the energy.'

'It's a long temporary hold up…
Yeah
… very long
Your life stops for a while, doesn't it? You don't have a life…
You can't have a life.'

Becoming THE default skilled helper also had another consequence. It had a very tangible effect on the relationship between the carer and care recipient. The carer could no longer be just, Mum, husband, daughter etc, they were THE skilled helper. Taking on this role had a ripple effect on the carer's relationships with other friends and family, adding strain to these too:

'It has a real effect on your relationship and sometimes you just get burnt out'.

'It really does, it affects everything, everybody. The strain it puts on your relationship because your time, is so consumed with caring.'

Becoming a carer resulted in an overwhelming sense of loss and huge levels of sacrifice:

'….dealing with huge amounts of negative change, loss of job, loss of income, loss of profession/career.'

'And this is what as carers we do, we give up a lot, we give up so much.'

And then there was the more concrete experience of grief:

'You live with grief, you know and although that gets easier over time it's always there because you've got to mourn the child that isn't what they should of been or if it's an acquired you know caring needs that you've got you know you mourn for the whole person that you've lost and that's ongoing because you can't put it to bed and say goodbye because they're there with you every, every day of your life…'

4.3.4 The Hidden World of the Carer

The fourth theme that emerged from the analysis was the concept of the hidden world of the carer. No one really knew what a carer did because most of it occurred behind closed doors, in the family home. From the perspective of service provision and professionals the spot light was on the care recipient. Meanwhile the carer moved around the shadowy edges trying to keep all the plates spinning with little recognition of the expertise they had or the job they did in the background.

'Society does not value what we do.'

'*…and for the NHS and the council, to actually understand that sometimes we're the ones with probably more experience, expertise than they themselves.'*

'Well it's because they're not listening to the family member who knows the most, you know, my son's a paranoid schizophrenic and when he's unwell I'm the devil incarnate and, and he can lie his way through somethings, but no one knows exactly, without talking to me…'

The lack of recognition of the role of the carer was compounded by the lack of acknowledgement of the impact the condition of the care recipient had on the carer:

'…they've kind of acknowledged my existence but beyond that it's like nothing, no sort of follow up in terms of the impact it's having on me.'

'What I've found is, er, is, I'm, I'm a, I was a professional social worker but I've found the complete lack of, um, emotional and counselling support in any of the services, all I seem to be offered by the professionals who come in was well you can always have, um, I can get you some respite care and they sort of smooth over anything that I'm, I might be feeling, you know….'

Not only were the tasks performed by carers invisible because they occurred, in the main, behind closed doors but carers were ignored by professionals to the point that they felt invisible and the feelings they experienced remained hidden because no one seemed to understand or be able to really listen to them:

'You know, a few times over the years I've got to the point where I've, you know, in terms of my mental health, I've just not been able to… in terms of my physical health as well… I got cancer at one point and at that point social services did pull out all the stops when I got cancer actually but not when I was suffering with my mental health.'

'It's just such a dark world, you know, the carer's world is such a dark world because people think they understand but actually until you're put in that position of day in, day out, they have no idea what it's like to, to apply yourself in the same situation over and over again.'

Carers even hid their caring role from the person they cared for. In fact, quite often it seemed preserving the self-esteem of the care recipient was tied up in underplaying the tasks and roles the carer played in supporting the care recipient. When this wasn't done it could lead to the care recipient becoming upset and even angry and behaving in ways that could be difficult for the carer to manage. This encouraged the carer to hide their caring role further from the person they cared for:

'….and of course, he thinks he doesn't need any help with any of this stuff, so I have to do it all in a way that he doesn't notice, or he gets angry with me.'

'It's an impossible situation. She doesn't think she needs help with washing and dressing and some days she doesn't, but those days are decreasing so I end up helping more and more but she still won't accept that she needs help.'

'My husband suffers with depression and anxiety. If he knew all the things I do for him behind the scenes to make it easier for him it would only make him more depressed.'

This resulted in the lives of carers becoming increasingly hidden as they isolated themselves more and more:

'You isolate yourself because other people don't understand.'

'Oh I don't talk to anyone about it.'

'Yeah, you don't feel like you want to talk to anyone anyway.'

Increasingly carers hid their feelings from others:

'And then when you get calls like from your son or you daughter and they go oh how are things? you go fine, fine.'

'It's birthday parties that always got me……it was the one thing, she goes to a birthday party, everyone else is there running around and yeah it was always a birthday party… and I'd get home and cry.'

As the world of the carer became smaller and more isolating so their feelings of desperation increased:

'…so I just sat there one day thinking, if I just got in the car and just drove it into a brick wall, just to get out of it all, that's awful, isn't it? I didn't do it, obviously but it just gets in your head, just to get away from it, just to get out of it, I don't know, it's just…'

'I fancied jumping out of a plane and not coming back.'

'But who cares about whether you live or die, when you're doing that job, when they're really ill, no one wants to listen to you, no one cares.'

And there was a loss of hope for the future:

'…you can't necessarily see an end point, it's not like, oh well I've only got this for a couple of months and then it will all be okay.'

4.3.5 Resilience as the ability to keep caring

Carers didn't necessarily see themselves as having a good QoL or experiencing a state of wellbeing but they did see themselves as resilient. For them resilience wasn't about their emotional state or QoL outcomes. Instead they saw resilience as being determined by the fact that they had the ability to keep caring.

'The ability to come back from, what appears to be devastating situations and, and carry on caring and loving.'

'When you're up in the night, sorry, been up in the night more than ten times at least and still having to get up and do all the daily things and personal things to keep them going… feeling like a zombie but still having to get on with it.'

'Wells it's just keeping going isn't it. Getting up every day, getting on with your jobs, keeping that person safe, happy. Well you love them at the end of the day don't you. Yeah understanding that this is your life now and you've just got to get on with it.'

'Still being able to put one foot in front of the other on the days that are devastating.'

Carers saw resilience as directly related to their lack of choice about being a carer. Many of them spoke about having no choice but to try and cope with the adversity of caring and this meant they had learnt to be resilient.

'Resilience is something that develops. It's a coping strategy. You have to go on, you have no choice. You have to manage the crisis because no one else can. It's tolerating having to unscrew and remove all the doors – including the toilet one. I would think thank god I have survived another day and then I would get up and do it all again.'

Many of the carers saw their ability to problem solve and hence continue to care as a key part of their personal resilience.

'Um, I think it's when, in my case, when the person you care for is finding something very hard to do or it's getting to the end of being able to do something and thinking round how you might be able to go on a bit longer by doing it a different way.'

'It's tough… it's really, really tough to be persevering, really tough to have the energy to keep going when you just feel so flagged, you know, but I think that's the empowering element is that you realise you can overcome some hurdles.'

There was a shared understanding among carers that being kind to themselves and prioritising their own needs occasionally were key aspects of remaining resilient.

'Ring fencing my own time, feeling like I might be able to get through.'

'Knowing that you've done the best that you can and coped the best you can without compromising yourself.'

'I find it's just having little things to look forward to, like, if I haven't got a, sort of, weekend, if I do get some time to meet my friends or something I just know that I can have a bit of a break and I know that I could just get out the cruddy atmosphere and just, kind of, have a nice time.'

Maintaining hope and for some having faith, were also seen as key components of their resilience.

'I would say resilience is hope, always hoping for something better, that things will get better.'

'For some people it's religion, you know, they've got the communities so, you know, and there's a better life afterwards, this is just a temporary hold up as it were.'

Carers also described further evidence of their resilience being about their ability to keep fighting, to do their own research and not take no as an answer.

'But you have to be mentally and physically strong, you have to be born lucky, I suppose, yourself to be able to continue doing all of the fighting, physical and mental that you need to do.'

'You've got to decide whether you're prepared to accept that, you know, to be known, thought of as being the pain in the neck or just to, just to give up.'

Carers commented on how important it was to ask for help.

'I think the other thing with resilience is, er, learning to trust, to trust those who are, who are there to support you.'

'Sometimes we perceive it or we think that others think we're weak if we ask for help… but actually it's, it's more, it's more strengthening because if we are kept in good mental and physical health then we do a better job so, you know, sometimes it's actually having, er, the courage to say, you know, I need help because that is a really difficult thing I've found, to ever ask for help.'

There was recognition by carers that no matter how hard they tried to maintain their own self-esteem to remain resilient it wasn't always enough. They saw their own

ability to be resilient as being directly connected to the attitudes of those around them.

'……it's having that, the support of other people's attitudes helps you to be resilient.'

'Yeah, I think that's true and if you've been knocked back by people, if you've asked for help and had it refused or if you've had that reaction when you've tried to, you know, that you're seen as a pain or somebody who's neurotic or, you know.'

Carers were also clear that resilience can run out or that the journey to being resilient can involve breaking and then recovering.

'I'd describe the bit where I couldn't possibly, wasn't able to do it as a, horrible black hole that I don't want to go down, I don't even want to go there… that's why you keep on doing it because you don't want the alternative.'

'It's funny isn't it cause we know every single day we are resilient but sometimes I don't feel as if I've got any resilience but actually I suppose if you analyse it we are still being resilient because you've got no choice well we've got a child that you, you know, you can't decide not to get out of bed that morning, you know and wallow in self-pity or illness or sickness.'

4.3.6 Identity

The transition between the role of spouse, parent, sibling, adult child to the role of carer was a difficult one and left many carers struggling with their sense of identity.

'You know so as well as everything else you're dealing with you've lost your life, you've lost your social status. I mean I'd been a store manager for Debenhams for 20 years that was who I was you know when I walked down to street I felt like a store manager, I felt, even if people didn't know I knew I was somebody, I knew I had a good job'.

'And I'm not going to get extra care and be able to work what I want to work or capable of working, I've got to do what care makes me do.'

There was a consensus that becoming a carer meant losing one's sense of identity and that being resilient was partly about re-claiming one's identity by managing to maintain other roles such as employee, friend, grandmother, volunteer etc. Carers reported that maintaining their self-esteem and feeling valued played a significant role in their sense of identity and ability to remain resilient.

'To have some part of yourself that's still there.'

'Well it's getting all your inner self together to, to, to keep yourself going.'

'Having or developing a thick skin against other people and their attitudes.'

'You've got to have faith in yourself, I think that's important, having faith in yourself to be able to do the job and it is a job.'

A sense of belonging or feeling part of a community helped carers to feel less isolated but also helped them to maintain their sense of identity outside their caring role.

'I think family is important, if you, if you've got a good family and, and friend network then that can be very helpful but with our more nuclear families and moving out of a district and away, you know, there, nowadays I think it's broken down more.'

'….we belong to a charity…….. More Vision so when we have days out and weekends away with other families similar to ours we all get to be together. Even the non-disabled sibling is 100% welcome and does all the things, you know just joins in so they don't miss out either….'

'And that's all I wanted, the only thing I ever wanted to do was to do tap dancing which I never did as a kid so I joined a group which I've been there for 10 years now but umm so I only go once a week but that's umm that's my little group, you know my support system as well.'

Carers stated that the role of caring had changed them and that this contributed to their resilience.

'I think I'm a different person than I would have been otherwise.'

'You learn you have strengths you never knew you had.'

'And certainly you learn, I think, in my case personally, more patience, you know, I'm a very impatient person and some say I still am, you should have seen me thirty years ago!'

'It changes what you think is important in life.'

4.3.7 The Context

The next theme that emerged from analysing the transcripts was the importance carers placed on a supportive community, a community that listened to and accepted their individual experience, as being crucial for their ability to keep caring and be resilient.

'I think it's important to, er, realise or to acknowledge that everybody's experience is different and everybody's needs are different and nobody fits into a set pattern.'

Carers mentioned particular paid care staff who had been crucial in providing support.

'Some [paid] carers though are absolutely marvellous, I mean we, we had a Macmillan nurse and you know, nothing was too much trouble and, er, sometimes you can meet up with people who are really good in their roles.'

But it was clear that whilst good staff, who they built a relationship with was important for their resilience, actually receiving such support was not a consistent experience.

'Unfortunately I think what happens is people that are good tend to be busiest because people come back to them because they've been helpful.'

'It's about having the relationship with the worker, yeah but they change too often.'

There was also recognition about the impact the wider community could have:

'One thing I've found quite nice when I've been out with my husband, how nice people have been, you know……one day the disabled toilet was shut for some reason so I had to sort of you know hope, send him into the gents and hope he might manage and a gentleman came out and said is that your husband in there and I said probably and he said all he's doing is washing his hands all the time. He went back in, bless him, and saw to him, but, I mean, it's just, you know, I have had that happen a few times where people have been ever so kind.'

And the impact access to technology and/or equipment could have:

'I must admit, me, the world of computers, they're a lifeline to us because not being able to go out … you know, it means it differs between whether we get clothes or we don't get clothes, whether we get food or we don't get food so it is a lifeline, the fact you can get it delivered to your door, it's how we've survived'.

'I would say, er, the, er, complete freedom of a mobility vehicle completely transformed our lives making, er, we're actually free to do what we want and when we want without asking for support and help with other transportation.'

Access to good, timely information and advice was also important:

'……with the carers' centre, it's, it's a full spectrum so they can, they can guide you and signpost you but also they give you, they give you information which is up to date and current which makes you feel confident that the information you're getting is, er, is as good as it can get, you know, unless you want to pursue it further and, and that made a huge difference for me to have somebody who I could trust and it's impartial.'

And finally, there was a sense that some carers wanted to see investment in raising awareness and changing attitudes towards carers:

'I would really like to see a much better educational, some sort of service where they're actually going into even schools……I would like to see this, this whole image of carers quashed and given far more respect and dignity, so that people realise the value of the carer not the, you know, we're not there just to push a wheelchair, we're not there just to sort of bombard people with questions, we're actually there, we have, um, a valid role and purpose.'

4.3.8 Experience of oppression and discrimination

Unanimously carers talked about how they were often not listened to and left out of decision-making processes.

'I had to do the talking because he's had a couple of strokes he can't, with me he can talk but with any other person his speech gets quite bad and so the doctor often talks to me but at him…….the doctor said to us you…….have to try and get John to do the talking cause they won't believe you because they probably, might possibly think that you're trying to stop him…..'

'I find you can keep ringing round different departments and no one listens to you, you know, they just don't listen, they don't see the urgency of what's going on in your life and how distressed you are.'

Carers also reported that their caring role exposed them to stigma and judgemental attitudes and restricted their ability to engage in other activities.

'……we are very restricted as to places we can visit, yeah, we have to, have to plan it all in detail as opposed to just impromptu, oh let's go here, you have to find out, you know, the accessibility, er, all this sort of stuff and no spontaneity again.'

Carers spent time meeting the needs of someone else which meant that they had less time and energy for developing their own interests and skills.

'I struggle to fit work in with caring, you know, it, it cuts down on what I can actually, to the point where I'm cut back…'

'because of your caring role, there are many opportunities that you don't get to take up in the same way that someone who is not a carer……..'

Many carers described being regularly exposed to disrespectful treatment.

'I said well what happens if I don't want to do it anymore and they, and, er, and I said I want people coming in to help out, this is about five or six years ago and they said well that's not going to happen, she'll go straight into a home and it might not be around here, it could be fifty, sixty miles away and I said is that the alternative you're giving me and they went yeah.'

Many carers reported incidents of not receiving the help they needed and as a result experiencing negative emotions and poor QoL outcomes.

'You know, a few times over the years I've got to the point where I've, you know, in terms of my mental health, I've just not been able to….'

There was also evidence to suggest that repeated individual or group experiences of oppression resulted in low self-esteem and a sense of not being valued or heard by society.

'I feel I'm looked at differently.'

'*I had a friend who erm, you know, seemed to think I spent the last twenty years sitting down watching daytime telly.'*

'Do you know what they do a lot, a lot of emotional blackmail'.

'I've been to a couple of appointments where the person there has said, you know, how are you? And so they've asked, they've kind of acknowledged my existence but beyond that it's like nothing, no sort of follow up in terms of the impact it's having on me…'

4.4 Discussion

The literature review on the emotions and quality of life outcomes experienced by carers identified the following common themes across carer groups:

- Carers experienced a mix of emotions and quality of life outcomes rather than only positive or negative ones (Shim et al, 2012; Cameron et al, 1992; Griffith et al, 2011; Hastings and Taunt, 2002).
- Carers often experienced a sense of love and pride (Kulhara et al, 2012; Lyons et al, 2007; Grant and Nolan, 1993; Zarit, 2012).
- Carers experienced a sense of loss (Kyriacou et al, 2008; Ulstein et al, 2008; Whittingham, 2013; Shim et al, 2012; Aoun et al, 2011).
- Carers experienced episodes of chronic stress (Langridge, 2002; Greenwood et al, 2008; Gray et al, 2009; Ulstein et al, 2007; Bosboom et al, 2012).
- Carers experienced oppression and discrimination (Alvarez and Leeuwen, 2015; Wilkins, 2015; Kam, 2014).

The findings from the focus groups confirmed that these themes still feature highly in the current lived experience of carers who live with the person they care for, regardless of the illness or disability of the person they care for or the nature of their relationship with that person. The previous literature referred excessively to carer burden and linked this to the volume of care provided and the impact it had on the lives of carers (Dimitropoulos et al, 2008; Blondin et al, 2019; Gray et al, 2009; Barrowclough et al, 2001; Hoskins et al, 2005; Pakenham, 2005b). The findings from the focus groups built on what was already known by providing more detail on the nature of the tasks carers undertook (in none of the previous literature had the tasks been listed); and by identifying just how many roles the carer played for the care recipient. The concept of roles was not widely discussed in previous literature, but carers in the focus groups were very clear that the number of roles they played for the care recipient, significantly added to the scale of their caring role. This was particularly important given the aim of this research was to explore whether there were commonalities across care groups and relationships. Whilst the tasks may differ due to different care needs the range of roles, the invisibility of these roles and the amount of 'head-space' and energy required by carers to perform them were common across care groups and relationships.

The findings also suggested that carers did not proactively 'choose' to care. There were blurred lines between where the relationship ended, and the caring role began and carers found themselves in a position where they could not say no to the caring role either because of the practicalities, finances or expectations placed upon them. These expectations came from a range of places. Expectations of themselves to be a good parent, wife/husband; or expectations of the care recipient that their parent,

wife/husband, son/daughter would automatically, without question, be there to care for them. The expectations of other family and friends and the expectations of health and/or social care professionals who made assumptions about the caring role a person would play without ever asking if they wanted to or felt capable of doing so. In fact, there was some evidence to suggest that some professionals (unconsciously perhaps) were very skilled at 'persuading' people to take on caring roles when discharging the person in need of care from hospital. This was reflected in another study by Westlake et al (2016) that discovered doctors working in accident and emergency departments used language that placed expectations to undertake carer activities on relatives accompanying patients to hospital.

The lack of choice in the context of the wide range of roles a carer performed and the commonality across care groups and relationships suggested, that for all carers, choosing to no longer care for their family member required the carer to change the relationship with their family member. For example, no longer performing certain tasks (such as using a domiciliary care agency to provide personal care) did not remove the variety of roles (cleaner, taxi driver, dietician, financial advisor, co-ordinator, etc) that the carer undertook. No longer performing these roles required a fundamental change in their relationship and in some cases the ending of the relationship. This is important in terms of policy and practice because unless social workers and other professionals understand the lack of choice carers have, they are unlikely to understand the emotional impact the caring role can have and how easily it can lead to carers feeling trapped, resentful and then guilty and ashamed for feeling that way (because they still love and care for the care recipient). Without an understanding of the emotional impact the lack of choice has on carers, the needs of carers are far more likely to be unmet or even dismissed by social workers and other professionals (Given et al, 2012; Benkel et al, 2012; Brimblecombe et al, 2017).

Linked to the concept of a lack of choice was the concept of carers being THE skilled helper. The idea of being THE skilled helper was not widely discussed in previous literature on carers, nor was the impact it had on the carer's life and their sense of identity. Throughout a lifetime our roles might multiply, change or diminish (McCall and Simmons, 1978). Likewise, our identities are not fixed but shift according to the roles we play at any one time (Gecas, 1982; Goffman, 1959), but this has not been greatly explored in relation to carers. Carers take on a range of roles in relation to the care recipient and the scale of the caring role meant they often had to give up other roles. It was not clear at this stage in the research how these dynamics changed through the course of the carer journey. There was a need to explore this further in part two of the thesis.

The concept of carers feeling isolated, frustrated, lonely, guilty and resentful had previously been discussed (Gray et al, 2009; Wingrove et al, 2019; Cameron et al, 1992; Draper et al, 1992; Ostman and Kjellin, 2002). However, the idea of the carer being invisible, of the caring task always taking place behind closed doors and the link between this, the emotions experienced, and poor QoL outcomes had not been explored in detail in previous studies. Neither had the link between changing roles and sense of identity and the connection to feeling resilient. Where these concepts had been discussed it had been limited to carers of a specific group such as carers of people with Multiple Sclerosis (Hughes et al, 2013).

This is key, even where these concepts had been discussed it was always limited to carers of a specific group or carers with a specific relationship e.g. spouses. The fact that this research indicated that these themes were common across care groups and relationships is again important for policy and practice particularly in relation to identifying carers and raising awareness of the challenges they face. If the degree of discrimination that carers face is to be reduced, then reducing the degree to which they are invisible and reducing ignorance about the enormous sacrifices they make is crucial.

Finally, there was a lack of discussion about resilience and carers in the previous literature. The final questions during the focus groups asked carers what they felt resilience was? Whether they felt resilient? What helped them to be resilient? All the carers described resilience as the ability to keep caring, to do it again and again. To do it again and again even when their maximum toleration had been superseded; to do it again even after feeling broken. The analysis identified that the scale of the caring role, being THE skilled helper, the hidden world of the carer, a sense of loss, and experience of oppression and discrimination all negatively influenced the carer's ability to be resilient. The wider context within which the carer was caring, and their sense of identity had the ability to either negatively or positively influence their ability to be resilient. The elements that positively influenced carers' ability to be resilient included problem-solving skills, social support, stamina, growing as a person, finding purpose and not giving up.

There seemed to be blurred lines about the differences between resilience, coping and wellbeing. Carers seemed to relate coping to individual situations and resilience to the ability to keep caring in the longer term. Carers described an ability to keep caring and hence be resilient whilst also experiencing a loss in their sense of wellbeing.

4.5 Limitations

Although the researcher was successful at keeping the focus group participants focused on the topic it was difficult at times to ensure that people spoke one at a time. This made it difficult when transcribing the focus group and resulted in some sentences being missed as it was impossible to decipher what was said. Another limitation of focus groups can be that some people dominate the discussion or that a dominant view prevents others with a divergent view from contributing (Smithson, 2000). The researcher mitigated against these risks by asking questions such as 'does anyone have a different view' or 'thank you X, we've heard a lot about your experience, would someone else like to share their thoughts'.

Smithson (2000) also highlights that participants of focus groups maybe unwilling to discuss personal issues in a group especially if they feel there is a lack of confidentiality. The researcher attempted to address these limitations by ensuring that the 'ground rules' around confidentiality were discussed with the group at the beginning. The researcher supported the participants to build some rapport prior to the focus group starting by allowing time for carers to get to know each other a little over coffee. It seemed the participants built rapport quickly because of the commonality between them and this resulted in them sharing intimate details about

their experience, and their emotions in relation to their changing relationship with the person they cared for. This fits other research undertaken on focus groups that suggests some people are more likely to discuss issues in a group (Finch and Lewis, 2003, p171).

The group size of two of the focus groups was small which made it difficult to generalise the results. There was also under representation of people caring for parents including parents-in-law. This was an issue when the Carers UK Survey (2015) states that 40% of carers are caring for a parent / parent-in-law. There was also under representation of BME groups, working carers and male carers.

Two focus groups took place at carers' centres which may have influenced people's responses as these centres are the main resource for any services they receive. Moreover, the implication is that we can say little about carers who do not access carers' centres

The other limitation is that none of the carers had stopped or reduced their caring role so there was a gap in knowledge of the limits to resilience. This needed to be explored in the next study.

4.5.1 Reliability

The focus groups were replicated in different parts of the country with a variety of carers who were caring for people with a range of different needs and with whom they had different relationships.

The same questions were asked in each focus group and as a trained facilitator the researcher was able to keep the discussion on topic. The researcher ensured that all participants had equal opportunity to share their views and that divergent views were listened to and respected.

4.5.2 Validity

The questions correlated with the research aims and the topics identified in the literature review. The questions were discussed with the researcher's two supervisors to gain a consensus. The questions were then 'tested' with the carer support workers before being used in the focus groups.

The use of grounded theory and situational analysis provided a systematic approach to analysing the data from the focus groups. This approach added value in terms of academic rigour and provided for validity in terms of traceability from initial data coding to the final theory.

5 Chapter 5: Part One – Second Set of Focus Groups

The previous chapter focused on carers who were living at home with the person they cared for. Throughout the focus groups it was clear that in many cases the care-recipients did receive care from paid carers too (either funded by the local authority / clinical commissioning group or privately funded) but that this did not necessarily result in a reduction of roles played by the carer or the carer burden they experienced (see section 4.4.7). Although carers did state it was a valued form of support. Previous research on home care has tended to focus on the impact on the care-recipient or paid carers rather than family carers (Cooper et al, 2017) and a literature search for research focused on the impact home care has on family carers did not result in the identification of any papers. Even a recent review by the Kings Fund on 'New Models of Home Care' (2018) did not consider the impact on family carers.

One area where the family carer perspective has been reviewed is end of life care at home. In this area there is evidence about the impact on family carers for example the evaluation of the hospice at home service by Jack et al (2015) demonstrated that carers valued the service, that it made them feel safe, gave them confidence to continue caring and enabled them to continue with other activities of normal life thus supporting their physical and mental wellbeing.

End of life care at home aside, the dearth of literature on the impact of home care on carers is mirrored in the lack of understanding about the interactions and dynamics of caring among social care professionals. Nowhere can this be seen more clearly than in the review of carer assessments by Seddon and Robinson (2015). Whilst carers have been entitled to a separate carers assessment for many years (and for some this has been a source of support) in general the practice of social care staff and the carer assessment processes do not reflect an understanding of the complexities of the caring dynamic including the willingness versus lack of choice carers have when it comes to being a carer. The review highlighted that many social care staff are ambivalent towards assessing carer needs because it raises the expectations carers' have about the support they will receive only for their hopes to be dashed when it becomes clear that the support they want does not exist. In particular social care staff were hesitant to discuss the emotional and relational aspects of caring and explore carers' associated support needs because staff did not feel such support was available.

The focus groups in the previous chapter suggested that the emotional aspects of caring result in significant stress and the researcher felt that exploring what happens when carers can no longer care for their family member at home would shed further light on the changing relationship between the carer and the care-recipient and the carer's experience of resilience. Therefore, the purpose of the second set of focus groups was to build upon the themes identified in study one by collecting data on the current, lived experience of carers across care groups and relationships whose loved ones had recently moved into a full-time care setting such as a care home. The aim was to explore how the caring task changed and to investigate the emotions and outcomes carers experienced. Moreover, to do this by bringing together a range of carers who differed in age, gender, ethnicity, the relationship they had with the

person they cared for and the nature of the condition of the care recipient. Within the context of the grounded theory approach the study aimed to use focus groups and situational analysis to answer the following research questions:

- What are the current, common, lived experiences of carers, across care groups and relationships, whose loved ones have recently moved into full-time care settings?
- What are the specific emotions and QoL outcomes that are common to carers across care groups and relationships whose loved ones have recently moved into full-time care settings?
- How do carers across care groups and relationships whose loved ones have recently moved into full-time care settings describe resilience?

5.1 Context

Some researchers and policy makers would define carers whose loved ones live in a full-time care setting as no longer caring or ex-carers (Carers UK, 2011). However, increasingly there is acknowledgement that carers continue to engage in a caring role even when their loved one is living in a full-time care setting (Dellasega and Nolan, 1997). It has been demonstrated that nine out of ten carers continue to care for their relatives beyond simply visiting (Kane and Penrod, 1995).

The literature on carers whose loved ones have moved into full-time care settings is sparse. What literature there is focuses on the emotional experience of carers and subjective quality of life outcomes i.e. their sense of identity etc. The review of literature on this topic did not provide any evidence for the objective quality of life outcomes such as the impact on finances or ability to work etc. Therefore, this section aims to summarise the literature that exists and examines the emotions and subjective QoL outcomes for carers whose loved ones have moved into full-time care settings.

5.1.1 Negative emotions and subjective quality of life outcomes

Kellett (1998) identified five key themes that were a significant aspect of the experience of family caring and placement in a care home: experiencing a loss of control; being disempowered; feeling guilt, sadness and relief simultaneously, possessing a sense of failure, and having to make a forced and negative choice. A variety of studies across care groups and relationships suggest that carers rarely experience a move to long-term care as desirable or a positive choice (Minichiello, 1987; Nolan et al., 1996a; Penrod and Dellasega, 1998).

The journey to a full-time care setting differs for different people. Previous research (Bigby et al, 2011; Davies and Nolan, 2003; Hennings et al, 2013; Heppenstall et al, 2014; Laditka et al 2017; Low et al 2017) suggests that the principle cause for deciding to move a loved one into a full-time care setting is a lack of ability to continue caring at home due to an increase in care needs or the affect it is having on the carer's health, their ability to work or relationships within the family. It is not a lack of dedication or desire to keep caring at home but an inability to do so (Buhr et al, 2006; Schulz et al 2012). Some people become carers overnight due to a loved one suffering an acute illness or major accident from which they never recover. A

return home from hospital is not possible and the cared for person moves from hospital, perhaps to a rehabilitation unit and then on to a care home. For others moving into a full-time care setting is simply the accepted path as the illness advances (Nolan and Dellasega, 1999). For parents of disabled children, it can be a result of a natural progression towards adulthood or a more traumatic experience of no longer being able to keep their growing child safe in the family home because of the challenging behaviours their child displays (James, 2016).

Subjective factors can also influence carers' decisions. Some carers want to continue to provide certain types of care themselves. This can range from personal care through to emotional support (Twigg and Atkin, 1994, p38; Arksey et al., 2005). It impacts the nature of the help they are willing to accept or ask for and, in many cases, reflects the private nature of these tasks and the strong bond between the carer and the care recipient (Arksey and Glendinning, 2007). After all, caring takes place in the context of an on-going relationship with strong notions of duty, obligation and expectations (Twigg and Atkin, 1994, p32).

Feelings of duty and responsibility associated with such close family relationships can leave the carer experiencing a sense of disloyalty and guilt making it difficult for the carer to make the decision (Arksey and Glendinning, 2007). Indeed, it is often not the carer who raises the possibility of alternative caring arrangements instead the matter is usually brought up by professionals or other family members (Lundh et al, 2000).

The support carers receive from other family members varies. In some cases, the family provides a place of solace and sustenance for the carer. In other cases, the carer and family members can be in conflict over the decision to move their loved one into a full-time care setting (Bloomer et al, 2016). Such family dispute can amplify an already stressful situation (Heppenstall et al, 2014; Davies and Nolan, 2003). It seems that the process of moving a loved one into a full-time care setting is one that is likely to increase the carer's need for support (Morgan et al, 1997). This is particularly true if the care recipient is also explicitly objecting or denying the need for increased support (Mooney et al., 2002; Wenger et al., 2002; Arksey et al., 2005).

Qualitative studies have suggested that once the decision to move into care has been made, carers are often left to manage the complex practicalities of locating and moving the person into a setting (Lundh et al., 2000; Nolan & Dellasega, 2000). Carers commonly report experiences of 'working in the dark' and 'not knowing where to start' (Davies and Nolan, 2003). For those carers working within the context of pressure to vacate an acute hospital bed there can be added stress and a restricted ability to make an informed choice (Cotter et al, 1998; Dellasega and Mastrian, 1995). This is not least because professionals do not always involve carers in discussions about the future care of their relative. Even when this does happen, it does not always signify a true partnership approach (Davies and Nolan, 2003).

Previous literature highlights that carers often feel relief when their loved one moves into a full-time care setting because many carers arrive at the decision during a time of increased care needs and crisis. But the sense of relief is tinged with guilt, shame, sadness and a sense of failure about having to accept defeat, feeling that they have abandoned their loved one, a sense of loss and - for spousal carers - a betrayal of

marital vows (Aneshensel et al. 1995, Dellasega & Mastrian 1995, Dellasega & Nolan 1997, Nolan and Dellasega, 1999, Tilse, 2000).

Such feelings can be exacerbated if little attention is given to the knowledge, experience, and views of the carer (Lundh et al, 2000), or if there are concerns about the quality of care or financial worries (Dellasega and Nolan, 1997). That said, for many carers, feelings of failure are softened by the realisation that they cannot carry on any longer without serious consequences to their own health or family circumstances (Dellasega and Nolan, 1997).

Grant et al (1998) in their study on the 'Rewards of family caring' found that many carers experienced a sense of loss at '*not experiencing the 'uplifts' of sharing the everyday mundane things in life with their loved one*' (p60). Grant et al (1998) conclude that: *'a decision based on the best of intentions to reduce stressfulness may, in the short-term at least, increase stress, and at the same time, reduce the continuing experience of rewards.*' (p60).

The sense of role loss at this time, has been described by several authors (Aneshensel et al. 1995, Dellasega & Mastrian, 1995, Gladstone 1995, Kellett 1999). Once in a care setting the carer is no longer the main person responsible for the care of their loved one. It is presumed that carers will hand over their care responsibilities to paid professionals who often have no existing relationship with the care recipient. Given that the care role can account for a significant proportion of the life of a carer, it is not surprising that relinquishing their role whether in part or full can lead to carers feeling helpless, lost and lonely (Bloomer et al 2016). Admission to a care setting can leave carers feeling overwhelmed and ignored by the system (Haesler, Bauer, & Nay, 2007). The system is often disempowering and results in carers experiencing an acute loss of control (Bloomer et al, 2016; Bauer et al, 2009). These emotions often continue throughout the time that their loved one remains in care (Johnson 1990; Dellasega and Mastrian 1995; Tilse 1997; Kellet 1999; Ryan and Scullion, 2000).

Such feelings are not helped by well-meaning staff who imply that they will now take over and that the carer no longer needs to worry or be involved in the caring tasks (Davies and Nolan, 2004). Indeed, many professionals regard the admittance to a care setting as a removal of the carer role from the carer. The assumption is that the burden of caring is removed and there is little recognition that this perceived handing over of responsibility is a traumatic experience (Davies and Nolan, 2004).

The reality is that the move to a full-time care setting indicates another change in an already changing relationship. When carers are viewed simply as visitors it makes their ongoing caring role even more invisible and prevents them from feeling valued and able to adapt to the changing relationship (Kellet, 1998).

It is not until the move itself that the experience of separation becomes a reality. The time immediately following the move is particularly difficult for many carers. Most describe feeling like an `outsider', with the powerlessness they experience during the move worsening due to the lack of influence they are now able to exert over the way the care is delivered. Staff working in care settings place little emphasis on

discussing the future role and involvement of the carer leaving carers feeling anxious, lost, out of control and grieving (Lundh et al, 2000).

Carers are faced with the need to accommodate a change in their relationship with the care recipient. Carers often struggle to find ways to protect or even continue to feel a sense of attachment and belonging with their loved one. Other family members, friends and care home staff often fail to appreciate the lived experience of being forced to make a negative choice. The more disempowered and misunderstood a carer feels the harder (in some cases impossible) it is to adapt to the changing relationship (Kellett, 1998).

5.1.2 Positive emotions and subjective quality of life outcomes

Kellet (1998) found that carers who had lived through the experience of moving their loved one into a full-time care setting gained insight into how meaningful their caring role had been. As their sense of identity and attachment became threatened so they recognised how important to them their identity and role as a carer was. The threat to carers' sense of personal identity prompted by the move to a full-time care setting has been described in several other studies (Tilse 1997, Fleming 1998, Ryan & Scullion 2000). Previous research has also identified that successful adaptation and maintaining a sense of wellbeing is more likely if roles other than carer are developed or maintained throughout the carer journey (Dellasega and Nolan, 1997).

The key to a successful less traumatic and stressful experience for the carer when the care recipient moves into a full-time care setting seems linked to the availability of a confidant who can empathise and so can support, listen, and offer advice and comfort (Davies and Nolan, 2004).

Several studies suggest that role redefinition is a crucial task for carers following placement of a relative in care (Dellasega and Mastrian, 1995; Ryan and Scullion, 2000; Sandberg et al., 2001). Fleming (1998) suggests that carers provide 'special care' for their relative following placement into a full-time care setting and that this gives carers a purpose in their lives that enhances their sense of self-esteem. Kellett (1996) highlights four themes that encapsulate the way families seek to maintain a sense of attachment to their relative:

- engaged involvement - to reduce role loss and create new ways of caring
- worth - ensuring that their specialised knowledge of the person is used as a basis for planning quality care
- concern - to negotiate boundaries between themselves and staff in the home
- continuity - remaining involved and continuing to share a fruitful relationship with the person.

Sandberg et al. (2001) identified 'keeping' as the key process relatives engage in:

- 'keeping in touch' with their relatives' care and ensuring they were aware of life outside the home
- 'keeping it special' by maintaining cherished routines within their relationship

- ‘keeping an eye’ by observing the care their relative received and trying to ensure that staff were providing the quality of care that the carer thought acceptable

These activities sustain both the carer and the care recipient (Kellett, 1996). Most carers continue to experience strong feelings of love and affection towards their family member and experience a range of positive emotions from their continued involvement (Davies and Nolan, 2006).

For many the move into a full-time care setting also resulted in new freedom and possibilities related to the ability to reclaim more of a `normal' life after years of caring (Lundh et al, 2000).

5.1.3 Oscillating and conflicting emotions and quality of life outcomes

Like carers who are caring for their loved ones at home, most carers whose loved ones have moved into a full-time care setting experience both positive and negative emotions and outcomes, and the overwhelming experience is one of conflicting emotions.

The role of caring and the experience of doing so is in a constant state of flux as the needs of the care recipient change and the dynamics of the relationship between carer and care recipient change with it (Hennings et al, 2013; Smith, 2001; Twigg and Atkin, 1994). Carers often find themselves caught between the opposing worlds of carer burden (the stress and responsibility) and carer reward (the love and sense of fulfilment). Some carers are caught between these opposing worlds for many years without any ability to resolve or reconcile their position. This does not change when the care recipient moves into a full-time care setting. In fact, it can be exacerbated as the carer struggles to redefine their role (Hennings et al, 2013).

Most carers feel a sense of freedom from the physical aspects of caring, but they also experience a loss of control, sense of powerlessness and many experience great loneliness as the care recipient is no longer there and the world of the carer has shrunk so much during their caring journey that they no longer have the same contact with friends and family. The carer’s physical wellbeing may increase as they are finally able to sleep, exercise, etc, but their emotional wellbeing does not always improve as they experience grief, guilt and sometimes shame (Lundh et al, 2000).

When a family member moves into a full-time care setting, carers often find themselves trying to live between ‘two worlds’, the world of the care setting and their world at home. Their role is no longer clear and for those whose loved ones will continue to deteriorate there is a sense of living in limbo and waiting for the inevitable. The world of a carer whose loved one lives in a full-time care setting seems to be full of ambiguities and contradictions (Kiely et al, 2008; Woods et al 2008).

5.2 Focus Groups

Three focus groups were conducted to explore the lived experience, emotions and quality of life outcomes for carers whose loved ones were living in a full-time care setting. Data were collected via audio recording which ran the full length of the focus groups. The recordings were then transcribed.

5.2.1 Participants

Three focus groups were conducted, with the aim of recruiting between six and ten participants for each group. The criterion for participation was that participants were adult carers and the person they were caring for had recently moved into a full-time care setting.

As with the previous study, participants were recruited by reaching out to carer support organisations to recruit participants from among the carers they knew. This is known as referral sampling or snowball sampling (Morgan, 2008 p816) and for this study further referral sampling was used by reaching out to care homes too.

A total of 17 participants, including 11 women and 6 men participated in the three focus groups. All participants were White British, reflecting the local population. The participants ranged in age from 48 to 78 years old (with an average age of 66 years). Participants were either caring for their son or daughter, their parents or for their spouses. Each focus group contained a mix of carers from across carer groups with carers caring for people with a range of care and support needs due to a range of long-term conditions and/or illnesses.

Table 7: Demographic characteristics of the participants

Participant Number	Gender	Age	Who they cared for	Condition requiring care
1	Female	73	Husband	Stroke
2	Female	55	Parent	Dementia
3	Female	67	Parent-in-law	Physical Frailty
4	Male	68	Parent	Physical Frailty
5	Female	66	Parent	Dementia
6	Female	64	Parent	Dementia
7	Female	72	Husband	Dementia
8	Male	75	Wife	Dementia
9	Male	68	Son	Learning Disability
10	Female	67	Parent	Alzheimer's
11	Male	78	Wife	Dementia & Stroke
12	Male	67	Wife	Alzheimer's
13	Female	69	Husband	Dementia
14	Male	48	Partner	Stroke
15	Female	65	Husband	Stroke
16	Female	57	Parent	Stroke
17	Female	57	Parent	Dementia

5.2.2 Structure of the focus groups

The first focus group had 7 participants, 3 men and 4 women and was held at a carers' centre in a market town in the West-Midlands. The participants ranged in age from 64 to 78 years of age. The second group had 6 participants, 2 men and 4 women and was conducted at a carers' centre in a large town in the East-Midlands. The participants ranged in age from 48 to 69 years old. The third focus group had 4 participants, 1 man and 3 women and was conducted in a care home in the south-east. The participants ranged in age from 55 to 73 years old. Each focus group was scheduled for two hours.

5.2.3 Data collection

After the consent forms were completed the researcher asked carers to introduce themselves and to tell the group who they cared for (i.e. spouse, adult child, sibling, parent, etc) and the condition the person had that resulted in them needing care.

The following questions were asked at each focus group:

- How would you describe resilience? What does it mean to be a resilient carer?
- On a scale of 1-10 how resilient are you? Why?
- Has your ability to be resilient changed since your caring role changed? Why? Why not?
- What factors played a part in the decision for your loved one to move into a full-time care setting.
- How were you left feeling? What were the outcomes for you?
- Do you wish anything could have been done differently? What and why?
- In what ways would it have impacted on your resilience then and now?

As with the focus groups in the first set, the questions were built upon and refined based on responses from the participants. The researcher used open-ended questions and the discussion on each question continued until it seemed all discussion had been exhausted. The researcher used the same process for study one and two: i.e. summarising the comments that had been made to check that her interpretation of the comments was correct and to clarify anything that was unclear; thanking the participants and agreeing contact information and the intention to share the completed research.

5.3 Data Analysis

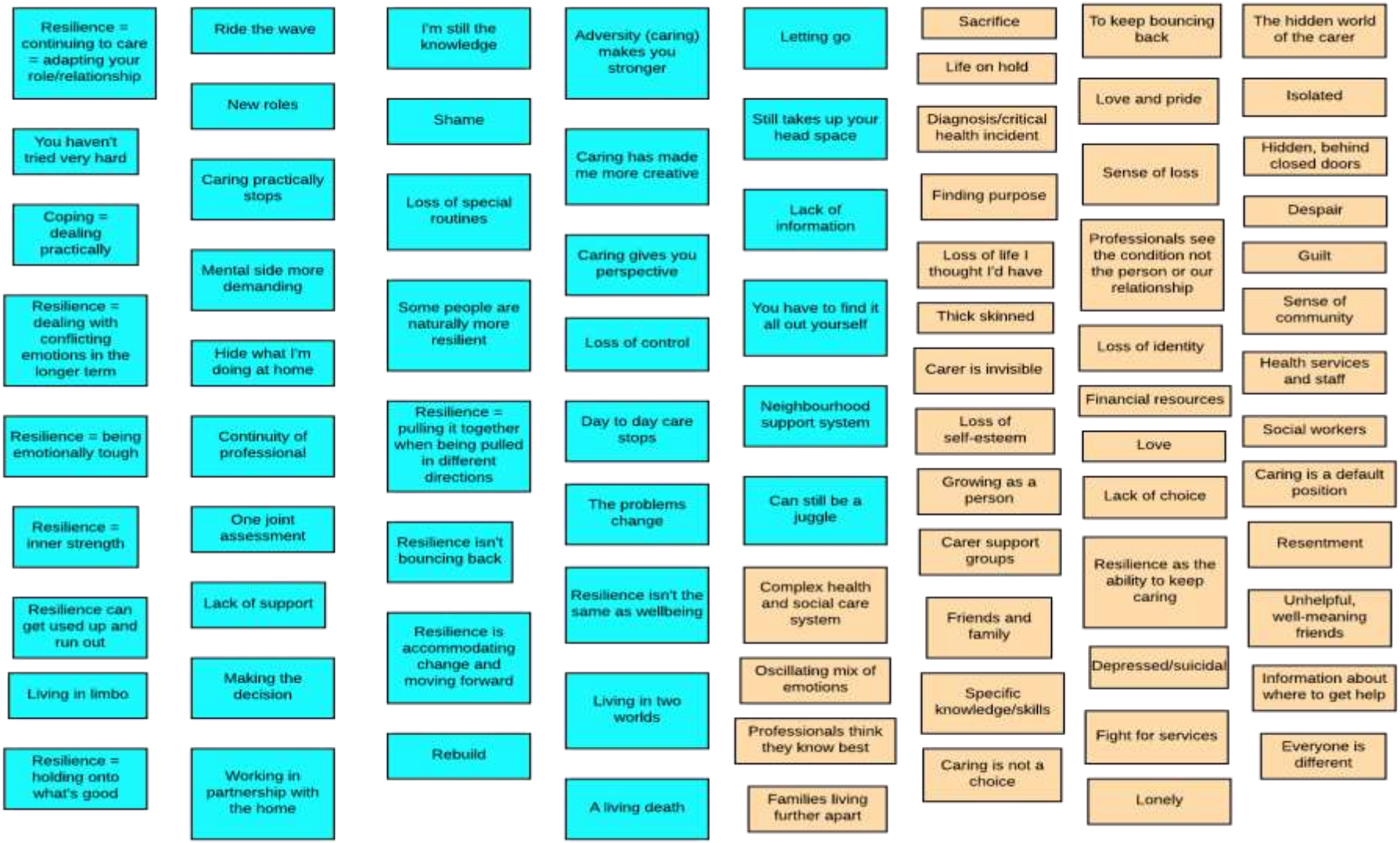
The first set of focus groups used situational analysis to analyse the data and to allow emerging themes to surface. The same methodological approach was used for the second set. The transcripts were coded line by line producing initial codes.

5.3.1 Situational map

As with the first study, the data was analysed using situational analysis to produce a situational map. Memos were made to capture thoughts, ideas and links with study one and the literature reviews which in turn led to new codes. The situational map identified the emerging themes from study one and added to them. The map was exploratory in nature and aimed to capture the complexity of the situation.

Figure 14 shows the early ‘saturated’ situational map. The orange boxes are initial codes from the first set that reappeared in the second set. The blue boxes are new initial codes from the second set.

Figure 14 Second set of focus groups: Situational Map



The ordered map below was a revised version of the ordered map from study 1. Some codes have been removed and some added. As decribed in the methods section the mapping is an evolving process involving the researcher writing reflective memos after each coding and mapping exercise, reflecting on the memos again before the next coding and mapping exercise and hence there were many versions of the map along the way. Not all the codes that appear in the early map above appear in the ordered map below. Throughout the process the researcher 'tested' the maps with her supervisors, other academics and carer networks. The codes that appear below are the ones that the researcher and her supervisors agreed resonated the most with the data, reflective memos and the comments from others as the maps were tested.

Table 8: The second set of focus groups: Ordered Situational Map
The orange codes are initial codes from the first set of focus groups that reappeared in the second set. The blue codes are new initial codes from the second set.

Individual human elements/actors (e.g. key individuals and significant people in the situation) ▪ Carer ▪ family member cared for	Nonhuman elements/actants (e.g. technologies, materials, knowledge, infrastructure) ▪ information about where to get help from ▪ complex health and social care system ▪ carers' centres
Collectives human elements/actors (e.g. particular groups, specific organisations) ▪ family ▪ friends ▪ carer support groups/organisations ▪ Neighbourhood support system ▪ Well-meaning but unhelpful friends/family	Discursive constructions of individual and/or collective human actors ▪ carer is invisible ▪ professionals think they know best ▪ professionals see the condition not the person or the relationship between carer and care recipient ▪ a person does not choose to be a carer, it is a default position ▪ carer as THE skilled helper
Key events in the situation ▪ critical health incident e.g. stroke ▪ changing the caring role ▪ Making the decision to no longer care at home and to move loved one into a 24 hour care facility e.g. care home	Implicated/silent actors/actants ▪ silent voices of carers ▪ hidden world of the carer ▪ sacrifice ▪ life on hold ▪ loneliness ▪ isolation ▪ despair ▪ depressed – suicidal ▪ resentment ▪ Shame ▪ Guilt
Political/economic elements (e.g. the state, particular industries, political parties) ▪ financial resources	Discursive constructions of nonhuman actants

	▪ resilience as the ability to adapt and move forward throughout the carer journey ▪ sense of loss ▪ resilience as the ability to deal with conflicting emotions over the long term ▪ resilience as the ability to be emotionally tough
Temporal elements (e.g. historical, seasonal, crisis and/or trajectory aspects) ▪ health and social care system in crisis ▪ life on hold/loss of life I thought I'd have ▪ oscillating mix of emotions ▪ loss of hope over time ▪ finding purpose and growing as a person ▪ losing physical and mental health ▪ Carer journey	Socio-cultural/symbolic elements (e.g. religion, race, sexuality, gender, ethnicity, nationality) ▪ families living further apart ▪ changing expectations about caring responsibilities towards parents, spouses, etc ▪ sense of community ▪ sense of identity ▪ social support
Major issues/debates (usually contested) ▪ carers not being valued by society ▪ carers not being involved in discussions about care ▪ where does the relationship end and the caring role begin e.g. the line between being spouse or carer, parent or carer, daughter or carer. ▪ Fight for services ▪ Carers whose loved ones move into a 24 hour facility are no longer carers	Related discourses (historical narrative, and/or visual) (e.g. normative expectations, moral/ethical elements, mass media, popular cultural discourses) ▪ Discourses on relationships ▪ Discourses on caring as a choice ▪ discourses on social care as the place of last resort ▪ discourses on lifestyle ▪ discourses on wellbeing ▪ discourses on resilience ▪ discourses on coping and positive appraisal ▪ discourses of person centred care ▪ discourses on oppression and discrimination
Other kinds of elements ▪ Resilience and wellbeing are different ▪ Coping and resilience are different	Spatial elements (e.g. spaces in the situation, geographical aspects) ▪ discussion is missing on the impact the caring role has on the original relationship between the carer and the cared for

5.3.1.1. Reflections on the situational mapping and memo writing

What did the situational mapping reveal?

The situational mapping identified several new codes and reinforced several original codes. One of the key original codes that was reinforced was the 'hidden world of the carer'. In policy and practice carers whose loved ones have moved into a care home are often no longer seen as carers and the caring tasks they engage in are not perceived to be too onerous, time-consuming or emotionally challenging. And yet the situational mapping identified that the experience of carers is quite the opposite. There was also a sense of carers living between two worlds and often feeling like they must hide what they do in their world outside the care home from the care recipient. New codes included loss of control as carers lose the ability to remain in charge and hence in control of the care recipient's daily care and a sense of shame as some family and friends judged their decision as a sign that the carer had not tried hard enough. For many carers the decision to move their family member into a care home resulted in a range of conflicting emotions that could be difficult to cope with and impacted on their sense of resilience and wellbeing.

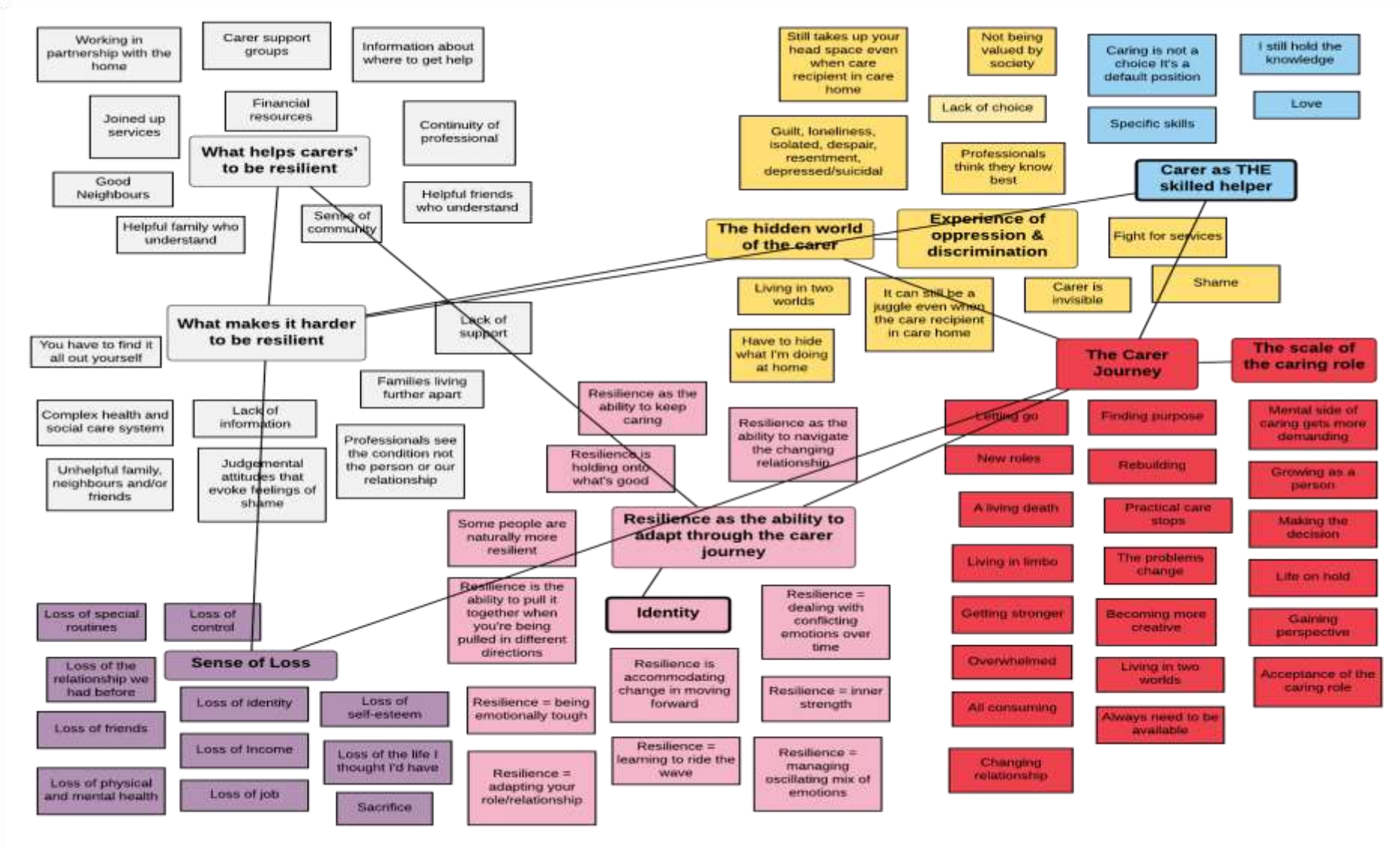
What new understanding surfaced through the situational mapping?

Broader issues that seemed to arise through the process of situational mapping were the tension between the caring role and the relationship between the carer and care recipient. A lack of attention was paid to the changing nature of the relationship between the carer and the care recipient as the caring role increased. This highlighted the idea that carers went through a journey that often started with negative changes that resulted in a need for them to care which they wished they didn't have to do; through to acceptance of the carer role, their learning journey to expert carer followed by a need to let go and allow others to take on some of the role of carer and once again a need to adapt the role they played. The situational mapping also developed the concept of resilience to not just be about the ability to continue caring but to continue to accommodate change, adapt and flex throughout the carer journey and to cope with the conflicting emotions.

5.3.2 Relational Mapping

Again the mapping was an evolving process involving the researcher writing reflective memos after each relational coding and mapping exercise, reflecting on the memos again before the next relational coding and mapping exercise and hence there were many versions of the map along the way. In this way codes were reviewed to decide on the most important codes to retain and to further cluster them by commonality thus adding to and tweaking the emerging themes from the first set of focus groups. Again throughout the process the researcher 'tested' the maps with her supervisors, other academics and carer networks. The codes that appear below are the ones that the researcher and her supervisors agreed resonated the most with the data, reflective memos and the comments from others as the maps were tested. The themes and the link back to the initial codes are illustrated on the map below using a different colour for each theme. The relational analysis goes on to identify the connections between the themes. This is illustrated by using lines to connect the emerging themes (see Figure 15).

Figure 15 Second set of focus groups: Relational Map



5.3.2.1. Reflections on the relational mapping and memo writing

What did the relational mapping reveal?

The key themes were:

- The hidden world of the carer (which included the experience of oppression and discrimination)
- Carer as THE skilled helper
- The carer journey (which included scale of the caring role)
- Sense of loss
- Resilience as the ability to adapt through the carer journey (which included identity)
- What helped carers to be resilient?
- What made it harder for carers to be resilient?

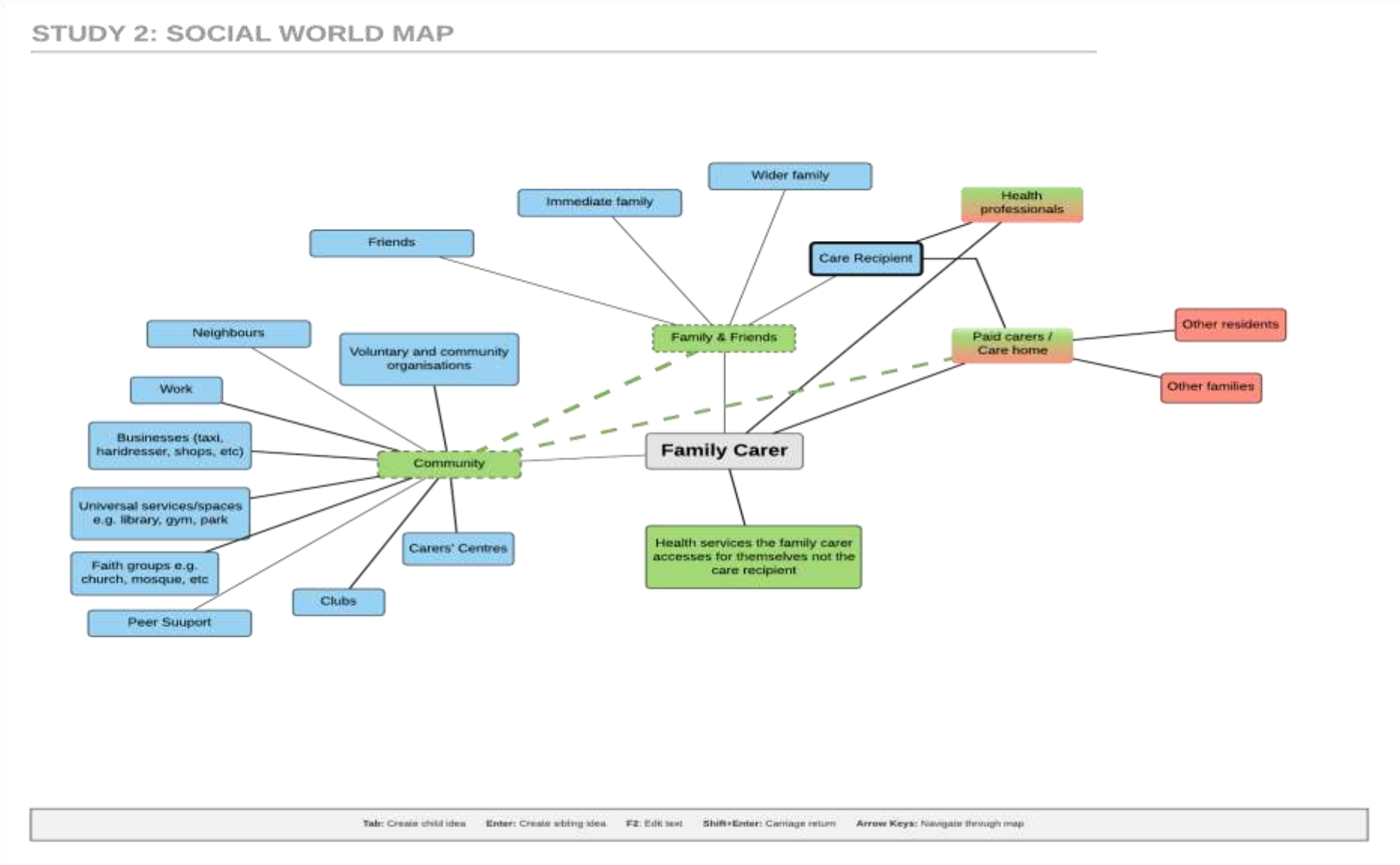
What new understanding surfaced through the relational mapping?

The new insight that the relational mapping allowed to surface was the concept that carers went through a journey. Much of that journey was hidden, they remained THE skilled helper due to the nature of their relationship with the person they cared for; and throughout the journey there was a sense of loss although the focus of that loss changed. Moving through the carer journey required an ability to accommodate change and adapt and the more the carer could adapt, the more resilient they were. The relational mapping also identified that being resilient wasn't just a personal characteristic there were factors that could help or hinder a carer that were related to family and friends, their community and their access to information and financial resources.

5.3.3 Social arena/world map

The social world map below builds on the social world map from the first set of focus groups. The researcher went back to the 'messy map' and the transcripts to ensure all the people and groups mentioned as being part of the carers social arena were captured. The mapping was again an evolving process that involved several iterations, reflective memos and testing the maps with supervisors, other academics and carer networks.

Figure 16 Second set of focus groups - Social World Map



5.3.3.1. Reflections on the social world mapping and memo writing

What did the social world mapping reveal?

There were a couple of changes to the social world map. Firstly, the range of things included in the community world expanded. Secondly, the researcher tried to clearly highlight the link between the community world and the family and friends' world because many friends were made through the community or in community settings. The researcher also tried to highlight more clearly the reality that usually carers could only access health professionals in relation to the care recipient via the care recipient. Furthermore, the carer's own needs were not always being met by the same health professionals and hence this was separated out into a separate social world. The analysis on the care home focus groups highlighted that the social world related to the care home, other residents and families of those residents was another social world the carer encountered. For some carers this new social world was where they experienced a sense of community again.

For carers whose loved ones had moved into a care home the social world of the community opened for them as they rebuilt their life outside of their caring role. However, there was evidence to suggest that some carers found it more difficult than others to rebuild their life in the community and that this was linked in some way to resilience.

The social world of family and friends shifted a bit as a loved one moved into a care home. In one sense it expanded again as the carer had an increased ability to meet up with friends, attend new clubs, visit family again. On the other hand, the social world shrunk as friends and family of the care recipient stopped visiting and moved out of the care recipient's social world and as a result out of the carer's social world too.

What new understanding surfaced through the social world mapping?

As with the first set of focus groups the memo writing on each social world highlighted how invisible carers were. This increased when the care recipient moved into a care home. At this point it was often perceived by others that the carer no longer had a care role and their identity reverted to spouse, sibling, parent (etc) of the care recipient.

The social world map revealed the degree to which the carer could only access some of the care recipient's social worlds via the care recipient. This aligns to the lack of attention paid to involving carers in the decision-making and care plans of the family member in need of care and support. From the perspective of the carer this situation is frustrating and nonsensical given that the carer is normally the expert in terms of the care required and the ways in which the care recipient likes to be cared for.

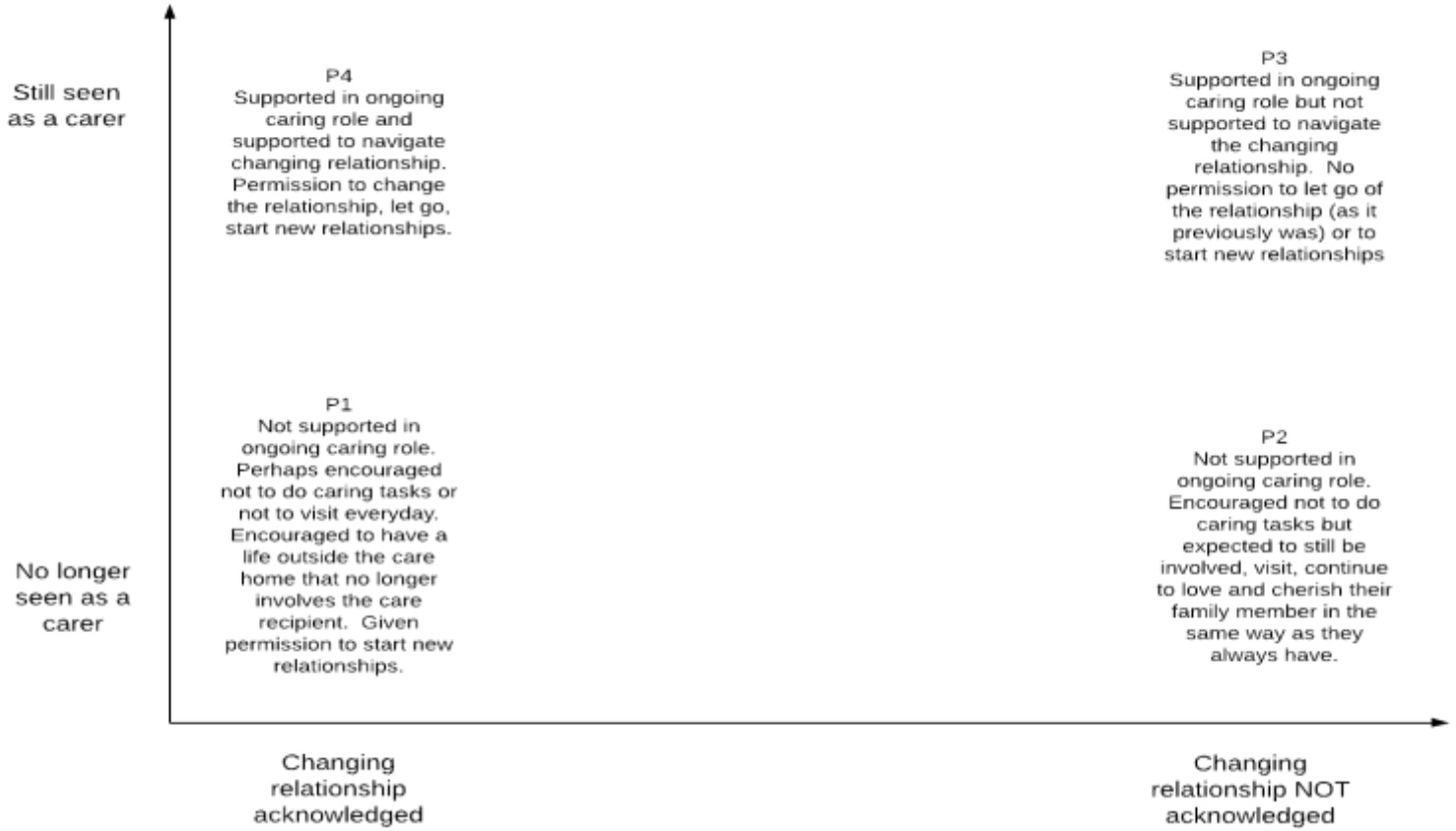
The social world mapping also revealed how the social worlds shrunk, expanded and changed throughout the carer journey and that the support received from social worlds was important in terms of how resilient a carer could be.

There was a lack of discussion on the changing relationship between the carer and the care recipient as the caring role increased and then changed when the decision to move the care recipient into a care home was taken. This was explored further by positional mapping.

5.3.4 Positional map

Reviewing field notes and memos enabled the researcher to identify the significant discourses and the process of coding these identified that the most significant discourse was the tension between whether the carer was still seen as a carer and whether the changing relationship was acknowledged. Hence the positional map focuses on the different opinions that were voiced about this issue.

Figure 17 Second set of focus groups: Positional Map



5.3.4.1. Reflections on the positional mapping and memo writing

What did the positional mapping reveal?
The map outlined the positions taken on the discourse around whether family members were still carers when their loved ones had moved into a care home and the silent debate about the degree to which relationships changed as the caring role increased through the move into a care home and beyond.

What new understanding surfaced through the positional mapping?
The mapping revealed that where there was a lack of understanding about the breath of the caring role, where caring was seen only as providing practical support e.g. personal care there was a lack of understanding that carers could continue their caring role even when their loved one moved into a care home.

The mapping also revealed that there could be a lack of insight about how feelings and the nature of relationships changed through the carer journey. It was almost as if there was a lack of understanding that the very nature of caring could change the relationship.

The positional mapping allowed some issues to surface: a lack of insight into and then support for the emotional journey that carers endured through the carer journey and the range of conflicting emotions that could undermine their resilience particularly when making the decision that they could no longer live with the care recipient.

The link between the carer journey and the way carers conceptualise resilience as the ability to accommodate change, adapt and flex throughout the journey needs to be explored further. It would be useful to do this in a focus group of carers at different stages in the journey including some carers whose loved ones have passed away.

5.4 Emerging Themes

This section describes the themes that emerged from the analysis above. (Some quotes do contain names. These names have been changed to protect the anonymity of participants and those they cared for).

5.4.1 The Carer Journey

The analysis identified that there was a temporal aspect to caring and that carers went through a journey in relation to their caring role. The journey was closely linked to the emotional aspects of being a carer and included (among other issues) recognition of the changing relationship, acceptance of the caring role, gaining perspective, making the decision to move their loved one into a full-time care setting, letting go, and rebuilding and/or adapting to a new life. How carers coped with the various stages of the carer journey depended on how easily they could adapt to the next stage and the support of their friends, family and community.

For some carers making the decision to move their loved one into a care home was emotional but supported by family, friends and paid care staff:

I think when the [paid] carers started looking after me I started to think there's something not quite right here…….and the carers were literally – you know, they said "This can't go on! You know, you – you've got to um"……

I've only got the one daughter. She's the one who's PUSHING me. She said "YOU'RE going to be ill! Then, I'm going to have Mum in that situation, you – you in hospital. And, well I'm living in London, what the hell am I going to do then?" You know, so she is very supportive of me doing whatever eases my life.

Some carers were left struggling to accept that their loved one was not going to come home:

About 12 months ago, when it became apparent that he wouldn't be able to come home, everyone kept saying to me "You need to…" and I kept on, like a bull in a china shop, saying "You must be able to do something, physically – there must be some things we can do! What can we do about that – that?" They said "You just need to go and, in your own time, just be able to let go – he's in the best place. You know, because he's not going to get better.

Some simply felt conflicted:

You've got these doubts, and the questions and the guilt……...She's happy. She's contented. But I've still got a nagging doubt. "Should I let her go home?"……That is the guilt, you know, in my case because she's quite – if you were to meet her – there's nothing wrong with her.

Interestingly many carers found their role as carer more demanding once their loved one had moved into a care home:

'I think in some ways I've found it more demanding…….where they lived in their flat, I could do that with my eyes shut. But now, I still visit three – at least three times a week, maybe four – um, I find it mentally more demanding'.

This echoes the theme from study one that the scale of the caring role is not just related to the tasks carers do but the variety of roles they perform. Many of these roles continued and even increased once a loved one moved into a care home.

I just spent two days doing paperwork because I – we had got no power of attorney.

5.4.2 The hidden world of the carer

The first set of focus groups identified that carers are often not recognised or valued and much of the work they do happens behind closed doors and out of sight because it happens within their own homes. The analysis above builds on this theme by revealing that the hidden world of the carer increased as loved ones moved into care settings not least because carers were often no longer seen as carers. This was due in part to a narrow view of caring being about practical care tasks rather than including the full range of activities and roles carers engaged in for their family member.

'……the finances and things like that. You know, making sure she's got everything she needs, there's still that element of, you know, needing to do things for her.'

One specific impact of the caring role that continued and carers felt was not visible to others was the amount of head space that was still taken up by thinking about their loved one:

'We sometimes say we go to bed thinking of her and we wake up thinking of her.'

'You don't ever stop worrying about them. Even though you're removed from them, you never stop.'

Carers reported that their lives were still restricted even though their loved one was in a home:

'I haven't had a holiday for 6 years.'

As with study one there was still an element of carers hiding their feelings from others:

So, those strategies had to be in place then, that same person had to re-emerge, the one that – in a morning could put the face on, put the earrings on, appear to the outside world to be coping, and then at night, be sat in the bath, tears running down my face, thinking "What the hell are we going to do?" "How am I going to sort this one out?"

And again, as in study one, hiding their feelings included hiding their feelings from their loved one:

'I mean my son visits once a week to see his dad, and he says to him sometimes "Oh of course, mum's been doing this, mum's been doing that", and I'm thinking "Please don't tell him that!"'

Other feelings that carers experienced but hid included feelings of guilt. Sometimes feelings of guilt centred on their loved one not wanting to live in a care home:

'And the guilt comes in, and he – he's generally accepted he's going to be here – here as in a nursing home – but every now and again, he says "Why can't I come home? Why can't you move to a bungalow so I can come home?" and in a way, he's sort of blaming me.'

For some it was because they felt they should do more:

'I'm beating myself up all the time. Because I think I should contribute – done more.'

'Emotional side is I think for people who are related – there's a guilt. Because you feel that you should be able to look after them. But you know you can't. So, initially, the guilt is massive and gradually you have to learn to live with that.'

Some carers reported feeling guilty about getting on with their own lives:

'My wife's been in care for two and a half years and I feel a terrific amount of guilt about a lot of things.'

'And it's almost like, you know, flicking a switch. Because when I come out of there I'm thinking "You know, I – actually – I'm fine! I'm active. I'm doing this. I'm doing that but that's where the guilt comes in for me. Because I walk away and leave him just, you know, sat in his chair.'

Some carers felt like they lived in two worlds:

'My husband is the youngest and has been and still is where he is. And you do sort of feel – I mean he's been there a long time – we're talking 6 years now. And I feel like I live in two totally different worlds.'

5.4.3 Carer as THE skilled helper

Being THE skilled helper continued in some ways even after the care recipient moved into a full-time care setting because the carer was still the person who held most of the knowledge. This was often needed by paid carers or health professionals to help them understand why the care recipient was behaving in a particular way or what previous medical issues there had been.

'….but in lots of ways, as far as dementia's concerned, I'm – I'm the knowledge…….because there isn't anything besides the dementia'.

"Ah, I remember now, funny enough, it must be about 8, 9 years ago, that cropped up!" Um, if I remember right, we did so-and-so, so-and-so and it helped! Yeah, try that!!"

5.4.4 Sense of loss

The second set of focus groups builds on the sense of loss theme from study one by pinpointing that, unlike carers living with their loved ones, carers of people living in a care home also report a loss of control.

'It's very difficult when somebody's in a Care Home. I mean my wife's in a specialist dementia ward, and um you tend to lose a lot of control over what's happening because you go into care and you have to have the GP who's at the Care Home, so you lose all continuity of GP care. Um, and so a lot of what goes on, as I say, you sort of, you have to make it your business and find out, because otherwise you don't get told some things.'

'Mine indeed goes one step further than you because my wife was sectioned. I have no rights. Everything is taken away from me, if I can be – all I can be is consulted.'

Carers described ways in which they attempted to regain some control:

'Yeah, you feel as if you aren't in control, at least I did. I was going to say I sort of tried to take back control by going and getting him and taking him [home].'

For many moving into a care home meant that their loved one had changed significantly, and they were left grieving for someone who was still physically present but whom had changed so much that their relationship had also completely changed:

'And, um, you know, you're grieving for the loss of somebody who is still here basically.'

'When I was talking about my wife to my children, I often find myself talking about her in the past tense. And yet she's still here.'

'I saw a psychiatrist after my husband had been diagnosed, and he sat there, and he turned around to me and he said, "Well you're going through a living bereavement, then aren't you?"'

The loss of family time, special routines, doing things together was something that many carers grieved for and the reality of separation was something that had a huge emotional impact leaving most struggling to find ways to still spend time together.

'I've gone as a volunteer in the nursing home where my wife is. She doesn't get up until eleven o'clock. For a couple of hours, I'm Jack the lad down in the MI unit, serving breakfast. I go and talk to a couple of residents who organise stuff. Then, I'm close to her.'

'…what I have been doing is going and getting him – and – because I find it, you know, he loves coming back home. And so, although it's getting very difficult getting him in and out of the car, um, you know it's nice to have him at home. I usually go and get him most afternoons, and keep him, and take him back about 8-ish...I don't know quite what I'm going to do now it's gone cold.'

5.4.5 Resilience as the ability to adapt through the carer journey

Carers whose loved ones lived in full-time care settings described resilience as an ability to be flexible. They did not think being resilient meant being able to return to how they were prior to being a carer, they saw it as an ability to accommodate change, rebuild their lives and find purpose:

'I suppose resilience to me means the ability, should you have it, to dance on a shifting carpet, to adapt to altering situations and just sort of, you know, go with the flow really – which is very hard to do.'

'If you're not flexible you can't survive.'

'I think it's accommodation of change.'

'My life has changed, and I will never get my life back! I will never be as I was 10 years ago. My life has changed completely. What I've got to do is accommodate that change.'

'Finding purpose – I opened a business to keep, make sure I got up every morning.'

Carers also saw resilience as an ability to withstand the emotional rollercoaster:

'But, when he went into the Home, the coping aspect went……coping in regards when physically and mentally you have to deal with the situation in front of you on a day to day basis……..but that goes, but then the resilience kicks in. The resilience, in the sense that you go through quite a few months of guilt. You feel guilty that you had to resort to that situation.'

'But then resilience – mentally – to be able to be mentally hard – deal with a situation which you've actually created in one way – it had to come about – knew it was going to be there – had been preparing for it, but although you think you've prepared yourself for it, when it kicks off, you're not prepared at all.'

'When you talk of resilience it's teaching yourself to cope with being able to walk away and think "Well, Mum's safe. She's being looked after". And whatever she might say it's only because she's in here and doesn't want to be here in her mind…and you've got to educate yourself to be able to cope with all of that. It's being able to pull back and just look at the bigger picture all the time, and think it is an emotional roller coaster.'

Carers did not think that if you were resilient you would necessarily experience wellbeing:

'When you're visiting someone who's, you know, you can see them deteriorating all the time you're visiting them, um it's not fun! I mean it doesn't make you feel you're happy. But the resilience comes in that you're actually fighting for them, aren't you?'

'And you're having to do what you can in their best interests. I mean it's not something that you get a great deal of sort of happiness from.'

There seemed to be a shared consensus that resilience was something you had to work at and learn:

'I've always worked at it.'

For many carers resilience was in part about learning to live with the avalanche of guilt:

'And then when I walk away is when I feel like hell! But slowly, I manage to push that back, and try and go on with other things.'

'And that's the reality of it, you know and um, so that – and that makes you feel guilty as well because, you know, you're thinking "She's still here, and I'm talking about her as if she isn't".

Finally, resilience was about finding a way to redefine their relationship and care role with their loved one. In many cases it was about finding an approach that enabled them to maintain some of their carer roles and a sense of connection and togetherness with their loved one.

'You know I still do, and sometimes, you know, I – perhaps I shouldn't but I mean I don't know whether they notice or not but, I mean sometimes you know, his hair and that – I've never seen him with greasy hair, you know, and little things like that – so I put him under the shower and I say "Do you feel better?" "Yes!"'

'Yeah, I sit and feed her, you know and it's those kind of things – I've still got a caring role. But it's just different.'

5.4.6 What makes it harder to be resilient?

Carers described experiences of being desperate for help prior to their loved one moving into a full-time care setting but struggling to get any:

'*Every time I rang for help when I was absolutely desperate because he needed help but he wouldn't accept it. And I thought perhaps if someone else went in, he would accept it. And, I mean, every time I rang, and I was even crying the once, they just said "Oh well that's self-funding. (Almost) - Get off the line!"'*

'It's having somebody in the know, who's in the business, because as I say, we're all new to this, we've not been through this before. We don't know what happens. I didn't know about the funding. Didn't know about this. Didn't know about that.'

'So, you're repeating everything a dozen times, and you – as you said – nobody's listening!'

Even when the cared for person was receiving health care there was still a lack of support for carers who were trying to work out what to do next:

'When my wife was at the National Neurological Hospital where she was diagnosed with Alzheimers, you know, they send you home and that's it! And there's no correlation between Health and Social Care, you sort of arrive home, and what do you do now? You know, and nobody tells you. You have to find everything out for yourself.'

'You go to the doctor. The doctor refers you to the Memory Clinic. You go to the Memory Clinic who refer you back to the doctor. What the hell!'

'I've been fortunate to meet someone to explain the finances but it's all by chance. I just happened to be in the right place at the right time.'

Carers described a disconnected system that resulted in adhoc interactions with professionals and conflicting messages:

'I've lost count of how many have popped in, done an assessment, and said "Oh we'll be in touch" and then you hear nothing until the next time somebody else pops in.'

'It's all very hit and miss. You might speak to one person one day, who tells you one thing, and another day you speak to somebody else, and they'd tell you something totally different.'

As the crisis phase passed and the reality of separation set in, so carers experienced an increase in loneliness:

'And the loneliness is beginning to fill that space. I find that the evenings tend to be the worst I find – I don't know about you – but, because during the day you tend to be doing things.'

'…and you sit down in the evening, and then you know that's when you, weekends as well.'

Another factor that affected resilience was feeling blamed and stigmatised:

' "Well, are you happy with him being in this Home?" And I said "Tell me the – the alternative?" "Well there isn't one". And I thought "Why ask the question then?"'

'And the other thing is, of course, is dealing with friends. "You haven't tried very hard!" – not said – but the implication - We saw her once and she seemed alright!'

5.4.7 What helps carers' to be resilient?

For carers whose loved ones lived in a care setting one of the key things they identified as helping was being able to work in partnership with the staff working in the care setting.

'I think a big part – communication is so important (consensus – mmm) when your parent's in here it's such a big part that the Home does speak to us, you know.'

'…..when Mum moans at us about something, we can go – we go to Martha and she'll listen to us, and she'll do something about it. Then we go away…..it's having someone you can go to and say "Mum said this, and that …'

5.5 Discussion

The assumption professionals often make is that moving the care recipient into a full-time care setting alleviates the pressures on the carer and reduces their caring role (Carers UK, 2011; Lundh et al, 2000; Morgan et al, 1997; Wenger et al, 2002; Davies and Nolan, 2004). However, analysis of the focus groups suggested that whilst the nature of the challenges and pressures of caring changed, the impact of the caring role did not. This was due to the emotional strain the move into a full-time care setting had on carers and the ongoing challenge of living with oscillating and conflicting emotions that were never resolved or reconciled. This mirrored findings from some of the previous literature (Dellasega and Nolan, 1997; Kellett 1998; Grant et al, 1998) and built on it by confirming that this was a common theme across care groups and relationships.

The analysis above identified a temporal aspect to caring which the researcher called the carer journey. A search of previous literature revealed that other researchers also identified a temporal aspect for example Cavaye (2006, p21) identified that carers go through the following stages:

- dawning realisation

- adopting the carer role
- going it alone
- gaining expertise
- sinking or swimming
- accessing services
- carers as clients
- continuation of caring
- new horizons

Cavaye's research focused on carers of older people but the analysis of the focus groups for this research indicated that the temporal model was relevant to carers of different ages, across care groups and relationships. Furthermore, Cavaye (2006, p66) identified that caring became more stressful the further along the journey the carer was because stress has a cumulative effect. Therefore, whilst the carer became more competent in the caring tasks this did not reduce the level of stress or the emotional impact caring had over time. This was confirmed by the analysis for carers in study one in comparison to carers in study two which highlighted that carers who were further down the caring journey and whose loved ones had moved into full-time care settings, were reportedly struggling more than those who were living with the person they cared for.

Linked to this temporal model was the carers' definition of resilience which carers from this second study defined as:

'The ability to continue caring, to continue navigating the changing relationship and to do this by adapting roles and behaviours throughout the carer journey.'

The more able carers were to make these adaptations quickly, the more resilient they seemed to be. This ability to adapt was closely linked to the concept of identity and was not widely discussed in previous literature. Changing roles and behaviour had an impact on the way the carers viewed themselves and were viewed by others. The assumption that when a loved one moved into a full-time care setting the carer was no longer a carer removed the carer role and identity from the carer. Whilst we might presume that this would result in a sense of freedom and an ability to take up new roles and a different identity, this was not necessarily experienced positively by carers whom, by this stage in the carer journey, often valued their carer identity. Previous studies also identified that carers rarely experienced the move as a positive experience (Minichiello, 1987; Nolan et al, 1996a; Penrod and Dellasega, 1998). Furthermore, as with the previous literature, carers acknowledged that they still undertook many carer roles and activities for their loved one (Arksey et al, 2005; Arksey, 2007). The removal of their carer identity resulted in carers from this second study reporting a heightened sense of the hidden world of caring.

Connected to this hidden world of caring was an increased sense of loneliness and guilt which was discussed in previous literature (Anehensel et al, 1995; Tilse, 2000). The ability to withstand these emotions was seen by carers who participated in focus groups as an indication of resilience. It was clear that in some cases the guilt led to feeling inadequate and a downward spiral of low self-esteem, depression and

anxiety. This was particularly true if the guilt carers felt was intensified by friends and family questioning their decision and shaming them. Negative reactions and unhelpful support from family members was mentioned in the previous literature (Bloomer et al, 2016; Heppenstall et al, 2014) and the findings from the focus groups once again confirmed the commonality of this experience across care groups and relationships.

Carers felt that this was where resilience could play a part as they saw resilience as the ability to keep caring by making decisions that were in the best interests of the care recipient (e.g. moving the care recipient into a home because they could no longer keep them safe caring for them at home); and to live with that decision even though they felt guilty and others were (intentionally or otherwise) judging and shaming them. The ability to make difficult, perhaps pragmatic decisions and live with the emotional consequences was a process that many carers described as helping them build their resilience throughout the carer journey.

The ability to steer a steady line of caring whilst weathering an oscillating line of conflicting emotions was a central aspect of resilience for carers. When this was explored further it became clear that the concept was associated with navigating their changing relationship with the care recipient and to developing an approach to continuing their carer role once their loved one was in a full-time care setting. Navigating the changing relationship was a theme that was present in the previous literature (Lundh et al, 2000; Hennings et al, 2013; Smith, 2001) and again the focus groups highlighted the commonality of this experience. Carers of family members living in full-time care settings were clear that they found it harder to be emotionally strong once their loved one moved into a full-time care setting. This suggested that the emotions related to the practical caring tasks were easier to manage than holding together conflicting emotions when the caring role changed.

The need to adapt and develop new lives was mentioned in previous literature (Dellasega and Nolan, 1997; Ryan and Scullion, 2000; Sandberg et al, 2001). This ability to adapt to new routines and create new roles outside of the caring role was something that carers who participated in the focus groups saw as a sign of resilience but again something they suggested was not easy to do. Linking this to the temporal model of caring, suggested that the point at which a carer was transitioning between stages was the point at which their resilience was both tested and developed. At the beginning of the transition they were less resilient but due to the challenges of withstanding the oscillating and conflicting emotions, moving through the transition increased their resilience as they learnt an ability to withstand such oscillating and conflicting emotions. This concept has some resonance with the literature on mindfulness. Williams and Penman (2011, p5) describe mindfulness as an ability to be compassionate with oneself, to catch negative thought patterns before they result in a downward spiral, to be curious about them, let them drift by and stay in control of one's life. In other words, being mindful is an ability to not let the negative thoughts control how you feel and act.

The focus group data analysis detected a clear connection between resilience and wellbeing but it was also evident that these concepts were not the same and being resilient did not always mean a carer was experiencing wellbeing. There was a sense that the physical wellbeing of carers often did improve when their loved ones moved

into full-time care settings not least because they were often able to get more sleep and the physically demanding care tasks stopped. However, the emotional wellbeing of carers did not improve due to conflicting emotions.

This sense of conflicting emotions was connected to the concept that carers often found themselves living in two worlds where their role and identity in both was ambiguous. This sense of living in limbo was cited in the previous literature (Kiely et al, 2008; Woods et al, 2008) and the focus groups added to this by revealing that it had an impact on resilience. The more able the carer was to flex between these two worlds and establish their sense of identity in both, the more resilient they were perceived to be.

The analysis illuminated an emerging picture of resilience. Carers described resilience as the ability to continue caring, to continue navigating their changing relationship with their loved one and to do this by adapting their roles and behaviours throughout their carer journey. There was also a suggestion that resilience was something to learn throughout the journey and at different stages of the journey resilience decreased and increased. It also became clear that resilience wasn't just about the personal characteristics of the carer but was linked to the context within which the carer cared and the support they received from family, friends and their community. There were some indications that the support they required changed throughout the carer journey too.

Fundamentally the impression was that caring was all about relationships. Carers were only carers because of a close relationship with someone who needed care and support and their ability to be a resilient carer was closely connected to their relationship with themselves and their sense of identity, their relationship with others such as other family, friends and their community and their ability to navigate their changing relationship with the care recipient.

Clearly across care groups and relationships the concept of resilience was the same for all carers and there were commonalities that were useful for both policy and practice. Carer resilience can only be developed through the carer journey and through the journey resilience will oscillate. Carer resilience was negatively impacted by the hidden world of caring, the sense of loss carers experienced and a lack of and/or inappropriate support carers received. Carer resilience was positively impacted by an acknowledgement that the carer was THE skilled helper, professionals/services working in partnership with the carer and timely, appropriate support that the carer felt actually helped.

5.6 Limitations

Although the researcher was successful at keeping participants focused on the topic it was difficult at times to ensure that people spoke one at a time. This made it difficult when transcribing the focus group and resulted in some sentences being missed as it was impossible to decipher what was said.

There was under representation of people caring for their children and people caring for those with mental health problems (not including dementia or Alzheimer's). There was also under representation of BME groups.

Two focus groups took place at carers' centres which may have influenced people's responses as these centres were the main resource for any services they received. The third focus group took place at a care home which again may have influenced their responses as it was the care home their loved ones were living in.

The other limitation was that all the carers still had a caring role so there was a gap in knowledge of how former carers viewed and experienced resilience. This needs to be explored in the next study.

5.6.1 Reliability

The focus groups were replicated in different parts of the country with a variety of carers who were caring for people with a range of different needs and with whom they had different relationships i.e spouse, parent etc.

The same questions were asked in each focus group and as a trained facilitator the researcher was able to keep the discussion on topic. The researcher ensured that all participants had equal opportunity to share their views and that divergent views were listened to and respected.

5.6.2 Validity

The questions correlated with the research aims and the topics identified in the literature review. The questions were discussed with the researcher's two supervisors to gain a consensus. The questions were then 'tested' with the carer support workers before being used in the focus groups.

The use of grounded theory and situational analysis provided a systematic approach to analysing the data from the focus groups. This approach added value in terms of academic rigour of approach and provided for validity in terms of traceability from initial data coding to the final theory.

6 Chapter 6: Part One – Third Set of Focus Groups

The purpose of the third set of focus groups was to test the emerging themes with a mixed group of carers who had not previously been involved with the research. In the end the researcher could only recruit enough participants for one focus group in this third set. The focus group explored whether the themes that had been identified resonated with carers still living with their loved ones, carers whose loved ones had moved into full-time care settings and former carers whose loved ones had died. The rational for a mixed group of carers centred on the desire to test whether data saturation had been reached.

Moreover, to do this by bringing together a range of carers who differed in age, gender, ethnicity, the relationship they had with the person they cared for and the nature of the condition of the care recipient. Within the context of the grounded theory approach the study aimed to use a focus group and situational analysis to answer the following research questions:

- What are the emotions and quality of life outcomes that carers experience? Are there commonalities across care groups and relationships?
- How do carers across care groups and relationships define resilience? Do they see themselves as resilient?

6.1 Context

There is extensive literature about carers who are actively caring but there is less research on former carers. There is also a lack of consistency by researchers using the term 'former carers'. Some researchers' use the term when referring to both care home carers and carers whose loved ones have died (Cronin et al, 2015). Larkin and Milne (2017, p1398) identified six routes to becoming a former carer:

When the cared-for person:

1. dies
2. is admitted to a hospital
3. is admitted to a hospice
4. is admitted to long-term care (i.e. permanently admitted to a nursing or residential care home or continuing care in hospital)
5. recovers from their health problem (e.g. hip fracture)
6. goes into remission (e.g. for cancer patients)

For the purposes of this thesis former carers only refers to those whose loved ones have died. This is for two reasons. Firstly, the earlier focus groups with care home carers identified that these carers were still caring and secondly there were a lack of studies on former carers whose loved ones had recovered as pointed out in Larkin and Milne's (2017) research on older former carers.

The mixed focus group was the only one that included former carers and the previous literature reviews did not explore the literature on former carers. Therefore, this section briefly summarises previous literature that examines the emotions and QoL outcomes for carers whose loved ones have died (former carers).

The literature review for study two (see section 5.1) highlighted that there was an assumption that stress and carer burden were relieved when a loved one moved into a full-time care setting. However, the focus groups with these care home carers demonstrated that this was not the case. There was a similar assumption made in relation to former carers where it was assumed that after an initial period of mourning; carer stress, depression, and other symptoms resolved. This may be true for some but not for all.

A recent review of the literature by Cavaye and Watts (2018) evidenced that the emotional experience and QoL outcomes of former carers were correlated with the nature, duration and chronicity of the illness of the care recipient; pre-existing relationships and the degree to which the care recipient experienced a 'good death'. High-quality, family-centred care at the end of life resulted in carers experiencing positive feelings of self-esteem, feeling uplifted, and realizing their essential role in the care of the care recipient (Given and Reinhard, 2017).

Corey and McCurry (2018) in their study of former carers of people with dementia found three themes:

- sleep disturbances
- changes in health status
- learning to live again

For some former carers sleep disturbances continued for as long as ten years. Changes in health were characterised by acute health crises soon after the death of the care recipient, ongoing physical or mental health problems that began during the carer journey and did not resolve after the death of the care recipient, or several mild health problems in quick succession.

Larkin (2009) also identified the theme 'learning to live again'. Her interpretation of post-caring involved three iterative stages:

- the post-caring void
- closing down the caring time
- constructing life post-caring

The 'post-caring void' involved feelings of acute loneliness, grief and loss. The second phase was characterised by changes in routines and activities that provided a sense of closure. The final stage was not about returning to a past, pre-caring life (as former carers report that they and their situation had changed so much that returning to their old lives was not possible), instead it was about building a new life.

Similarly, Cronin et al (2015) found post-caring was represented as a transition that comprised of three stages:

- loss of the caring world
- living in loss
- moving on

The transition to losing the caring world was significant for carers because in becoming a carer they lost their previous world e.g. friends, leisure activities, employment etc. To then lose the caring world often meant that they found themselves in a 'void' as Larkin (2009) described it. Cronin et al (2015) reported that this void left carers feeling that they no longer belonged anywhere or had an identity.

What was clear from the literature was that bereavement was not perceived by former carers as the end. Instead bereavement was experienced as another transition within the carer journey (Cavaye and Watts, 2018).

A review of previous literature by Larkin and Milne (2017) highlighted that older former carers experienced particular post-caring legacies and had a range of ill-recognised support needs. These post-caring legacies included:

- Debt due to care expenses incurred.
- Income reduction as paid work reduced or even stopped to care. This resulted in a reduced pension.
- Increased risk of social isolation.
- Increased risk of both physical and mental health issues.
- New health problems occurred when caring ended e.g. sleep problems, eating problems, and increasing alcohol consumption etc.
- Increased prevalence of depression due to loss of self-esteem, role and purpose. High prevalence of negative feelings such as anger guilt and sense of failure.
- Bereavement could be more challenging for carers than non-carers. This was linked to other losses for example loss of freedom, hopes for the future, etc. which gave rise to a multitude of complex emotions during caring and after death.

The Care Act (2014) does address the duty on local authorities to support carers but it focuses solely on active carers and there was little recognition of the support former carers may need (Cavaye and Watts, 2018). There was also a lack of recognition in practice of the support carers may need when transitioning to former carers and hence providing end-of-life care (Kenny et al, 2010). At this stage care recipients were often in receipt of formal care services (and were perhaps living in a full-time care setting). The involvement of formal care services often resulted in the assumption that the carer was no longer caring which the focus groups in this research have demonstrated is not the case. Making the decision to stop curative care and change to palliative care was one of the most difficult decisions for all concerned including carers. Carers needed support and guidance in processing their emotions and fears around these decisions (Given and Reinhard, 2017). Carers moving through this end-of-life stage also needed information about managing end-of-life symptoms and the dying process. Carers needed emotional support for their loved one, as well as for themselves.

Larkin and Milne (2017) highlighted in their review of the literature that former carers experienced better outcomes if they had a good relationship with the care recipient, if they were part of a well-functioning family, if they had a high level of self-esteem, they had access to socio-emotional support, high levels of education and a sufficiently high income. Hughes (2015) ascertained that certain strengths emerged through the provision of end-of-life care and the transition to former carer. These strengths included courage, determination, acceptance, humour, and empathy.

6.2 Focus Groups

A mixed focus group aimed at testing the emerging themes was conducted. Data was collected via audio recording which ran the full length of the focus group. The recording was then transcribed.

6.2.1 Participants

One focus group was conducted. The criterion for participation was that participants were adult carers or former carers.

Participants were recruited by reaching out to a carers' support group that had not previously been contacted as part of the research and using referral sampling whereby the support group recruited participants from among the carers they knew, being careful to include carers from all stages of the carer journey.

A total of 10 participants, including 9 women and 1 man participated in the focus group. All participants were White British. The participants ranged in age from 53 to 88 years old (with an average age of 70 years). Participants were either caring for (or had previously cared for) their son or daughter, their parents or for their spouses. The focus group contained a mix of carers from across carer groups with carers caring for people with a range of care and support needs due to a range of long-term conditions and/or illnesses.

Table 9: Study 3 Demographic characteristics of the participants

Participant Number	Gender	Age	Who they cared for	Condition requiring care	Where the care recipient lived
1	Female	55	Parents	Cancer	With Carer
2	Female	70	Daughter Husband	Mental Health End of Life	Own home Nursing home
3	Female	53	Parent	Physical Frailty	Care home
4	Female	74	Husband	Alzheimer	With Carer
5	Female	65	Husband Parent	Dementia Stroke	With Carer Care home
6	Female	71	Husband	Dementia	With Carer
7	Female	75	Husband	Dementia	With Carer
8	Female	75	Husband	Dementia Stroke	Died 1 year ago
9	Female	76	Husband	Brain Tumour	Died 3 years ago
10	Male	88	Wife	Dementia Cancer	With Carer

6.2.2 Structure of the focus group

The focus group was held at a community hall in a small market town in the South East. The focus group was scheduled for two hours. Two carers cared for two people, the other eight cared (or had cared) for one person. Two people were former carers, six carers were living with at least one of the people they cared for and three carers were caring for a loved one living in a care home.

6.2.3 Data collection

After the consent forms were completed the researcher asked carers to introduce themselves and to tell the group who they cared for or had cared for (i.e. spouse, adult child, sibling, parent,etc) and the condition the person had that resulted in them needing care.

The following questions were asked at the focus group:

- How would you describe resilience? How does a resilient carer behave?
- Do you consider yourselves to be resilient? Can you give an example?
- How has your resilience changed throughout your carer journey?
- Researcher to summarise the theme 'THE skilled helper' – does this theme resonate with you? How does being THE skilled helper affect your ability to be resilient?
- Researcher to summarise the theme 'Hidden world' - does this theme resonate with you? How does the hidden world of the carer affect your ability to be resilient?
- Researcher to summarise the theme 'sense of loss' - does this theme resonate with you? How does your sense of loss affect your ability to be resilient?
- What helps you to be resilient?
- What reduces your resilience? What happens to your resilience when your loved one passes away?

As with studies 1 and 2 the questions were refined by the research process and were built upon based on responses from the participants. The researcher used open-ended questions to solicit the views and experiences of the participants. The discussion on each question continued until it seemed all discussion had been exhausted. At the end the researcher summarised the comments that had been made. This provided an opportunity for the researcher to check that her interpretation of the comments was correct and to clarify anything that was unclear. The researcher then thanked the participants and discussed contact information and the intention to share the completed research with them.

6.3 Data Analysis

Situational analysis was used to allow emerging themes to surface. The transcript was coded line by line producing initial codes. Only three new codes emerged:

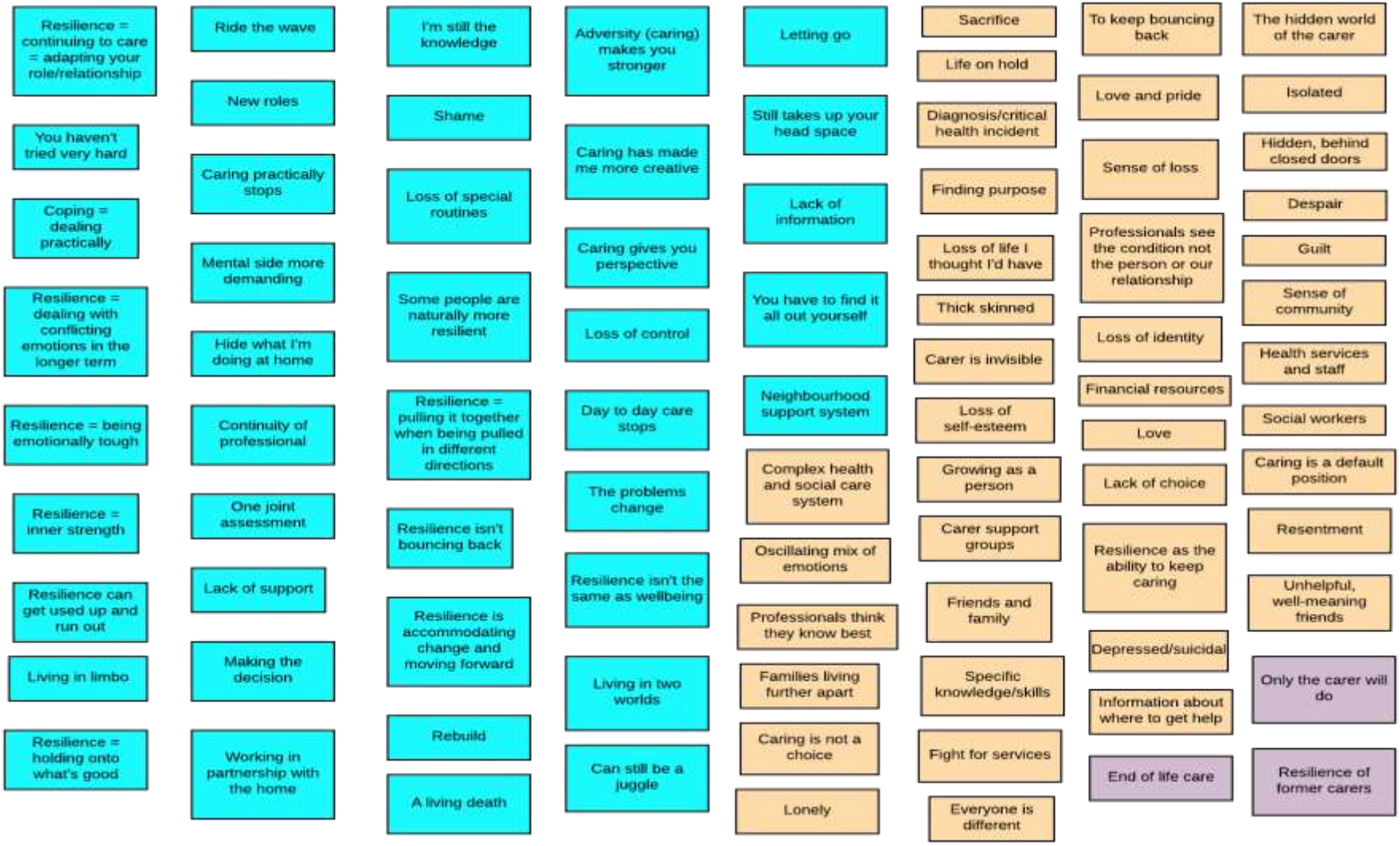
- End of life care
- Only the carer will do (care recipient refuses to receive care from anyone else)
- Resilience of former carers

6.3.1 Situational map

The data was then analysed using situational analysis to produce a situational map.

Figure 18 shows the early ‘saturated’ situational map that includes the codes from all of the focus groups. Orange boxes are codes from the first set that reappeared, blue are from the second set, purple are the three new codes from the third set.

Figure 18 Third Set: Situational Map



Study 3: Ordered Situational Map
The new codes did not alter the ordered map from the second set of focus groups and so it has not been reproduced here.

6.3.1.1. Reflections on the situational mapping and memo writing

What did the situational mapping reveal?
The situational mapping revealed that the coding process was reaching saturation point as only three new codes were found:

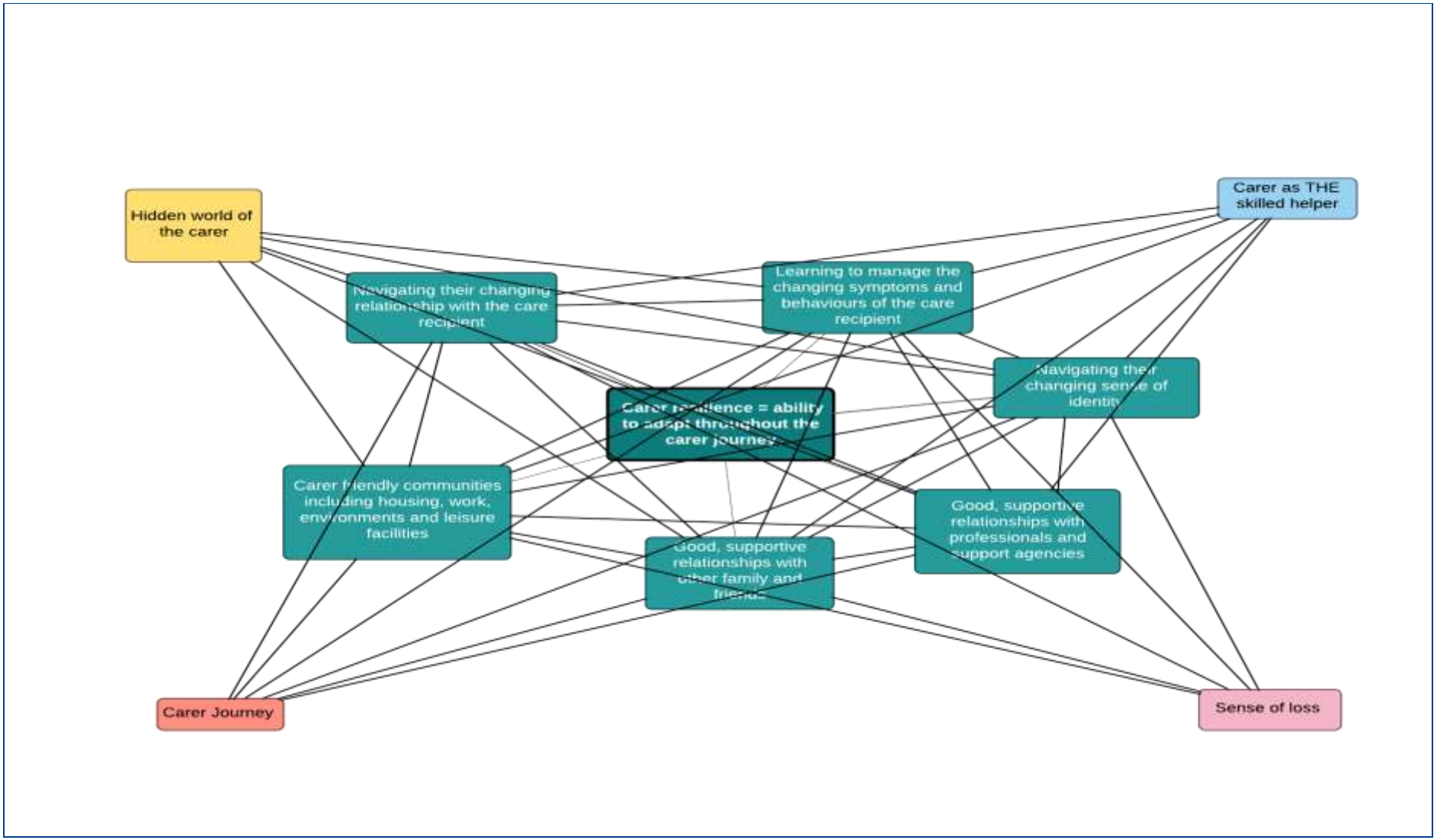
- end-of-life care
- only the carer will do
- resilience of former carers

What new understanding surfaced through the situational mapping?
The first and third codes (end-of-life care and the resilience of former carers) identified that the ending of the caring role could be traumatic and uplifting. There was evidence that carers experienced a mix of emotions at this stage that continued whilst they transitioned into the stage of former carers. It was also clear that former carers struggled to remain resilient after the death of their loved one and that this was strongly correlated to their sense of loneliness and isolation. Evidently one of the consequences of being a carer was that a carer's world did shrink. Therefore, when carers lost the caring world too, they struggled to reintegrate themselves back into their family, friend and community networks.

6.3.2 Relational Mapping

Codes were reviewed, and a relational map was drawn as a way of deciding on the most important codes to retain and to further cluster them by commonality thus adding to and tweaking the emerging themes from study 1 and 2. A second relational map was drawn that moved the analysis on from themes to identify emerging categories that were the foundation blocks of the emerging theory on resilience and carers. Themes were clustered into categories that epitomised what carers said were important factors in their ability to be resilient. This second map is illustrated below:

Figure 19 Third Set: Relational Map (2)



6.3.2.1. Reflections on the relational mapping and memo writing

What did the relational mapping reveal?

The relational mapping focused on clustering codes/themes into categories that aimed to answer the question 'what factors were important in terms of carer resilience?' 'In what areas did carers need to be able to adapt?' 'What things supported them to do so throughout the carer journey?' The relational mapping resulted in some new categories emerging as the main factors seemed to be:

- Navigating their changing relationship with the care recipient
- Learning to manage the changing symptoms and behaviours of the care recipient
- Navigating their changing sense of self / identity
- Good supportive relationships with other family and friends
- Good supportive relationships with professionals and support agencies
- Carer friendly communities including housing, work environments and leisure facilities

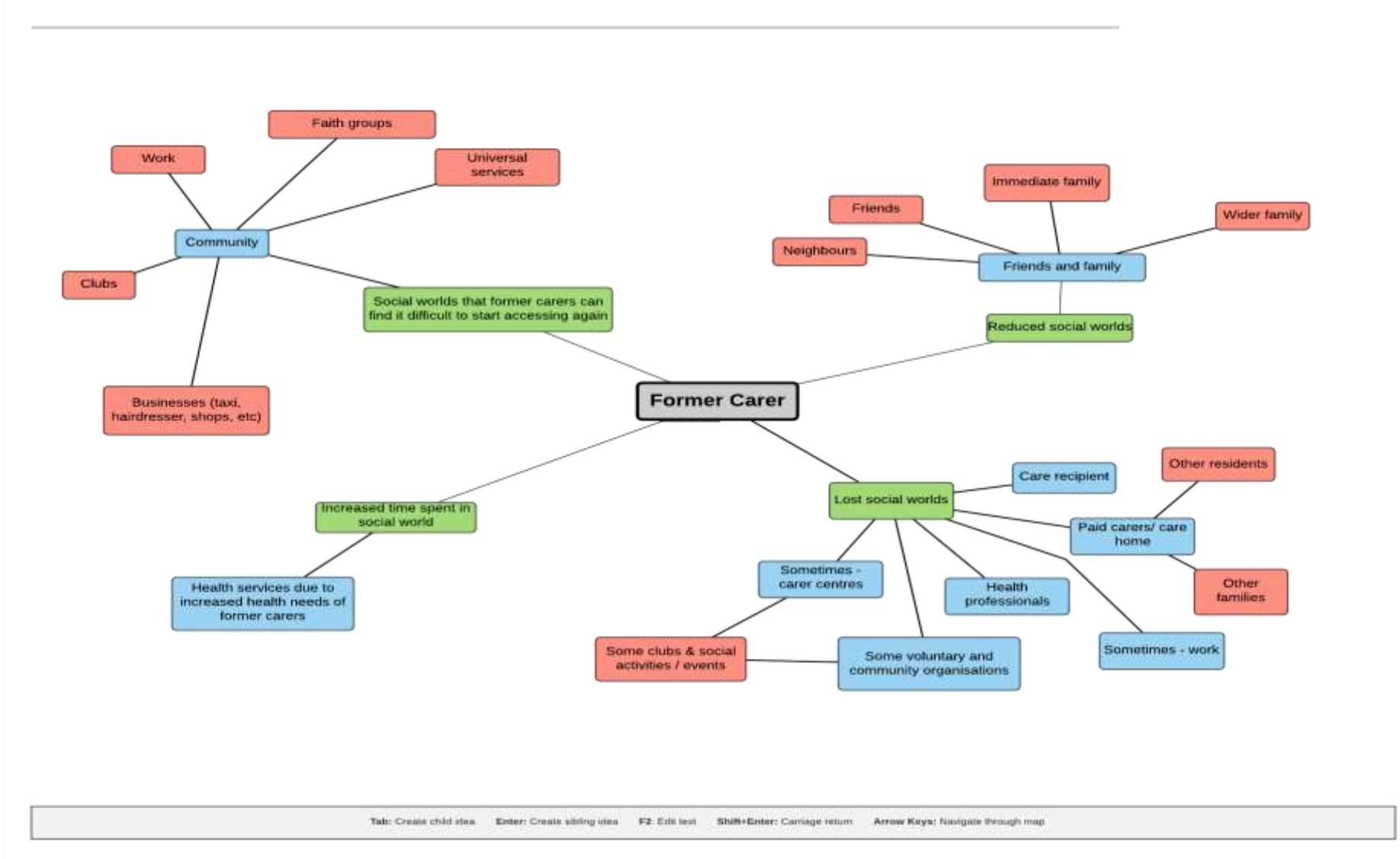
What new understanding surfaced through the relational mapping?

The relational mapping identified six important factors that had an influence on the carers ability to be resilient. The mixed focus group consolidated the fact that carers at all stages in the carer journey defined resilience as the ability to adapt. The six factors listed above also resonated with carers throughout the carer journey and across care groups and relationships. The relational map illustrated the close links between the six factors and the original themes.

6.3.3 Social arena/world map

During the data analysis process several social world maps were drawn. The most useful is depicted below and focused on the social world of the two former carers. It is useful because it identifies the lost worlds of the two former carers, which is difficult to draw generalisations from due to the analysis only being based on two former carers but the loss of social worlds and the potential connections with coping, wellbeing and resilience seem important.

Figure 20 Third Set Social World Map



6.3.3.1. Reflections on the social world mapping and memo writing – former carers

What did the social world mapping reveal?

The social world mapping highlighted the worlds that were lost and reduced for former carers as well as the worlds that they had difficulty re-engaging with. The social worlds of the community were still present, but it was difficult for the former carer to re-engage with them depending upon how disengaged with them they had become through the carer journey. Likewise, the social worlds of family friends and neighbours were also still present but again if the carer had struggled to maintain those relationships throughout the carer journey it was difficult for them to re-engage. Finally, the social world carers often began to access more was the social world of health services as many former carers experienced an increase in health issues after the death of a loved one.

The social worlds connected to the care recipient were often all lost. These included the social world of paid carers, care homes and other professionals. It also included the social worlds of some voluntary and community organisations if the carer's access was dependent upon the care recipient.

What new understanding did the social world mapping surface?

There was a surprising lack of support for former carers and a lack of specialist bereavement services to support former carers through, what was often, complicated grief. This seemed to be a result of the assumption by professionals and policy makers that the carer burden lifted when the care recipient died and that, after a period of mourning, former carers did not require further support and in fact should regain their ability to thrive. However, both previous literature and the findings from the focus group suggested that this was not the case and that former carers suffered a range of carer legacies that left former carers experiencing poor QoL outcomes.

Reflecting on this social map in comparison to the previous two, illustrated that social worlds changed throughout the carer journey. Social worlds were linked to the roles people played and their sense of identity. The reduction, loss of and difficulty re-engaging with many social worlds resonated with Larkin's (2009) description of former carers entering a void.

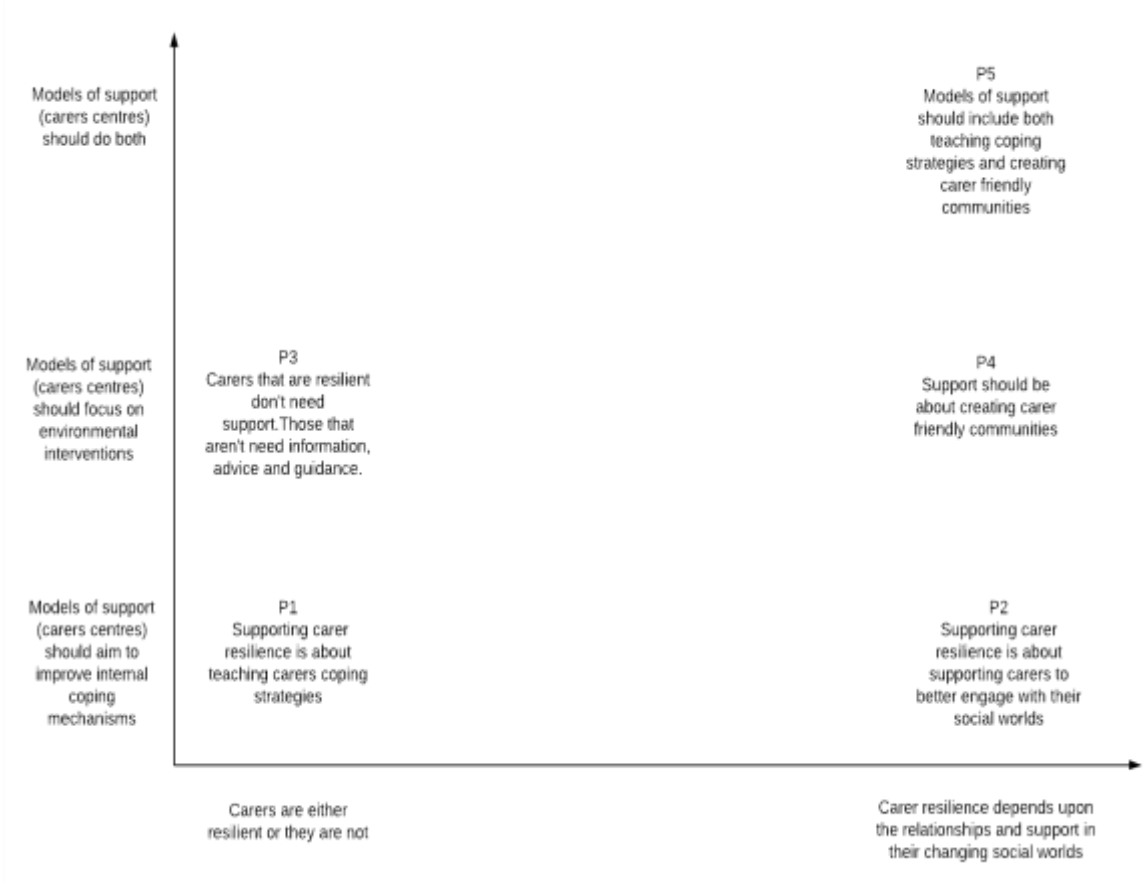
This sense of entering a void substantiated the concept that carer resilience was about adapting roles and behaviours throughout the carer journey and that the carer journey didn't end immediately the care recipient past away.

Carer resilience was an ability to adapt roles and behaviours and navigate changing relationships and the concept of developing resilience was a learning process that was influenced by the social context. As mentioned in the thesis introduction there has been a focus on developing the personal resilience of carers, but policies imply that the solution is to teach carers how to manage their caring role and come up with their own solutions. There is a lack of recognition that carer resilience cannot be achieved without environmental interventions such as raising awareness of carer issues and developing carer friendly communities i.e. adapted housing that makes their caring tasks easier, carer friendly employees that enable them to work flexibly and carer friendly community facilities that make reasonable adjustments to account for the challenges faced by carers.

6.3.4 Positional map

Several positional maps were created but the one included here looks at the tensions between models of support and the concept of carer resilience as a personal characteristic or relationship with changing social worlds. Carers in the focus groups had mentioned their local carers' centres within the context of community support. The two former carers had also mentioned the loss of contact with their carers' centre and this was highlighted on the social world map. The connection to resilience and the focus of this thesis on carers' centres meant that this was an important positional map to reflect upon.

Figure 21 Third Set: Positional Map



6.3.4.1. Reflections on the positional mapping and memo writing

What did the positional mapping reveal?

The positional mapping and memo writing revealed several approaches to supporting carer resilience that were based on whether resilience was a personal characteristic, a learnt skill and/or dependent upon support from and interaction with the carer's social worlds.

Where resilience was a personal characteristic and hence carers were either resilient or not, models of support focused on teaching coping strategies and/or providing information advice and guidance.

Where resilience was conceptualised as being dependent upon supportive social worlds, models of support focused on enabling carers to engage more effectively with their social worlds and creating carer friendly communities.

The final position was one that recognised the need for models of support to address both the personal coping skills of the carer and the community approach to carer resilience.

What new understanding surfaced through the positional mapping?
Reflecting on the positional map revealed that policies focus on addressing the personal coping skills of carers whilst campaign groups such as Carers UK focus more on developing carer friendly communities. It is not clear at this stage of the research what carers' centres focus on. This was explored in part three of this thesis.

6.4 Emerging Theory

This section describes the emerging theory from the analysis above.

6.4.1 Adapting to their changing relationship with the care recipient

Adapting to their changing relationship appeared to be a key part of carer resilience. Throughout the previous focus groups carers had described how, at the beginning of the carer journey there was often the dawning realisation that the relationship was changing and as the carer journey continued so the relationship changed forever. As a result, carers described their changing relationship as a loss which they had to adapt to:

'I kept a diary when my husband was first diagnosed with dementia…… at one stage I wrote that I felt there was a loss of coupledom.'

'All the tasks which perhaps your husband did before or your partner you now have to do, you take up all the financial bits, all the maintenance bits of the house. You aren't just caring for the patient but you're also doing his, the tasks that he used to do.'

As the carer journey continued and the carer became THE skilled helper, so the care recipient became increasingly dependent upon the carer often wanting only their family member to provide care for them:

'….they don't always want to be looked after by somebody else.'

This changing relationship and dependency was extremely restrictive for the carer:

'I'm trying to not let it take over my life but I'm finding that it gradually is.'

*'…and only this morning when I'd just got it organised and I think the 3 of us have bought our train tickets so we could all get there, he [*my husband*] suddenly said to me 'I can't have that person looking after me'.'*

However even though the relationship had changed some carers reported that the sense of connection had remained:

'It's not all negative, I've found that you know the relationship may have changed slightly but, it was a good relationship and we became closer I think as a result of his dependence on me.'

6.4.2 Learning to manage the changing symptoms and behaviours of the care recipient

The second component of carer resilience outlined the importance of carers learning how to manage the care recipient's symptoms and behaviours. There was a suggestion that the more able carers were to do this the easier their caring role and the better the outcome for both them and the care recipient:

'I've only got to look at my husband's face and I know instantly that this is going to be a difficult day and I've got to be there for him to keep him up because if he's up we cope but if he doesn't, if I don't get him up at that moment in time then it's going to be a bad day for both of us.'

As with the previous focus groups carers reported a sense of achievement when they were able to manage the symptoms and behaviour well:

'Yeah I think if you have a bad day and they really are up tight and having a go at you and then you gradually get them calmed down and then, as you say, a smile or something yeah….makes it all worthwhile.'

6.4.3 Adapting to their changing sense of self / identity

In connection with the changing relationship carers described a need to adapt and change their identity:

'You change, you change from at least I found, I changed from being a wife to being a carer and there is a difference.'

Again, as with the previous focus groups carers reported the challenges around maintaining activities and connections with other social worlds as they progressed along the carer journey. Increasingly they found themselves struggling to prioritise time for themselves as the scale of the caring role became all-consuming:

'It's quite hard to keep up with the things that you were doing, that's the problem. And that's why your life changes almost instantly doesn't it really, you don't think it's changing…then all of a sudden you're in that swamp and I, that's what I find difficult.'

Carers made the connection between the all-consuming, isolating nature of the caring role and a loss of confidence over time:

'Well I suppose I was so focussed for so many years on just that one thing that I lost the life that I had before really and now it's difficult to take it up again.'

'…..the life you had before caring gets lost because the caring role takes over and it's really hard to rebuild it.'

Carers highlighted the fact that being resilient required an ability to adapt and reinvent oneself even though one didn't want to:

'You have to be strong enough to reinvent yourself……and half of you doesn't….it takes time, half of you doesn't want to. You don't want to reinvent yourself, you want it to be like it was before and it can't be…..and that's acceptance as well.'

6.4.4 Good supportive relationships with other family and friends

Similarly, to the previous focus groups carers identified how important friends and family were in their ability to keep caring:

'I think it for me it was support from other people which was so essential both friends and family.'

However, carers across the caring journey also emphasised that having friends, even good, supportive friends did not stop them from feeling lonely or a sense that they must cope with caring alone:

'Being a man looking after a woman I feel like I'm being weak if I go around asking people for help, so I tend to battle on my own and I've coped well enough.'

'Really there comes a time when you just can't keep telling people about these things.'

'It's interesting what you said about being lonely I feel, even though all the help I've got, lovely family, some days I can feel very alone.'

6.4.5 Good supportive relationships with professionals and support agencies

Support from friends and family was not enough and there was a recognition in this focus group as with the previous ones, that good relationships with professionals and support agencies helped carers to continue caring:

'The carers who were engaged to come in 3 or 4 times a day would have a cup of tea with me and I said to them once you, you know this is taking your time and they said actually talking to you is built into it so the physical built in system can be really crucial thing that helps you survive.'

Carers also reported that poor support from such professionals and agencies could push them towards breaking point:

'……..my resilience was knocked a great deal, um, by the way that I was, that news was broken to me…….. I think that when someone said you need to read that book and it was called 'understanding schizophrenia' that wasn't the best way.'

'And you can be very bothered by long phone calls trying to get a particular service like a dental service for instance and you get handed from one office to another and nobody seems to have an answer, they say they'll ring back, and they don't and I think that can lead to the sort of breaking point of the resilience.'

6.4.6 Carer friendly communities

Carers across the caring journey and particularly former carers emphasised how important it was that communities support carers by tackling loneliness and isolation:

'Well I was just going to say even if somebody comes to visit for an hour a day that's 23 hours when there's nobody there, and I think that's the thing, its lovely to see them and they go away, and you've still got the other 23 hours to get through.'

Isolation and loneliness were also particular issues for older carers, especially those who were nearing the end of their caring journey as the health of their loved one deteriorated:

'I think one main factor is age, I've lost most of my relatives because I'm very old and you don't make new friends and if I was left on my own I would become a hermit, I could see that as the only way I could cope.'

The concept that the caring world was a hidden world that others did not understand and somehow separate to the rest of the world was once again a strong theme:

'Makes all the difference….getting back into the real world.'

'Until you're actually a carer I don't think you really ever understand until it happens to you.'

Carers also indicated that meeting up with carers but engaging in activities that were not related to caring was a useful form of support that gave some carers a boost. However, it was suggested that these opportunities were rare:

'I would do anything to, for the odd day that one could meet up with carers, but it not be about caring but be with people that needed it as much as we, but not necessarily always about the sad side of it all.'

6.5 Discussion

The two former carers in the focus group mirrored themes from the literature review on former carers emphasising that the carer journey did not end when the care recipient died (Cavaye and Watts, 2018). On the contrary the two former carers described their journey as a transition to nothing, a vacuum or post-caring void as Larkin (2009) described it. The two former carers described living in a world full of grief. They portrayed a loss of the person they had cared for but also a loss of role, identity and purpose that reflected the phrase used by Cronin et al (2015) 'living in loss'. The two former carers went on to explain the final stage of moving on and learning to live a new life as previously described by Corey and McCurry, 2018; Larkin, 2009 and Cavaye, 2006. The study builds on the sparse literature on former

carers by confirming these themes and stages to the carer journey. The analysis provided further tentative insight as the two former carers stated that reaching this final stage required them to once again adapt their behaviours and change their roles, in other words to be resilient, a concept that had not been discussed in the previous literature.

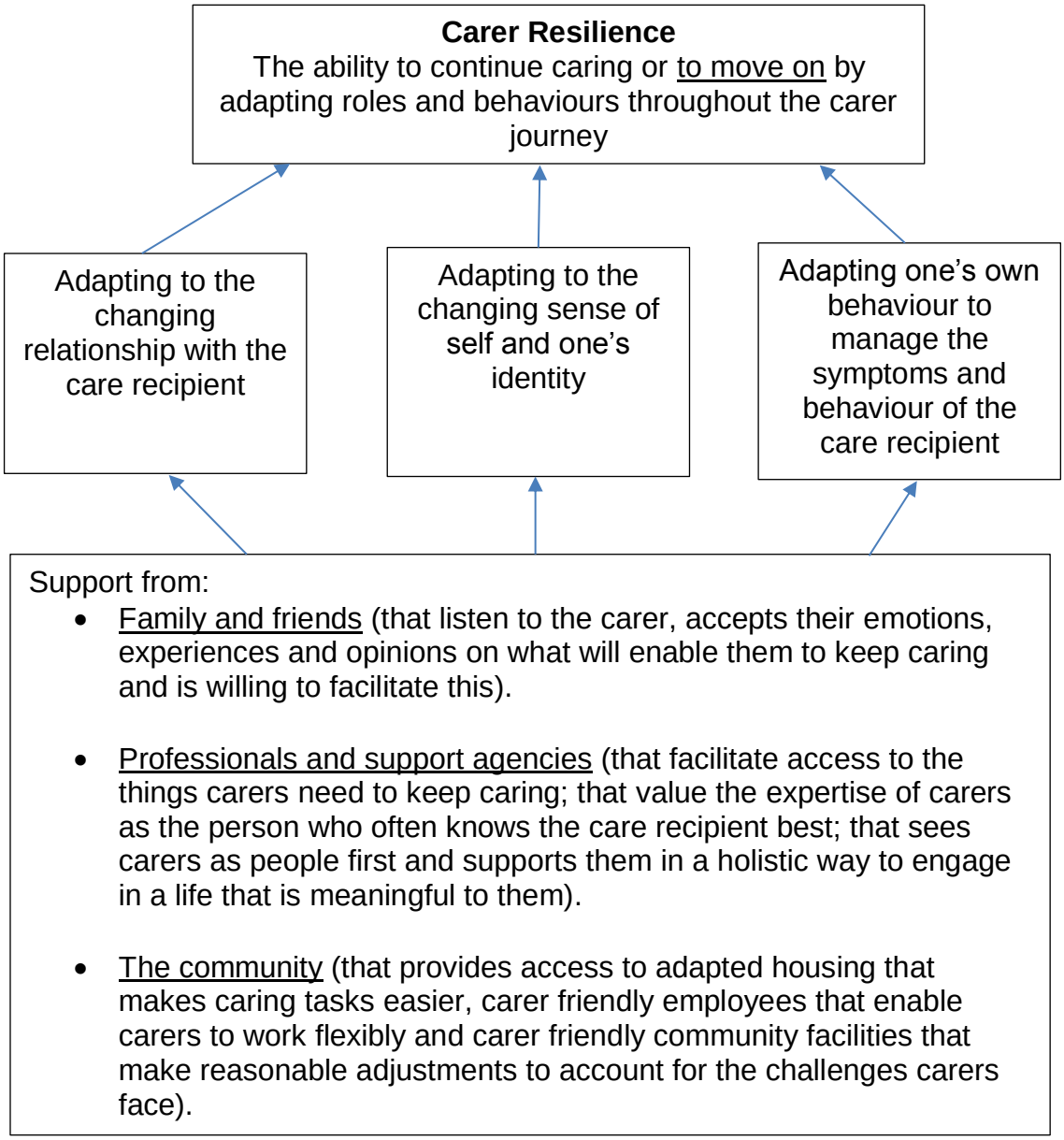
Larkin and Milne (2017) identified several factors that, if present resulted in better outcomes for former carers. These included a good relationship with the care recipient, being part of a well-functioning family, a high level of self-esteem and access to socio-emotional support. These themes were also reflected by the two former carers in the focus group and emerged as categories that were important for promoting carer resilience in the relational mapping.

Carers from the focus group whose loved ones were living in full-time care settings also described the need for good relationships and support from family and friends, professionals and the wider community. These were all themes that previous literature on carers of people in full-time care settings had identified (Davies and Nolan, 2004; Lundh et al, 2000; Dellasega and Nolan, 1997). The previous literature also mentioned that outcomes for carers were more positive if they had an ongoing, positive relationship with their loved one (Sandberg et al, 2001; Kellett, 1996) and if they were able to redefine their role in a way that maintained or increased their self-esteem (Fleming, 1998). The focus group built on previous literature by ascertaining the commonality of these themes for carers across care groups and relationships and across the carer journey. The key aspect of this final focus group was that data saturation was reached and the themes identified by the previous analysis was refined.

For example, commonality was further confirmed by carers from the focus group who lived with the care recipient. They too emphasised the importance of the relationship with the care recipient, their sense of identity and self-esteem, relationships with family and friends, access to a carer-friendly community, good relationships with professionals and an ability to manage the behaviours and symptoms caused by the condition their loved one had. Previous literature on carers at this stage of the carer journey had touched on these themes (Lazarus and Folkman, 1987; Pearlin et al, 1990; Dimitripoulos et al, 2008; Kramer, 1997) but the focus group built on this by underlining the commonality of these themes across care groups, relationships and stages of the carer journey.

The refining of the themes in the analysis resulted in an emerging model of carer resilience that is illustrated in the diagram below:

Figure 22 Emerging Model of Carer Resilience



(N.B. The addition of '*or to move on'* to the definition of carer resilience was to ensure that former carers and the entire carer journey was included within the definition).

6.6 Limitations

Although the researcher was successful at keeping participants focused on the topic it was difficult at times to ensure that people spoke one at a time. This made it difficult when transcribing the focus group and resulted in some sentences being missed as it was impossible to decipher what was said.

There was under representation of people caring for their children, male carers and there was also under representation of BME groups. A very small number of former carers (only two) were involved in the focus group making it difficult to generalise the results.

6.6.1 Reliability

The focus group participants included carers at different stages in the caring journey and carers who were caring for people with a range of different needs and with whom they had different relationships i.e. spouse, parent etc.

As a trained facilitator the researcher was able to keep the discussion on topic. The researcher ensured that all participants had equal opportunity to share their views and that divergent views were listened to and respected.

Data saturation was achieved with only three new codes arising from the data collection.

6.6.2 Validity

The questions correlated with the research aims and the topics identified in the literature review and previous focus groups. The questions were discussed with the researcher's two supervisors to gain a consensus. The questions were then 'tested' with the carer support workers before being used in the focus group.

The use of Grounded Theory and situational analysis provided a systematic approach to analysing the data from the focus group. This approach added value in terms of academic rigour of approach and provided for validity in terms of traceability from initial data coding to the final theory.

Part Two: Developing the model of carer resilience and the audit tool

7 Chapter 7: How do definitions, concepts and models of resilience relate to carers?

This chapter summarises the narrative review of the conceptualisation of resilience in previous research. Definitions, concepts and models used to describe resilience are identified and discussed. Factors that predict resilience are reviewed and the differences between coping and being resilient are highlighted. Attention to the usefulness of mapping models of resilience against models of grief and oppression in determining how best to support carers is outlined. A comparison is made between the themes from the focus group analysis and the concept of resilience in previous literature. This comparison is drawn together into a refined model of support for promoting carer resilience.

7.1 Why is resilience important in the context of carers?

Informal caring provided by carers is often viewed as a form of adversity (Cohen et al, 2002). Part One of this research summarised the research supporting this view and outlined the evidence suggesting that many carers suffer high levels of stress, grief and oppression as a central part of the carer experience. However, this was not the whole story and it was clear from the research that many carers also experienced positive emotions and QoL outcomes. What was interesting was the considerable diversity in the experiences of carers and the fact that much of the time they experienced a mix of oscillating and conflicting emotions.

Successful adaptation to the caring role and ability to sustain it seemed to require flexibility and an ability to adapt. Whilst a sense of loss and the negative emotions related to it were perhaps not things that can be annihilated for carers, models of grief suggest that carers cope best if they do oscillate between negative and positive emotions and linked to this, avoidant and problem-solving coping styles.

Recently research has begun to examine the role of resilience in enhancing the capacity of individuals to 'bounce back', enabling them to continue to care whilst also maintaining their sense of wellbeing (Minnes et al, 2007). How resilience has been conceptualised in previous literature and how this compared to the perspective of carers who participated in this study was explored and is discussed throughout the chapter.

7.2 Definitions of Resilience

In Latin re means "back" and salire means "to jump, leap". The word resilience comes from the Latin word resilire meaning 'to rebound or recoil'. To 'rebound or recoil' suggests an element of elasticity and an ability to do so repeatedly. In contrast definitions of coping centre round a person's ability to successfully manage a stressful event or overcome a challenge. The Oxford Dictionary definition of 'cope' is

'to deal effectively with something difficult'. The Lazarus and Folkman's (1984) stress process model is a linear model rather than a cyclical one.

In part one of this research study it became clear that carers often experienced repeated adversity, ongoing challenges and ever-changing circumstances. Their experience was one of mixed emotions and oscillation between positive and negative QoL outcomes. In this context the concept of coping and its focus on single events and a linear process seems an inadequate framework for investigating how to maintain carers' ability to endure and continue caring let alone increasing their experience of positive emotions and QoL outcomes. The concept of resilience may offer a useful alternative.

Multiple definitions of resilience exist within the literature, but there is no accepted single definition or operational model that provides consistency across disciplines. Examples of some of the most commonly cited definitions of resilience are presented in the table below.

Table 10: Definitions of Resilience

Reference	Definition
Masten, Best, & Garmezy, 1990	The process of capacity for, or outcome of successful adaptation despite challenging or threatening circumstances.
Fraser et al, 1999	Unpredicted or markedly successful adaptations to negative life events, trauma, stress, and other forms of risk.
Luthar et al, 2000	A dynamic process encompassing positive adaptation within the context of significant adversity.
Connor & Davidson, 2003	The personal qualities that enables one to thrive in the face of adversity.
Bonanno, 2004	The ability of adults in otherwise normal circumstances who are exposed to an isolated and potentially highly disruptive event such as the death of a close relation or a violent or life-threatening situation to maintain relatively stable, healthy levels of psychological and physical functioning, as well as the capacity for generative experiences and positive emotions.
Rutter, 2006	Reduced vulnerability to environmental risk experiences, the overcoming of a stress or adversity, or a relatively good outcome despite risk experiences.
Ungar, 2008	In the context of exposure to significant adversity, whether psychological, environmental or both, resilience is both the capacity of individuals to navigate their way to health sustaining resources, including opportunities to experience feelings of wellbeing and a condition of the individual family, community and culture to provide these health resources and experiences in culturally meaningful ways.

Whichever definition of resilience you use, resilience is defined as being multifactorial, changing over time, and different for different people. It extends from genetic variables such as personality and intelligence, to contextual ones such as family or community resources (Smith, 1999). Clearly resilience has been conceptualised in a variety of ways.

7.3 Conceptualising resilience

There is still debate in the literature as to whether resilience is a personal characteristic, an acquired skill, or a process.

7.3.1 Resilience as a personal characteristic

Some researchers have described resilience as a personal characteristic. For example, Greene (2002, p6) described it as: 'an innate self-righting mechanism that assists people in redirecting their lives onto an adaptive path following disadvantageous or stressful circumstances'. In their study testing a personal characteristic's model of resilience with Canadian forces recruits, Skomorovsky and Stevens (2013) found that the tendency to experience purposefulness in activities, to have a sense of control over life experiences, to attach positive meaning, and to perceive stressors as challenges in life, protected individuals against stressful events.

Several personal characteristics have been identified as contributing to or predicting how resilient a person is likely to be. Tugade and Fredrickson (2004) suggested that resilient people think positively about adverse situations and have access to an increased reserve of positive information than those who are not so resilient. Garmezy (1993) established that resilient individuals believe that they can directly influence the events that occur in their lives and translate their beliefs into actions. Bluglass (2007) identified that the capacity to find humour in past and present events was one of the most important keys to living positively (p21). Tusaie et al (2007) in their study on psychosocial resilience in adolescents found that adolescents with higher levels of optimism and higher levels of perceived support of family and friends also showed higher levels of psychosocial resilience even if they experienced multiple bad life events. Van Kessel (2013) found that older people who had the ability to use personal resources and see the world beyond their own concerns were more likely to be resilient.

In Antonovsky's model (1987 and 1993) resilience depended upon three characteristics: comprehensibility, manageability and meaningfulness. The person who experienced the world as comprehensible expected that future stimuli would be predictable or, when things did come as surprises, it would be orderable and explicable. The person who experienced their world as manageable would have the sense that, aided by their own resources or by those of trustworthy others, they would be able to cope. A person who experienced the world as meaningful would not be overcome by unhappy experiences but would experience them as challenges, be determined to seek meaning in them, and do his/ her best to overcome them with dignity.

Machin (2007, p60) summarised the ways in which resilience as a personal characteristic have been described in the literature by outlining three key elements:

- Personal resourcefulness: involving qualities such as flexibility, courage, and perseverance;
- A positive life perspective: in which there is optimism, hope, a capacity to make sense of experience and motivation in setting personal goals;
- Social embeddedness: in which there is availability of support and a capacity to access it.

Shalev et al (2008, p155) suggested that humans have an inherent ability to recover from transient misery and hence resilience should be the default outcome or the norm. Bonanno (2004) supported the idea that resilience is the norm. For example,

a growing body of research has demonstrated that most bereaved persons display stable, healthy levels of psychological and physical functioning as well as the capacity for generative experiences and positive emotions even relatively soon after a loss (Mancini and Bonanno, 2009).

A variety of studies have shown that given a group of people who have experienced a similar level of adversity, most of these people will exhibit resilient profiles (i.e. the absence of significant dysfunction and psychopathology) (Bonanno, 2004; Masten, 2001). These and other similar studies characterised resilience by identifying resilient and non-resilient people.

Some studies have taken this a step further by describing resilient people as experiencing a range of outcomes. In her conceptual analysis of resilience, Earvolino-Ramirez described the significant outcomes or behavioural consequences of resilience as effective coping, mastery, and positive adaptation (Earvolino-Ramirez, 2007). Robertson's (2012, p8) described a list of personal behaviours that demonstrated resilience:

- Healthy self-esteem, self-worth, or self-acceptance, and awareness of personal strengths and resources.
- Self-confidence, belief in your ability to perform competently in the face of adversity.
- Good problem-solving ability, the ability to make decisions and put plans into effect.
- Social skills, such as assertiveness, empathy, communication skills, etc.
- Good emotional self-regulation, the ability to appropriately handle your thoughts, feelings and impulses to action.

Expected outcomes or behaviours have often defined what we conceive as 'resilience' and resilience is likely to mean different things for different people at different times (i.e. the relevant outcome may vary between situations and according to personal, group or cultural expectations) (Shalev et al, 2008, p171).

Other studies have characterised resilience as the ability to respond flexibly to continuous demands. This notion of 'psychological flexibility' highlights the importance of moving past characterising resilient profiles as single adaptive responses to single events to characterising them as the flexible application of a variety of adaptive responses to a variety of life events (Kashdan & Rottenberg, 2010).

Ungar (2013) suggested that resilience was not a static characteristic of the person, but a dynamic, multidimensional process. An adaptive response that was only evident under stress and invisible or non-functioning when no stress was present. Reviewing the literature provided evidence that one of the key things that most researchers agreed on was that for resilience to be demonstrated, both adversity and positive adaptation must be evident. In other words, resilience could not be applied to individuals in the absence of a traumatic experience. This makes the concept of a 'resilient personality' meaningless because 'being resilient' cannot be demonstrated prior to the adverse event (Mancini and Bonanno, 2009).

Richardson (2002) took this concept a step further by proposing that resilience was developed 'as a result of' rather than 'in spite of' adverse events.

7.3.2 Resilience as a process

The idea that resilience is developed as a result of adversity rather than in spite of it has led to resilience being conceptualised as a process of adaptation rather than a personality trait. Those who support the concept of resilience as a process, challenge the notion of resilience as a static state. Luthar et al (2000) referred to resilience as a ''dynamic process encompassing positive adaptation within the context of significant adversity'' (p543).

Conceptualising resilience as a process recognises that it is a capacity that develops over time in the context of person - environment interactions. Sapountzaki (2007) described the process as an interaction between the person and the environment that enabled the person to adjust to hard times.

This fits neatly with modern theories on stress. Kabat-Zinn (2013) described stress as 'occurring on multiple levels, originating from many different sources, continually changing in its detail while its overall pattern remains the same' (p287). Kabat-Zinn stated that we all have our own version of stress but that thinking of it in terms of systems or process helps us to understand the enormous range of human responses into a single concept.

Van Kessel (2013) stated that the dynamic process of resilience may involve the negotiation and navigation of internal and external resources (Van Kessel, 2013). The idea of resilience being connected to the navigation of resources also fits with stress and coping theories. Lazarus and Folkman (1984) defined psychological stress as a relationship between the person and the environment that is viewed by the person as jeopardising their sense of wellbeing because it is beyond their ability to cope with. This explains why an event might be more stressful for one person, who for one reason or another has fewer resources or skills for dealing with it, than for another who has greater coping mechanisms.

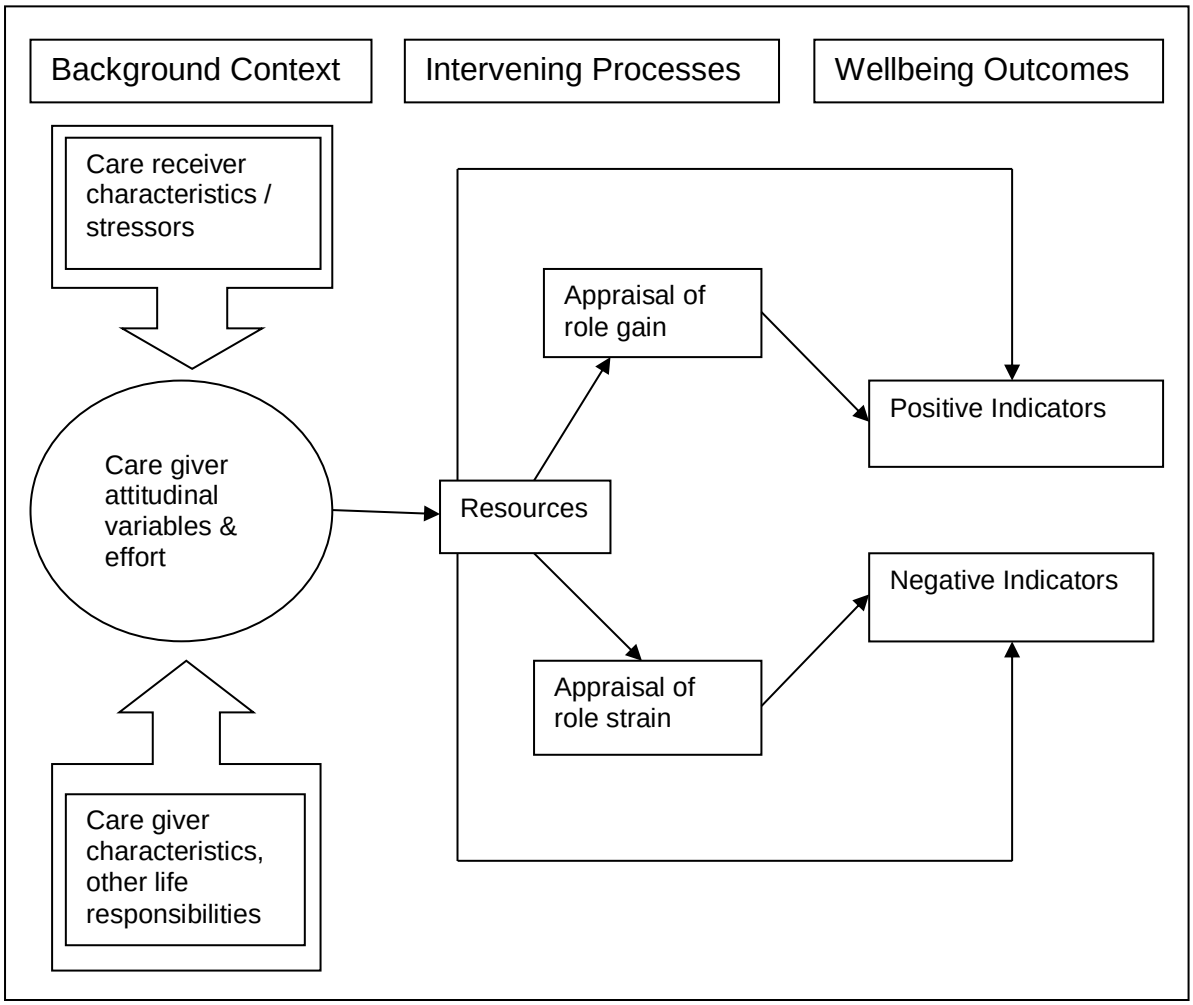
The concept of resilience as a process has resulted in a greater focus on the risk and protective factors that might be involved. The risk and protective factors experienced vary according to genetic influences, life experience and the way life events are cognitively processed. The risk with any single risk factor on its own may be small but it is the pattern of multiple risk factors that dominate the resilience literature (Rutter, 1999). It is similar when we look at protective factors. The loss of one protective factor on its own may not have a significant impact on resilience but the loss of several can be catastrophic. Conceptualising resilience in this way, as a process influenced by risk and protective factors, means that it has often been closely associated in the literature with concepts of coping. The similarities and differences between the concepts of resilience and coping will now be explored in more detail.

7.4 Resilience and Coping

Richardson (2002) proposed that resilience is ''the process of coping with stressors, adversity, change or opportunity in a manner that results in the identification, fortification, and enrichment of resilient qualities or protective factors'' (p. 308). This

has links with the Conceptual Model of Carer Adaptation (Kramer, 1997) discussed in Part One and depicted again below for easy reference.

Figure 23: Conceptual Model of Carer Adaptation (Kramer, 1997)



Fletcher and Sarkar (2013) characterised resilience as 'its influence on one's appraisal prior to emotional and coping responses and by its positive, protective impact, whereas coping is characterized by its response to a stressful encounter and by its varying effectiveness in resolving outstanding issues' (p 16).

Focusing on resilience as one's appraisal prior to emotional or coping responses, Pakenham (2005a) described appraisal as an evaluative process that reflects the person's subjective interpretation of the event. If a carer appraises a caring-related event as exceeding their coping resources, they will experience negative emotions and/or QoL outcomes. Fletcher and Sarkar (2012) presented an integrated concept of resilience and coping by suggesting that resilience influences the stress process at multiple stages:

- An individual's appraisal of stressors.
- His or her understanding of felt emotions and strategies for regulating them.
- His or her selection of coping strategies.

The findings of a study by Johnson et al (2010) investigating testing the schematic appraisals model of suicide mirror Fletcher and Sarkar's (2012) integrated concept of resilience and coping. Johnson et al (2010) found that positive self-appraisals were inversely related to suicidality and moderated the impact of stressful life events. The findings also emphasised the importance of three types of self-appraisal in the prevention of suicidality:

- Appraisals concerning the individual's ability to cope with difficult situations.
- Appraisals concerning the ability to regulate felt emotions.
- Appraisals concerning the ability to gain social support.

It seems then, that resilience and coping are conceptually different, but that coping does represent an essential component of resilience. No wonder developing coping skills have been a basic, critical target from the standpoint of fostering resilience through prevention and intervention. Various models of resilience have been designed and used as frameworks for interventions. Many of these resilience models incorporate elements of coping and stress. Some of these models will now be investigated further and their relevance for carers discussed.

7.5 Models of Resilience: How useful are they when applied to carers?

What might be the components of a useful model of resilience based on what we know so far? We know from the literature review in Part One that carers often experienced chronic stress due to the relentless nature of the care-giving tasks. We also know that carers frequently experienced chronic sorrow and feelings of grief or a sense of loss. There was also evidence to suggest that carers were often subjected to oppressive behaviours and responses from the very people and services designed to support them. Any useful model of resilience will need to address these issues.

Analysis of the focus groups identified that carers define resilience as:

'The ability to either continue caring or to move on, and to do this by adapting their roles and behaviours throughout the carer journey.'

The analysis also identified that the factors that constitute carer resilience are:

- An ability to adapt to the changing relationship with the care recipient.
- As ability to adapt to their changing sense of self and identity.
- An ability to adapt their behaviour to better manage the symptoms and behaviour of the care recipient.

To adapt their roles and behaviours carers need a variety of support, this includes:

- Support from family and friends.
- Support from professionals and support agencies.
- Support from their community.

Any useful model of resilience found in the literature needed to address these issues too. Hence, the most useful way of conceptualising resilience at this point seemed to be as a process resulting in a wide range of outcomes. Resilience meant something different to different groups of people and varied depending on situation and culture. The literature also suggested that coping was a key element of resilience, but that

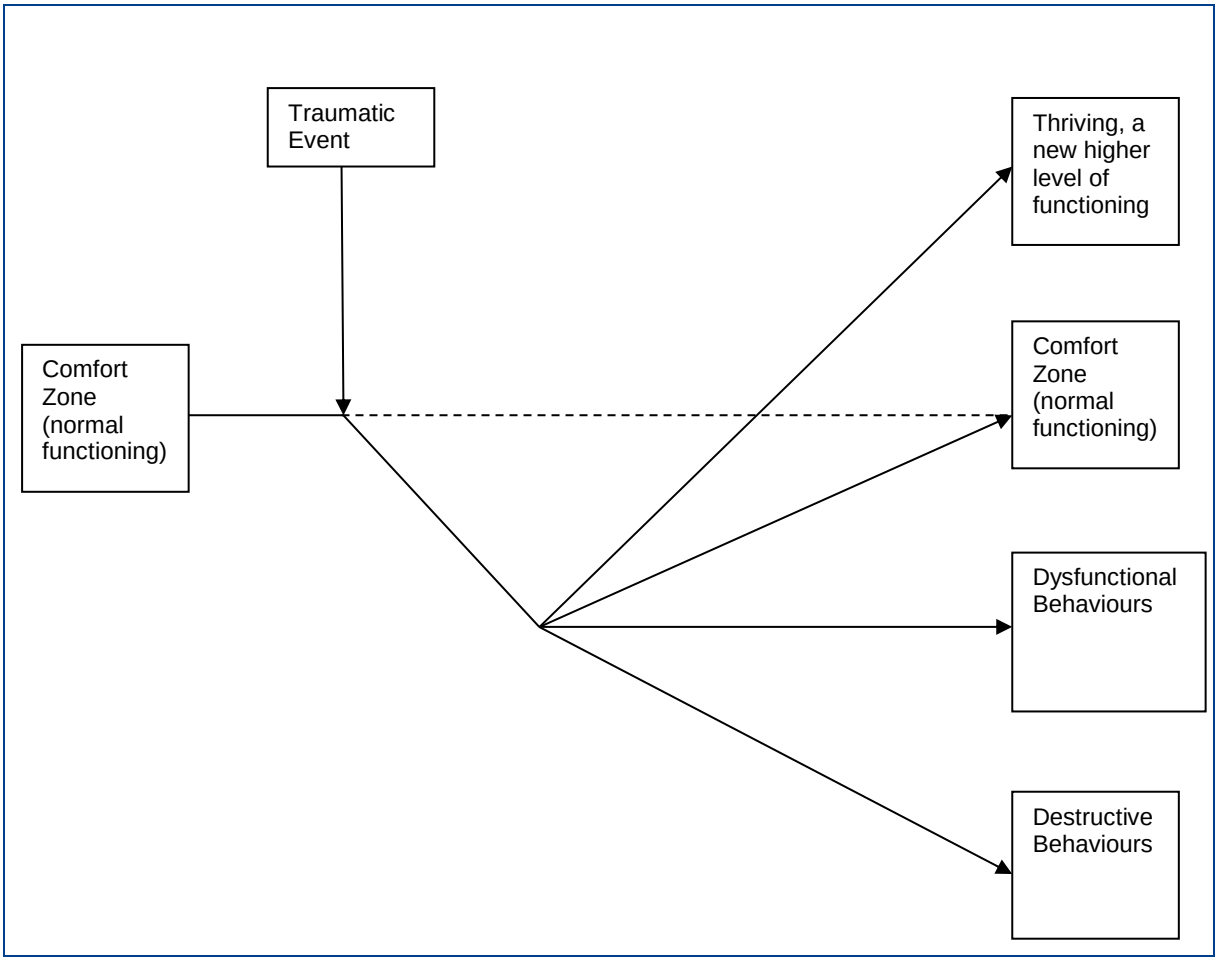
resilience assumed a repeated pattern of overcoming adversity as opposed to coping with a single traumatic event. Finally, the research evidence suggested that 'being resilient' involved successful navigation of internal and external resources. Once again, any useful model of resilience needed to encompass these elements.

7.5.1 Metatheory of Resilience

One commonly cited model was the metatheory of resilience and resiliency (Richardson, 2002; Richardson et al, 1990). The model described a comfort zone or a normal level of functioning. Traumatic events could disrupt this normal level of functioning and the process led to one of four outcomes:

- Destructive behaviours
- Dysfunctional behaviours
- A return to normal functioning
- A new, higher level of functioning

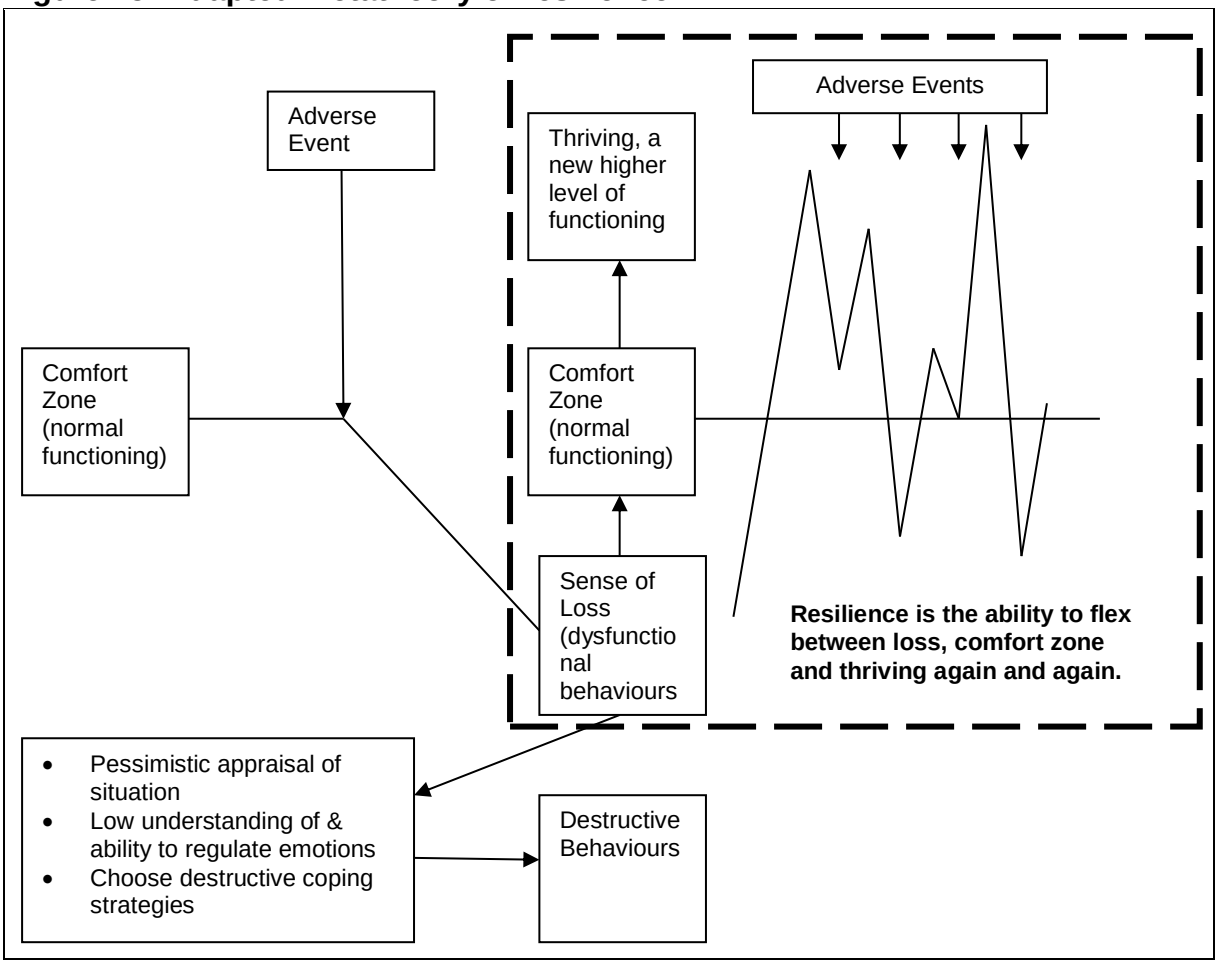
Figure 24: Metatheory of resilience (Richardson, 2002)



The above illustration of this model immediately highlighted some limitations. For a start it focused on overcoming a single traumatic event rather than depicting resilience as a repeated pattern of overcoming adversity. Secondly it did not demonstrate what might predict a person's pathway after the traumatic event. The researcher's adapted version of this model illustrated below attempted to address

these issues by incorporating other elements of resilience defined in some of the literature.

Figure 25: Adapted metatheory of resilience



The adapted model above attempted to illustrate that resilience was the ability to flex between loss, comfort zone and thriving again and again. The model above also attempted to incorporate the concept that adverse events often resulted in feelings of loss which fitted with the experience of carers. Finally, it attempted to recognise that an individual's appraisal of the situation and choice of coping strategies predicted the outcomes they experienced and the behaviours they displayed.

Carver (1998) suggested that the term resilience should be used to refer to 'returning to the same condition as a person was prior to the adverse event' and thriving should be used to refer to the 'better-off-afterward' experience (p246). He went on to describe psychological thriving as representing a kind of growth: growth in knowledge, skill, confidence etc. This growth occurred in circumstances where growth was unexpected.

Resilience had been used to describe both positive development and thriving under stress (Liebenberg and Ungar, 2009). These applications involved two very different benchmarks of identifying resilience. The question became whether positive adaptation was enough to demonstrate resilience, or whether such adaptation needed to be exceptional? What was the difference between adequate and exceptional positive adaptation? How did the concepts of positive adaptation and

thriving fit with the carer definition of resilience that focused on the ability to adapt the carer role throughout the carer journey? One way of reconciling these approaches was to conceptualise resilience as a matter of degree (Kolar, 2011).

Kinard (1998) identified three types of resilience: positive outcome despite high-risk environments; competent functioning in the face of acute or chronic major life stresses, and recovery from trauma.

Rutter and Rutter (1993) pointed out that traumatic events resulted in both positive and negative effects and that these coexisted. Smith (1999) stated that both vulnerabilities and resiliencies coexisted within a complex matrix of biological, social and phenomenological issues. The idea that resilience was domain specific suggested that individuals could be resilient in one area and impaired at the same time in another area. For example, the carer was resilient in their ability to continue to perform as an effective parent carer, but they were unable to continue to perform at work. Kaufman et al (1994) found that almost two thirds of maltreated children showed academic resilience, but only 21% also showed resilience in relation to their social competence. It was possible to be both vulnerable and resilient simultaneously, and in this sense, it was possible to consider several components and levels of resilience (Smith, 1999).

Consequently, exhibiting resilience did not mean eliminating anxiety and other forms of distress. Therefore, it was likely that few people were resilient in all areas of life, and there were always more aspects of resilience that could be developed. It was unreliable to decide that someone was resilient if there was reliance on just one data source, or if there was measurement at only one point in time, or if too narrow a range of outcomes was considered (Rutter, 1999; Fergusson et al, 1996). The adapted model of resilience depicted in figure 25 above did not adequately illustrate the range of possible outcomes, the use of external resources or that resilience could be domain specific.

7.5.2 Community Resilience

Individual resilience appeared to be valued over collective resilience in the literature. The role of the wider social institutions in maintaining (or undermining) our psychological health was often underestimated. Instead failure to maintain psychological health was interpreted as an individual's inability to cope or adapt (Smith, 1999).

Like individual resilience, community resilience had been described as a process, not a trait or a product (Nuwayhid et al 2011). Ungar (2013) described resilience as the capacity of both individuals and their environments to interact in ways that optimised developmental processes. Ungar (2008) defined resilience as:

'In the context of exposure to significant adversity, whether psychological, environmental or both, resilience is both the capacity of individuals to navigate their way to health sustaining resources, including opportunities to experience feelings of wellbeing and a condition of the individual family, community and culture to provide these health resources and experiences in culturally meaningful ways' (p.225).

In their review of the literature Sousa et al (2013) described community resilience in the context of political violence as encompassing the following elements:

- There were certain traits, capacities, and emotional orientations toward hardship that enabled the process of resilience.
- The emotional orientations that appeared to build resilience on the community level included a collective sense of hope, agency, altruism, trust, and patterns of interdependence.
- Community characteristics, including collective identity, community cohesion, and a hardiness borne of previous experience with violence built the potential for resilience.
- Resources that built community resilience included educational and health service networks run by trusted leadership, as well as technical, organisational, social, and economic resources.
- Formal and informal networks built community resilience.
- Activities related to collective memory of the trauma of political violence also appeared to be important in building community resilience.

However, some studies showed that in situations of adversity, resilience was only observed when individuals engaged in behaviours that helped them to navigate their way to the resources they needed to flourish (Ungar, 2011a). Consistent with Ungar, Cohen et al (2011) stated that resilience depended on individual attributes, and on the protective structures that operated around the individual.

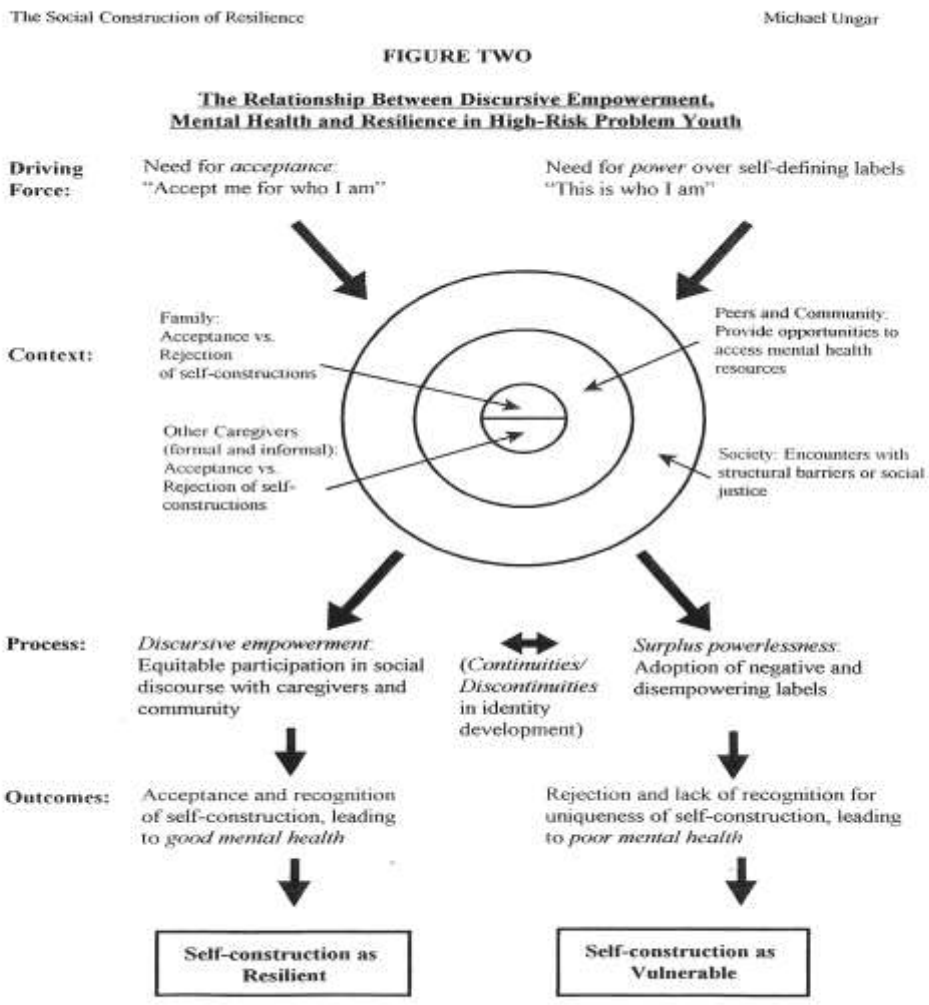
An overemphasis on personal attributes or abilities naively assumed that individuals experienced resilience because they maintained a positive attitude and engaged in the effective use of coping strategies (Seccombe, 2002; Ungar, 2011b) (Ungar, 2013). Yet the research demonstrated that the individual's ability to navigate and negotiate for what they needed was dependent upon the capacity and willingness of people's formal and informal social networks to meet those needs and provide resources in ways that were culturally meaningful (Bottrell, 2009; Easterbrooks et al, 2011). This seemed to resonate with the experience of carers that participated in this research.

Taking a behavioural perspective, a facilitative environment changed developmental pathways regardless of/or in combination with individual differences. Personal motivation, sense of control, mood, behaviours, etc were triggered or suppressed by the environment (Ungar, 2013). Individuals were not born with resilience, nor did they develop it as a stable personal characteristic. On the contrary, levels of resilience varied over time according to facets of the social environment (Schoon, 2006, p19). Again, this seemed to resonate with the temporal model of caring discussed in part one study two and the reduction of resilience carers experienced when transitioning between stages of caring.

A search of the literature for examples of research that investigated both individual and environmental influences on resilience showed that the adverse effects of traumatic events were more likely to be relieved by making changes that addressed the environment's shortcomings, rather than focusing on psychological interventions that helped individuals to cope better (DuMont et al, 2007; Landau et al, 2008; Obrist et al., 2010; Ungar, 2013).

Ungar's (2001) model of resilience depicted below in figure 26 illustrated the concept that the willingness and capability of formal and informal social networks influenced how the young person viewed themselves and hence experienced resilience or vulnerability.

Figure 26: Ungar's Model of Resilience (2001, p151)



Ungar (2001)

Maton's (2005, p119) work on social transformation cited the importance of designing intervention processes to build resilience within the community at individual to social levels to achieve 'collective resilience'. His model fleshed out the local to societal interdependencies, as well as the possibilities for engagement of local people in deciding their own directions and attempted to bridge the deficit strengths divide. The critical element here was the interdependency between the individual, local community and societal resources. Only when these resources worked together did

people and communities experience resilience. Wild et al's (2013) model builds on this by describing the links between individual, household, family, neighbourhood, community and societal resilience. Wild et al (2013) state that there are various important elements of resilience in later life: psychological, mobility, financial, environmental, physical, social and cultural. An older person may be resilient in one area but not another. Their ability to be resilient may rely on their own strengths or assets or that of their family, neighbourhood or community. For example an older person's mobility resilience may depend on their ability to walk, how flat their neighbourhood is, accessible, frequent public transport, etc.

There were various aspects of these models that link individual, community and societal resilience that were useful when applied to carers. For a start it could be used to depict the experiences of oppression that many carers experienced when they encountered informal and formal social networks. Secondly, the model emphasised that resilience was not dependent on individual, internal factors alone. Resilience was also influenced by the person's ability to access the external resources that empowered them and enabled them to flourish. Finally, research, good practice guidance and now policy in the UK all provided evidence that supporting people to achieve desired QoL outcomes, supporting them to have positive experiences and access to good quality services that meet their needs was dependent upon a cultural shift towards person-centred care. Examples of current policy attempting to influence this cultural shift could be found throughout the Care and Support Statutory Guidance for the Care Act (2014). For example:

'Local authorities must consider how to meet each person's specific needs rather than simply considering what service they will fit into' Clause 1.9, page 8.

This shift was required at an individual, service, community and societal level. By moving the focus from people who needed support to carers who provided support it seemed rationale to think that improving the experiences of carers, empowering them and building their resilience required a change in attitudes and culture at all levels. Focusing solely on building the individual psychosocial resilience of individual carers was simply not enough if resilience was to be achieved and / or maintained.

Missing from this model of resilience was the grief and sense of loss that many carers reported experiencing as a key aspect, thus limiting how useful it was when applied to carers. Furthermore, it highlighted that whilst theory provided evidence that a cultural shift was needed and policy provided evidence that a cultural shift was desired it did not mean that in practice a cultural shift was achieved.

7.5.3 Range of Response to Loss Model

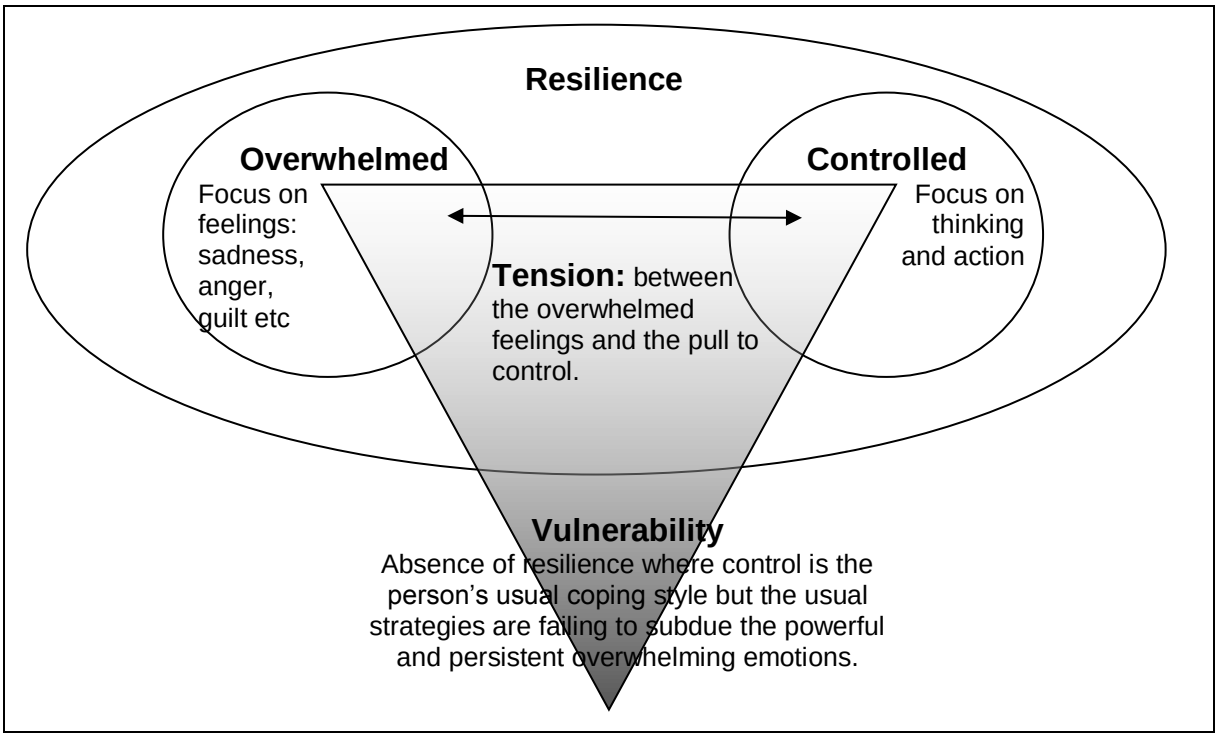
Machin's (2001; 2009) framework for conceptualising grief put resilience at the centre. Known as the Range of Response to Loss (RRL) model it proposed that two elements lie at the heart of a grief reaction:

- The overwhelming distress generated by the powerlessness of loss;
- The desire to recover a sense of control.

Machin explained that managing the conflicting aspects of these two responses to grief is what characterises grieving.

For some people feelings of sadness, anger and guilt dominated and they felt overwhelmed. Others concentrated on practical day to day concerns and planning for the future. This focus on thinking and action demonstrated a controlled loss response. If an individual oscillated between the two dimensions, it resulted in a distressing internal tension between a sense of powerlessness and the desire to regain some personal control. This correlated with the experience of carers in the focus groups who reported that they oscillated between positive and negative emotions, a sense of control and loss of control, avoidant and proactive coping strategies.

Figure 27: Range of Response to Loss Model



Machin (2009) described a resilient grief response that sat alongside the overwhelming and controlling responses. She described this resilient reaction as: 'an ability to face feelings of distress, while still being able to distinguish those areas of life where control and active choice are possible' (p97).

In other words, if someone was resilient they were better able to reconcile the distress and tensions of the overwhelming and controlling responses to grief via a recognition of personal resourcefulness, an ability to access and utilize social support and an evolving sense of meaning. This was a useful concept when applied to carers who often experienced chronic sorrow and recurring episodes of grief; and who described resilience as the ability to hold a range of conflicting emotions whilst steering a steady course through their caring role. The model was limited though when the wider community and collective elements of resilience (discussed in the section above) were considered.

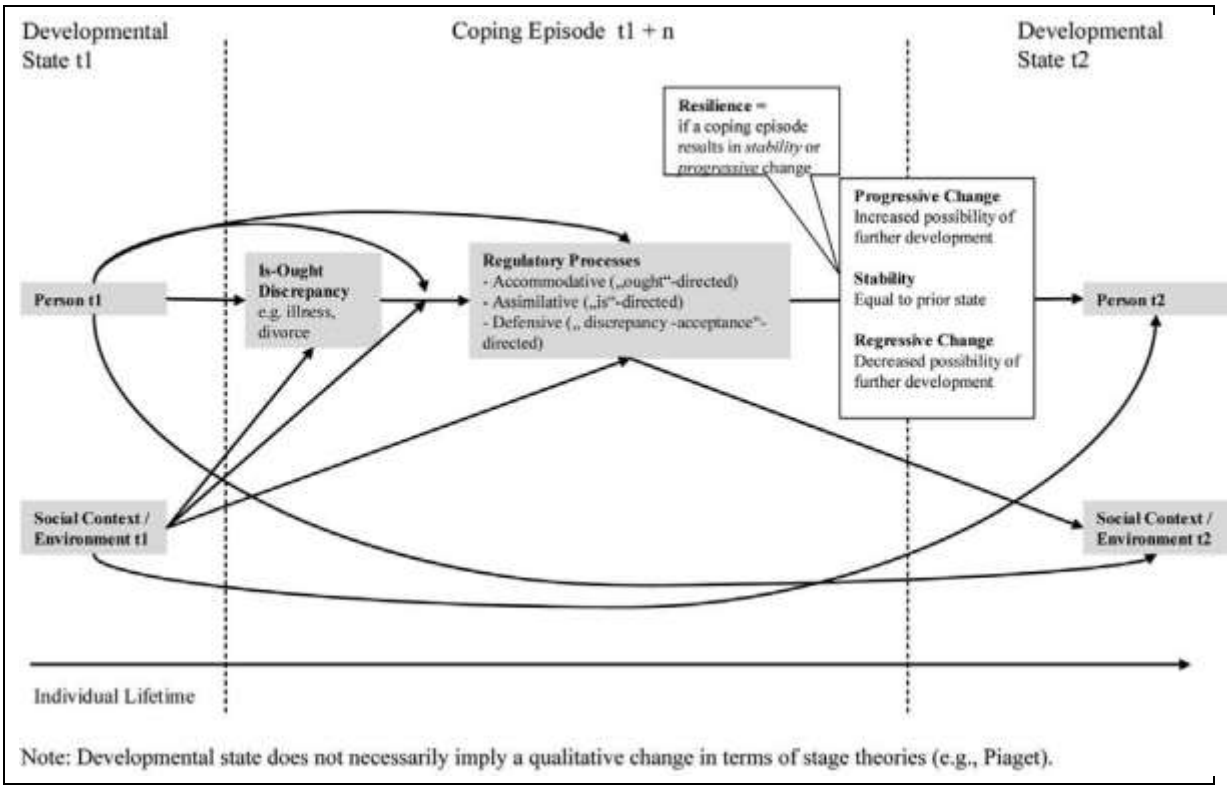
A useful concept identified by the literature in this area was the evidence suggesting the developmental nature of resilience and that learning resilience was even more relevant for people who were having difficulty adapting to their circumstances than for

those who were adapting well (Neimeyer et al, 2006). This linked to the developmental concept of resilience described below.

7.5.4 The developmental concept of resilience

Leipold and Greve's (2009) developmental concept of resilience had at its centre, the idea that resilience must be learnt. They described a process by which an individual experienced an adverse event, the individual selected coping mechanisms based on their internal resources and the social context. Resilience was demonstrated if a coping episode resulted in stability or progressive change (i.e. increased possibility of further development).

Figure 28: Leipold and Greve's Developmental Concept of Resilience



Leipold and Greve provided an example of the developmental nature of resilience:

'*A confrontation with authority that has become inevitable will only succeed when one has the social and communication skills plus a sufficient emotion regulation competence (to avoid uncontrolled outbursts of anger) and cognitive abilities (to hold one's own in an argument but also to cleverly plan the discussion strategically)' (p44).*

The concept that resilience was not just a process but a developmental one, that resilience was something that one learnt through experiencing adverse events and developing skills that allowed one to adapt one's behaviour and adjust to inevitable changes in a way that got one's needs met was a useful concept when applied to a carer's journey. The example illustrated how useful this concept was when the oppression carers experience and the 'fight' they have to access the support they need was considered. There were also connotations to Weiner's Attribution theory in that if a carer does not believe they will be able to manage the carer's behaviour but

out of necessity they do, they are more likely to believe they can do it next time and more likely to try harder to do so.

7.6 Recent developments in the resilience literature

This narrative literature review was originally undertaken in the early stages (2014) of this grounded theory study. The researcher wanted to capture and reflect upon any recent developments in the resilience research and hence conducted a further review of the research using the same criteria in the late stages of this study (2019). This resulted in the identification of three key papers that discussed the concept of resilience in ways that either mirrored or built upon the previous literature. The first was a study undertaken by Sisto et al (2019) that described resilience as a 'transversal attitude'. In other words that through perseverance and self-awareness a person can grow to be resilient. This mirrors previous concepts of resilience as a personal characteristic and a developmental process.

The second key paper was written by Ntontis et al (2019) and reviewed the varying ways community resilience was conceptualised in UK Government policy and guidance documents on flooding. The researchers highlighted the need to operationalise the concept of resilience within the context it was being used if it was to have a useful impact on the population of concern. They also identified that vulnerability and resilience were not opposites but an intertwined dynamic and hence seeing people as vulnerable and passive recipients of support was not only unhelpful but oppressive. Finally, the paper emphasised the need to understand community values and social processes within communities if communities were to be empowered and enabled to be resilient in a way that was meaningful to them.

This builds on the previous literature on community resilience and is important when reflecting on the usefulness of the model for carers. It re-emphasises the need for a specific concept of resilience for carers and recognises the need to be careful not to treat carers as passive recipients or to place non-caring assumptions about what is normal or what would help on the carer community.

The third key paper was written by Doorn et al (2019) and stresses the different ways resilience is conceptualised across engineering versus social sciences and how frequently the term resilience is currently used in both engineering and social science UK government policy as the 'ideal' or the thing to reach. Yet currently there has been no comprehensive integration of the resilience literature across these two disciplines. The social science literature does not recognise the role that engineered objects, and especially infrastructure, could play in community resilience. Vice versa, some of the engineering literature does not adequately take into account the interaction of human beings with infrastructure and the impact this has.

It is this interaction between people and infrastructure that is of particular interest. It builds on resilience models by Ungar (2001), Maton (2005) and Wild et al (2013) mentioned earlier in this chapter. These models all argue that resilience isn't a personal characteristic or even something learnt by going through a process; but that an individual can only be resilient if they have supportive interactions with their communities and the infrastructures within them. Infrastructures have to give carers access to the things they say will help before carers can be resilient. However, this is a rather passive, recipient-orientated view of resilience. Doorn et al (2019) argue that this view does not recognise that resilient infrastructures (ones that can adapt

and meet the needs of the community) have been developed and shaped by the interactions between community members and the infrastructure. It is not a passive, one-way interaction but a circular, dynamic, co-dependency relationship between individuals and the infrastructure that result in resilient people and communities. This is important because when we consider developing models of support it must be recognised that effective models of support will only be developed if those needing them are involved in shaping them.

7.7 What are the limitations of previous research on resilience?

There was a lack of agreement as to what resilience was and a model of carer resilience had not previously been developed. There was also a lack of agreement and definition of adversity. Much of the resilience literature had focused on children and adolescents. There were very few studies on adults across the life span. What there was had focused on personal attributes rather than the interplay of different factors. Resilience measures tended to be developed on specific populations so different studies used different measures. Some measures were designed on the understanding of resilience as a personal characteristic and some on resilience as a process.

Current models of resilience when applied to carers did not address all the themes identified via the focus groups conducted in part one of this research. It was suggested at the beginning of this section that a useful model of resilience for carers would need to address the issues of chronic stress, grief and oppression. The subsequent analysis of models of resilience demonstrated that no single model addressed all these issues.

The analysis did suggest that the most useful way of conceptualising resilience thus far was as a developmental process, resulting in a wide range of outcomes. The literature also suggested that 'being resilient' involved successful navigation of internal and external resources. Most models relating to caring were individually oriented and not situated in their wider context. This was not so much the case for models relating to resilience. As oppression and discrimination were socially produced these models did make links between the macro external world and the micro internal world of the carer.

Furthermore, the literature suggested that a holistic approach to resilience involved a need to develop (Smith, 1999):

- Constitutional resilience – having a robust neurobiology.
- Adequate internal coping mechanisms – a strong sense of personal identity with a toleration for negative affect and strategies to deal with traumatic stressors.
- A supportive immediate context – a context which listens to the experience of the individual and which readily accepts the emotions they experience and their opinion about what may help them feel resilient. A context which does not think it is the fault of the individual and is prepared to help people come to terms with it.
- A wider supportive social context in which is embedded the immediate context – a context which also believes in the traumatic experience of the individual, which does not blame the individual or oppress them, is prepared to provide resources to help ameliorate the situation for the immediate family, carer and the person in need of care.

Ungar (2013) argued that resilience was culturally specific and hence it was unlikely that a single model of resilience worked for all vulnerable populations, cultures and events. It is vital therefore that interventions aimed at building resilience pay attention to the unique features of the population of interest and the context in which the approach is employed (Fergus and Zimmerman, 2005). It is also vital that interventions aimed at building resilience do not treat people as passive recipients and recognise that instrumental in shaping infrastructures that foster resilience is the interaction and involvement of the people the infrastructure needs to serve (Doorn et al, 2019).

7.8 Reflective summary

This section summarises the memos written during the literature review.

What did the narrative literature review on resilience reveal?

Multiple definitions of resilience existed within the literature and there was no accepted single definition or model. Coping and resilience were conceptually different. Coping was associated with overcoming a single traumatic event where as resilience was a repeated pattern of overcoming adversity.

There was still debate as to whether resilience was a personal characteristic, an acquired skill, or a process. The idea that resilience was developed because of adversity led to resilience being conceptualised as a process of adaptation. The concept that resilience was not just a process but a developmental one, that resilience was something that one learnt through experiencing adverse events and developing skills that allowed one to adapt one's behaviour and adjust to inevitable changes in a way that got one's needs met was a useful concept when applied to a carer's journey.

Current models of resilience when applied to carers did not address all the themes identified via the focus groups.

What new insights surfaced through the memo writing?

Individual resilience appeared to be valued over community resilience in the literature. However, Maton's (2005, p119) model illustrated that a critical part of developing resilience was the interdependency between the individual, local community and societal resources. Only when these resources worked together did people and communities experience resilience.

Conceptualising carer resilience as a developmental process that occurred by living through adversity was closely correlated to how carers in the focus groups described resilience. The best way to conceptualise resilience was not as an actual entity but as a construct that embodied a range of different behaviours that resulted in a variety of outcomes that related to an individual's QoL, wellbeing, functioning and their ability to navigate their caring role. Certain characteristics and accessibility to a variety of external resources increased the likelihood that, when faced with adversity, a person learnt to engage in the range of behaviours that maintained or increased their QoL. This enabled them to sustain their caring role. There might have been instances when QoL was low, but it might still be just high enough (perhaps intermittently so) to keep going or the alternative so abhorrent and damaging to the carer's QoL that continuing to care was the only option. If the balance between negative and positive

consequences was not enough and the carer's QoL deteriorated so much, then eventually the carer's behaviour changed and resulted in the carer either adapting, reducing or stopping their caring role.

Findings from the focus groups highlighted the importance of relationships within the context of the definition of carer resilience. This included the relationship the carer had with the care recipient, the relationship they have with themselves and their sense of identity, and their relationship with others (family, friends, professionals, community). Previous models of resilience were inadequate when applied to family carers, which necessitated the development of an appropriate model.

Ultimately reflections on the literature review confirm that it is credible to develop definitions of resilience for individual populations, in this case carers. Secondly, the definition of carer resilience developed in Part One: *'The ability to continue caring or to move on by adapting roles and behaviours throughout the carer journey'* echoes the previous literature whilst also addressing the specific issues related to carers and hence it is a valid definition for this population.

8 Chapter 8: Developing the model of carer resilience

The literature review has answered the question:

- How do current definitions, concepts and models of resilience relate to carers across care groups and relationships?

This chapter aims to answer the following question:

- What is a carer model of support that applies across care groups and relationships and promotes resilience?

The question will be answered by developing further the emerging model from Part One, within the context of the literature review above and via further discussions with carers and carer support workers. The model will be converted into an audit tool to use in the final scoping review stage (Part Three) of this thesis.

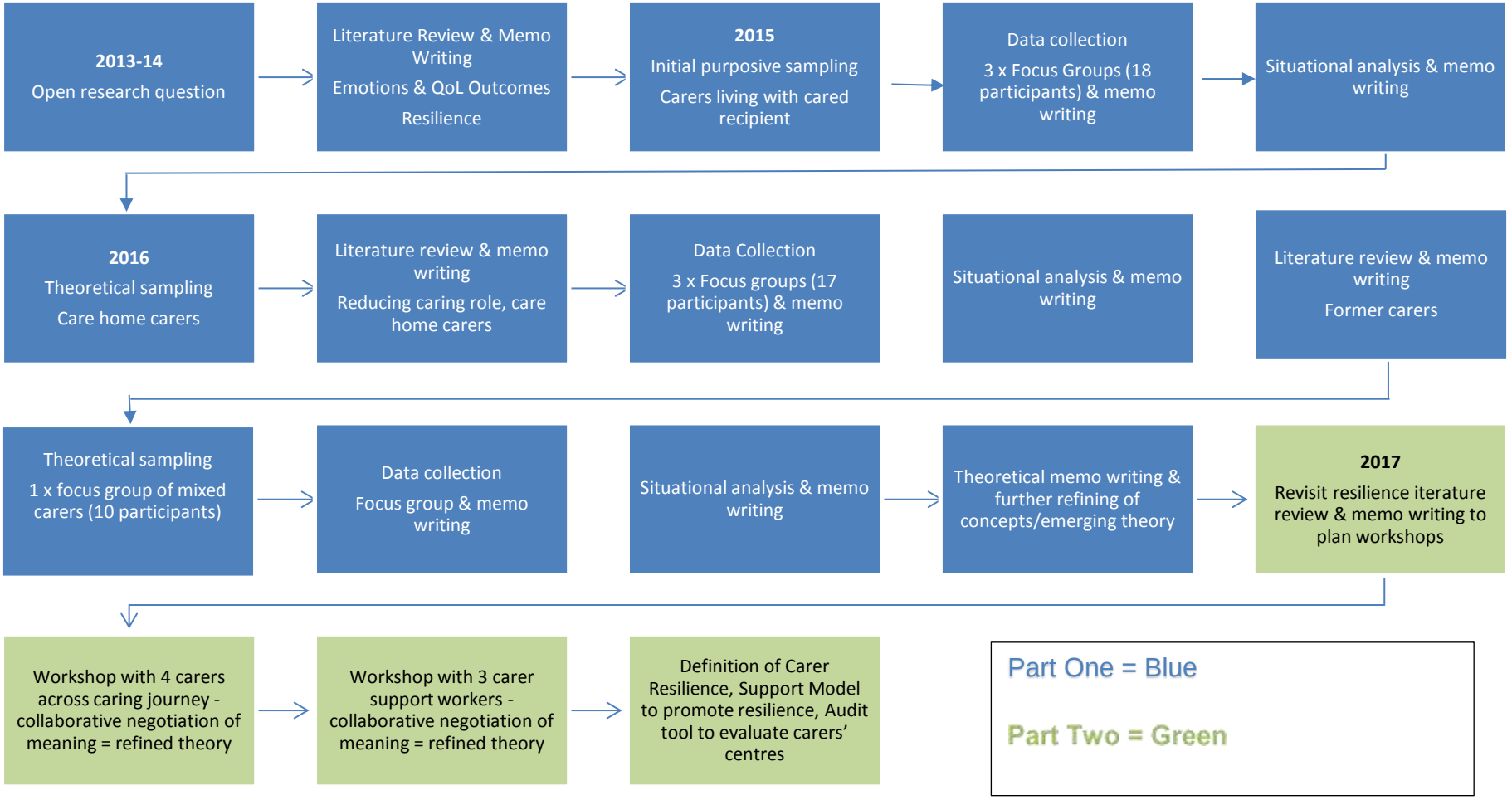
8.1 A Reminder about the Methodology

In other qualitative research methods the researcher usually validates their interpretation of the data by going back to the research participants and checking it with them (Seale 1999, p92). Whereas in grounded theory the researcher undertakes an ongoing cycle of checking that provides a critical element and validates their interpretation. Checking is built into the research process through the constant comparative analysis and theoretical sampling (Elliott and Lazenbatt, 2005). The process of theoretical sampling and constant comparative analysis requires that the researcher moves on to involve other groups who have different experiences to see if the findings hold as new data is collected (Seale, 1999, p92). This dynamic relationship between data collection and analysis enables the researcher to check if preliminary findings remain constant when further data is collected. The methodology of theoretical sampling, constant comparative analysis and data collection offer the researcher an opportunity of generating research findings that represent accurately the phenomena being studied (Strauss and Corbin, 1998, p297).

8.1.1 The research process

The diagram below outlines how the research process for this study in Part Two builds on the studies in Part One.

Figure 29: Part One and Two Research Process



8.2 The workshops

Two workshops were conducted. The first was undertaken with carers across the caring journey and the second with carer support workers.

8.2.1 Carer workshop

Four carers participated in the workshop.

Table 11: Demographic characteristics of participants (Carer workshop)

	Gender	Age	Context
Carer 1	Female	79	Former carer. Cared for her husband with Alzheimer's who died 18 months ago.
Carer 2	Female	65	Caring for her mother who has recently moved into a care home.
Carer 3	Female	43	Cares at home for her 9-year-old autistic son. Also cares intermittently for her ex-husband who suffers from anxiety, depression and alcoholism.
Carer 4	Female	34	Cares at home for her husband who has advanced MS.

Carers 1 and 2 were both in contact with a small, peer support carers group and were invited to attend the workshop via this group. Carers 3 and 4 were not in contact with any carers' organisations or peer support groups. The researcher was acquainted with them via a school mum's network and sent them the invite to participate in the workshop via this route as the researcher felt it was important to gain the perspective of carers not currently in receipt of carer support services. The workshop was held in a small community venue and lasted for 90 minutes.

Carers were provided with a summary of the research findings from Part One. The carer workshop aimed to finalise the definition of carer resilience and create the model of support for promoting carer resilience. To do this the workshop was divided into 5 stages.

8.2.1.1. Stage 1

Carers were asked to describe their carer journeys. Carers were then asked to reflect on their carer journey within the context of the categories that emerged in Part One:

- Navigating their changing relationship with the care recipient
- Learning to manage the changing symptoms and behaviour
- Their changing sense of identity
- Relationships with professionals and support agencies
- Relationships with other family and friends
- How carer-friendly their communities were (including housing, work and leisure)
- Hidden world of the carer
- Carer as THE skilled helper
- Sense of loss

8.2.1.2. Stage 2

To identify any significant gaps in the categories that emerged in Part One carers were asked if they had any feelings or experienced anything that did not easily fit into one of the categories. These feelings and experiences were captured on flipchart paper and once all four carers had spoken the group had a discussion that summed up and categorised the gaps:

- No choice – carers were keen to make sure that the concept that caring was a default position rather than a choice was emphasised
- Guilt and shame – carers felt it was important to recognise that some of what motivated/reinforced their caring behaviour and QoL outcomes was linked to feeling (or trying to avoid feeling) guilt and shame
- Moving in and out – carers called attention to the notion that some carers move in and out of the carer role for example caring for someone with an intermittent mental health issue, or those on the transplant list who recover, or those caring for someone with a chronic illness that they recover from.

8.2.1.3. Stage 3

Carers were asked to reflect on the steps of their carer journey within the context of Cavaye's (2006) temporal model. The researcher facilitated a discussion exploring the steps of Cavaye's temporal model and the carers were asked to make any amendments they felt would be useful when applied to carers' centres and models of support. The carers condensed the carer journey into six stages that they felt reflected the key points and transitions during which carers required support:

Dawning realisation	Adopting the caring role	Doing it alone	Accessing services	Adapting the caring role	Ending and moving on

8.2.1.4. Stage 4

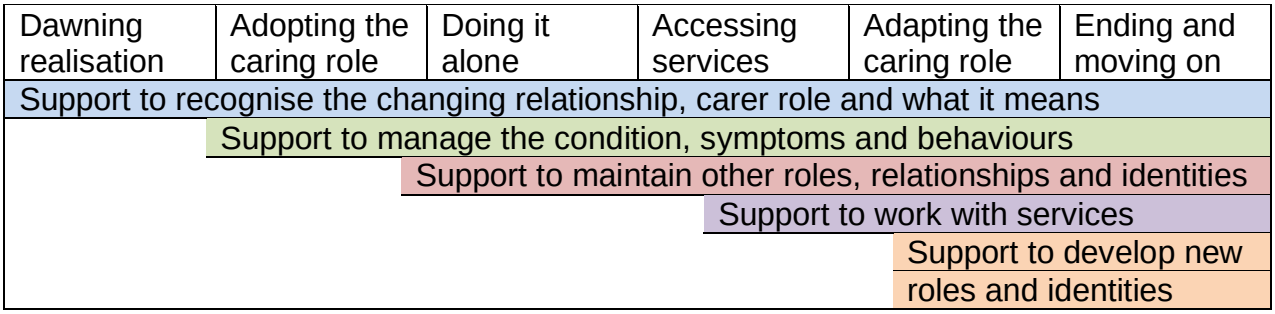
Carers were presented with the definition of carer resilience from Part One and asked to make any changes they felt appropriate. All four carers agreed that carer resilience was: *'the ability to continue caring or to move on by adapting roles and behaviours throughout the carer journey'*. The carers did not wish to make any changes to the definition of carer resilience.

8.2.1.5. Stage 5

All the categories from Part One and the workshop were written on individual cards. A card with the words 'Resilient carer' was put on the table and the carers were asked to place the categories that promoted resilience on the table.

Carers were then asked to turn this into a blueprint for a model of support that could be used by carers' centres to promote resilience. Carers felt strongly that the model of support should address the needs of carers across the carer journey. The carers used their condensed, six stage carer journey and applied the categories they had placed on the table to map the support across the journey.

Figure 30: Carer model of support across the carer journey



This was the final product from the carer workshop.

8.2.2 Carer Support Worker Workshop

Three carer support workers attended the workshop. The carer support workers were employed by two different carer centres, neither of which were involved in Part Three (the evaluation stage) of this research. The carer support workers were all female, aged between 42 and 55 and had been working as carer support workers for between 3 and 8 years.

The carer support workers were provided with a summary of the research findings. They were also shown the definition of carer resilience and the model of support to promote carer resilience developed in the carer workshop.

The carer support worker workshop aimed to finalise the model of support and create the audit tool. To do this the workshop was divided into 3 stages.

8.2.2.1. Stage 1

The carer support workers were asked to think about carers they had supported and to reflect on the usefulness of the model of support in considering the support carers had required and received. The carer support workers commented that their resources tended to focus on providing carers support to manage the condition, symptoms and behaviours of the care recipient and support to work with care and support agencies. The carer support workers felt that there was a lack of resource and time spent with carers supporting them to navigate changing relationships or manage their own sense of identity. Furthermore, carer support workers commented that reflecting on the definition and model reminded them how important these issues were and highlighted the fact that they were not concepts clearly understood by commissioners and therefore such support was not reflected in contracts or commissioned support for carers. The carer support workers refined the model of support to reflect their experience that different carers required different support at each stage of the carer journey depending upon their circumstances. Carer support workers didn't feel there were any gaps in the support required but that carers should be able to access any such support at any time throughout their carer journey.

Figure 31: Refined model of support for promoting carer resilience[1]

Dawning realisation	Adopting the caring role	Doing it alone	Accessing services	Adapting the caring role	Ending and moving on



Information and advice

8.2.2.2. Stage 2

To create the audit tool each of the six categories were renamed domains. For each domain the carer support workers were asked to list the standards that, if achieved, would ensure that a carers' centre was promoting resilience in that domain. This was the hardest stage of creating the audit tool and many versions were written before agreement was reached. Each time the carer support workers felt stuck the researcher encouraged them to look back at the research summary and the situational analysis maps to help ensure that all the themes and categories that had emerged throughout Parts One and Two were considered. The carer support

[1] The model is included in two National Guidance documents I have written as part of my current job role. National Commissioning Board (2018) *Guidance for Regional Partnership Boards - Integrated Commissioning of Services for Families, Children and Young People with Complex Needs* and Social Care Wales (2019) *Assessing Carers' Support Needs.*

workers found this a useful way of ensuring that themes such as sense of loss, feelings of guilt or shame, etc were embedded in the audit tool.

The carer support workers also added a domain which they named 'measuring resilience' as they felt it was important for managers and funders to know whether carers' centres were improving resilience, wellbeing and QoL outcomes for carers.

8.2.2.3. Stage 3

Once the standards were agreed the carer support workers outlined the activities carers' centres would need to be engaging in to achieve the standards. The Audit Tool can be found in appendix nine.

8.3 Reflection on the workshops and memo writing

What did the workshops reveal?

The workshops resulted in an agreed definition of carer resilience and a model of support to promote carer resilience that emphasised the default nature of the caring role and the range of factors that influenced the carer's ability to continually adapt their role throughout the carer journey. The model of support and the audit tool detailed the areas of support that a carers' centre would need to address and the activities they would need to engage in to deliver such support.

What new insights surfaced through the memo writing?

The model of support helped to illustrate that carers were likely to need different types of support at different stages in the carer journey. Discussions during the workshop pinpointed that carers at the start of the journey 'dawning realisation' do not always identify with the label 'carer'.

Further reading indicated that 'Carer' is a label that many carers do not identify with (Hennings et al, 2013; Smith, 2001; Ribeiro et al, 2007). The research suggested that as many as half of people who provide care to a loved one do not 'own' the word carer (Larkin and Milne 2017; Carers UK 2006, Lloyd 2006, Molyneaux et al. 2011). More often, carers identified themselves in terms of their relationship with the care recipient (Ribeiro et al, 2007). Spousal carers tended to regard caring as an extension of the normal, expected marital relationship (Hennings et al, 2013; O'Connor, 1999; Gillies, 2012); parent carers tended to regard caring as an extension of the normal, expected parental relationship as did those caring for an ageing parent.

Lack of identification with the label 'carer' was one reason that most carers in the early stages of the carer journey were unlikely to approach carers organisations for support. Carers often had contact with services such as the hospital or G.P. as they often supported the care recipient at appointments, but these services/professionals did not always identify them as carers either or signpost them to carers' organisations.

The discussions with carer support workers underlined the notion that there were gaps in the support provided by carers' centres as they focused on providing information, advice and guidance on the carer role, managing the symptoms and behaviour of the care recipient and supporting the carer to work in partnership with

care and support agencies. The carer support workers all stated that they did very little work to support carers in navigating their changing relationship with the care recipient or relationships with their wider circle of family and friends. Carer support workers felt that they did encourage carers to continue other roles but that they had few resources or time that could be spent on supporting this. Carer support workers gave a few examples of working with the wider community to raise awareness and develop carer friendly communities but again it felt like there were insufficient resources to do this well and it was not the focus of their work.

Part Three: Scoping review

9 Chapter 9: Introduction, logic model and description of carers' centres

9.1 Introduction

Part three aims to answer the final research question:

Do two carers' centres promote the resilience of carers across care groups and relationships and is there a need for a more comprehensive evaluation of carers' centres?

The scoping review in this thesis used a mixed methods evaluative research approach. The definition of carer resilience and associated model of support and audit tool developed in parts one and two of this study were used to evaluate two carers' centres and the impact they had on carer resilience at what cost.

9.1.1 A reminder about the research process

Figure 32: Research Process

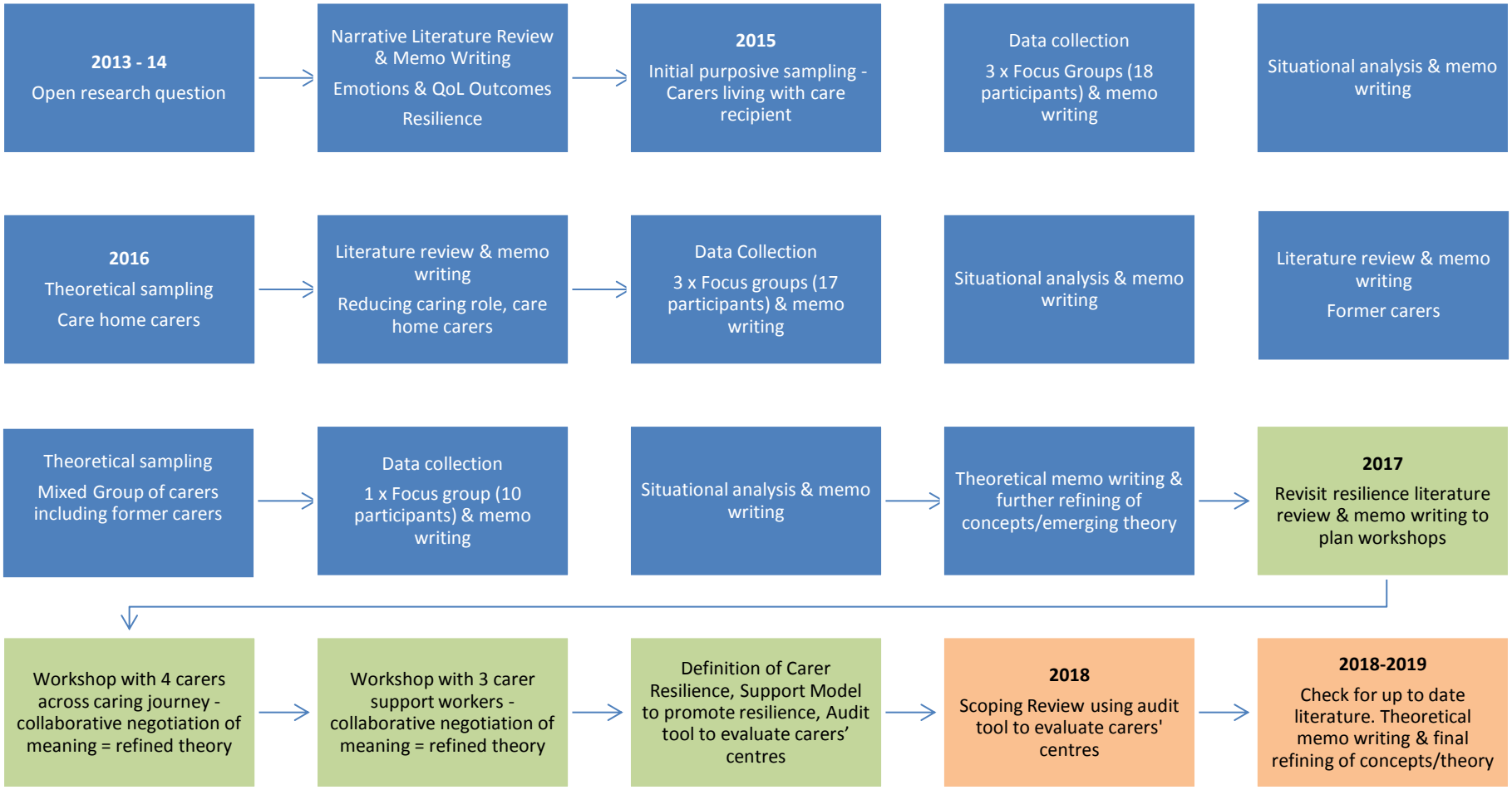
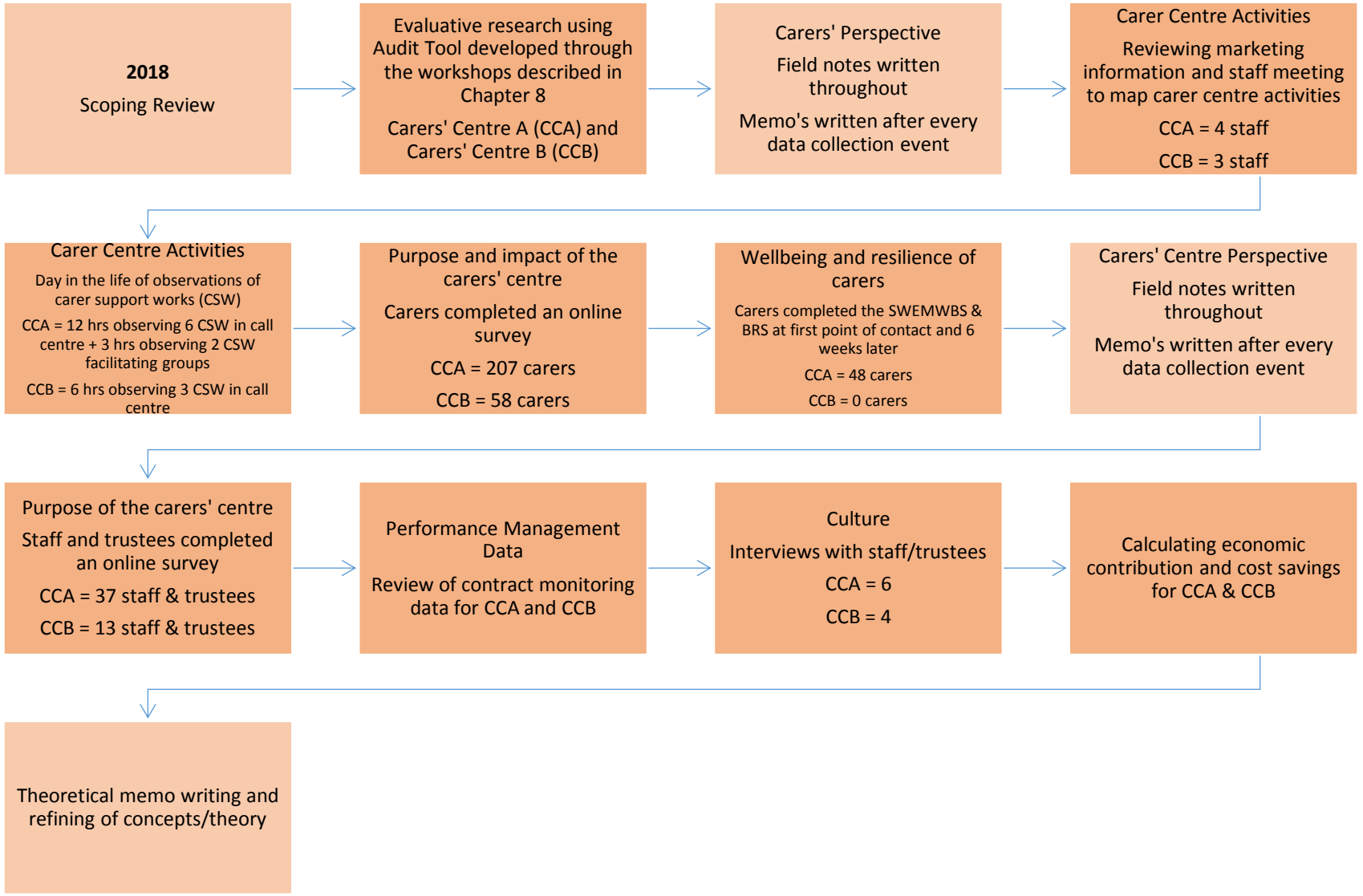


Figure 33 : Detailed Diagram of Scoping Review Process



9.1.2 A reminder about the Logic Model

The audit tool developed in Chapter Eight provided a framework upon which to build the logic model. The logic model below illustrates how the carer's centres were evaluated to explore whether the purpose of carers' centres was to promote resilience and how this related to the activities the carers' centres undertook, their resources and the outcomes they achieved for carers. The logic model outlines the data collection and analysis methods used to answer the research questions. The connection between the logic model and the audit tool is illustrated in appendix nine.

Figure 34: Logic Model

<table>
<tr><td colspan="4">PURPOSE OR MISSION
What is the purpose of the carer's centre?</td></tr>
<tr><td colspan="4"><u>Data Collection</u>
A Survey that asks 'What is the purpose of the carer's centre?' The survey collected data from:
The Governance Board
The senior management team
Carer support workers
Commissioners and other funders
Carers</td></tr>
<tr><td colspan="4"><u>Data Analysis</u>
Thematic analysis to explore what people thought the purpose of the carers' centre was and to identify the degree to which people thought the purpose was about maintaining or improving resilience using the carer definition of resilience = 'ability to continue caring or to move on by adapting roles and behaviours throughout the carer journey'.</td></tr>
<tr><td>INPUTS
What were the resources used by the centre? E.g.
Finance
Staff
Buildings
Partnerships
Volunteers
etc</td><td>ACTIVITIES
How did the centre use the resources? What information, advice and support did the centre offer to carers?</td><td>OUTPUTS
What evidence was there that the activities were performed?</td><td>OUTCOMES
What were the outcomes for carers?
Was their resilience maintained or improved?
What were the cost savings to the state?</td></tr>
<tr><td><u>Data Collection</u>
Workshop with the senior management team to map the resources.</td><td><u>Data Collection</u>
Workshop with the senior management team and carer support workers to map the activities.</td><td><u>Data collection</u>
Collating the data the carers' centre already collected e.g. number of referrals, demographics of carers, number of carers that access</td><td><u>Data Collection</u>
All new referrals for a period of 2 weeks were asked to complete the brief resilience scale and the short wellbeing questionnaire.</td></tr>
</table>

	Review of the marketing information on the services available. Ethnographic 'day in the life of' observation of 2 carer support workers.	different types of support, complaints and compliments, annual carer survey, contract monitoring information.	The measures were repeated 6 weeks later. Online survey for carers asking about the impact the carers' centre had on them. Cost information collected from accounts and discussions with finance staff.
Data Analysis Summarised the inputs. Calculated the Unit Cost of the carers' centre.	**Data Analysis** Mapped the activities against the resilience audit tool. Content analysis on the marketing information and mapped it against the resilience audit tool. Thematic analysis on the notes from the carer support worker ethnographic observations and mapped it against the resilience audit tool.	**Data Analysis** Benchmarked the reach (i.e number & demographics of carers) against the estimated prevalence of carers locally. Mapped the data the carers centre already collected against the resilience audit tool.	**Data Analysis** Statistical analysis using SPSS for the resilience scale and wellbeing questionnaire. Thematic analysis of the online survey to identify the impact carers said the centre had on them. Financial calculations on economic contribution and savings to the state.
CONTEXT What is the context and culture (attitudes and beliefs) within which the carer's centre operates? **Data Collection** Used the resilience audit tool to structure interviews with the Chair of the Board, The CEO, 2 senior managers, 3 carer support works, 1 administrator.			
Data Analysis Thematic analysis mapped against the resilience audit tool.			

Two carers' centres were evaluated as part of this study, Carer Centre A from the East-Midlands and Carer Centre B from the West-Midlands. Both carers' centres had been involved in parts one and two of the research.

9.2 The Carers' Centres

9.2.1 Carers' Centre A

Carers centre A is an independent local charity established to support unpaid, carers. Carers centre A is part of the Carers Trust national network of carers' centres around the UK. The carers' centre is commissioned by the local County Council and offers support to carers of all ages and in different caring roles.

The local authority area covered by the carers' centre is one of the home counties. The south of the area is densely populated, and the north is very rural. The main centre is situated in a town near the middle of the area and a second, smaller hub is situated in a town in the more densely populated south part of the area. All the carer support workers are based in the main centre or the hub, although they do run groups from other buildings in the community.

Census data in 2011 (ONS, 2011) estimated that there were 49,514 carers in the local authority area covered by the carers' centre. Given the increasingly ageing population there is agreement that the number of carers will have increased, although by how much is not currently clear. At the time of this evaluation 9966 carers were registered with carers' centre A. (Note: once a year the carers' centre contacts all carers to check that they are still a carer and still want to be registered with the carers' centre). This would be equivalent to approximately 20% of the carer population living in the county based on the 2011 figures. In the year to date the carers' centre A had registered 1244 new referrals (approximately 2.5% of the carer population based on 2011 figures).

Table 12: Demographic data on registered carers (Carers' Centre A)

Domain	%
Gender	
Male	24%
Female	76%
Ethnicity	
Asian or Asian British	8%
Black or Black British	1%
White British	47%
Other White Background	14%
Other	1%
Opted not to disclose	27%
Unknown	2%
Age	
17-25	1%
26-34	4%
35-44	9%
45-54	17%
55-64	18%
65-74	17%
75-84	14%
85+	6%
Not disclosed	14%
Who carers were caring for	

Spouse/partner	44%
Parent (in-law)	33%
Child (including adult child)	19%
Other (e.g. sibling, neighbour, friend)	4%
Number of hours carer is caring for per week (this data was only available for a third (3194) registered carers)	
0-29	5.5%
30-49	22%
50+	72.5%

Approximately three quarters of the registered carers were female, and a quarter were male. 27% opted not to disclose their ethnicity, 47% were white British. The highest proportion of carers were aged 45 to 74. Just under a half were caring for their partner/spouse and a third were caring for a parent or parent-in-law. Almost three quarters of registered carers who supplied information about how many hours they were caring for per week were caring for 50 or more hours.

It is difficult to know the degree to which the population of registered carers matches the local or national population of carers as there is limited data available to compare. The State of Caring Survey 2019 was completed by 7525 carers across the UK and does provide some comparison. For example 18% were male (compared to 24% for carers' centre A); 5% were BAME (compared to 9 % for carers' centre A); 63% were caring for over 50 hours a week (compared to 72.5% for carers' centre A); for both 4% were aged 25-34; 63% were caring for 50 hours or more (compared to 72.5% for carers' centre A). Whilst there does appear to be some similarities the State of Caring Survey does not provide data on who carers were caring for and the data for Carers' Centre A does not provide information about whether cares were working or not. These gaps in data make it difficult to compare and hence impossible to draw comparisons as to how much the populations match.

The Centre is governed by a board of Trustees and managed by the Chief Executive and five senior managers. There are four key teams: the adult carer team, the hospital team, the young carers team and the fundraising and admin team. At the time of this evaluation there were 52 members of staff, 28 full-time and 24 part-time. In the adult carer team there were 3.5 full-time equivalent carer support workers, a full-time team co-ordinator, a part-time administrator and a full-time service manager.

Whilst the Centre does fundraise and does secure funding for a variety of bespoke projects, mapping the finance for this evaluation focused on the main contract with the council for supporting adult carers. At the time of the evaluation carers' centre A received an annual amount of £482,950 from the council for supporting adult carers across the county. This equates to an investment of £9.75 per carer across the county and £48.46 per registered carer (although this amount decreases with every carer that is registered).

At the time of the evaluation the carers' centre had 22 volunteers who contributed a total of 157 days throughout the year. The Centre was also working in partnership

with a wide range of community organisations such as Age UK, Narcotics Anonymous, local Autism Charity, etc.

9.2.2 Carers' Centre B

Carers' centre B is also an independent local charity set up to support unpaid carers. Similarly, to carers' centre A, carers' centre B is part of the Carers Trust national network of carers' centres around the UK. The carers' centre is commissioned by the local County Council and offers support to carers of all ages and in different caring roles. A few months prior to the evaluation the council significantly cut the funding for the carers' centre. As a result, the carers' centre had to restructure and rethink how they would provide support to carers and to achieve what outcomes.

The local authority area covered by the carers' centre is one of the most rural and sparsely populated counties in England. The carers' centre is situated in the most populated town that lies roughly in the middle of the county. There are no hubs elsewhere in the county and the cut in funds and restructure means that the carer support workers no longer run groups from other community buildings.

Census data in 2011 (ONS, 2011) estimated that there were 20,627 carers in the county. Given the increasingly ageing population there is agreement that the number of carers will have increased, although by how much is not currently clear. At the time of this evaluation 5774 carers were registered with carers' centre B. (Note: once a year the carers' centre contacts all carers to check that they are still a carer and still want to be registered with the carers' centre). This is equivalent to approximately 28% of the carer population living in the county (based on 2011 figures). In the year to date carers' centre B had registered approximately 800 new referrals (approximately 3.9% of the carer population based on 2011 figures).

Table 13: Demographic data on registered carers (Carers' Centre B)

Domain	%
Gender	
Male	30%
Female	70%
Ethnicity	
Asian or Asian British	0.2%
Black or Black British	0.1%
White British	71.9%
Other White Background	1.1%
Other	0.2%
Not disclosed	26.5%
Age	
17-25	3.8%
26-34	5.9%
35-44	11.5%
45-54	19.6%
55-64	21.5%
65-80	26.9%
80+	10.8%

Who carers were caring for	Data unavailable
Number of hours carers were caring for	Data unavailable

Similarly, to carers' centre A, most registered carers were female. The ethnic diversity was less for carers' centre B with over 70% of carers being white British. This reflects the ethnic diversity of the geographical areas where the centres are located. Although it must also be recognised that 26.5% opted not to disclose their ethnicity which may skew the distribution. The highest proportion of carers were aged 45 to 80.

Again it is difficult to draw conclusions as to the degree to which the population of registered carers matches that of the local of national population of carers as there is limited data available to compare and the data provided by Carers' Centre B has many gaps.

The centre is governed by a board of Trustees and managed by the Chief Executive. At the time of this evaluation there were 3 full-time equivalent carer support workers and a finance administrator.

Carers' centre B does fundraise but again this evaluation focused on the main contract with the council for supporting adult carers. At the time of the evaluation carers' centre B received an annual amount of £160,000 from the council for supporting adult carers across the county. (This was a decrease of £115,000 (41.8%) from £275,000 the previous year). The monies paid by the council equates to an investment of £7.76 per carer across the county and £27.71 per registered carer.

At the time of the evaluation carers' centre B was working in partnership with a wide range of community organisations such as Alzheimer's Society, British Red Cross, Stroke Association, Hospice at Home, etc. Information on the number of volunteers and the hours they contributed was unavailable at the time of the evaluation.

10 Chapter 10: Scoping Review - the carer perspective

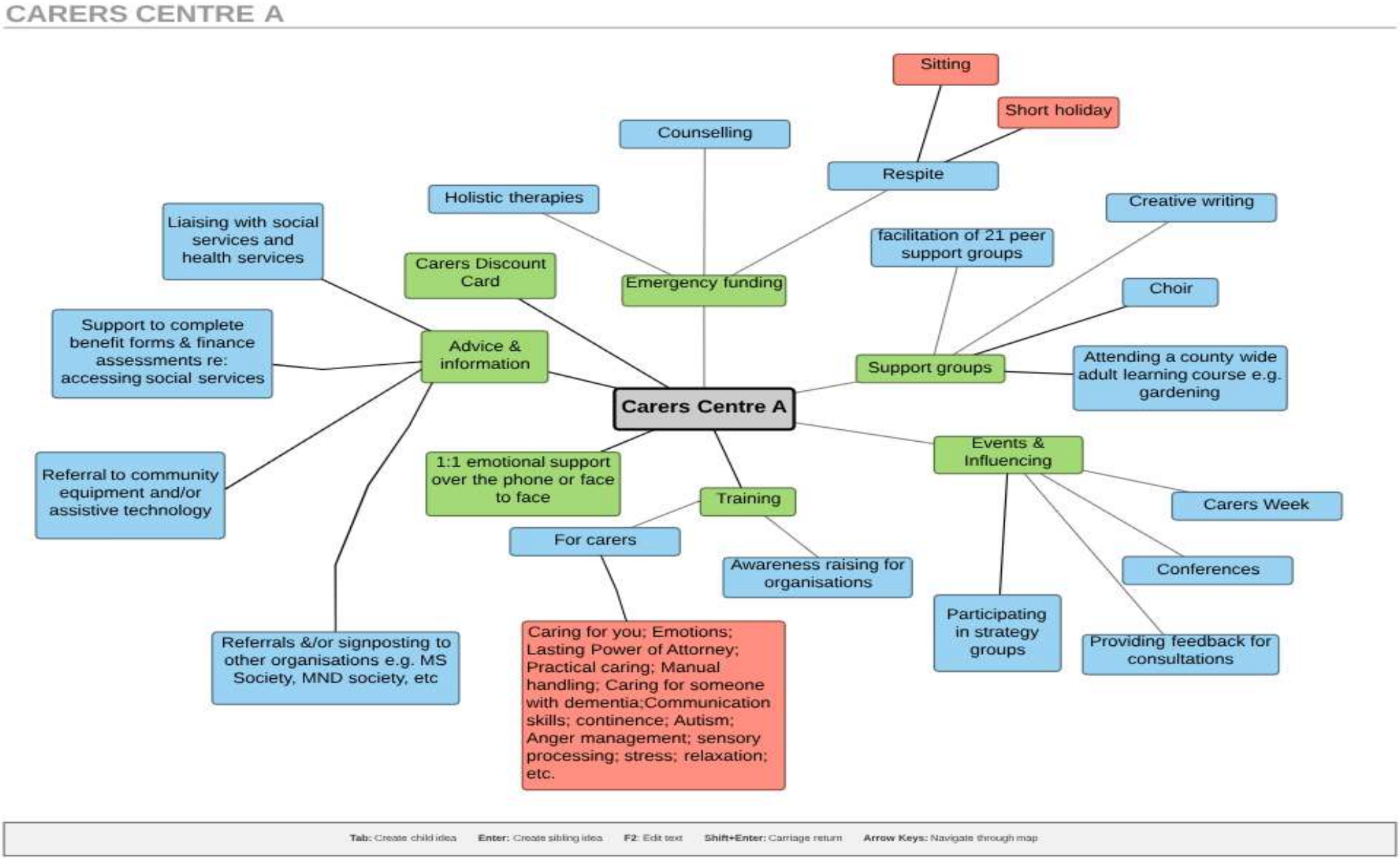
This chapter summarises the results of the data collection methods used to collect both quantitative and qualitative data from carers and the data on the activities the carers' centre provided. The results of the data collection are presented for each carers' centre and then analysed, compared and discussed. Limitations of the study are considered.

10.1 Carers' Centre Activities

10.1.1 Carers Centre A

Below is a diagram (figure 35) representing the activities that took place under the adult carer contract with the council. The diagram is a product of the staff meeting and the review of the marketing materials.

Figure 35: Carers' centre A Activities



A summary of the themes from the field notes and memos from the 'day in the life of' observations and activity mapping is provided below and is structured using the domains outlined in the audit tool.

Empowered to manage the condition, symptoms and behaviours: the training delivered by the carers centre and the signposting to condition specific organisations did demonstrate a focus on supporting carers to manage the condition, symptoms and behaviour their loved one displayed. This was also evident in some of the telephone conversations where experienced carer support workers were able to give informed, symptom/behaviour specific advice. Carer support workers also clearly spent time with carers undertaking emergency planning.

Empowered to work in genuine partnership with professionals: many of the phone calls came from carers who were in varying levels of distress because they needed support that wasn't yet in place. A significant number were looking for support to help them navigate the social care system. In most cases, carer support workers ended up calling the local authority or health staff to ask (on behalf of the carer) what the current situation was and when a decision about support might be made. There was some suggestion from the activity mapping that the carers' centre did advocate for carers by raising awareness and training other organisations.

Positive relationship with family and friends: the activity mapping indicated a strong focus on peer support groups to address this and observations of the support groups did demonstrate that carers were able to discuss the challenges of their family dynamics with other carers experiencing similar situations. Observations of the phone calls also illustrated that some carers took the opportunity to discuss such issues within the context of the conversation with the carer support worker. There was no indication that the carers' centre undertook or signposted families to family therapy services.

Positive sense of self: the training delivered by the carers' centre to carers and the discussions within the peer support groups did imply that carers were encouraged to maintain other roles and identities. Observations of the phone calls confirmed that carer support workers completed an outcomes star (see appendix thirteen) with all new referrals. The outcomes star gave carer support workers a structured way of asking carers about their health, their work, time to themselves, etc. Whilst the outcomes star does not specifically focus on maintaining or developing other roles and identities outside the caring role inevitably talking through topics such as work and time to themselves meant that the subjects of roles and identities were often touched upon. There was also an attempt to provide opportunities for carers to engage in different roles via the choir, signposting to other clubs and societies the carer might be interested in and the carers discount card which gave discounts on certain activities in the community. However, the main issue seemed to be that although carer support workers rang carers back 6 weeks after their initial contact and talked through the outcomes star again and recorded any changes, there was a lack of focused support (such as coaching) for carers who were unable to make the changes without support.

Empowered to access and valued by the community: As mentioned above there was evidence of good signposting to community activities and the discount card was another good incentive but there was a lack of practical assistance for those who might need it. It was also unclear from the mapping activity and observations the degree to which the carers' centre engaged in working with local businesses to create carer friendly employers and communities.

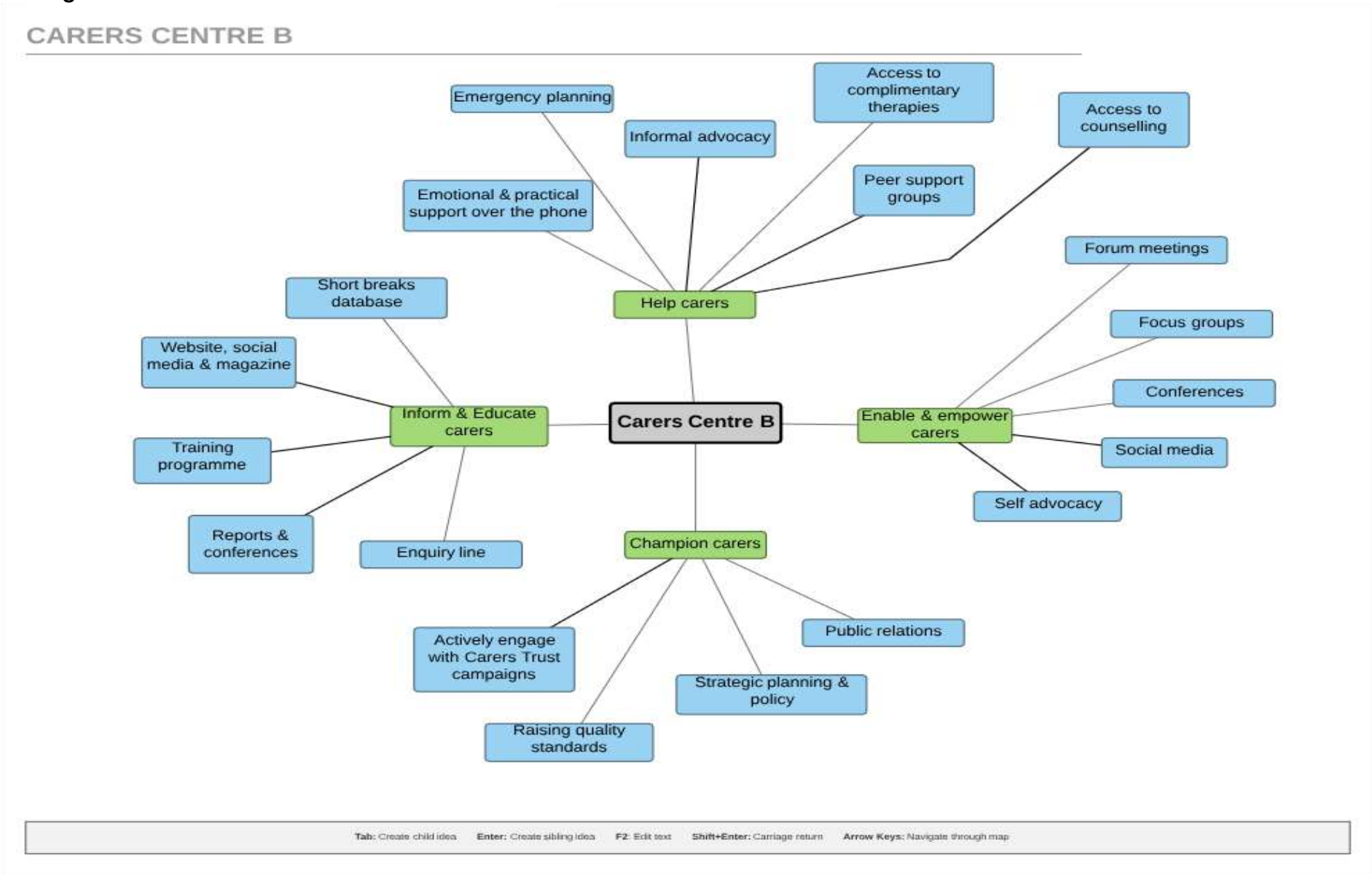
Positive relationship with the care recipient: During the observations the researcher witnessed carers trying to deal with a sense of loss that was wide ranging and experienced on different levels. The peer support groups and phone calls did seem to touch on these issues but quite often the conversations reverted quickly back to trying to find practical solutions. The activity mapping did indicate that carers could be signposted to (and assisted to fund) counselling but this was for the few rather than the many. There seemed to be limited access to couples counselling.

At no point in the observations, staff meeting, or review of marketing materials did the word resilience appear.

10.1.2 Carers Centre B

Below is a diagram (figure 36) representing the activities that took place under the adult carer contract with the council. The diagram is a product of the staff meeting and the review of the marketing materials.

Figure 36: Carers' centre B activities



A summary of the themes from the field notes and memos from the 'day in the life observations' and activity mapping is provided below and is structured using the domains outlined in the audit tool.

Empowered to manage the condition, symptoms and behaviours: the signposting to condition specific organisations did demonstrate a focus on supporting carers to manage the condition, symptoms and behaviour their loved one displayed. The training delivered by the carers' centre had been reduced to just a few courses although the centre did encourage peer support groups to access training by inviting speakers from other organisations to come along to sessions. Carers could access an emergency plan template via the website which they could complete on their own and they could sign up to a carer's emergency card.

Empowered to work in genuine partnership with professionals: the activity mapping and subsequent conversations with staff did suggest that since the cuts there was an added focus on championing carers' rights and raising standards by raising the awareness of other organisations via public relations and campaigning.

Positive relationship with family and friends: conversations with staff during the activity mapping indicated that there was concern that the peer support groups would not be sustained by carers without carer support workers to organise and facilitate them.

Positive sense of self: the activity mapping and discussions with staff suggested that the carers' centre aimed to encourage carers to have roles outside of their caring role but that they had very little 1:1 contact with carers to help them achieve this. Again, the approach appeared to focus on working with other organisations to create carer friendly employers and communities. However, with limited staff resources it was unclear what capacity the carers' centre had to achieve this.

Empowered to access and valued by the community: As mentioned above there was evidence of good signposting to community activities but there was a lack of practical assistance for those who might need it.

Positive relationship with the care recipient: the activity mapping indicated that carers could be signposted to counselling. Further exploration of this revealed that the carers' centre worked in partnership with the local college by providing placements for trainee counsellors so that carers could access up to six counselling sessions for free. Although the feedback from carers who had accessed the counselling service was very positive the service was only taken up by a handful of carers.

10.2 Purpose and impact of the carers' centre

10.2.1 Carers centre A

207 carers completed the survey (which represented 2% of the carers registered with the carers' centre). It was not possible to fully ascertain whether this was a representative sample but there were similarities. For example, the highest

percentage of carers were caring for their spouse/partner for more than 50 hours a week which reflects the profile of carers registered with the centre however, the carers' centre did not routinely collect data on who the carer cared for or what condition the care recipient had.

Table 14: Demographic data on Carer Survey Respondents (Carers' Centre A)

	Number	Percentage
Who do you care for?		
Child	58	28.6%
Spouse/Partner	95	46.8%
Parent/Parent-in-law	50	24.6%
Other	4	2%
What condition do they have?		
Stroke/Aquired Brain Injury	26	12.6%
Dementia/Alzheimers	43	20.8%
Parkinsons	7	3.4%
General Ageing & Fraility	14	6.8%
Autism/Learning Disability	45	21.7%
Mental Health Condition	26	12.6%
Arthritis	5	2.4%
MS / MND	15	7.2%
COPD / Asthma	8	3.9%
Cancer	6	2.9%
Other	12	5.8%
How many hours of care do you provide a week?		
No response	10	4.8%
0-10	20	9.7%
11-20	16	7.7%
21-30	13	6.3%
31-40	8	3.9%
41-50	5	2.4%
50+	135	65.2%

Question 1: What do you think the purpose of the carers' centre is?

None of the carers used the word resilience in their answer to 'what is the purpose of the carers centre' and only 1 carer responded with a phrase related to resilience ('to enable carers to continue caring'). The overwhelming statement was simply 'to support carers' and there was a lack of clarity as to what that support might be. The second most popular response was 'to provide information'. Other themes from the carer responses are summarised below:

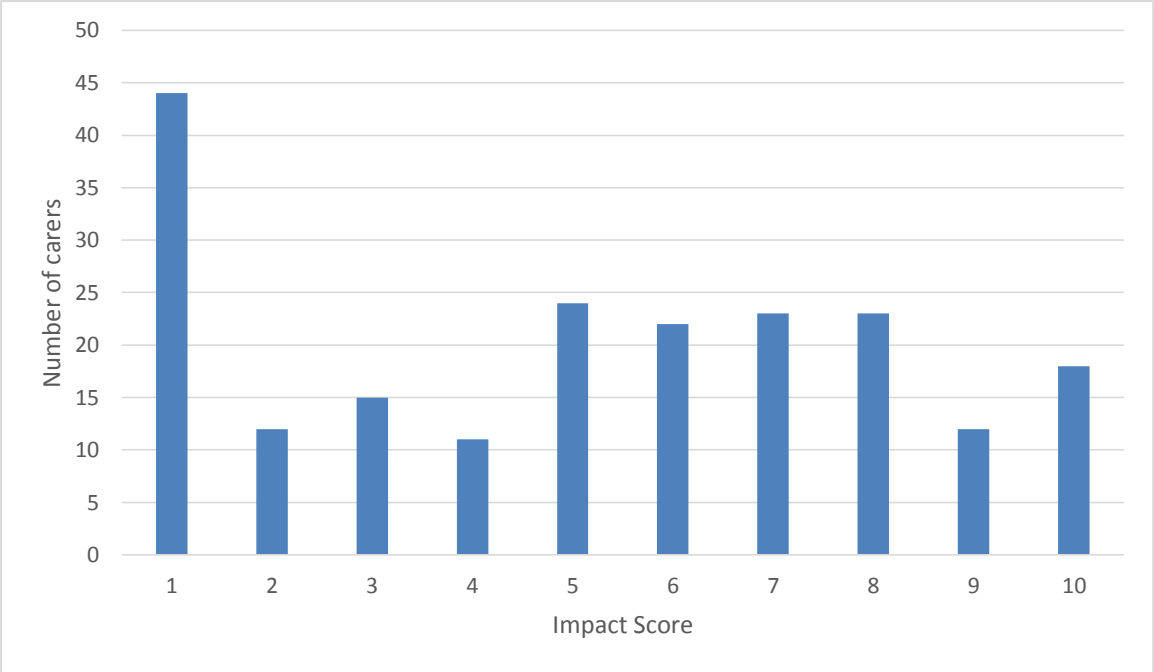
- Peer support
- Provide a break from caring
- Someone to talk to

- Reduce isolation
- Advocate for carers
- Reduce the burden on the state
- Don't know

Question 2: Impact Score

Carers were asked to rate on a scale of 1 to 10 the impact the support from the carers' centre had on their ability to keep caring where 1 equalled 'no impact at all' and 10 equalled 'could not continue to care without their support'.

Chart 1: Impact Score (carers' centre A)



The average score was 4 (ranged from 1 to 10). An impact of 1 was the score most frequently rated by carers (22%) (44 carers). 14.7% (30 carers) rated an impact of 9 and 10. A score of 9 or 10 suggests that the carer would be likely to stop caring without the support of the carers' centre.

Chart 2: Who carers were caring for (carers' centre A)

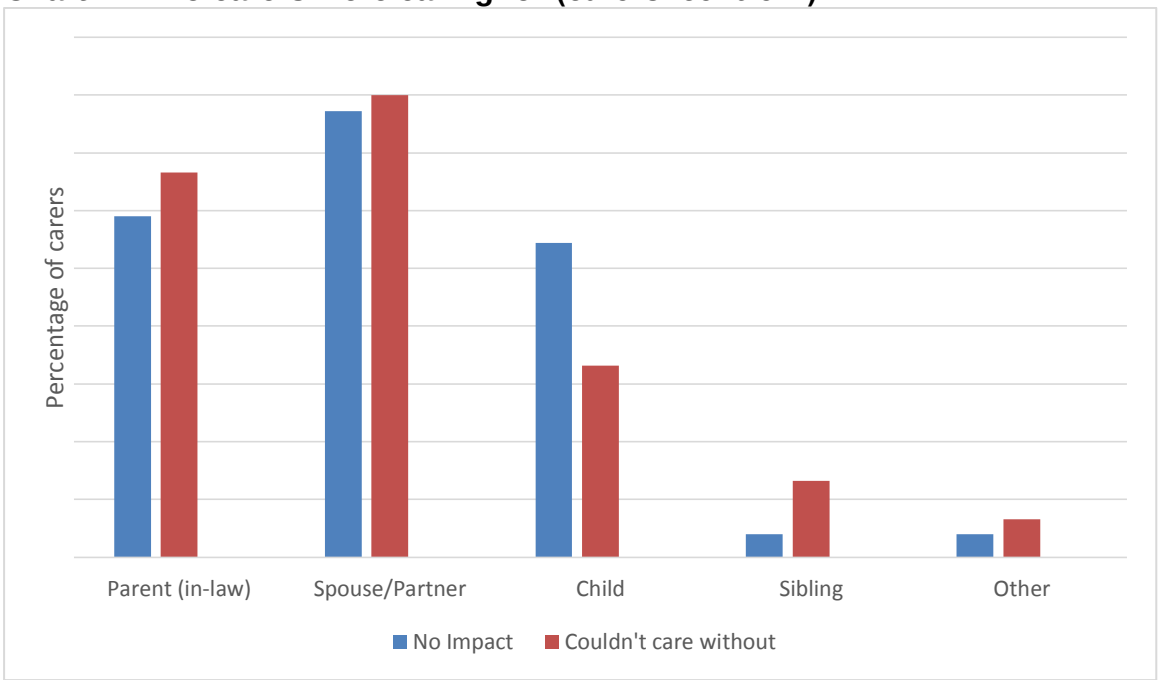
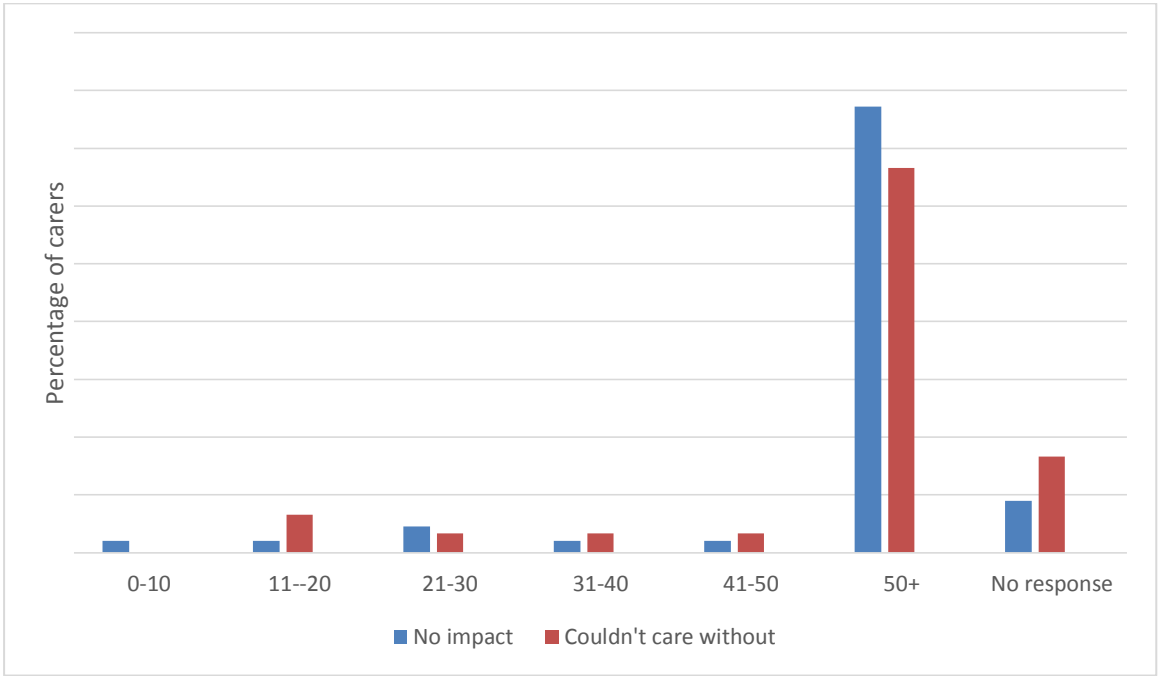


Chart 3 : Number of hours carers were caring for (carers' centre A)



There were no significant differences in relation to who carers were caring for or the number of hours they were caring for between those that rated the impact of the carers' centre as 'no impact' and those who rated it as 'couldn't care without'.

Question 3: What has the carers centre helped you with?

Carers were asked what the carers' centre had helped them with. The key themes were:

- Information and signposting
- Carers Discount card
- Training
- Contact with other carers
- Emotional support and a listening/non-judgemental ear

19.5% of carers that participated in the survey stated that *'the carers' centre has not helped me with anything'.*

Question 4: Is there anything the carers centre has been unable to help you with?

Finally, carers were asked whether there was anything that the carers' centre had been unable to help them with. 16.7% of carers who participated in the survey said that they hadn't asked for any help; 33.3% mentioned things (such as respite) that the carers' centre had been unable to help them with and 50% stated the opposite i.e. that there hadn't been anything that the carers' centre had been unable to help them with.

10.2.2 Carers' Centre B

58 carers completed the survey (which represented 1% of the carers registered with the carers' centre). It was not possible to ascertain whether this was a representative sample. Anecdotally the carers' centre states that most of their registered carers care for over 50 hours a week and the biggest proportion of them care for their partner/spouse. This was reflected in the profile of carers who responded to the survey.

Table 15: Demographic data on carer survey respondents (Carers' Centre B)

	Number	Percentage
Who do you care for?		
Child	15	25.9%
Spouse/Partner	26	44.8%
Parent/Parent-in-law	16	27.6%
Friend/Neighbour	1	1.7%
What condition do they have?		
Stroke/Aquired Brain Injury	6	10.3%
Dementia/Alzheimers	19	32.8%
Parkinsons	3	5.2%
General Ageing & Frailty	5	8.6%
Autism/Learning Disability	10	17.2%
Mental Health Condition	5	8.6%
Arthritis	3	5.2%
MS / MND	3	5.2%
COPD / Asthma	2	3.4%
Cancer	2	3.4%
How many hours of care do you provide a week?		
0-10	5	8.6%
11-20	11	19%
21-30	3	5.2%
31-40	2	3.4%
41-50	2	3.4%
50+	35	60.3%

Question 1: What do you think the purpose of the carers' centre is?

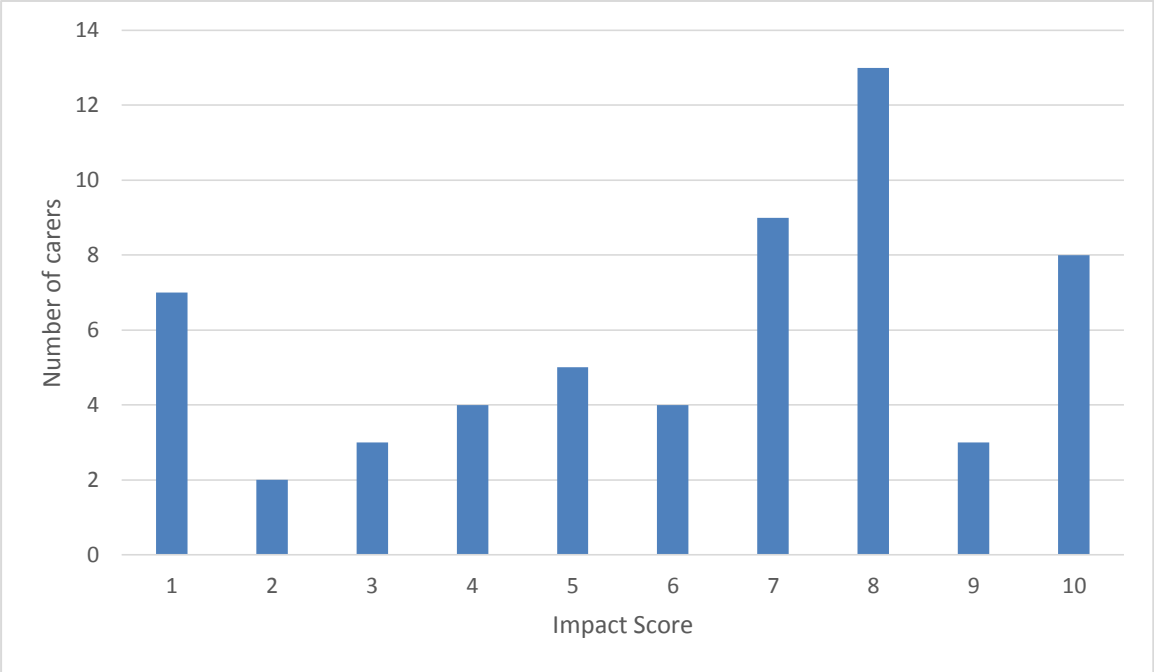
59 carers responded to the survey. None of the carers used the word resilience in their answer to 'what is the purpose of the carers' centre' and only 2 carers responded with a phrase related to resilience ('to support carers to keep going without destroying their own lives'). The overwhelming statement was simply 'to support carers' and again, there was a lack of clarity as to what that support might be. The second most popular response was 'to signpost to other organisations that could help and provide information'. Other themes from the carer responses are summarised below:

- Peer support
- Provide a break from caring
- Advocate for carers
- Provide training
- Raise awareness locally of carers issues
- Don't know

Question 2: Impact score

Carers were asked to rate on a scale of 1 to 10 the impact the support from the carers' centre had on their ability to keep caring where 1 equalled 'no impact at all' and 10 equalled 'could not continue to care without their support'.

Chart 4: Impact Score (carers' centre B)



The average score was 7 (ranged from 1 to 10). An impact of 8 was the score most frequently rated by carers (22%). 19% (11 carers) rated an impact of 9 and 10. A score of 9 or 10 suggests that the carer would be likely to stop caring without the support of the carers' centre.

Chart 5: Who carers were caring for (carers' centre B)

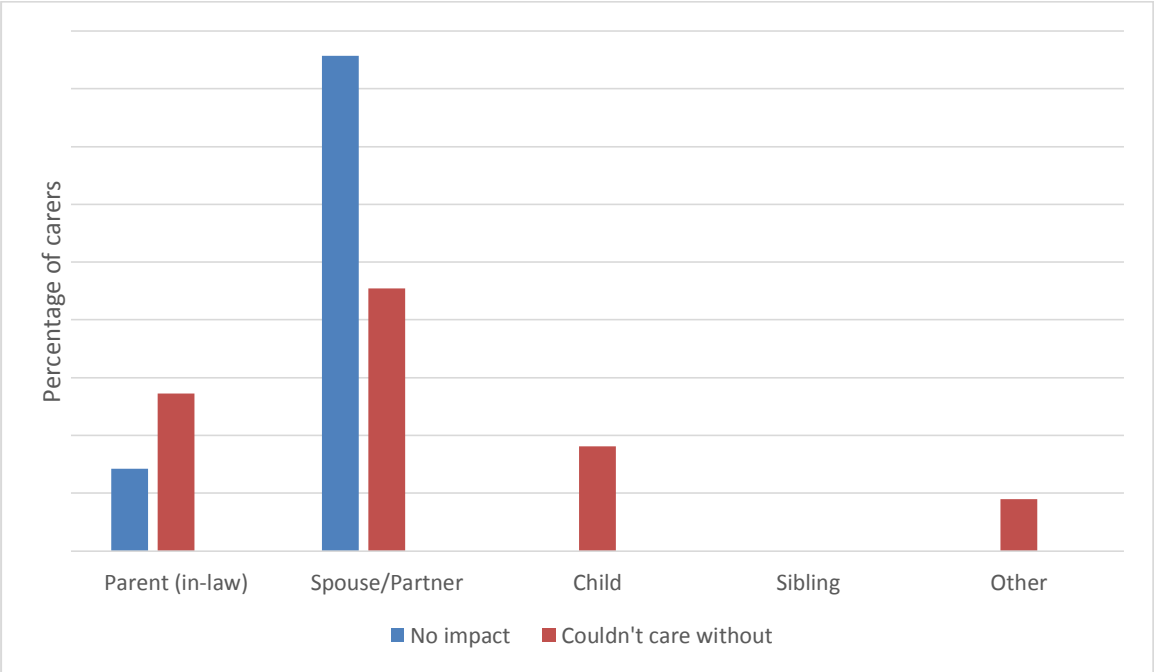
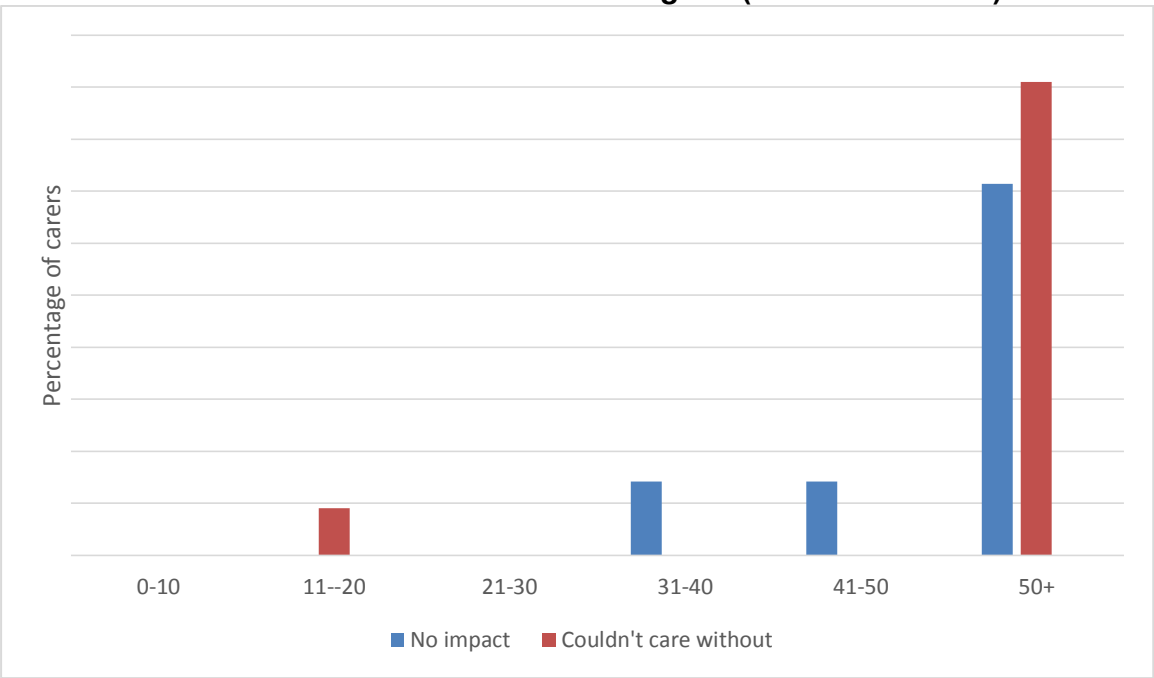


Chart 6: Number of hours carers were caring for (carers' centre B)



There were some slight differences between the profile of carers who rated 'no impact' and those who rated 'couldn't care without' but the numbers are very small (7 carers rated no impact and 11 carers rated couldn't care without) so it is hard to draw any conclusions.

Question 3: What has the carers' centre helped you with?

Carers were asked what the carers' centre had helped them with. The key themes were:

- Reducing isolation
- Training
- Advice on the support available
- Contact with other carers
- Emotional support and a listening/non-judgemental ear

19% of carers that participated stated that '*the carers' centre has not helped me with anything'.*

Question 4: What has the carers' centre been unable to help you with?

Finally, carers were asked whether there was anything that the carers' centre had been unable to help them with. 14.8% of carers who participated in the survey said that they hadn't asked for any help; 20.4% mentioned things (such as respite) that the carers' centre had been unable to help them with and 64.8% stated the opposite i.e. that there hadn't been anything that the carers' centre had been unable to help them with.

10.3 Wellbeing and resilience of carers

10.3.1 Carers' Centre A

Both the SWEMWBS and the BRS were completed with new referrals during their initial conversation with the carers' centre. The scales were then repeated at the follow-up conversation 6 weeks later. 98% of new referrals (n=48 carers) agreed to participate over a 2-week period. 52% (n=25 carers) were female and 48% (n=23 carers) were male.

The maximum wellbeing score possible is 35 and the minimum score possible is 7. The average score for wellbeing at T1 (initial conversation) was 25.1 (SD 5.14) and the average score at T2 (6-week follow-up) was 25.9 (SD 4.60). The average score for all people in England is 24 (DH, 2011) suggesting that the average score for carers is not significantly different from the population.

The difference in wellbeing scores between T1 and T2 were compared using a related samples Wilcoxon Signed Rank Test. The results were not significant ($p>0.05$). Hence the null hypothesis that wellbeing is not improved after contact with the carers' centre had to be retained.

The maximum resilience score possible is 5 and the minimum score possible is 0.83. The average score for resilience at T1 was 3.23 (SD 0.62) and the average score at T2 was 3.30 (SD 0.55). There are no population level studies that can provide an average score for people in England. A population study for Germany found the average (mean) score was 3.48 (Chmitorzet al, 2018) and a population study for Spain found the average score was 3.01 (Rodríguez-Rey et al, 2016). It is unlikely that the average score for England will be dramatically different. The score for carers is not significantly different to that of the two western populations mentioned.

The difference in resilience scores between T1 and T2 were also compared using a related samples Wilcoxon Signed Rank Test. The results were also not significant ($p>0.05$). Hence the null hypothesis that resilience is not improved after contact with the carers' centre had to be retained.

The correlation between wellbeing and resilience was tested both at T1 and T2 using a Pearson's Correlation. The results were significant at both T1 and T2 ($p<0.01$). Hence the hypothesis that wellbeing and resilience are positively correlated was accepted.

10.3.2 Carers' Centre B

Unfortunately, carers' centre B were unable to collect data using either the SWEMWBS or the BRS due to their limited resources.

10.4 Discussion

The data analysis revealed that the concept of carer resilience did not feature strongly in carer statements about the purpose of the centres suggesting that, whilst overarching policy maybe focused on building the resilience of carers; this focus has not translated into practice. This lack of translating policy into practice is something that has been reported by Carers UK who have testified again and again that the Care Act has not been consistently implemented across England resulting in the

needs of many carers going unmet (Carers UK, 2016; Carers UK, 2017; Carers UK, 2018).

Results from the BRS suggested that support from the carers' centre did not improve carer resilience. Based on this and put in evaluation terms the 'merit' of the service (i.e. the outcomes it was achieving for its customers) was poor. However, the results also indicated that on average, carers were as resilient as the general population and it could be argued that maintaining their resilience in situations where they are caring for people whose situations are deteriorating is a positive outcome.

It is possible that the resilience scale was simply not sensitive enough to capture changes or was not measuring the right things. The BRS did not measure all aspects of resilience (as defined in previous literature) as it focused on personal attributes rather than domains such as the availability of resources from family and community. The BRS did not therefore fit neatly with the definition of carer resilience or the model of support. The very fact that the BRS focuses on personal attributes could explain why the results evidenced that carers were resilient at the first point of contact. Data from the focus groups in part one suggested that the carer journey resulted in carers developing personal attributes which they felt made them more resilient.

The data collected did suggest that the carers' centres provided support across all domains outlined in the audit tool and that this support was provided to carers caring for people across client groups and relationships. A more holistic measure of resilience might have brought gaps to the surface in domains such as access to community resources or good relationships with family and friends that would have provided more insight into carer resilience and the impact the support from the carers' centres had. However, the definition of carer resilience arrived at in part one and two of this research describes resilience as, in part, being an ability to keep caring. Given that carers are still caring means they are resilient. In this case, measuring resilience would be about measuring how many carers continue to care. Alternatively, it could be argued that maintaining their level of resilience (as measured by the BRS) is an indicator of the willingness of the carer to continue caring. That said, given the fact that many carers state they have no choice but to continue this interpretation is questionable.

The other elements of the definition include 'an ability to move on by adapting roles and behaviours'. Factors associated with the ability to move on or the ability to adapt roles and behaviours are not features that dominate current measures of resilience (Windle et al, 2011) suggesting there could be a need to develop a bespoke measure for carer resilience.

There was a clear distinction between the two carers' centres in that carers' centre A was able to engage in more face-to-face and 1:1 contact with carers. The significant reduction in funding for carers' centre B seemed to have drastically reduced the centre's ability to engage in such support. For carers' centre B there was a heavier focus on working to raise the awareness of other organisations so that these organisations were better placed to meet the needs of carers. The proportion of carers stating what help they had or hadn't received/asked for followed a similar pattern for both centres though. The key difference between the centres was the average impact score (Centre A = 4; Centre B = 7) although the percentage of carers

for whom the carers' centre had a significant impact was again similar (Centre A = 15%; Centre B = 19%).

There is some suggestion in previous research that carers feel valued when someone takes an interest in them, builds rapport, works with them to identify support they might find helpful and facilitates its implementation. It is this process of 1:1 support that enables carers to keep caring even if the outcomes of the support are not positive (Larkin et al, 2019). It is possible that the reason this process is valued by carers is because it helps to reduce the hidden world of the carer and their sense of isolation. It may also provide them with a sense of hope that things will get easier. Previous literature suggested that it is the sense of hope, and not whether things do get easier or not, that is important (Holtslander and Duggleby, 2008). Furthermore, good and supportive relationships with professionals is another key aspect carers in this research highlighted as an important element of carer resilience and face to face, 1:1 support helps to foster such relationships.

It is impossible to place much weight on any conclusions drawn from analysing the impact rating scale because there is no evidence that the carers who completed it were a representative sample and because of the small numbers of carers from carer centre B that completed it. That said, the data does suggest that a small number of registered carers would be unable to continue caring without support from the carers' centre. It is surprising though that the impact score for Centre A, which provided more 1:1 support, was lower than the impact score for Centre B, especially given that the profile of carers that responded to the online survey was strikingly similar for each centre. The data collected does not shed any further light on why this might be. It is unfortunate that due to time and resources the researcher was unable to follow up the survey by interviewing some carers as this may well have provided some explanations.

Whilst both carers' centres identified emotional support (and counselling) as a significant part of what they did the 'day in a life of' observations and conversations with staff suggested that only a minority of registered carers took up the opportunity for counselling and conversations with carer support workers often quickly reverted to finding practical solutions either because support workers felt out of their depth or because they felt under pressure not to talk for too long to one carer.

Neither carers' centre seemed to tailor their activities to different stages of the carer journey. There also seemed to be a lack of graded support to meet the ability of carers to access support. For example, data from part one of this research suggested that where carers were in their journey and the specific challenges they were facing impacted on whether they simply needed information and/or opportunities to meet and talk to others in similar situations or whether they needed some assistance to access the support available to them. Other carers, if in crisis, would require a significant amount of 'hand-holding' if they were going to be able to continue their caring role. Whilst carers' centre A had more resources and so was better equipped to grade the support the reality for both carers' centres was that they had little capacity to do so and there was a real risk that carers who needed more than information or advice did not receive the assistance required to ensure that their support needs did not escalate.

Previous literature has identified specific types of support that have been effective in supporting carers of people with specific conditions. Examples included: respite care, peer support groups, home help, counselling, psychological interventions such as CBT or mindfulness, family therapy, person-centred support tailored to the specific needs of the carer, support from a key professional e.g. social worker, mental health nurse, etc. (Hoskins et al, 2005; Sundar et al, 2014; Sheppard, 2016).

However, there is a lack of previous literature that considers the effectiveness of support across care groups and/or relationships. Furthermore, previous literature fails to adequately examine the effectiveness of support on the outcomes for both the carer and the care recipient or more complexly, the effect on their relationship and/or the dynamics of the immediate family (Larkin et al, 2019). This is important because as the findings from part one and two of this research have shown, caring does not operate in a vacuum but within the context of an ongoing relationship and navigating this changing relationship is a crucial part of carer resilience.

The conclusion at this stage is that the standardised measures have not provided strong evidence of the 'merit' of the service as resilience and wellbeing were not improved although they were maintained. Both carers' centres did provide some support across all domains of the audit tool and a small proportion of carers from each centre stated that without support from the carers' centre they would be unable to continue caring. The next chapter will explore whether the cost of the service can be justified by the small impact on carer resilience and hence whether the carers' centres have, in evaluation terms, a high or low 'worth' (cost-effectiveness).

10.5 Limitations

The use of quantitative data collection such as standardised measures alongside qualitative data collection in the form of a survey and observations enhanced the reliability and validity of the data and allowed the researcher to address a broader range of questions than collecting only quantitative or qualitative data would have provided. Whilst qualitative data is (to a greater or lesser extent) subjective, adding text and narrative to the quantitative data resulted in a deeper understanding of the findings on carer resilience and the impact of the carers' centres.

It was unfortunate that the resilience scale used was not holistic i.e. the BRS did not measure all aspects of resilience as it focused on personal attributes. However, it was important that the carer support workers felt comfortable with the measure used to capture the data and so the use of the BRS was a necessary compromise.

There was a low response rate from registered carers for the online survey (2% of registered carers for carers' centre A and 1% of registered carers for carers centre B). This means it is difficult to draw any generalisations from the data.

The impact measure used in the online survey was not a standardised measure of resilience however, the use of numerical rating scales is common in both research and clinical situations and has been proven to be a reliable and valid method. Unfortunately, it did not provide an opportunity to explore all the factors within the model of support for promoting resilience. The triangulation of this data with the BRS and the positively correlated SWEMWBS did enable some tentative conclusions to be drawn though.

Online surveys are a fast and efficient way of collecting data especially when resources to do so are limited. The online survey provided flexibility for participants because they could answer the questions in their own time and when it was convenient for them. The responses were automatically stored in a database which reduced the possibility of data errors (Wright, 2005). The disadvantages were that carers who did not use the internet did not receive the survey. The absence of the researcher and the lack of capacity to undertake follow-up interviews meant that answers to the questions could not be fully explored.

Ethnography is “the description and interpretation of a culture or social group” (Holloway et al., 2010, p. 76). A mini-ethnography, also known as a focused ethnography, is used when the investigation focuses on a specific area and is often used when resources are restricted. Traditional ethnography can take a great deal of time to accomplish, but with a mini-ethnography data saturation is reached far sooner because the research is focused and boundaried (Fusch et al, 2017). Taking an ethnographic ‘day in the life of’ approach to the observations provided insight into the culture and attitudes of the carer support workers.

There are some limitations to direct observation as the presence of the researcher by default changes the environment and hence the researcher cannot separate herself from the research. However, the researcher was transparent and clear about her role to everyone she observed which helped to reduce the impact of the observations on the carer support workers and any changes in behaviour.

11 Scoping Review – The Carers' Centre perspective

This chapter summarises the results of the data collection methods used to collect both quantitative and qualitative data from carers' centre staff, and to investigate the business aspects of the carers' centre. The methods used to collect data on the staff perspective of the purpose of the carers' centre, the culture it operates in and the method used to calculate the unit cost and cost savings are all outlined in chapter 3. The results of the data collection are presented here for each carers' centre and then analysed, compared and discussed. Limitations of the study are considered, and some conclusions are drawn.

11.1 Purpose of the carers' centre

11.1.1 Carers' Centre A

37 staff and trustees responded to the survey. 35 out of 37 participants answered the question as to their role, of those, 7 were trustees (out of a possible 8), 4 were senior managers (out of a possible 5), 18 were carer support workers (out of a possible 18), 6 were fundraisers and administrators.

None of the participants mentioned the word resilience in their answer to the first question on what the purpose of the carers' centre was. 5 participants did mention phrases related to the definition of carer resilience such as:

'To support unpaid carers…… enabling them to sustain and where possible thrive in their caring roles'.

'To support carers to maintain their caring role…… and empower them to make choices about their ongoing situation'.

There was no pattern regarding the role of the participants (eg. seniority, being a trustee, being a manager, being a support worker, etc) that mentioned phrases related to carer resilience. 11 responses suggested that the main purpose was to provide information, advice and/or guidance, again there was no pattern regarding the role of the participants. 3 participants mentioned improving or maintaining wellbeing and 6 participants mentioned providing emotional support.

In answer to the second question 'what should the carers' centre achieve for carers' again none of the participants mentioned the word resilience although 3 participants mentioned the centre should enable/empower the carer to continue their caring role and reduce the need for secondary care. 15 responses stated that the carers' centre should provide carers with information, advice or guidance. 1 participant mentioned preventing the relationship between the carer and the care recipient from breaking down.

In response to the final question related to funders, again none of the participants mentioned resilience or any phrases related to resilience. 14 participants stated that the carers' centre should achieve value for money (although there was a lack of clarity on what value for money constituted) and/or a reduction on the demand for publicly funded services or contact with the council. Other responses included

achieving support for as many carers as possible and achieving positive outcomes for carers.

In terms of the commissioner perspective the contract with the council clearly states that the purpose of the service is to support carers in their caring role so that carers:

- Have access to information, advice and guidance
- Have access to integrated and personalised services
- Have a life of their own
- Have support to stay mentally and physically well
- Experience financial wellbeing.
- Have a voice about services for the care recipient and for themselves
- Are seen as expert care partners and involved in planning services in partnership with local services.

The carers' centre's charitable aims and objectives state that the purpose of the charity is for:

'The relief of persons with a disability arising from age, sickness or physical or mental disability in the area at present covered by the County Council and who are dependent on others for their care by the provision of practical help, advice, assistance, service, support, advocacy and information to spouses, partners, relatives and others who have or assume an unpaid responsibility for their care and treatment ('the carers').'

'To promote the interests of the carers defined above including the relief of hardship and mental or physical sickness or suffering amongst the carers.'

'To advance public education concerning the care and treatment of those requiring such care and treatment and their carers.'

11.1.2 Carers' Centre B

All 13 staff members and trustees responded to the survey (5 trustees, 1 senior manager and 7 staff members).

None of the participants mentioned the word resilience in their answer to the first question on what the purpose of the carers' centre was. 6 participants did mention phrases related to the definition of carer resilience such as:

'to enable Carers to continue caring and having a life beyond caring role'.

'To mobilise the expertise and resources that Carers already have to improve their lives by helping them care for themselves and balance a life of their own with the responsibilities of their caring'.

There was no pattern regarding the role of the participants that mentioned phrases related to carer resilience. 8 responses suggested that a key purpose was to provide information, advice and/or guidance, again there was no pattern regarding the role of the participants. 5 participants mentioned providing emotional support and 5

participants mentioned that a key purpose was to raise awareness in the community so that more carers were identified, and their needs were addressed providing them with better access to community resources and facilities.

In answer to the second question 'what should the carers' centre achieve for carers' again 1 of the participants mentioned the word resilience and 7 participants mentioned phrases related to our definition of carer resilience. 9 responses stated that the carers' centre should provide carers with information, advice or guidance.

In response to the final question related to funders, again none of the participants mentioned resilience or any phrases related to resilience. 6 participants stated that the carers' centre should achieve value for money (although there was a lack of clarity on what value for money constituted) and 8 participants stated a reduction on the demand for publicly funded services.

In terms of the commissioner perspective the contract with the council states that the aims of the service are to provide a carers support service for unpaid carers that seeks to:

- prevent, reduce or delay the need for carers to receive 'formal' support
- improve carers quality-of-life and opportunities
- build on carers assets at an individual and community level
- support older carers and the older cared for people within the Hospital discharge pathway.

The contract states that these aims will be achieved by:

- facilitation of community-based resources to access relevant health and social care support for themselves and the person being cared for
- practical support and signposting to independent financial legal and benefit advice
- provide access to information by signposting and access to training and networking opportunities
- access to peer support or other activities provided through the carers centre or other organisations and universal provision

The carers' centre's charitable aims and objectives state that the purpose of the charity is:

'To ensure that carers are universally recognised as fundamental to the communities in which they live and to ensure that there is a balance between their caring responsibilities in their lives outside their caring role'.

11.2 Performance management data

11.2.1 Carers' Centre A

Below is a table illustrating the contract monitoring data required by the council. The data below represents a 9-month period from April 2017 to December 2017. The data are reported for each quarter (i.e. Q1, Q2, Q3, which each relates to a 3-month period e.g. Apr-Jun, Jul-Sept, Oct-Dec).

Table 16: Carers' Centre A Performance Data

Apr – Dec 2017	Q1	Q2	Q3	Average	%
No. of Registered Carers					
Total number of carers on database	9468	9770	10023	**N/A**	**N/A**
Number of new carers in quarter	304	317	274	**298**	**N/A**
Referrals					
No. Referrals from Council	11	14	10	**12**	**4%**
Community mental health team	22	27	27	**25**	**8.4%**
GP	107	102	90	**97**	**32.7%**
Hospital	46	38	36	**40**	**13.5%**
Self Referral	70	86	66	**74**	**25%**
Voluntary Organisations	29	20	23	**24**	**8.1%**
Other	19	30	22	**24**	**14.8%**
Activity					
Total number of contacts	3433	2723	3253	**3136**	**15 contacts/day per support worker**
No. referred to Council for Carers assessment	34	35	24	**31**	**1%**
Emergency planning	87	42	62	**64**	**2%**
Signposting	213	204	220	**212**	**6.8%**
More complex (emotional) support	87	69	75	**77**	**2.5%**
Support groups					
No. of support groups	19	19	19	**19**	**-**
No. of sessions	60	48	64	**57**	**-**
No. of Attendees	788	531	778	**699**	**-**
No. of members	Information not available				**-**
Training Sessions					
No. of Training sessions	29	5	13	**16**	**-**

No. of Attendees	260	50	160	**157**	**-**

On average there are 298 new referrals a quarter, one third of which come from the GP surgery and one quarter of which are self-referrals. Surprisingly there are very few referrals from the Council. Most carers that contact the centre each quarter are signposted to information and advice. On average only 31 carers a quarter are referred to the council for a carer's assessment under the Care Act. On average 57 peer support groups run every quarter and there are approximately 700 attendees in total. It is not clear how many carers this relates to as carers attend more than one session in the quarter.

Unit cost

The unit cost for the adult service at the carers' centre was calculated to be £297 (see appendix fourteen for calculation). The unit cost refers to the actual cost for one day of support from one adult carer support worker. The output data collection demonstrated that on average a carer support worker engages in 15 contacts a day (a contact could be anything from providing information and/or support via a phone call, email, or support session) which means each contact costs on average £19.80.

Based on the monies the council currently pay (£482,950), the council invests £9.75 per carer across the county and £48.46 per registered carer (although this amount decreases with every carer that registers with the carers' centre).

11.2.2 Carers' Centre B

Below is a table illustrating the contract monitoring data required by the council. The data below represents a 9-month period from April 2017 to December 2017. The data is reported for each quarter (i.e. Q1, Q2, Q3, which each relates to a 3-month period e.g. Apr-Jun, Jul-Sept, Oct-Dec).

Table 17: Carers' Centre B Performance Data

Apr – Dec 2017	Q1	Q2	Q3	Average	%
No. of Registered carers					
Total number of Adult carers on database	5512	5610	5730	**N/A**	**N/A**
Number of new carers registered	167	166	183	**172**	**N/A**
Referrals					
No. Referrals from Council	16	7	12	**12**	**7%**
Community mental health team	5	6	6	**6**	**3.4%**
GP	48	50	66	**55**	**31.9%**
Hospital	8	7	14	**10**	**5.8%**
Self Referral	51	59	47	**52**	**30.2%**
Voluntary Organisations	19	13	14	**15**	**8.7%**
Other	20	24	24	**23**	**13.3%**
Activity					
Total number of contacts	3393	2672	2256	**2773**	**15 contacts/day per support worker**
No. referred to Council	16	23	19	**19**	**0.7%**
Emergency planning	24	6	0	**10**	**0.4%**
Signposting	223	185	167	**192**	**7%**
More complex (emotional) support	129	89	80	**99**	**3.6%**
Support groups					
No. of groups	16	17	17	**17**	**-**
No. of sessions	42	38	33	**38**	**-**
No. of Attendees	158	284	319	**254**	**-**
No. of members	272	272	309	**284**	**-**
Training Sessions					
No. of Training sessions	5	13	7	**8**	**-**
No. of attendees	38	56	45	**46**	**-**

On average there are 172 new referrals a quarter, just under one third of which come from the GP surgery (similar to Carers' Centre A) and 30% of which are self-referrals (slightly more than carers' centre A). Again, there are very few referrals from the Council. Most carers that contact the centre each quarter are signposted to information and advice. On average only 19 carers a quarter are referred to the council. It is not clear whether this is for a carer's assessment under the Care Act or for other purposes. On average 17 peer support groups exist of which there are 284 members. On average 38 peer support sessions run every quarter and there are approximately 254 attendees in total.

Unit cost

The unit cost for the adult service at the carers' centre was calculated to be £288 (see appendix fifteen for calculation). The unit cost refers to the actual cost for one

day of support from one adult carer support worker. The same as carers' centre A, the output data collection demonstrated that on average a carer support worker engages in 15 contacts a day which means each contact costs on average £19.20.

The monies paid by the council equates to an investment of £7.76 per carer across the county and £27.71 per registered carer.

11.3 Culture

The results below summarise the key themes identified from the thematic analysis of the interview transcripts for each carers' centre[2]. The results are structured using the interview questions as headings.

11.3.1 Carers' Centre A

6 people took part in the interviews, 2 carer support workers, 1 team leader, the manager for the adult carers service, the Chief Executive and the Chair of the Board of Trustees.

What is the aim of the carers' centre?

Everyone thought the service was for all carers, no matter what their age or situation. For all there was a sense that the aim was to improve the lives of carers in some way and to do so by providing information, offering advice and supporting carers so that they didn't feel alone.

'The aim is to reach out to all carers.'

'Health and wellbeing of carers. Maintaining that.'

'Our job is to do that through information, advice, but also very often so that people do feel they have some support or somewhere to go.'

To what degree do you think the carers' centre currently achieves that aim?

Everyone agreed that the centre did a good job of providing information, advice and emotional support and that the centre was open to all carers. Unanimously people thought that the centre was improving the lives of carers although there was some concern that the centre was only in contact with a small proportion of the local caring population.

'There is a lot of anecdotal evidence from carers we support, both in terms of what they tell us and in terms of what the staff tell us about what they're doing with carers that would all suggest we are improving people's wellbeing'.

'The carers we're in contact with say we're providing a reasonable service and without us they couldn't cope but we're not in touch with the majority of people that are providing care.'

[2] More detailed situational analysis was conducted as part of the over-arching grounded theory approach to this thesis and the results are discussed in the final chapter (chapter 12).

What would be your vision going forward if you had all the resources you need?

Some people believed going forward they would like to see respite services so that carers got a break, home help services to help carers stay on top of household chores and help with transport for those who were struggling to get out. Everyone wanted to be able to provide more face-to-face support through home visits and some people thought that it would be important to run more activities, such as another carers' choir, due to the positive impact such activities seemed to have on carers' sense of wellbeing.

'Carers biggest thing is sitting service, just getting a break, a regular break.'

'What I would love to be doing if resources weren't a problem and we had all the money in the world: to provide services like home visiting.'

'Being able to have another choir or those sorts of things.'

'Being able to hand hold some people into the services they need would be useful to be able to provide something more like life coaching or something for those carers that need it would be useful.'

What would need to be different for that to happen?

Everyone agreed that insufficient funding was the main barrier. There was also a suggestion that helping some carers required further training for carer support workers. This was particularly evident in relation to emotional support and difficult conversations with carers.

'There are some specialities, as well, that we are not trained, substance misuse.'

'Men will call, now this is a very difficult thing, men if they are supporting a wife who's got whatever and bedridden and can't do anything, they call, and they say, "I miss the intimacy." We're not trained; it's really difficult to talk about those issues.'

A further challenge felt by some was the tension between the pressure to increase the number of new referrals versus being able to adequately support a growing number of carers. Resources and hence the number of carer support workers was not linked to the number of registered carers and so increasingly there was a sense of supporting more with less.

'I think that balance is a bit of a challenge between identifying the new people and what we can do and how we can support them with the increasing number of people who are remaining registered with us.'

What activities does the carers' centre currently do in each area described in the audit tool?

The overwhelming view was that the carers' centre did provide support that covered all areas of the model.

'As a whole, we do try to cover a lot of these in the support and things that we do, obviously tailored around the carer.'

Although there was a sense of agreement that work related to creating carer friendly communities and work places was not something there was much capacity to invest in and organisations in the community were not always that interested.

'We tried to work with employers and got no success really, I've sort of given up on trying to do that work because in terms of bangs for your bucks and putting staff resources into that it hasn't really born any fruits, so we might as well put our staff resources into something else.'

Further probing did unearth an awareness that whilst the centre did touch on every aspect of the model, there was a sense that they often only managed to touch the tip of the iceberg and that many emotional needs went unmet because of a lack of resources and time constraints.

'No, because it dips into deeper waters, it really does. We just start to feel that, 'I don't know what to say, how to help him' because it might take a bit longer than just these forty minutes that I'm allowed to talk to you.'

Do you have any other comments?

It also became clear that the emotional needs of carers were not always being met because there were some situations where carer support workers felt out of their depth.

'The other thing that we are having more of is people in the caring role who are telling us that they want to end their lives……So at the moment, I'm supporting support workers who are saying, "Look, we're not trained to deal with these, what is it that we do?" and it is really hard doing some of that. That is a challenge for us because we're having more around the emotional side of caring.'

Everyone felt that there was more scope to support carers in a more person-centred and/or community centred way.

'I think we would probably find ourselves still giving information, advice, helping people understand but it would be done in more in a, not that we don't tailor it now, but it would be done more in what is key for that person at that moment, what they're looking for.'

11.3.2 Carers' Centre B

4 people took part in the interviews, 1 carer support worker, 1 team leader, the Chief Executive and a Trustee.

What is the aim of the carers' centre?

Everyone mentioned that the purpose was to provide carers with information and support. There was also a sense that the centre aimed to improve the lives of carers:

'It's really to provide something of a lifeline for people who don't know quite where else to turn…….Just to be able to talk to somebody and get some direction and information and some support, even just listening to them is what we're really here for.'

Two out of the four interviewees were very clear that part of the purpose was to raise awareness of carers so that other professionals did a better job of recognising and supporting them:

'To raise awareness to universal services and the community about carers so that carers are more likely to be recognised especially by professionals when they're looking to engage with services.'

To what degree do you think the carers' centre currently achieves that aim?

The overwhelming message from everyone was that the centre was no longer able to achieve what it wanted to or what it had achieved in the past.

'Nowhere near like we could in the past.'

The main issue was the reduction in funding that had resulted in a cut in service provision that meant carers were no longer supported in the way they had been:

'One of the particularly valuable services which we were able to do in the past has been face-to-face, one-to-one spending time with carers visiting them in their own homes and understanding what their challenges are and looking for ways in which either we can help them, or other agencies can help and supporting them in getting that help. That kind of personal touch is becoming increasingly, if not impossible, to carry out because we don't have the resources to do it.'

What would be your vision going forward if you had all the resources you need?

The key theme throughout everyone's responses was the desire to do more face-to-face support:

'Definitely the face-to-face and definitely being able to do home visits if it's appropriate because isolation is a huge, huge issue.'

There was also a desire to provide respite services:

'I think a huge issue is the carers respite service, there's no respite service, the biggest mistake they made, I think, was taking away the carers' break service because no matter what you do, whatever you put on for carers, actually if they

haven't got anybody to come in and care for the person they're looking after, they can't go anywhere or engage in anything.'

Finally, two of the interviewees described an aspiration to have the means once again to raise carer awareness and develop carer champions:

'Getting that carers awareness training out there and actually having carers champions in the council.'

What would need to be different for that to happen?

Everyone agreed that reduced funding was one of the key issues:

'Well, it's a combination, primarily financial. Unless you've got the resources to have the staff to be able to carry out the work then it's not possible to do it.'

However, there was also a clear sense that commissioners and funders had a lack of understanding about the challenges faced by carers, the ways in which they could best be supported and the ways in which organisations could work together if empowered to do so:

'I think it's just getting the message across, the current people that we seem to meet don't seem to understand or get it, they keep saying money is the barrier, it doesn't need to be. We know there isn't much money and the money is reduced out there but there are other ways that we could be working together and more reason to be doing it.'

What activities does the carers' centre currently do in each area described in the audit tool?

There was a consensus that the carers' centre did do activities in all domains to a greater or lesser extent:

'There's nothing there that I would say we don't do on some level.'

'The relationship stuff is done in low numbers but when it's done it's intense.'

There was also a sense that the capacity to provide face-to-face emotional and/or hands-on support had diminished and that made it hard to engage in activities that supported carers through their emotional journey particularly in relation to their own sense of identity and challenges of the changing relationship with the care recipient.

'That's a big element that we're missing, I think, it's that face-to-face support.'

'That's what I always tell carers, caring completely changes your relationship.'

However, the reduced funding had resulted in a bigger emphasis on working to raise awareness with other services in the community.

'By working with everyone else to try and 'Think Carer' and bulk up their resources, well actually we can now signpost to rather than try and do it ourselves.'

Do you have any other comments?

The key theme that came through from answers to the final question was a sense that the turnover in council staff had a negative impact and that there was a disconnect between the priorities identified by the current commissioner and what had gone before.

I went to a meeting back in March where the commissioner was actually doing a presentation and she'd got on the board a list of things that were their priorities for the year: a carers' lead in each GP surgery, a discount card, and emergency card. I sat there, and I said, "We've been doing all that so why take all the funding away so that we can't do it? And then state that they are your priority for the year and start doing them again.

11.4 Cost Analysis

The cost analysis aimed to answer the following questions:

- What economic investment are local authorities making in carers given the huge economic contribution carers make?
- Do carers' centres result in fiscal benefits i.e. savings to commissioners' budgets?

11.4.1 Carers' Centre A

Economic Contribution versus Investment

Buckner and Yeandle (2015) estimated that carers in county A were making an economic contribution of £716.1 million a year (based on the average rate for homecare and carer prevalence rates). The average economic contribution each carer makes (based on the 49,514 carers estimated by the census) is £14,462 a year. The investment that the council is making in each carer in County A is just £9.75 a year. If we do the same calculation but just for registered carers then the amount the council is investing is £48.46 per carer a year.

Cost savings to the council

The economic contribution figure above is estimated based upon the equivalent cost of replacement domiciliary care. However, given that the number of hours the majority of carers were caring for was 50 hours plus, an assumption was made that instead of receiving homecare from a domiciliary homecare company, care recipients would be admitted to residential care if carers were unable to continue. Furthermore, New Economy et al (2014) have not calculated fiscal benefits for reducing homecare so using homecare instead of residential care was not an option for this scoping review.

Based on this assumption and the weekly average cost of £702 for residential care,[3] the replacement care cost for one year for one carer would be £36,504 a year. The replacement care cost for the 30 carers who rated an impact score of 9 or 10 would be £1.1m. According to the fiscal benefits calculated by New Economy et al (2014) 67% of this cost would fall to the local authority. This would total £737,000. The council currently pay £482,950 for the carers' centre so the estimated saving is £254,050 a year. Based on these calculations commissioners are saving approximately £0.53 for every £1 they invest.

As discussed in the limitations below though it must be noted that these calculations are not reliable and can only be used as an indication that there would be merit in undertaking a full cost-benefit analysis.

11.4.2 Carers' Centre B

Economic Contribution versus Investment

Buckner and Yeandle et al (2015) estimated that all carers living in county B were making an economic contribution of £331.3 million a year. The average economic contribution each carer makes (based on the 20,627 carers estimated by the census) is £16,061 a year. The investment that the council is making in each carer in County B is just £7.76 a year. If we do the same calculation but just for registered carers then the amount the council is investing is £27.71 per carer a year.

Cost Savings to the council

Based on the weekly average cost of £702 for residential care,[4] the replacement care cost for the 11 carers who rated an impact of 9 or 10 would be approximately £401,544.

According to the fiscal benefits calculated by New Economy et al (2014) 67% of this cost would fall to the local authority. This would total £269,034. The council currently pay £160,000 for the carers' centre so the estimated saving is £109,034 a year. Based on these calculations commissioners are saving approximately £0.68 for every £1 they invest.

As discussed in the limitations below though it must be noted that these calculations are not reliable and can only be used as an indication that there would be merit in undertaking a full cost-benefit analysis.

11.5 Discussion

The data analysis suggests that the carers' centres did make a cost saving for the councils. Whilst in the previous chapter it was concluded that the 'merit' of the service (i.e. the outcomes for carers) was not very evident from the data on wellbeing and resilience, the conclusion here is that the 'worth' (i.e. the cost-effectiveness) of the service is potentially high. Even though it is suggested that good outcomes (in terms of ability to carry on caring) were only achieved for a small number of carers it still resulted potentially in a sizeable cost saving for the council due to the cost of

[3] https://www.which.co.uk/elderly-care/financing-care/financing-a-care-home/381597-care-home-fees
[4] https://www.which.co.uk/elderly-care/financing-care/financing-a-care-home/381597-care-home-fees

replacement care. This is significant when we consider that in the tax year 2016/17 County A reported that 50 state funded people were admitted to long-term care in a residential and/or nursing home and County B reported 90 people were admitted (NASCIS, 2017). It is impossible to know how many of these people were previously cared for at home by carers or how many were admitted to long-term care due to carer breakdown or how many carers were either not receiving support from the carers' centre or the nature of the support they were receiving was not tailored to their needs, but it does not seem unrealistic to conclude that it was at least a handful. Previous research on carer breakdown by Carers UK (2014) revealed that 6 out of every 10 carers had been pushed to breaking point. This suggests that there would be value in a more comprehensive cost-benefit analysis of carers' centres.

The contract monitoring data used by councils to determine the effectiveness of the carers' centres focused on the number of carers registered with the carers' centre and the number of carers receiving different types of support. Thus, it gave little insight into whether the support provided helped carers to continue caring and it could be argued that councils should not base their judgements about the effectiveness of the centres on contract monitoring data alone. The poor quality of data that is used to make funding decisions on social care services is documented elsewhere (Foot et al, 2014). Lack of insight into the challenges carers face, how they define resilience and the support they feel would help, coupled with poor quality data on service performance and effectiveness means that local authorities are less likely to be making well informed decisions about carer support services.

In comparing the data from both centres, it materialised that there were many similarities. For example, most referrals for both centres were either self-referrals or they came via the GP. The average number of contacts per carer support worker per day was the same for both carers' centres and the percentage of contacts that were signposted to information and/or other organisations was also similar, as was the percentage of contacts that resulted in more complex/emotional support. In both cases relatively few carers were supported by the carers' centres in comparison to their total local carer populations.

Whilst this suggested that the carers' centre operational models were similar it also suggested that both centres were supporting a similar profile of carers. A significant majority of carers accessing the carers' centres were caring for over 50 hours a week. Previous research highlighted most carers known to services provide more than 50 hours care per week because the emphasis had always been placed on supporting the carers who provide substantial care (Carers UK, 2014). Therefore, those providing less than 50 hours care were less likely to self-identify or be referred to services and were more likely to be 'hidden'. This may have implications for the model of support provided by carers' centres. Whilst carers throughout their journey will need information and advice, those caring 50 hours or more a week are often going to need more support to maintain other roles, relationships and identities. Councils and carers' centres need to think more broadly than information and advice by focusing on developing tailored support for carers across each stage of the caring journey. The tailored support needs to empower carers to maintain different roles and identities whilst grieving for and navigating the changing role and relationship with the care recipient.

The concept of carer resilience did not feature strongly in statements about the purpose of the carers' centre for either centre. Neither staff, trustees or the contract information referred consistently to the purpose of support being to promote carer resilience. It was unclear whether carers supported by the centres tended to be at certain points in the carer journey or how this related to carer resilience or wellbeing. But staff from both carers' centres said they found the definition of carer resilience and the associated model of support useful.

Both carers' centres identified a gap in the model for promoting carer resilience around the practical support carers required due to the scale of the caring task and being THE skilled helper. Both carers' centres highlighted the need for and importance of respite care if supporting carers to maintain other roles and identities was to be achieved. These types of services were not delivered by the carers' centres and it was unclear how easy it was for carers to access such services from elsewhere. There was also a recognition across both carers' centres that many carers needed more emotional and (hands-on / face-to-face) support than staff capacity allowed.

Given that the main source of funding for each of the carers' centres came from the Council it was natural to assume that councils and carers' centres worked in partnership. It was therefore very surprising that there were so few referrals from the Council to the carers' centres with the aim of preventing carer breakdown. The number of referrals from G.P.s could suggest that partnerships between primary healthcare and carers' centres would be a better fit. Some carers' centres do receive funding from clinical commissioning groups to undertake work in G.Ps and/or hospitals but this is not the case everywhere.

It did seem that the carers' centres potentially delivered value for money and that most carers who accessed the carers' centres were caring for a huge proportion of their time and this was likely to be having a negative impact on their wellbeing. If they stopped caring the loss of economic contribution (of the care they provided) and potential cost to the council may be vast. More investment that allows carers' centres to tailor their support and better access to carers' support via healthcare services could increase carer identification, reduce carer breakdown and potentially result in significant cost-savings to the state. The scoping review does suggest that there would be value in further evaluative research that ascertains both the cost and the benefit of carers' centres. Such information may help commissioners and policy makers to make better decisions about how to use scarce resources.

11.6 Limitations

Estimating the economic contribution of carers is not an exact science as it is impossible to value the contribution carers make simply in monetary terms. It is also unfortunate that the most recent census data available is from 2011 as this does not provide an accurate figure for the number of carers for 2017. It is likely to be an underestimate rather than an over-inflation of the figures, though and the economic contribution calculated using Buckner and Yeandle's (2015) method is a useful way of quantifying caregiving especially when compared to the very low investment in carers that the two councils were making.

The fact that every carer journey and context is so different and the support a carer needs is varied, made it impossible to calculate the unit cost for supporting the carer

through their journey. Instead the unit cost for a carer support worker was calculated. It was noteworthy that the unit cost and the number of contacts per day were similar across the two carers' centres, suggesting that there may be some regularity. Nevertheless, only evaluating two carers' centres means that the results cannot be generalised even though the striking consistencies do add weight to the tentative conclusions that have been drawn. Evaluating a larger number of carers' centres would have strengthened the research but this was not possible within the time and resources available.

Accurately calculating the cost-savings to councils would require a research design that collected more detailed information from carers and involved the councils themselves. This was not possible within the capacity and resources of this research and so an approach used by commissioners to inform their decision making was used (New Economy et al, 2014). However, the reliability of the data on the number of carers who would not be able to continue caring was poor due to the small sample size and the lack of standardised tool to measure the impact of the carers' centre. This means the cost-saving figures are not reliable. That said the data commissioners often work with when making hard financial decisions is very poor and this scoping review was simply an attempt to decipher whether there was merit in undertaking a full cost-benefit analysis in the future. The methodology and the results do suggest that there would be merit it undertaking a full cost-benefit analysis.

The interviews with staff consisted of open questions, which generated qualitative data by allowing the participant to use their own language and talk in depth about the issues. This helped the researcher develop a real sense of the person's understanding of the context and culture. Semi-structured interviews increase validity because the researcher can seek clarification by probing further. The disadvantage is that such semi-structured interviews are time (and hence resource) intensive and the research needs good interviewing skills to collect robust, rich data (McLeod, 2014).

The combination of qualitative and quantitative data collection did result in a mixed-methods research approach that provided useful insight into the impact of carers' centres on carer resilience. This thesis is largely a grounded theory study and so, during the research on the carers' centres memos were written and related research was read. Chapter 12 summarises the final situational analysis and concludes with a final theory of carer resilience.

12 Chapter 12: Reflections and final model of support for promoting carer resilience

This final chapter aims to place the data collected throughout the scoping review on the carers' centres into the context of the wider grounded theory approach and to summarise the situational analysis used to interrogate the data further into a final project map, leading to a final theory of carer resilience. The chapter then reflects on the concept of resilience and its relevance for carers; it discusses the implications for services and ends with some recommendations for future research.

12.1 What has the study revealed so far? How has it added to the previous research?

The literature review on the emotions and QoL outcomes of carers confirmed that previous research has focused on carers in silos and whilst this has demonstrated the importance of individual care group nuances, it has missed opportunities to expose common themes that carers across all care groups and relationships relate to. Reviewing the literature across all care groups and relationships revealed that carers across care groups and relationships all experience:

- A mix of emotions and QoL outcomes rather than only positive or negative ones.
- A sense of love and pride.
- A sense of loss.
- Episodes of chronic stress.
- Oppression and discrimination.

The focus groups with carers who were still living with the care recipient allowed further common themes to surface that had rarely been referred to in the previous literature. These included:

- The idea that for all carers the scale of the caring role isn't just about the practical caring tasks but also the 'head space', emotional energy, patience and sacrifice it requires.
- The concept that the carer is 'The' skilled helper. Carers across all groups reported that being a carer was NOT a choice but more of a default position they found themselves in.
- Carers across all groups described a hidden world. With the spotlight on the care recipient, the needs of the carer and their journey were rarely a priority. Carers portrayed shrinking worlds in which they became increasingly isolated because of the practicalities of not being able to go out, or the desire to retreat from unhelpful family or friends or simply a lack of energy or head space to engage with anything else.

Whilst the emotions and QoL outcomes have been explored in previous research, as has the wellbeing of carers, the definition of carer resilience has rarely been studied. The literature on carers tends to focus more on wellbeing than resilience. Where it does focus on resilience it tends to focus on using a resilience measure to explore whether carers are resilient or not. There is a paucity of studies that explore how carers across all groups define resilience themselves or how they see the common factors that help or hinder carer resilience.

The review in chapter 5 on carers whose loved ones had moved into full-time accommodation-based support found that most carers feel a sense of freedom from the physical aspects of caring, but they also experience a loss of control, sense of powerlessness and many experience great loneliness. The carer's physical wellbeing may improve as they are finally able to sleep, exercise, etc but their emotional wellbeing does not always improve as they experience grief, guilt and sometimes shame (Lundh et al, 2000). Carers often find themselves trying to live between 'two worlds', the world of the care setting and their world at home. Their role is no longer clear and for those whose loved ones will continue to deteriorate there is a sense of living in limbo and waiting for the inevitable (Kiely et al, 2008; Woods et al 2008).

The focus groups with carers whose family members had moved into full-time accommodation-based support built on the themes identified by previous research by asserting that carers define resilience not just as the ability to keep caring but as:

'The ability to continue caring or to move on by adapting their roles and behaviours throughout their carer journey.'

Analysis of the focus group data pinpointed that the carer's ability to be resilient is closely connected to:

- their changing sense of identity
- their relationship with others such as other family, friends and their community
- their ability to navigate their changing relationship with the care recipient.

Larkin and Milne (2017) highlighted in their review of the literature that former carers experienced better outcomes if they had a good relationship with the care recipient, if they were part of a well-functioning family, if they had a high level of self-esteem, they had access to socio-emotional support, high levels of education and a sufficiently high income.

The findings from the mixed focus group involving two former carers suggested that the carer journey does not end when the care recipient dies and that reaching this final stage requires the former carer to once again adapt their behaviours and change roles.

Very few evaluations have been undertaken on carers' centres and none have looked at the carers' centre's impact on carer resilience and cost-savings to the state. The results of the scoping review undertaken for this study revealed new knowledge about how little attention is paid by carers' centres and commissioners to measuring changes in the wellbeing or resilience of carers. Carers' centres may potentially result in cost-savings to the state and there may be scope for achieving better outcomes.

12.2 What new insights emerge from the final analysis?

A final analysis was undertaken on the memos written throughout the scoping review. The memos were coded and analysed using situational analysis which added to the themes and categories from part one and two of the research.

The final situational and relational maps resulted in two key themes being retained (carer resilience and hidden world) and two new themes emerging (carer support, and cultural and organisational change).

All four areas were interconnected. Carer resilience was defined as the ability to continue caring or to move on by adapting roles and behaviours throughout the carer journey and this could only be achieved if the carer had positive relationships with, experiences of and attitudes towards the:

- Care recipient
- Condition and symptoms
- Community
- Family and friends
- Professionals
- Themselves and their sense of identity

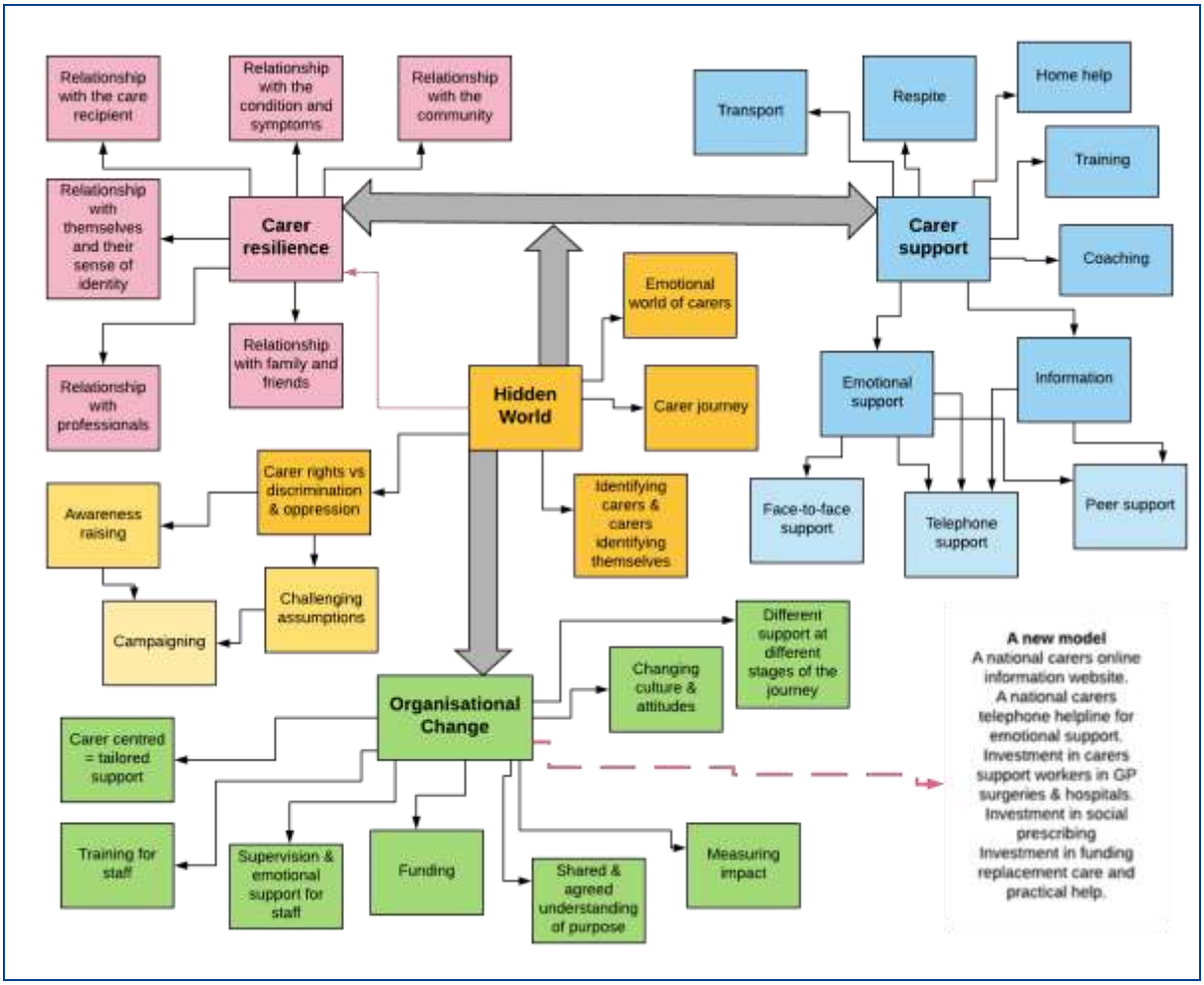
Achieving positive relationships, experiences and attitudes required carer support in the form of:

- Information
- Emotional support
- Coaching
- Training
- Respite (which could be residential or home care based)
- Home help with tasks such as cleaning, gardening, shopping, etc.
- Help with transport

All these areas were threatened by the hidden world of the carer. The carers' emotional world, their personal carer journey, their desire and ability to identify as a carer, and their experiences of discrimination were often either denied, ignored or happened out of sight of the care recipient, their friends and family, the professionals and their community. Reducing the hidden world requires cultural and organisational change. The scoping review suggested that carers' centres and the way in which they are currently commissioned results in a lack of attention on providing different support at different stages of the carer journey, measuring impact, agreeing the purpose of support, training and emotional support for staff, and developing carer centred, tailored support. These are areas that would benefit from further exploration in future research.

The results of the final situational analysis were summarised in a final project map. Project maps draw upon the earlier situational analysis maps, but they do not further the analysis and instead are maps tailored to illuminate aspects of a project to intended audiences (Clarke, 2005 p137). The intended audiences in this case are policy makers, commissioners and carers' centre managers as these are the people most likely to affect change in carer support services.

Figure 37: Final Project Map



Pink = carer resilience Yellow = hidden world Blue = carer support Green = organisational change

12.3 Definition of Carer Resilience and Final Model of Support

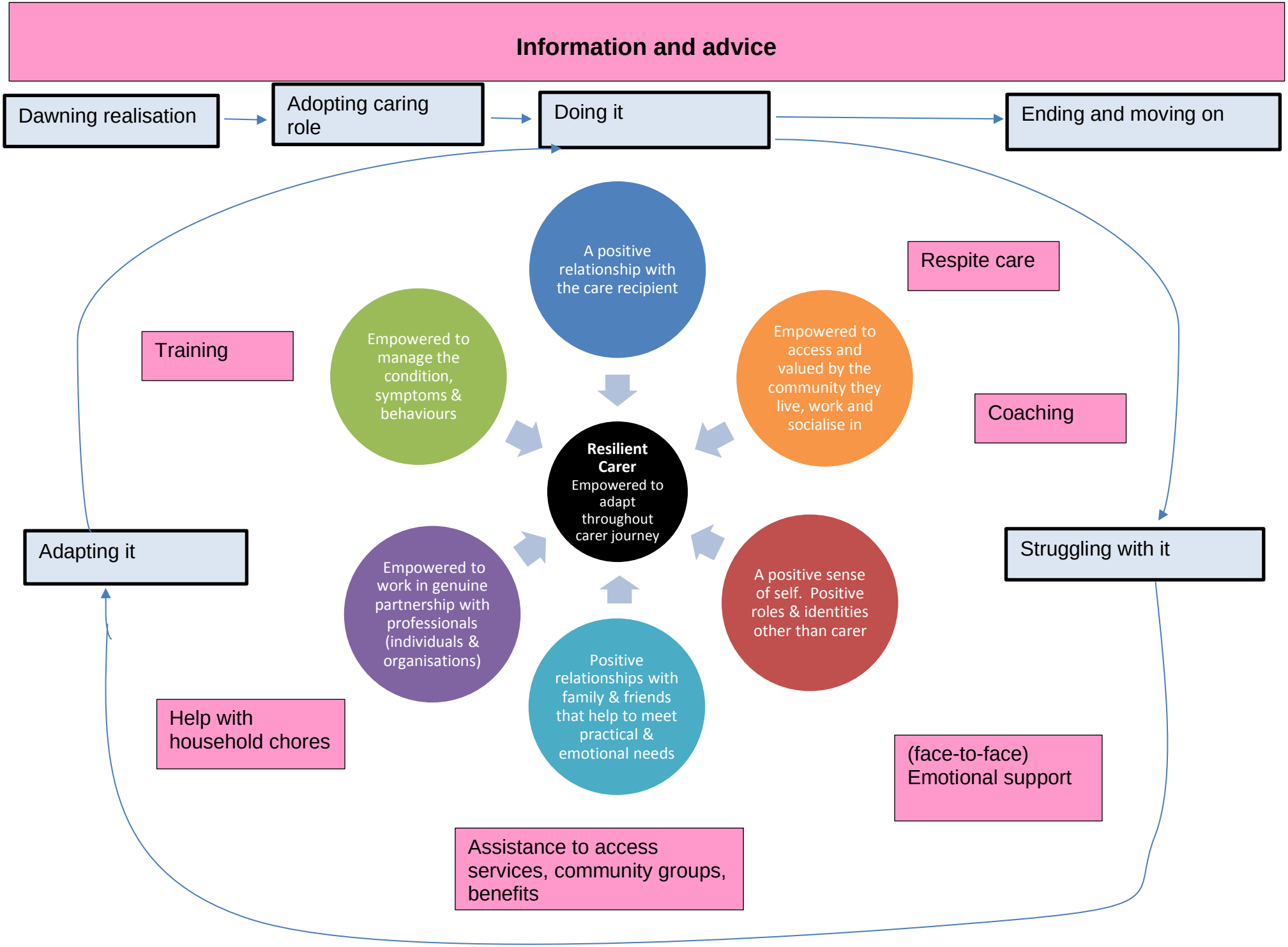
Definition of Carer Resilience:

Carer resilience is the ability to either continue caring or to move on, to continue navigating the changing relationship and to do this by adapting roles and behaviours throughout the carer journey.

This includes adapting to the changing relationship with the care recipient; adapting one's identity; adapting one's behaviour to manage the symptoms and behaviour of the care recipient.

This can only be done if the carer receives information and both practical and emotional support from family and friends, professionals and the wider community.

Figure 38: Final Model of Support for Promoting Carer Resilience


Information and advice
Dawning realisation
Adopting caring role
Doing it
Ending and moving on
A positive relationship with the care recipient
Respite care
Training
Empowered to manage the condition, symptoms & behaviours
Empowered to access and valued by the community they live, work and socialise in
Coaching
Resilient Carer
Empowered to adapt throughout carer journey
Adapting it
Struggling with it
Empowered to work in genuine partnership with professionals (individuals & organisations)
A positive sense of self. Positive roles & identities other than carer
Positive relationships with family & friends that help to meet practical & emotional needs
Help with household chores
(face-to-face) Emotional support
Assistance to access services, community groups, benefits

Carer resilience was an ability to adapt roles and behaviours and navigate changing relationships and the concept of developing resilience was a learning process that was influenced by the social context. As mentioned in the thesis introduction there has been a focus on developing the personal resilience of carers, but policies imply that the solution is to teach carers how to manage their caring role and come up with their own solutions. There is a lack of recognition that carer resilience cannot be achieved without environmental interventions such as raising awareness of carer issues and developing carer friendly communities i.e. adapted housing that makes their caring tasks easier, carer friendly employers that enable them to work flexibly and carer friendly community facilities that make reasonable adjustments to account for the challenges faced by carers. Throughout the research I met resilient carers. The question is whether resilience is a useful construct.

12.4 Reflections on resilience and its relevance for carers

The narrative literature review of resilience in chapter 7 described the various ways resilience has been conceptualised i.e as a personal characteristic, a skill learnt through a process of overcoming adversity, a set of positive outcomes that can only be achieved through positive interactions between the individual, their social environment and a supportive socio-economic and political context. One of the main criticisms of resilience theory is that it supports a neoliberal ideology that leaves individuals responsible for improving their lives with little or no support from the state (van Breda, 2018). However, others argue that the issue is not with resilience theory but the way that old concepts of resilience as a personal characteristic or learnt skill have been adopted and used by neoliberal policy makers (Harrison, 2013; Hart et al 2016). This is certainly the case in the current context of carers' policy and carers' support in England. As described in chapter 1, one of the aims of current local and national policy is to make carers resilient and this is replicated in contracts for carers' centres where commissioners clearly state that the aim of the carers' centre is to help carers to continue caring by supporting them to be resilient. In both policy and commissioning the implication is that resilience is a personal characteristic or learnt skill. This approach reflects a neoliberal agenda where structural accountability is denied, and poor outcomes are understood to be the result of poor choices made by individuals (Hart et al, 2016).

However, a more sophisticated view of resilience contradicts neoliberalism (van Breda, 2018). This resilience research places resilience within a socio-economic and political context that recognises that an individual is not fully in control of improving their own outcomes and that interactions with structures, such as the state, play a major role (Ungar, 2001; Maton, 2005; Wild et al, 2013). People in the individual's social environment and the structures (such as the welfare state) have to acknowledge the challenges individuals face, accept what they say will help and facilitate access to it if the individual is to be resilient. In a new fourth wave of resilience research, some researchers have taken this a step further placing resilience in the arena of social justice (Bottrell, 2009; van Breda, 2018; Hart et al 2016).

Both Hart et al (2016) and Bottrell (2009) state that a system that creates inequality doesn't leave marginalised people lacking resilience, quite the opposite, inequality breeds resilience as a form of survival. Furthermore, being resilient has been seen as achieving positive outcomes but these outcomes have often been defined by mainstream society. If you are marginalised, conforming to these values may feel

less like achieving a positive outcome and more like oppression. It could be argued that in these circumstances achieving resilience is about resisting mainstream norms and creating one's own positive sense of identity even when the behaviours and outcomes associated with that identity may not be seen as positive in mainstream society (Bottrell, 2009).

Both Hart et al (2016) and Bottrell (2009) express the need to start asking how much adversity should be tolerated before social arrangements become the focus of interventions rather than marginalised people. If we are going to place resilience in a social justice context we also have to recognise that resilience can only be seen when an individual achieves the outcomes they perceive as positive (not what is perceived as positive by the mainstream non-marginalised majority) AND when the socio-economic political structure is fundamentally changed in a way that reduces the adversity in the first place. Hart et al (2016) defines resilience as:

'Overcoming adversity, whilst also potentially changing, or even dramatically transforming, (aspects of) that adversity' (p7).

I would suggest that this definition of resilience is very useful in the context of carers. Using this definition of resilience the focus is not about accommodating the adversity, or rising above it, but challenging it. There is a focus on empowerment, activism and systemic change (van Breda, 2018). In this context, empowerment means supporting individuals to increase their control over the events that determine their health and well-being in the first place (World Health Organization, 2014). Therefore, resilience interventions should include some form of activity designed to empower people (either as individuals or groups) to challenge adversity conditions (Hart et al, 2016).

Larkin and Milne (2014) in their paper *'Carers and empowerment in the UK: a critical reflection'* describe how, even though there is greater awareness of carers, policy supposedly supporting carers' rights and a strong carers' movement in the UK, carers are still not empowered. Larkin and Milne suggest that this is due, at least in part, to the shortage of a clear, single carer voice due to the very different needs carers have. I would argue that there is far more commonality than researchers think but as long as researchers continue to explore carer issues in silos, emphasising the nuances and paying little attention to the commonalities, a single voice will not surface and it will continue to be difficult to empower carers.

If we compare the carer definition of resilience and model of support developed in this study with this social justice conceptualisation of resilience we find that there are some alignments. Firstly, the social justice conceptualisation emphasises the importance of the marginalised population (in this case carers) defining what resilience and positive outcomes are in their context which was one of the aims of this study on carers resilience. Secondly, the final project plan above clearly identified in the 'hidden world' theme the need to raise awareness, campaign and challenge assumptions. I would argue that the concept of resilience is a useful one for advancing carers' rights but resilience researchers and practitioners need to start challenging the unsophisticated representation of resilience in policy that progresses a neoliberal agenda.

A sophisticated understanding of carer resilience also requires commissioners and policy makers to better understand that caring takes place within a relationship. The ethic of care debate is important here. Recognising that everyone gives and receives care in their lives advocates for a welfare state that empowers people to both give and receive care (Lloyd, 2010). The fact that caring is a common experience and part of the human condition is at the centre of why this thesis places importance on understanding the commonalities as it is through this understanding that effective policy and practice will be developed.

This point links with a related point about family members who do not identify as a carer, but who are providing much care and support. In Molyneaux et al's (2011) critique of the binary categorisation of carer and care recipient they conclude that the term 'carer' is ineffective because it does not reflect the relationship between 'carers' and 'care-recipients', resulting in a polarisation which can prevent them working together. Furthermore, because so many 'carers' do not identify with the label carer for exactly these reasons, they do not seek support from carers' centres.

The focus groups in this study highlighted how becoming a carer could completely change the nature of the previous relationship. However, the previous relationship could also cause others to place expectations on the carer that they would and should start or continue caring. Research by Rand et al (2019) provides evidence that carers report greater strain where they provide care because it was expected of them. Henwood et al (2017) point out that there is a significant gap in knowledge about relationships, how they change over a lifetime and the impact that changes have on the relationship dynamic. It seems that this may be an important area to explore further if we are to fully understand the complexities of caring, carer identity and the carer label.

Finally, it must be noted that as well as an unsophisticated understanding of resilience, current policies (local and national) make abstract statements about the aim of the policy i.e. 'promoting carer wellbeing', 'improving resilience'. Whether these are meaningful statements can only be measured within the context of a social justice approach to resilience where support, services and the policy/commissioning narrative allows carers to exercise real choice. This can only be achieved when support, services, policies and commissioning frameworks are co-produced with carers (Hart et al, 2016).

12.5 Implications for services

The reflections on resilience throw up some challenges for policy makers, commissioners and carers' centres. Policy makers and commissioners currently use an unsophisticated understanding of resilience that promotes a neoliberal agenda as a way of reducing the financial strain on the state. This approach raises questions about the ethics of locating responsibility for improving outcomes on the shoulders of carers and the morality of making assumptions that place carers in a position of being forced to continue caring. The carer model of resilience presents some challenges for carers' centres too, as it emphasises the need for emotional and practical support for carers and the need to campaign and challenge the structures that add to the carer burden. The lack of local authority funding makes it difficult for some carers' centres to deliver emotional and practical support to carers or to engage in campaigning for systemic change. This is particularly difficult in a local context where a carers' centre may need to challenge local authorities' policies and

procedures whilst still relying on the local authority funding as their main source of income. The question is whether better outcomes for all (including the state) could be achieved in a system where carers are supported as co-client's rather than seen as resources (Molyneaux et al, 2011) and resilience is seen as achieving the outcomes carers want whilst also empowering them to shape the structures designed to support them?

One contested issue seems to be whether we can afford to invest in services that empower carers versus whether we can afford not to invest in such services. But finding the money to do so in a time of austerity is becoming increasingly difficult and the conversation that seems to be missing is whether the carers' centres themselves are the right way to support carers or whether we need to think differently. On the one hand carers' centres are the only place that support all carers across all groups and relationships. Given the common experiences across carers this seems important. On the other hand, the data collected as part of this study does not suggest that carers' centres have a significant impact on the resilience or wellbeing of carers. Of course, this could be linked to limitations in the methods, such as sampling issues, the difficulty measuring resilience, and the lack of use of a standardised tool to measure the overall impact of the carers' centre, but this aside, carers' centres are caught between the agendas of politicians, funders and carers themselves. It is not always possible for carers' centres to meet all these agendas because the agendas are often in conflict (e.g. reducing the financial burden on the state does not necessarily result in good outcomes for carers).

Some research provides evidence that carers report high-levels of unmet need due to cuts in services (Brimblecombe et al, 2017). Certainly carers in the focus groups for this study reported a lack of specialist support from services and/or an increasing need to pay for care for the care-recipient themselves. The counter-balance to the increasing cost or gap in services was carers undertaking increasingly complex tasks or tasks they could do but did not want to. The social justice approach to resilience suggests that within a context of reduced community resources, poverty, lack of support from services etc, there might be a role for carers' centres in working to improve these wider social issues within their local communities.

There is certainly a need to put the spotlight on the hidden world of caring and to raise awareness of the challenges faced by carers. National carers' organisations such as Carers UK do this at a national level but awareness raising must also take place at a local level if it is to be effective. Carers' centres attempt to do this locally, but they often lack the resources to do it well, whilst also trying to resource and provide support to carers. Perhaps one way to address this is to consider whether there are any forms of support that would be better done by pooling resources and delivering them at a national level? For example, emotional support for carers perhaps needs to be 24/7, 7 days a week and yet no local carers' centre is able to provide an all hour's service. A national carers' helpline similar to Samaritans or Childline could be one way to address this.

However, the model of carer resilience depicted above illustrates that carers need a range of different support at different points in their carer journey. One important element of support was respite (residential or home care). In recent years councils have reduced spending on respite services. In a time of shrinking budgets, respite care has been seen as a luxury and something that carers will increasingly have to

cope without or pay for themselves. But the model of carer resilience above is clear, and particularly so for carers who are caring for a significant number of hours a week, without respite care it is impossible for them to be resilient and continue caring. Without someone else coming along and providing a few hours of replacement care the carer will be unable to engage in other activities outside the home that provide different roles and identities which are a crucial part of remaining resilient.

The main problem is that council budgets are set yearly and so staying in budget for the year is the focus of every commissioner and Director of social care. This gives little opportunity to consider the right things to invest in to achieve the desired impact on outcomes and savings to the budget over the longer-term (Norris et al, 2014). A social justice approach to resilience might suggest that commissioners would have an ambivalent relationship with resilience because achieving resilience would involve carers challenging current structures and an investment in enriching community resources, alleviating poverty and increasing the level and range of support for carers and care recipients. But this is a slightly adversarial attitude towards commissioners and local authorities that suggests the majority don't care and don't want to make things better. However, that's not my experience. The commissioners and local authorities I've worked with want to make a difference but have to do so within very tight budgets that result in very hard decisions (Robertson et al, 2019). This is coupled with a lack of knowledge about complex issues and a gap in research topics that might help. For example, little research has been undertaken on the challenges of translating policy into practice. The sparse literature on the subject that does exist suggests some of the factors involved are (Norris et al, 2014):

- Difficulties of measuring progress
- Complexity of factors involved that cannot be controlled by policy makers
- Lack of focus on long-term sustainability often due to political risk and associated need for quick wins

Translating policy into practice for carers will require a common, sophisticated understanding of carer resilience, an ability to measure it, a commitment to supporting carers across the carer journey and a more insightful understanding by policy makers of the challenges carers face.

12.6 Limitations

This thesis is largely a qualitative, grounded theory study. Qualitative research is a naturalistic, interpretative approach concerned with understanding people's lives, lived experiences, behaviours and emotions (Strauss and Corbin, 1990, p11). The reason for choosing a largely qualitative approach was due to the nature of the research that aimed to understand the social reality of carers and the way in which they interpret their reality.

Critiques of qualitative research would state that a more scientific approach would have been to undertake a quantitative study. Quantitative methods emphasise the objective measurement and statistical analysis of data. A quantitative study on resilience and family carers might have focused on the number of resilient carers or whether groups of carers were resilient or not. However, the research method selected in any study should be driven by the research questions relevant to the topic

(Maxwell, 2005, p229). Answering the research question ('Understanding Resilience and Family Carers') and producing a theory of carer resilience required a largely qualitative research approach.

Quantitative researchers state that quantitative approaches produce results that are more reliable, valid and generalisable to a larger population whilst qualitative research involves fewer participants, is more subjective and hence less robust. The researcher enhanced the reliability and validity of this study by using grounded theory, situational analysis and mixed method evaluation.

Whilst other qualitative methods (e.g. ethnography, case study) could have been used one of the key strengths of grounded theory is its systematic approach to data analysis. This systematic approach of analysing data is beneficial in judging, generalising and comparing the results of grounded theory research (Strauss and Corbin, 1990, p13). This meant it was possible to compare the analysis across all three parts of the study previous research. Using situational mapping rather than content or narrative analysis enabled the researcher to break down the complex situations of inquiry into manageable chunks of information that she could then reflect upon. This approach surfaced new ways of thinking and coupled with the grounded theory approach, enhanced the reliability and validity of the resulting theory.

Quantitative researchers would favour the use of systematic literature reviews. A systematic literature review is a review of the evidence on a clearly formulated question that uses systematic and explicit methods to identify, select and critically appraise relevant primary research, and to extract and analyse data from the studies that are included in the review. Whereas, a narrative literature review is a comprehensive, critical and objective analysis of the current knowledge on a topic. Narrative reviews (rather than systematic ones) are an essential part of a qualitative approach as rather than testing an already formed research question they help to establish what the research question(s) should be by identifying gaps in the literature.

The use of focus groups allowed the researcher to gather several perspectives on the same issue in a relatively short amount of time (Powell and Single,1996). The group setting enabled the participants to build on the responses and ideas of the others, which increased the richness of the information gained. The researcher could have used an interview approach which might have resulted in more insights being collected at a deeper level. However, the advantage of using focus groups (apart from being less time consuming) was that in focus groups people are encouraged to talk to one another, ask each other questions, exchange stories and comment on each other's experiences and points of view. By their very nature focus groups provide the opportunity for peer support and a stronger social context which offers an opportunity to see how ideas and language emerge in a more naturalistic setting than an in-depth interview (Bloor et al, 2001, p21).

There were limitations though. Using the carers' centres as the main way of recruiting participants for the focus groups meant in the main carers' who knew about, were in contact with and were receiving some support from the carers' centres participated. There were only a handful of carers (5 in total) who were not in receipt of carer support services which means this perspective is limited in the data collection. Furthermore, there was under representation of BME groups, working

carers and male carers. Other ways of recruiting carers (such as through employer carer schemes) might have addressed this.

Information on the number of hours carers participating in the focus groups were caring for was not collected and given how this may impact on resilience this is a limitation. That said the focus groups also highlighted that sometimes it wasn't the number of hours spent caring but the 'headspace' and the emotional aspects of caring that had a greater impact on the carers' resilience.

There was an under representation of former carers (2 in total) and it would have strengthened the research if there had been capacity to undertake more focus groups with this cohort. The voice of former carers who are former carers because they ended the relationship e.g. got divorced is completely absent. In researching the best way of recruiting carers to participate the researcher spoke to a charity supporting people with acquired brain injuries. They had hoped to help recruit divorced former carers but, perhaps unsurprisingly, none of the divorced former carers they contacted responded. The lack of any subgroup analysis undertaken to check out whether certain aspects of resilience or support were more important to carers of certain care groups or relationships means it is difficult to be confidant about how far the findings are attributable to each particular 'group' of carers.

The researcher felt that simply developing a theory of carer resilience was not enough and that testing whether carers' centres enhanced resilience was both practically important and added to the academic rigour of this study. The generic goal of most evaluative research is to provide "useful feedback" to a variety of stakeholders. Most often, feedback is perceived as "useful" if it aids in decision-making. In an environment of limited resources, evaluative research is an essential part of making informed decisions on funding (Carman, 2013). This part of the research would have been enhanced had there been capacity to evaluate more than two carers' centres and/or if it had been possible to compare the carers' centre intervention with a different type of carer intervention e.g. condition specific support for carers' from a condition specific charity.

It was important that the scoping review to evaluate the impact and cost of two carers' centres took a mixed-methods approach. The use of quantitative data collection such as standardised measures alongside qualitative data collection in the form of a survey and observations enhanced the reliability and validity of the data and allowed the researcher to address a broader range of questions than collecting only quantitative or qualitative data would have provided. However, limitations included the fact that the resilience scale (BRS) did not measure all aspects of resilience as it focused on personal attributes. The impact measure used in the online survey was not a standardised measure of resilience and did not provide an opportunity to explore all the factors within the model of support for promoting resilience this therefore limits the value of the findings in relation to the potential savings. The robustness of the research would also have benefitted from the capacity to collect data at 12 weeks after initial contact and to have been able to collect comparative data from carers' centre B.

The online survey was a fast and efficient way of collecting data but carers who did not use the internet did not receive the survey. This is a limitation given that the carers' centres both report that many of their registered carers are older people who

do not use the internet. It would also have been beneficial had the researcher built into the research design follow-up interviews with carers. This would have provided richer data on the reasons that some carers found the carers' centres helpful and others did not. It might also have shed more light on whether this was linked to where carers were in their carer journey.

Accurately calculating the cost-savings to councils would require a research design that collected more detailed information from carers and involved the councils themselves. It would have been particularly useful to analyse data collected via councils and or care homes on the reasons for care home admission and the percentage of self-funders. This was not possible within the capacity and resources of this research and so a logical approach to estimating such costs was taken. Whilst the results do not accurately reflect the likely cost-savings they do give an indication that savings are made without over inflating the figures.

Theoretical sensitivity is an important skill, necessary for successfully using grounded theory. Using the Rolfe et al, (2001) reflective framework helped to provide the researcher with a structured approached to memo writing which in turn helped her to interact with the data and the emerging ideas rather than taking a distanced view that could have resulted in the researcher making assumptions based upon her own bias.

Mitigating the risk of bias also required careful coding and analysis, and critical feedback from others including supervisors, stakeholders involved in the research and other academics in the research community which the researcher did build in time for. However, these risks may have been further mitigated had the research been co-produced with carers. A co-produced approach might also have included carers in a more meaningful way and improved the impact of the research by reducing any 'relevance gap' by highlighting relevant questions that may have been neglected by the researcher and her supervisors (Beebeejaun et al, 2015).

12.7 Suggestions for future research

Suggestions for future research must be based on a clear understanding of the questions that need answering if support for carers is to improve and be financially sustainable. Some of the questions that need answering include:

- Are the commonalities highlighted in this study common across carers when a large sample is used and sub-analysis undertaken?
- Is carer resilience an indicator for carer willingness to care?
- What support is effective (both in terms of outcomes and cost) across care groups and relationships?
- What is a reliable and valid approach to defining and measuring resilience as defined by a large sample of carers?
- What cost-savings to the state does carer support achieve?
- What are the workforce implications for promoting carer resilience?

Having identified some of the questions that need answering it is necessary to consider the methods that could be used to do so. The limitations of previous research centre around studies undertaken on carers in silos, a perception of caring as a set of physical tasks, the lack of importance placed on the impact of the

changing relationship between the carer and the care recipient, minimal attention to the nuances of the carer journey, the over simplistic approach to carer outcomes and the use of standardised measures that do not address what is important to carers.

Future research must use mixed-methods to tackle the complexity of the data required to gather both the carer perspective and measure the effectiveness of interventions and support services. There may also be cause for a large sample, longitudinal approach to answer some of the research questions outlined above as such an approach would be more likely to capture the data on the effect of caring on the health of the carer and the interplay between the variety of factors carers saw as important to their ability to be resilient. There needs to be an increase in studies that involve carers across care groups, across relationships and across the carer journey rather than studying carers in silos. Finally, research must endeavour to build on cost-analysis, evaluation methods in attempting to gauge both the 'merit' and 'worth' of carer support services. The scoping review did provide evidence of the value in undertaking further evaluative research. Indeed robust research that includes carers and evidences both the effectiveness and cost effectiveness of support to carers would greatly assist the on-going promotion of carers' rights (Knapp, 2012). Appendix sixteen provides a rationale for a cost-benefit evaluation using the Social Return on Investment (SROI) methodology.

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APPENDICES

Appendix One: Carer experience commonalities and differences……..276

Appendix Two: Part one and two ethics application and approval letter……279

Appendix Three: Letter to ethics committee and approval letter…… 291

Appendix Four: Part three ethics application and approval letter…….. 293

Appendix Five: Letter to ethics committee and approval letter…….. 315

Appendix Six: Initial findings from the first set of focus groups……317

Appendix Seven: Example of line by line coding……321

Appendix Eight: Example memos……...323

Appendix Nine: Audit Tool……326

Appendix Ten: Short well-being scale (SWEMWBS)……330

Appendix Eleven: Brief Resilience Scale……331

Appendix Twelve: Example of 'Day in the life of….' Field notes……....332

Appendix Thirteen: Carer's Outcome Star……..335

Appendix Fourteen: Unit cost calculation for Carers' Centre A……339

Appendix Fifteen: Unit cost calculation for Carers' Centre B……340

Appendix Sixteen: Outline for a large scale evaluative research project……341

Appendix One: Carer Experience Commonalities and Differences

Reference	Relationship Carer Group	Research Design	Emotions of carer group	QoL Outcomes of carer group	Predictive Variables likely to reduce carer experience & QoL	Coping Resources that improve carer experience & QoL
Summary of Analysis (see below for analysis of individual papers)	Examples of studies across carer groups and relationships	Variety of research designs across the carer groups and relationships	Increased stress and a sense of loss were common themes across all groups. Negative emotions were a common theme, particularly depression and anxiety.	Reduced QoL was a common theme, specifically reduced physical and mental health. Experience of stigma was also common.	This is where there was most variety, the factors that predicted negative emotions and reduced QoL did vary although there was still a common theme around the greater the help the care-recipient needed, the greater the behaviour issues and the greater the lack of support (formal or informal) the more likely the carer was to experience negative emotions and QoL outcomes.	Regardless of the predictive variables there was commonality in terms of what helped. Social and emotional support were common. Positive reframing and problem solving skills were also common themes.
Bhopti et al 2019	Parents Children with disabilities	Mixed-methods approach using the Beach Centre Family Quality of Life (FQOL) Survey, a demographic	Increased stress.	Mixed results. FQOL scores were high but when interviewed parents reported that 'Our FQOL is hard,	Behaviour issues. Mainstream schools unable to cope. Lack of accessible recreational activities.	Sharing good times as a family supports FQOL. Services and supports are valued and help FQOL.

Reference	Relationship Carer Group	Research Design	Emotions of carer group	QoL Outcomes of carer group	Predictive Variables likely to reduce carer experience & QoL	Coping Resources that improve carer experience & QoL
		questionnaire (n=50) and 12 qualitative interviews. Descriptive analyses and Spearman's Rho correlations.		limited, dreadful, terrible, challenging, fluctuating; however, there are positives about having a child with a disability.' Decreased physical wellbeing. Financial loss due to restricted ability to work and care.	The greater the need for care and support the lower the quality of life for the parent carer.	
Walden et al 2000	Parents Adults with ID	Interviews with 62 UK parents of adults with ID. Standardised measures also undertaken with the sample. Sample compared to caregiving parents in the US and non-caregiving parents in the US.	Increased stress Disempowered & not listened to by services. Depression Feelings of being trapped and life opportunities limited. Feelings of being proud and a sense of achievement.	Reduced physical and mental health	Behaviour issues. Lack of support. The greater the need the care-recipient has for practical assistance/personal care	Informal support Emotional support
Whittingham et al 2012	Parents Children with cerebral palsy	Cross-sectional design using multiple regression analysis. 94	Increased stress Sense of loss. Grief Anxiety Depression	Reduced physical and mental health	Behaviour issues. Experiential avoidance coping styles. Low self-esteem.	Adaptive problem-solving focused coping skills. Social support.

Reference	Relationship Carer Group	Research Design	Emotions of carer group	QoL Outcomes of carer group	Predictive Variables likely to reduce carer experience & QoL	Coping Resources that improve carer experience & QoL
		parents. Standard measures.				Maintaining engagement in hobbies, work & leisure activities.
Blondin et al, 2019	Parents Anorexia	50 mothers & 38 Fathers completed the Experience of Caregiving Inventory and the Family Questionnaire.	Sense of loss.	Stigma.	Difficult behaviour. Expressed emotion. Level of dependency. Problems with services.	Good relationship with their child.
Dimitropoulos et al 2008	Parents Anorexia	Cross-sectional study using self-report (n=63). Standard measures. Regression analysis.	Increased stress. Emotional distress. Sense of loss. Anxiety. Depression.	Reduced finances and employment opportunities. Reduced mental health. Experience of stigma.	Stigma Behaviour issues. Poor service provision. Family conflict.	Social support.
Kyriacou et al 2008	Parents Anorexia	Cross-sectional study using self-report questionnaires (n=151). Standard measures. Regression analysis.	The strain of a developmental 'inappropriateness' involved in caring for dependent adult children. Lack of information Stressful experiences in obtaining help. High stigma & lack of understanding.	Impaired QoL	Poor social support Strained interpersonal relationships within families. Over-protective care giving styles and high expressed emotion.	Not mentioned in the study.

Reference	Relationship Carer Group	Research Design	Emotions of carer group	QoL Outcomes of carer group	Predictive Variables likely to reduce carer experience & QoL	Coping Resources that improve carer experience & QoL
			Being blamed for the illness. Feel isolated and alone. Frustration. Depression. Anxiety. Emotional distress			
Wingrove et al 2019	Mental Health Parents and carers	234 participants. Self-report, standardised measures for stress, caregiver burden, activity restriction, self-efficacy and coping. Multiple regression analysis.	Increased stress, emotional distress and isolation.	Reduced ability to engage in leisure activities or socialising with friends.	Reduced social support. Stigma. Sense of guilt.	Confidence in their own ability to manage the behaviour and symptoms of the care-recipient's condition. Ability to continue to engage in leisure and social activities.
Lavoie 2018	Mental Health Carers	Integrative Review	Anxiety, fear, frustration, loss, sense of being invisible / dismissed by professionals, guilt.	Isolation, reduced ability to engage in other activities or socialise. Reduced physical and mental wellbeing. Sometimes reduced financial resources.	Lack of information about the illness or who to contact for support.	Empowerment, sense of legitimacy, personal support.
Raune et al 2004	Mental Health	Cross-sectional study. 46 carers	Increased stress and emotional distress.	Reduced mental health.	High expressed emotion. Behavioural issues.	Positive appraisal.

Reference	Relationship Carer Group	Research Design	Emotions of carer group	QoL Outcomes of carer group	Predictive Variables likely to reduce carer experience & QoL	Coping Resources that improve carer experience & QoL
	Parents Partners Siblings Other relatives & friends	Interviewed using standard measures Statistical analysis				
Gray et al 2009	Mental Health Family carers	Semi-structured interviews with 65 professionals supporting carers. Content analysis.	Increased stress and emotional distress. Isolation. Sense of loss. Fear and anxiety. Disbelief. Guilt. Anger. Desolation & depression. Grief. Embarrassment. Shame. Hope, pride & achievement.	Reduced employment opportunities & income. Experience of stigma. Reduced ability to engage in education, training or leisure activities. Reduced ability to maintain relationships with extended family, friends & neighbours.	Stigma & marginalisation. Changes in personality. Psychiatric and behavioural symptoms.	Emotional support. The ability emotionally to adjust to the huge changes being a carer brings.
Roen et al 2018	Cancer Spouses Parents	Qualitative, semi-structured, individual interviews with 14 family carers. Analysed using systematic text condensation.	Increased anxiety, stress, sense of vulnerability and being overwhelmed.	Not mentioned.	Not being seen or valued by professionals – all the focus on the patient. Lack of palliative care.	Receiving information and support to talk to their loved one about palliative care and death. Support to maintain a good relationship with their loved one.

Reference	Relationship Carer Group	Research Design	Emotions of carer group	QoL Outcomes of carer group	Predictive Variables likely to reduce carer experience & QoL	Coping Resources that improve carer experience & QoL
Kelly et al 1999	Cancer Partners Adult children caring for parents	178 carers were assessed at time of referral to palliative care support and again after the death of the care recipient. Standard measures and multiple regression analysis.	Emotional distress. Sense of Loss. Grief	Reduced physical and mental health.	Greater number of adverse life events. Poor quality of the relationship prior to cancer. Lack of social support. Reduced finances. Low satisfaction with service provision.	Good palliative care support. Acceptance. Avoidance coping.
Aubeeluck et al 2012	Huntington's disease Partners Other family members	6 focus groups with carers (n=47). Interpretative Phenomenological analysis.	Increased stress and emotional distress. Sense of loss. Depression Anxiety Feeling overwhelmed, tired and exhausted. Isolated. Lonely. Guilt. Anger. Frustration.	Reduced QoL Difficulty managing finances. Poor physical and mental health.	Low satisfaction with service provision. Personality changes, psychiatric and behavioural symptoms.	Family support. Practical and emotional support.
O'Connor and McCabe 2011	Degenerative Illness Partners Other family carers	192 carers self-report questionnaires at time 1 and time 2 (12 months later). Regression analysis.	Marital dissatisfaction.	Reduced QoL Financial burden	Economic pressure Low social support Low satisfaction with marital relationship	Financial resources Social and emotional support
Pakenham 2005	MS	225 MS carers.	Increased stress. Depression	Reduced QoL	Young age of the person with MS.	Positive reframing. Avoidance coping.

Reference	Relationship Carer Group	Research Design	Emotions of carer group	QoL Outcomes of carer group	Predictive Variables likely to reduce carer experience & QoL	Coping Resources that improve carer experience & QoL
	Partner Other family carer	Self-report questionnaires at time 1 and time 2 (3 months later). Regression analysis.	Anxiety		The greater the need the person with MS had for practical assistance/personal care. Progressiveness of the condition. Care-recipient life satisfaction and adjustment.	Supportive relationship focused coping strategies. Practical assistance.
Lou et al 2017	Stroke Range of family carers	A systematic literature using PRISMA guidelines.	Anxiety and feelings of uncertainty about what the future holds.	Difficulty getting their own space to engage in other activities or socialise. Loss of autonomy, independence and identity.	Social isolation. Lack of practical and/or emotional support. Lack of information.	Good rehabilitation that supports the carer and patient. Sense of hope, fulfilment and pride.
Greenwood et al 2008	Stroke Range of family carers	Systematic Review	Increased stress Depression Anxiety Low self-esteem	Reduced QoL Difficulty managing finances. Poor physical health. Exhaustion.	Severity of stroke and greater the need for practical assistance/personal care. Emotional distress of cared for person. Carer's view of the future as hopeless. Low satisfaction with service provision. Personality changes.	Family functioning. Avoidance coping. Positive appraisal. Sense of hope. Employment.

Reference	Relationship Carer Group	Research Design	Emotions of carer group	QoL Outcomes of carer group	Predictive Variables likely to reduce carer experience & QoL	Coping Resources that improve carer experience & QoL
Servaes et al 1999	Stroke Range of family carers	Review of published papers	Emotional distress. Guilt Depression Lonely Frustration	Difficulty managing finances. Reduced physical and mental health. Reduced social life. Experience of stigma.	Changes in personality, behaviour and marital relationship. Stigma.	Increased knowledge of the condition. Social and emotional support.
Hammar et al 2019	Dementia Spouses	Semi-structured interviews with 9 carers. Content analysis.	Feeling alone and isolated. Frustrated. Fear of doing things wrong. Guilt. Increased stress.	Reduced ability to engage in leisure or social activities. Reduced physical and mental wellbeing.	Lack of knowledge about dementia. Social isolation. Poor service provision and staff with a lack of knowledge or understanding. Behaviour issues.	Having someone to talk to. Respite care.
Burns and Rabins 2000	Dementia Range of family carers	Review of published papers on carers who care for people with dementia or Alzheimer's	Increased stress Depression Anxiety	Poor physical and mental health.	The greater the cognitive impairment of the care-recipient. The greater the need for practical assistance/personal care. The greater the personality change, presence of psychiatric symptoms and behaviour issues. Being female. Low amount of formal and informal care available.	Positive reframing. Practical and emotional support. Behaviour programmes. Activity programmes and support groups. Respite care.

Reference	Relationship Carer Group	Research Design	Emotions of carer group	QoL Outcomes of carer group	Predictive Variables likely to reduce carer experience & QoL	Coping Resources that improve carer experience & QoL
					Poor quality of the relationship prior to dementia.	
Martin-Cook et al 2003	Dementia Partners Adult children caring for a parent	37 carers (18 in the control group, 19 in the intervention group). 4 week psychoeducational intervention. Standardised measures and statistical analysis.	Overwhelmed Depression Sense of sacrifice Resentment Grief Increased stress Emotional distress	Reduced QoL	Behavioural issues and psychiatric symptoms. Belief that the care-recipient was being manipulative & controlling rather than their behaviour being due to the illness.	The intervention to teach carers about the condition and how to manage behavioural issues had no impact on carers' sense of resentment or depression.
Bristow et al 2008	Dementia Partners	25 carers and 36 non-carers all completed standardised measures. Saliva samples were also taken.	Increased stress Lower positive mood Increased psychological distress Depression Anxiety Feeling incompetent.	Poorer mental health Lack of self-esteem Less well-being	Behavioural issues. Psychiatric symptoms. Low self-esteem and feelings of incompetency.	Not reported on in this study

Appendix Two: Part One Ethics Application and Approval Letter

SCREENING FORM FOR ETHICS SUBMISSION

Research title: Developing a model of resilience relevant to carers

Status: (Please circle) Postgraduate

Researcher: Sarah Broadhurst

Supervisor (for UG/PG students):

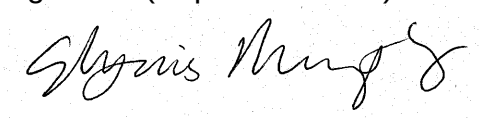
1	Is this research going to be subject to NHS Local Research Ethics Committee or Social Care Research Ethics Committee approval? If No, proceed to question 2.	1. No (no need to answer any further questions)
2	Does the research gather information from: • Children (under 16 years)? • Adults at risk such as individuals with mental health problems, learning disabilities, prisoners, young offenders, elderly people with dementia • Staff • Carers	 No No No Yes
3	Does the research involve the use of materials or questions that could upset or offend participants? (e.g. asking people to talk about difficult life events)	Yes

□ I have answered NO to all the above categories (from Qs 2-3) and do not consider that this project needs to be submitted for more detailed ethical review.

X I have answered YES to at least one of the categories and am submitting an application for departmental ethics approval.

If you have answered YES, please complete the attached Checklist. A number of documents are available on the T drive (only accessible to staff). Any required guidance for student applications is available on Moodle.

Signature (Supervisor/Staff)



Date: 22/02/15

Signature (Student)



Date: 22/02/15

The purpose of this screening is to ensure that the research will be ethical, maintain confidentiality and anonymity and will not cause harm.

ETHICAL REVIEW CHECKLIST

The Tizard Centre Ethics Committee meets three times a year. Any members of staff or students are welcome to attend a meeting when their proposal is being discussed. If you wish to attend the meeting, please inform the Ethics secretary (Jo Ruffels) at least 2 days prior to the meeting. The outcome of the review of proposals will be announced by email and/or post approximately 2 weeks after the meeting.

Please note that when completing your proposal, you should use the proforma exactly as it is set out below. Please also ensure that your checklist has page numbers and the completed proforma should not exceed 6 pages excluding consent forms and other attachments. Please complete in plain English. Dissertation proposals should not be attached to the checklist.

Section 1 Background including literature review and rationale for study including aims and objectives (and/or hypotheses or research questions) of the project (no more than 2 pages) *(the aim is what you will actually do in the study, and the objective is what you hope to achieve).*

Many informal carers suffer high levels of stress as a central part of the caregiver experience (Grant and Whittell 2000; Walden et al 2000; Emerson 2004). Such high levels of stress can result in admission to institutional care for those being cared for in informal care settings (Philp et al 1995). Recently research has begun to examine the role of resilience in enhancing the capacity of individuals to 'bounce back', enabling them to continue to care (Minnes et al 2007). Masten, Best and Garmezy (1990) defined resilience as 'the process of, capacity for, or outcome of successful adaptation despite challenging or threatening circumstances' (p426).

The systematic application of existing knowledge about resilience to prevention services is almost non-existent. Few prevention programs are based on resilience theory or are specifically designed to increase resilience (Kumpfer, 1999; Bartley et al 2012). Of the interventions that do attempt to do this, few have been evaluated in terms of the outcomes they achieve and the costs of implementing them (Emerson et al 2011).

The aim of this study is to develop a model of resilience for carers. The first two phases of the study have involved reviewing the literature on:

- The emotions and quality of life outcomes carers experience.
- Current models of resilience and their relevance to carers.

Theses first two phases have led to the development of a theoretical model of resilience. The third phase of this study aims to test and further develop this model with carers via the use of focus groups.

This Ethical Review Checklist is written in relation to this third phase. The focus groups aim to answer the following questions:

- What are the stress related emotional issues that carers face?
- What are the quality of life outcomes that carers experience?
- What does resilience look and feel like?
- What are the components of resilience that are most relevant to carers?

Section 2 Conduct of Project

a) Study Design
The study is an exploratory one and hence does not involve an intervention. The focus groups will gather qualitative information aimed at testing a model of resilience for carers. The focus groups will involve carers who care for people with a range of conditions such as those caring for people with Learning Disabilities, Mental Health problems, older people and neurological conditions.

b) Location
The research will be carried out in the counties of Kent, Buckinghamshire, Oxfordshire and the London Borough of Enfield. The focus groups will be conducted in carer or community centres. Participants will be asked to attend the focus group taking part in their local carer or community centre to avoid the need for carers to travel.

c) Brief description of participants (and number)
Carers will be caring for adults or children. The only exclusion will be young carers as this group have specific needs and this study does not cover young carers. At least 5 focus groups of between 6 to 10 people will be conducted. Carers will be identified via their local carers groups/networks. Carers groups/networks will contact carers with the information about the focus groups and instructions on what to do if they wish to participate.

d) Expected start date and duration
April 2015 for a duration of 3 to 4 months.

e) Measures
The focus groups will last approximately 1.5 hours. The focus groups will be structured
around a set of carefully predetermined questions but the discussion will be free-flowing. Hopefully, participant comments will stimulate and influence the thinking and sharing of others.

f) Procedure
The focus groups will be recorded via video.
Key points will be recorded on flip chart paper during the focus group.
Focus group recordings will be transcribed.

g) Analysis
The data collected will be analysed using thematic analysis. Thematic analysis has been chosen as the researcher feels it is the most appropriate methodology for

analysing whether similar themes occur across focus groups and hence carer groups.

Section 3 Ethical Considerations

a) Will you pay participants for taking part in the research? State your rationale for paying/not paying and the likely impact on participation.

No payment will be offered as participation is entirely voluntary and there is no wish to affect participants' right to withdraw from the research.

b) How do you intend to give feedback to participants (and, where relevant, other interested parties)?

Participants will be offered the opportunity to discuss the research results from this phase. It is hoped that the results will inform the basis for further research and study and be developed for publication. In addition participants will be offered a summary document of the findings of the research as will the carers centre.

c) How will you obtain informed consent from potential participants?

It is believed that all participants will be able to give informed consent. Information sheets, consent forms and complaint forms will be provided to participants in order to establish informed consent.

d) How will you ensure that the identities of participants are kept confidential during the project, and in any subsequent data analysis, conference presentations and publications?

Participants will be informed that the information they supply will be discussed with the researcher's supervisor and the results may be published in journal form. However, all identifiers such as names, addresses etc will be removed, so that data will be anonymous. Data will be kept in accordance with the Data protection Act (1998). All focus group material will be kept in locked cabinets and linked computer records will be password protected. In terms of confidentiality amongst the group, ground rules (including confidentiality) will be discussed at the beginning of each focus group. The researcher, the assistant facilitator and the researcher's supervisor will view the video recordings as all three people will be involved in the data analysis. At the end of this stage of the research the video recordings will be destroyed.

e) Explain how you will meet the four main ethical principles of research,
   I. Causing no harm: consider what risks or burdens (e.g. distress, embarrassment) your research could have for participants and how you can minimise these. Are there any risks for you as the researcher?

The study will build on previous studies and findings. Participants will have the right to withdraw at any time without having to give a reason. Each focus group will be run by the researcher and an assistant facilitator (carer support worker from the carer's centre). If participants at any time become upset the focus group will be paused. The participant will be encouraged to have a conversation with the

assistant facilitator outside the room and support will be offered. If the participant choses to withdraw at this point, their choice will be respected. The rest of the focus group will be asked if they wish to continue. All participants will be provided with information and advice as to how they can access ongoing support via their carer network. The researcher will discuss any significant issues that arise with her supervisor.

II. *Doing good: consider what good could result for the participants and how the potential for good can be maximised.*

Many carers feel 'unlistened to', so even for these carers who are participating, they may benefit from meeting each other and sharing their experiences, as well as from being formally listened to, as part of the research. In addition, it is believed that the research will do good in the long run as it will be used to help the development of better support for carers.

III. *Respect: consider how you will treat your participants with respect including giving them sufficient information and ensuring they are able to make their own choices about participating.*

Information sheets, consent forms, and complaint forms will be provided to participants in order to establish informed consent. Autonomy will be respected by using a focused conversation style of inquiry into subjective meaning from the participants i.e. how people feel, make sense of and interpret their feelings.

IV. *Justice: consider the likely outcomes of your research and to whose advantage or disadvantage the results of the research might be put.*

It is believed that the research will be an advantage to carers, carers' families, services and practitioners in the long run, and it may benefit participants in the short run (see above under 'doing good'). The main disadvantage for participants is that it will take some of their time and carers often feel hard pressed for time. However it is only 1.5 hrs long and will be held locally to each carer centre so as not to use up too much of carer's valuable time..

The researcher will also benefit as the focus group will be part of her PhD.

f) Are there any power imbalances between researcher and participants that may make it difficult for participants to refuse their participation?

It is possible that some carers could experience a power imbalance between themselves and the researcher that might make it difficult for participants to refuse participation initially. This will hopefully be overcome by contacting potential participants via the carers centres rather than the researcher contacting people directly. There is also some potential for people to feel like they cannot withdraw once the focus group has started and so it must be made clear that this is acceptable and participants will be supported to do so without them having to justify why. Having an assistant facilitator present who is a known and trusted carer support worker to the participants is crucial in trying to ensure that participants feel able and supported to withdraw at any time. Furthermore, because the researcher holds a position of authority and perceived influence during the

focus group it is important that the researcher remain neutral hence refraining from agreeing/disagreeing, or praising/denigrating any comment made.

g) How the research will pay attention to cultural diversity: e.g. include the experiences of people from Black and minority ethnic communities; be respectful of cultural differences; provide appropriate interpreters where necessary (NB. researchers should note that this often involves more than simply finding someone who speaks the same language).

To respect cultural diversity the researcher will seek guidance from the Carers Centres and Networks, who will be advising on potential participants. It is hoped that these Centres will have a working knowledge of the participants' cultures, beliefs etc. No one will be excluded on the basis of culture, religion or beliefs. Any steps required to increase accessibility to people whose first language is not English will be taken such as the use of an interpreter.

Section 4 Attachments

Tizard Centre, University of Kent
Canterbury, Kent, CT2 7LZ
Researcher: Sarah Broadhurst
E-mail: sb793@kent.ac.uk
Tel. number: 07824569466
Supervisor: Prof. Glynis Murphy
E-mail: g.h.murphy@kent.ac.uk

Information Sheet

Title: ***Understanding resilience in family carers***

Dear Carer,

You are being invited to take part in a research study conducted by Sarah Broadhurst, who is a PhD student at the Tizard Centre at University of Kent. Her supervisor is Professor Glynis Murphy who works at the University of Kent.

Your participation in this study is entirely voluntary. Before you decide whether you want to take part it is important for you to understand why the research is being conducted and what it will involve.

What is the purpose of the study?
The purpose of this study is to understand resilience in family carers. I would like to talk to you about this with other family carers in a focus group.

The focus group aims to answer the following questions:

- What are the issues that family carers face?
- What is life like as a family carer?
- What does resilience look and feel like?
- What elements of resilience do family carers think are the most important?

Why have I been invited to take part in one of the focus groups?
You have been invited to participate in a focus group as you are a member of [ADD IN NAME OF LOCAL CARERS CENTRE].

What would I have to do if I agreed to take part?
The focus group is taking place on [ADD DATE & TIME] at [ADD ADDRESS OF LOCAL VENUE].
If you would like to take part in the focus group please sign the consent form attached and return it to [ADD IN NAME OF LINK CARER SUPPORT WORKER & LOCAL CARERS CENTRE]. We will send confirmation on receipt of your consent form.

Do I have to take part?
Your participation in this study will be entirely voluntary. It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at

any time, without giving a reason. It will not affect any of your services if you decide not to take part.

Will what I say in this study be kept confidential?
Material gathered during this research will be treated as confidential and securely stored. Only the researcher, her supervisor and [ADD IN NAME OFCARER SUPPORT WORKER FROM THE LOCAL CARERS CENTRE] will have access to the material. All participants of the focus group will be asked to adhere to a set of ground rules that require confidentiality amongst the group. The focus group will be recorded for purposes of analysis. The recording will only be watched by the researcher, her supervisor and the carer support worker. The recording will be destroyed once the analysis is complete.

What will happen to the results of the research study?
The information you provide us with will be used to produce part of the researcher's PhD, and will be published in a scientific journal. It will also be summarised on the Tizard website, presented at conferences to raise awareness of carer issues and will be published in a magazine such as Community Care. Specific individuals will not be identifiable from the results as no names will be used. At the end of the study the researcher will send you a summary of the results. Again no individuals will be identifiable at all.

Who is organising and funding this research?
The research has ethical approval from the Tizard Ethics Committee. The University of Kent is funding this research and will hold the findings as well as the actual report of the current study. The funds for the research study are small because I am a research student however it will be possible to refund any travel expenses participants incur as a result of participating in the focus group.

What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. In the first instance you can speak to the researcher, Sarah Broadhurst or her supervisor Professor Glynis Murphy (contact details below) who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by completing the complaints form attached.

Contact
Please do not hesitate to contact the researcher (Sarah Broadhurst, email: sb793@kent.ac.uk tel no: 07824569466) or the supervisor of the research (Prof. Glynis Murphy, email: g.h.murphy@kent.ac.uk) if you have any queries. If you wish to take part please complete the consent form and return it to [ADD IN NAME & ADDRESS OF LOCAL CARERS CENTRE].

Thank you for taking the time to read this.
Sarah Broadhurst

Consent Form

Title: ***Understanding resilience in family carers***

Researcher: Sarah Broadhurst
Supervisor: Prof. Glynis Murphy
Email: sb793@kent.ac.uk, g.h.murphy@kent.ac.uk
Telephone number: 07824569466

Please tick
To confirm

- ☐ I confirm that I have read and understood the information letter attached for the above study.
- ☐ I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.
- ☐ My questions have been answered to my satisfaction.
- ☐ I agree to take part in the focus group for the research study '*Understanding resilience in family carers'*.
- ☐ I agree to the focus group being recorded for the purposes of transcribing and capturing the information.

Name:_____ Date:_____

Signature:_____

Complaint Form

This form should be used for complaints involving the focus groups. Every effort will be made to ensure confidentiality, consistent with a full investigation of any complaint.

1. Name of complainant	
2. Address for correspondence	
3. Research Study Title	Understanding resilience in family carers
4. Date and time of focus group	
5. Principal/Chief Investigator	
6. Researcher(s)	

7. Details of the complaint (please ensure that all relevant details are provided, attach additional sheets if necessary).
8. Please summarise any informal action taken to resolve the complaint or explain why informal action was not considered to be appropriate:

I understand that a copy of this form will be provided to any member of staff who is the subject of the complaint, or who is otherwise involved.

I understand that a copy of this form will be provided to the Tizard Ethics Committee.

Signed_____ Date:_____

Completed forms should be returned to any of the following:

The researcher: Sarah Broadhurst sb793@kent.ac.uk
The Supervisor: Professor Glynis Murphy g.h.murphy@kent.ac.uk
Address: Tizard Centre, Woodlands, Giles Lane, Canterbury, CT2 7LR

The Head of School: Sarah Vickerstaff 01227 823072
Address: SSPSSR, faculty of Social Sciences, Cornwallis North East, University of Kent, Canterbury, Kent, CT2 7NF

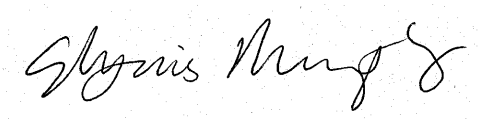
Tizard Ethics Feedback Form

Student Name:	Sarah Broadhurst
Supervisor:	Glynis Murphy
Title:	"*Developing a model of resilience relevant to carers"*

Following the amendments made the Tizard Ethics Committee confirm that the proposal has now been approved.

Signed: J.Ruffels **Date: 07.09.15**

On behalf of Tizard Ethics Committee

Alterations approved by Supervisor	 **Signature** **Date 07.09.15**
Final approval On behalf of Tizard Ethics Committee	 **Signature** **Date 07.09.15**

Appendix Three: Letter to Ethics Committee and approval letter

Letter to Ethics Committee

38 Parkers Circus
Chipping Norton
Oxon
OX7 5LZ
11th September 2015

Dear Ethics Committee,

Student Name: Sarah Broadhurst
Research Study: Understanding Resilience in Carers

I submitted an application to the ethics committee in March 2015. The application requested approval to undertake focus groups with Carers to discuss the topic of resilience. In the application I stated that:

Carers groups/networks will contact carers with the information about the focus groups and instructions on what to do if they wish to participate.

It was my intention that the carer organisation would write to people and send them the information sheet and consent letters. The aim being that people would come along to the focus group having completed a consent form.

Unfortunately, the majority of carer centres have been very stretched and so their capacity to do this has been limited. Instead Carers centres have suggested sending out invites to potential participants via their the Carer Centre Facebook Page or adding the focus group on as an optional session at the end of one of their drop in sessions. This has been a successful strategy in terms of advertising and carers sign up to the focus groups. However, it has also required a change to the procedure I originally outlined in that the signing of consent forms has had to be dealt with face to face at the beginning of the focus group.

I have been conscious that in this situation some people may feel unable to say no. I have addressed this by leaving the room for a short period once I have talked through the Information Sheet and Consent Form. This gives the carer support worker a chance to double check with people that they truly are comfortable and are giving informed consent.

Yours Sincerely,



Sarah Broadhurst

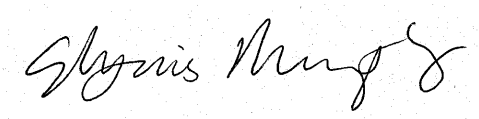
Tizard Ethics Feedback Form

Student Name:	Sarah Broadhurst
Supervisor:	Glynis Murphy
Title:	"*Developing a model of resilience relevant to carers"*

Following the amendments made the Tizard Ethics Committee confirm that the proposal has now been approved.

Signed: J.Ruffels **Date: 07.09.15**

On behalf of Tizard Ethics Committee

Alterations approved by Supervisor	 **Signature** **Date 07.09.15**
Final approval On behalf of Tizard Ethics Committee	 **Signature** **Date 07.09.15**

16.11.15 An adjustment made to the consent procedures of the proposal (see letter dated 11.09.15) has been approved by the Chair of the Committee. (Dr Paraskevi Triantafyllopoulou)

Appendix Four: Part Three Ethics Application and Approval Letter

SCREENING FORM FOR ETHICS SUBMISSION

Research title: Understanding Resilience in Family Carers

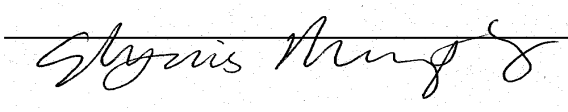
Status: (Please circle) Undergraduate/**Postgraduate**/Staff
Researcher: Sarah Broadhurst
Supervisor (for UG/PG students): Glynis Murphy and Nick Gore

1	Is this research going to be subject to NHS Local Research Ethics Committee or Social Care Research Ethics Committee approval? If No, proceed to question 2.	2. Yes (no need to answer any further questions)
2	Does the research gather information from: • Children (under 16 years)? • Adults at risk such as individuals with mental health problems, learning disabilities, prisoners, young offenders, elderly people with dementia • Staff • Carers	 No No Yes Yes
3	Does the research require a DBS check to be carried out? If yes, has the researcher applied for a DBS check or already obtains one?	No N/A
4	Does the research involve the use of materials or questions that could upset or offend participants? (e.g. asking people to talk about difficult life events)	Yes

□ I have answered NO to all the above categories (from Qs 2-3) and do not consider that this project needs to be submitted for more detailed ethical review.

✓ I have answered YES to at least one of the categories and am submitting an application for departmental ethics approval.

If you have answered YES, please complete the attached Checklist. A number of documents are available on the T drive (only accessible to staff). Any required guidance for student applications is available on Moodle.
Signature (Supervisor/Staff)



Date: 30/11/17

Signature (Student)



Date: 24/11/17

The purpose of this screening is to ensure that the research will be ethical, maintain confidentiality and anonymity and will not cause harm.

ETHICAL REVIEW CHECKLIST

Please note that when completing your proposal, you should use the proforma exactly as it is set out below. Please also ensure that your checklist has page numbers and the completed proforma should not exceed 6 pages excluding consent forms and other attachments. Please complete in plain English. Dissertation proposals should not be attached to the checklist.

Section 1 **Background including literature review and rationale for study including aims and objectives (and/or hypotheses or research questions) of the project** (no more than 2 pages) *(the aim is what you will actually do in the study, and the objective is what you hope to achieve).*

As part of my PhD a series of studies have already been conducted aimed at understanding how carers conceptualise resilience and developing a model of resilience that matches the carer view.
The studies involved reviewing the literature on:

- The emotions and quality of life outcomes carers experience.
- Current models of resilience and their relevance to carers.

These studies led to the development of a theoretical model of resilience which was then tested and further developed with carers via the use of focus groups. The model was validated by a group of carers and carer support workers. The model was then used to create an audit tool. The audit tool was again validated by a group of carers and carer support workers.

The aim of this study is to use the resilience audit tool to evaluate the degree to which carers centres improve or maintain the resilience of carers. Carers centres are the standard intervention for carers. Most local authorities and or clinical commissioning groups fund (at least in part) carers centres to provide support to family carers. There is a lack of research that evaluates these centres to determine if they successfully build resilience and/or improve quality of life outcomes or well-being for carers and at what cost.

This Ethical Review Checklist is written in relation to this last study which will evaluate two carer's centres.

Section 2 **Conduct of Project**

a) Study Design. *Is your study qualitative or quantitative? What kind of sample (e.g. total population? random? convenience? or purposive?). Is your study mainly exploratory/descriptive or does it involve an intervention?*
It will be an exploratory, evaluative study. Carers centres are charitable organisations that exist in most towns for carers of all ages, across all care groups. The centres offer advice, information and carer support services that range from peer support groups to counselling and replacement care. The resilience audit tool will be used to evaluate the degree to which a carer's centre is geared towards improving or maintaining the resilience of carers and will be used as the framework for the evaluation study. The study will aim to answer the following research questions:

1) What support aimed at improving or maintaining resilience does the carers centre provide?
2) Does the carers' centre improve and/or maintain the resilience of carers?
3) Does the carers' centre improve and/or maintain well-being of carers?
4) What is the cost of the 'carers centre' intervention?

The logic model below illustrates how the carer's centre will be evaluated to answer the research questions using the resilience audit tool. The logic model outlines the data collection and analysis methods.

<table>
<tr><td colspan="4">PURPOSE OR MISSION
What is the purpose of the carer's centre?</td></tr>
<tr><td colspan="4"><u>Data Collection</u>
A Survey that asks 'What is the purpose of the carer's centre?' The survey will be used to collect data from: The Governance Board, The senior management team , Carer support staff, Commissioners and other funders, A representative sample of carers.</td></tr>
<tr><td colspan="4"><u>Data Analysis</u>
Thematic analysis to explore what people think the purpose of the carer's centre is and to identify the degree to which people think the purpose is about maintaining or improving resilience using our carer definition of resilience = 'ability to keep caring'.</td></tr>
<tr><td>INPUTS
What are the resources used by the centre? E.g.Finance, Staff, Buildings, Partnerships, Volunteers, etc</td><td>ACTIVITIES
How does the centre use the resources? What information, advice and support does the centre offer to carers?</td><td>OUTPUTS
What evidence is there that the activities are performed?</td><td>OUTCOMES
What are the outcomes for carers?
Is their resilience maintained or improved?</td></tr>
<tr><td><u>Data Collection</u>
Workshop with the senior management team to map the resources.</td><td><u>Data Collection</u>
Workshop with the senior management team and carer support workers to map the activities.
Review of the marketing information on the services available.
Ethnographic 'day in the life of' observation of 2 carer support workers.</td><td><u>Data collection</u>
Collating the data the carers centre already collects e.g. number of referrals, demographics of carers, number of carers that access different types of support, complaints and compliments, annual carer survey, contract monitoring information.</td><td><u>Data Collection</u>
All new referrals for a period of 2 months will be asked to complete the well-being questionnaire and to rate on a 5 point scale the degree to which they feel able to continue caring. The measures will be repeated 12 weeks later.
Online survey for carers asking about the impact the carers centre has had for them based</td></tr>
</table>

			on the model of resilience. Collate Outcome star data already collected by the carers centre
Data Analysis Calculate the Unit Cost of the carers centre.	**Data Analysis** Map the activities against our resilience audit tool that is based on our model of carer resilience. Content analysis on the marketing information and map against resilience audit tool. Grounded theory analysis on the notes from the carer support worker ethnographic observations and map against our resilience audit tool.	**Data Analysis** Benchmark the reach (i.e number & demographics of carers) against the estimated prevalence of carers locally. Map the data the carers centre already collects against our resilience audit tool.	**Data Analysis** Statistical analysis using SPSS for the well-being questionnaire, resilience scores and the outcome star data to see if scores increase over time. Thematic analysis of the online survey to identify the impact carers say the centre has had.
CONTEXT What is the culture (attitudes and beliefs) within which the carer's centre operates? **Data Collection** Use the resilience audit tool to structure interviews with the Chair of the Board, The CEO, 2 senior managers, 3 carer support works, 1 administrator.			
Data Analysis Grounded theory analysis mapped against our resilience audit tool.			

Two carers centres will be evaluated as part of the study.

b) Location. *In what organisations and in what geographical areas will you be conducting your research?*
The research will be carried out in Buckinghamshire and Herefordshire.

c) Brief description of participants (and number). *Tell us how you will identify potential participants, approach them and recruit their participation. Who can and cannot take part i.e. what are your inclusion/exclusion criteria? How many do you hope to recruit and what will be their likely age/gender/ethnicity?*

The carers centres 'Carers Bucks' and 'Herefordshire carers' have been involved in the earlier phases of the research and are keen to be involved in this last phase. The online survey will be sent to all Trustees (approximately 14 people), all members of the senior management team (approx 4 people), all carer support staff (approx. 10 people), commissioners / funders (approx. 3 people) and a representative 10% sample of carers supported by the carers centre. The whole senior management team will be invited to the workshop to map the resources and activities. I will invite all the carer support workers to participate in the ethnographic observations. 2 carer support workers will be randomly selected from those who wish to participate. Carer support workers will be given some training on the well-being questionnaire.
Carer support workers will be asked to give all new referrals an information sheet explaining the research and those carers that wish to participate will be asked to complete the measures. Both measures are self-reporting tools. A representative 10% sample of carers supported by the carers centre will be invited to complete the online survey. The Chair of the Board, The CEO, 2 senior managers, 3 carer support works and 1 administrator will be invited to participate in a structured interview.

All staff and carers will be provided with an information sheet explaining the research. They will be given the opportunity to participate if they wish but naturally it will not be mandatory and they will be reassured that they are free to decline without risk to their employment (if they are staff) or their support (if they are carers). All the carers who will be sent the survey will be receiving support from the carers centres and will be adults who will be caring for adults or children. The only exclusion will be young carers as this group have specific needs and this study does not cover young carers. The support sessions I observe via the ethnographic observations will be arranged in partnership with the carers centre who will consult with carers first (using the research information sheet) to check whether carers will be comfortable with my presence. Then directly before the beginning of the session informed consent will be sought from the carers at the session using the consent form and with support from the carer support worker.

d) Expected start date and duration
December 2017 for a duration of 5 months.

e) Measures. *What measures e.g. questionnaires, interview schedules, observations etc will you use? Please make sure you give a rationale for the use of these particular measures. Provide full references for published measures and comment on whether they are designed for the population you are using them with. Also comment on how long your interviews/questionnaires are likely to take each participant to complete. If using a non-standardised questionnaire, please include an example of it (see 4c).*

The workshops with staff will be structured using the resilience audit tool to map the activities and resources. The discussion will be free-flowing and the information will be collected on flip chart paper. The workshops will last approximately 1.5 hours. The interviews with staff will be structured around a set of carefully predetermined questions but the discussion will be free-flowing. The interviews will be recorded and transcribed. The interviews will last approximately 30 mins. The online survey will also be structured around a set of carefully

predetermined questions but there will be opportunities for participants to add in other comments. The online survey will last approximately 15 mins. (NOTE: the information sheet for the online survey will be contained within the email sent to potential participants. There will not be a separate consent form. Instead consent questions will comprise of the start of the survey). The Well-being Questionnaire will be used to test whether there are any correlations between well-being and resilience. The Well-being Questionnaire is a standardised measure that has demonstrated strong validity and reliability. The well-being questionnaire has been tested with a variety of vulnerable groups including adult carers. It will take between 10 and 15 minutes to complete. (Wellbeing Questionnaire: Tennant, R ., Hiller, L., Fishwick, R., Platt, S., Joseph, S., Weich, S., & Stewart-Brown, S. (2007a). The Warwick-Edinburgh mental well-being scale (WEMWBS): development and UK validation. *Health and Quality of Life Outcomes, 5(1), 63.)* The resilience rating scale is based on our definition of resilience and comprises of a question to carers about 'how able to carrying on caring they feel at this point in time?' Followed by a question on each area of our resilience model (ability to cope with stress, ability to maintain other roles, family & friend support, community support). Carers rate their answers on a 5 point scale.

f) Procedure. *How will you actually collect your data?*
The well-being questionnaire will be completed by carers at the point of first contact with the carers centre and again 12 weeks later. It is a self-report measures. The interviews will be recorded via an audio recording device. Interview recordings will be transcribed. The survey will be completed online via survey monkey. Notes will be taken during the workshops and the ethnographic observation of carer support workers. The rest of the data is information that the carers centre already has systems and processes for collecting. They will provide me access to their databases at their office, with supervision.

g) Analysis*. What kind of analyses do you plan to undertake? Statistical? Interpretative Phenomenological Analysis? Thematic Analysis? Grounded Theory? Other?*

A range of analysis will be undertaken. Some of the data is qualitative and the Grounded Theory Approach that has been used in the previous phases of the research will be used again. Statistical analysis using SPSS will be conducted for the quantitative data e.g. the resilience scale and well-being questionnaire. The finance data will be analysed simply to calculate the unit cost of support. This will be done using standard cost analysis methodology.

Section 3 Ethical Considerations

h) Will you pay participants for taking part in the research? State your rationale for paying/not paying and the likely impact on participation.

No payment will be offered as participation is entirely voluntary and there is no wish to affect participants' right to withdraw from the research.

i) How do you intend to give feedback to participants (and, where relevant, other interested parties)?

The results for each carers centre will be written up into a cost-benefit report for their purposes. The carers centre and individual participants will be offered the opportunity to discuss the research results from this study. It is hoped that the results will inform the basis for further research and study and be developed for publication.

j) How will you obtain informed consent from potential participants?

It is believed that all participants will be able to give informed consent. Information sheets, consent forms and complaint forms will be provided to participants in order to establish informed consent.

k) How will you ensure that the identities of participants are kept confidential during the project, and in any subsequent data analysis, conference presentations and publications?

Participants will be informed that the information they supply will be discussed with the researcher's supervisor and the results may be published in journal form. However, all identifiers such as names, addresses etc will be removed, so that data will be anonymous. Data will be kept for 10 years and will be stored in accordance with the Data protection Act (1998). All material will be kept in locked cabinets and linked computer records will be password protected. In terms of confidentiality, ground rules (including confidentiality) will be discussed at the beginning of each workshop, interview and observation.

l) Explain how you will meet the four main ethical principles of research,

I. Causing no harm: consider what risks or burdens (e.g. distress, embarrassment) your research could have for participants and how you can minimise these. Are there any risks for you as the researcher?

The study will build on previous studies and findings. Participants will have the right to withdraw at any time without having to give a reason. If the participant choses to withdraw at any point, their choice will be respected. All participants will be provided with information and advice as to how they can access ongoing support via their carer network. The researcher will discuss any significant issues that arise with her supervisor.

If at any point a participant discloses information that causes the researcher serious concern (such as the immediate risk of harm) the researcher will discuss with the participant her need to disclose this information. She will then disclose the information to her supervisor and any other appropriate bodies that she has discussed with the participant. Participants will be made aware of these limits of confidentiality at the start of every research activity.

II. Doing good: consider what good could result for the participants and how the potential for good can be maximised.

Many carers feel 'unlistened to' and 'disempowered' so carers who participate may benefit from sharing their experiences and being formally listened to, as part of the research. In addition, it is believed that the research will do good in the long run as it will be used to help the development of better support for carers.

The carers centres have also been looking to develop cost-benefit reports to help them better understand the impact their work has, how they can improve that impact and to help them engage in a more informed conversation with commissioners and other funders.

III. Respect: consider how you will treat your participants with respect including giving them sufficient information and ensuring they are able to make their own choices about participating.

Information sheets, consent forms, and complaint forms will be provided to participants in order to establish informed consent. Autonomy will be respected by using a focused conversation style of inquiry into subjective meaning from the participants i.e. how people feel, make sense of and interpret their feelings.

IV. Justice: consider the likely outcomes of your research and to whose advantage or disadvantage the results of the research might be put.

It is believed that the research will be an advantage to carers, carers' families, services and practitioners in the long run, and it may benefit participants in the short run (see above under 'doing good'). The main disadvantage for participants is that it will take some of their time and both carers and carer support staff often feel hard pressed for time.

The researcher will also benefit as the evaluation will be part of her PhD.

m) Are there any power imbalances between researcher and participants that may make it difficult for participants to refuse their participation?

It is possible that some carers and staff could experience a power imbalance between themselves and the researcher that might make it difficult for participants to refuse participation initially. This will hopefully be overcome by contacting potential participants via the carers centres rather than the researcher contacting people directly. There is also some potential for people to feel like they cannot withdraw and so it must be made clear that this is acceptable and participants will be supported to do so without them having to justify why. Furthermore, because the researcher holds a position of authority and perceived influence during the interview it is important that the researcher remain neutral hence refraining from agreeing/disagreeing, or praising/denigrating any comment made.

n) How the research will pay attention to cultural diversity: e.g. include the experiences of people from Black and minority ethnic communities; be respectful of cultural differences; provide appropriate interpreters where necessary (NB. researchers should note that this often involves more than simply finding someone who speaks the same language).

To respect cultural diversity the researcher will seek guidance from the Carers Centres and Networks, who will be advising on potential participants. It is hoped that these Centres will have a working knowledge of the participants' cultures, beliefs etc. No one will be excluded on the basis of culture, religion or beliefs. Any

steps required to increase accessibility to people whose first language is not English will be taken such as the use of an interpreter.

3. Section 4Security Sensitive Material

Does your research involve access to or use of material covered by the Terrorism Act?

No

Section 5 Attachments

CONSENT FORM (Staff)

Title: ***Understanding resilience in family carers***

Researcher: Sarah Broadhurst
Supervisor: Prof. Glynis Murphy
Email: sb793@kent.ac.uk, g.h.murphy@kent.ac.uk
Telephone number: 07824569466

Please tick
To confirm

- ☐ I confirm that I have read and understood the information letter attached for the above study.
- ☐ I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.
- ☐ My questions have been answered to my satisfaction.
- ☐ I agree to take part in the (please tick as appropriate):
    - Interview
    - Workshop
    - Ethnographic observation

  for the research study '*Understanding resilience in family carers'*.

For the interviews only

- ☐ I agree to the interview being recorded for the purposes of transcribing and capturing the information.

Name:_____ Date:_____

Signature:_____

CONSENT FORM (carers)

Title: ***Understanding resilience in family carers***

Researcher: Sarah Broadhurst
Supervisor: Prof. Glynis Murphy
Email: sb793@kent.ac.uk, g.h.murphy@kent.ac.uk
Telephone number: 07824569466

Please tick
To confirm

- ☐ I confirm that I have read and understood the information letter attached for the above study.
- ☐ I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.
- ☐ My questions have been answered to my satisfaction.
- ☐ I agree to take part in the research study '*Understanding resilience in family carers'*.

Name:_____ Date:_____

Signature:_____

Information Sheet (Staff Online Survey)

Title: ***Understanding resilience in family carers***

NOTE: This will not actually be a paper information sheet. Instead it will be the information provided in the email sent to carers containing the link to the online survey.

Dear XXX,

You are being invited to take part in a research study conducted by Sarah Broadhurst, who is a PhD student at the Tizard Centre at University of Kent. Her supervisor is Professor Glynis Murphy who works at the University of Kent.

Your participation in this study is entirely voluntary. Before you decide whether you want to take part it is important for you to understand why the research is being conducted and what it will involve.

What is the purpose of the study?
The purpose of this study is to understand resilience in family carers. I would like you to complete an online survey.

The online survey questions consist of:

- What do you think is the purpose of the carers centre?
- What impact do you think the support from the carers centre has on the ability of carers to keep caring?
- Do you think the support results in any other outcomes for carers?

Why have I been invited to take part in the research study?
You have been invited to participate in an online survey as you are either a staff member, a Trustee or you fund the carers centre?

What would I have to do if I agreed to take part?
If you would like to take part in the online survey please click on the link below: (a link will be included).

Do I have to take part?
Your participation in this study is entirely voluntary. It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time, without giving a reason. If you are a staff member it will not affect your employment if you decide not to take part.

Will what I say in this study be kept confidential?
Material gathered during this research will be treated as confidential and securely stored. Only the researcher, her supervisor and her research assistant will have access to the material.

What will happen to the results of the research study?

The information you provide us with will be used to produce part of the researcher's PhD, and will be published in a scientific journal. It will also be summarised on the Tizard website, presented at conferences to raise awareness of carer issues and will be published in a magazine such as Community Care. Specific individuals will not be identifiable from the results as no names will be used. At the end of the study the researcher will send you a summary of the results. Again no individuals will be identifiable at all.

Who is organising and funding this research?
The research has ethical approval from the Tizard Ethics Committee. The University of Kent is funding this research and will hold the findings as well as the actual report of the current study.

What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. In the first instance you can speak to the researcher, Sarah Broadhurst or her supervisor Professor Glynis Murphy (contact details below) who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by completing the complaints form attached.

Contact
Please do not hesitate to contact the researcher (Sarah Broadhurst, email: sb793@kent.ac.uk tel no: 07824569466) or the supervisor of the research (Prof. Glynis Murphy, email: g.h.murphy@kent.ac.uk) if you have any queries. If you wish to take part please click on the link below (a link to the survey will be included).

Thank you for taking the time to read this.
Sarah Broadhurst

Information Sheet for Carers (online survey)

Title: ***Understanding resilience in family carers***

NOTE: This will not actually be a paper information sheet. Instead it will be the information provided in the email sent to carers containing the link to the online survey.

Dear Carer,

You are being invited to take part in a research study conducted by Sarah Broadhurst, who is a PhD student at the Tizard Centre at University of Kent. Her supervisor is Professor Glynis Murphy who works at the University of Kent.

Your participation in this study is entirely voluntary. Before you decide whether you want to take part it is important for you to understand why the research is being conducted and what it will involve.

What is the purpose of the study?
The purpose of this study is to understand resilience in family carers. I would like you to complete an online survey.

The online survey questions consist of:

- What do you think is the purpose of the carers centre?
- What impact has the support from the carers centre had on your ability to keep caring?
- Has the support you've received resulted in changes related to:
    - Your relationship with the person you care for?
    - How you feel about the condition, symptoms or behaviours you manage as a carer?
    - How you feel about yourself or your sense of identity?
    - Your relationships with other family or friends?
    - Your ability to maintain other roles such as being employed?
    - Your ability to access the support you need?
    - The degree to which you feel valued for the work you do as a carer?

Why have I been invited to take part in the research study?
You have been invited to participate in an online survey as you are a carer who has received support from the carers centre?

What would I have to do if I agreed to take part?
If you would like to take part in the online survey please click on the link below: (a link will be included).

Do I have to take part?
Your participation in this study is entirely voluntary. It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time,

without giving a reason. It will not affect any of your services if you decide not to take part.

Will what I say in this study be kept confidential?
Material gathered during this research will be treated as confidential and securely stored. All data will be anonymised by replacing names for ID numbers. Only the researcher, her supervisor and her research assistant will have access to the material.

What will happen to the results of the research study?
The information you provide us with will be used to produce part of the researcher's PhD, and will be published in a scientific journal. It will also be summarised on the Tizard website, presented at conferences to raise awareness of carer issues and will be published in a magazine such as Community Care. Specific individuals will not be identifiable from the results as no names will be used. At the end of the study the researcher will send you a summary of the results. Again no individuals will be identifiable at all.

Who is organising and funding this research?
The research has ethical approval from the Tizard Ethics Committee. The University of Kent is funding this research and will hold the findings as well as the actual report of the current study.

What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. In the first instance you can speak to the researcher, Sarah Broadhurst or her supervisor Professor Glynis Murphy (contact details below) who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by completing the complaints form attached.

Contact
Please do not hesitate to contact the researcher (Sarah Broadhurst, email: sb793@kent.ac.uk tel no: 07824569466) or the supervisor of the research (Prof. Glynis Murphy, email: g.h.murphy@kent.ac.uk tel no. 01227 823960) if you have any queries. If you wish to take part please click on the link below (a link to the survey will be included).

Thank you for taking the time to read this.
Sarah Broadhurst

Information Sheet for STAFF (workshops, observations, interview)

Title: ***Understanding resilience in family carers***

Dear XXX,

You are being invited to take part in a research study conducted by Sarah Broadhurst, who is a PhD student at the Tizard Centre at University of Kent. Her supervisor is Professor Glynis Murphy who works at the University of Kent.

Your participation in this study is entirely voluntary. Before you decide whether you want to take part it is important for you to understand why the research is being conducted and what it will involve.

What is the purpose of the study?
The purpose of this study is to understand resilience in family carers. I would like to talk to you about resilience, carers and the support provided by the carers centre. I am to do this via some workshops, ethnographic observations and interviews.

The workshops will focus on mapping the resources used by the carers centre and the activities the resources are used to deliver.

The ethnographic observations will involved spending a day with a carer support worker and observing the activities they engage in.

The interview questions will be structured on the model of resilience that has been developed with carers. The discussion will be free flowing and I will be asking for your opinion, experience and understanding of the various aspects of the model and the support provided by the carers centre. The interview will take approximately 30 minutes.

Why have I been invited to take part in the research study?
You have been invited to participate in an interview because you work at the carers centre?

What would I have to do if I agreed to take part?
If you would like to participate in any of the above then please complete the consent form attached.

Do I have to take part?
Your participation in this study is entirely voluntary. It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time, without giving a reason. It will not affect your employment if you decide not to take part.

Will what I say in this study be kept confidential?
Material gathered during this research will be treated as confidential and securely stored. All data will be anonymised by replacing names for ID numbers. Only the researcher, her supervisor and her research assistant will have access to the material. The interviews will be recorded for purposes of analysis. The recording will only be listened to by the researcher, her supervisor and her research assistant. The

recording will be destroyed once the analysis is complete. If at any point you disclose information that causes the researcher serious concern (such as the immediate risk of harm) the researcher will discuss with you her need to disclose this information. She will then disclose the information to her supervisor and any other appropriate bodies that she has discussed with you.

What will happen to the results of the research study?
The information you provide us with will be used to produce part of the researcher's PhD, and will be published in a scientific journal. It will also be summarised on the Tizard website, presented at conferences to raise awareness of carer issues and will be published in a magazine such as Community Care. Specific individuals will not be identifiable from the results as no names will be used. At the end of the study the researcher will send you a summary of the results. Again no individuals will be identifiable at all.

Who is organising and funding this research?
The research has ethical approval from the Tizard Ethics Committee. The University of Kent is funding this research and will hold the findings as well as the actual report of the current study.

What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. In the first instance you can speak to the researcher, Sarah Broadhurst or her supervisor Professor Glynis Murphy (contact details below) who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by completing the complaints form attached.

Contact
Please do not hesitate to contact the researcher (Sarah Broadhurst, email: sb793@kent.ac.uk tel no: 07824569466) or the supervisor of the research (Prof. Glynis Murphy, email: g.h.murphy@kent.ac.uk tel: 01227 823960) if you have any queries. If you wish to take part please complete the consent form attached.

Thank you for taking the time to read this.
Sarah Broadhurst

Information Sheet for CARERS (Rating Scales)

Title: ***Understanding resilience in family carers***

Dear Carer,

You are being invited to take part in a research study conducted by Sarah Broadhurst, who is a PhD student at the Tizard Centre at University of Kent. Her supervisor is Professor Glynis Murphy who works at the University of Kent.

Your participation in this study is entirely voluntary. Before you decide whether you want to take part it is important for you to understand why the research is being conducted and what it will involve.

What is the purpose of the study?
The purpose of this study is to understand resilience in family carers.

Why have I been invited to take part in the research study?
You have been invited to participate because you are a carer who has contacted the carers centre?

What would I have to do if I agreed to take part?
You can participate by completing the one page Well-being Questionnaire and rating how resilient you feel today on using our resilience rating scale. In 12 weeks time we will ask you to repeat the questionnaire and again rate how resilient you feel.

Do I have to take part?
Your participation in this study is entirely voluntary. It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time, without giving a reason. It will not affect any of your services if you decide not to take part.

Will what I say in this study be kept confidential?
Material gathered during this research will be treated as confidential and securely stored. All data will be anonymised by replacing names for ID numbers. Only the researcher, her supervisor and her research assistant will have access to the material. If at any point you disclose information that causes the researcher serious concern (such as the immediate risk of harm) the researcher will discuss with you her need to disclose this information. She will then disclose the information to her supervisor and any other appropriate bodies that she has discussed with you.

What will happen to the results of the research study?
The information you provide us with will be used to produce part of the researcher's PhD, and will be published in a scientific journal. It will also be summarised on the Tizard website, presented at conferences to raise awareness of carer issues and will be published in a magazine such as Community Care. Specific individuals will not be identifiable from the results as no names will be used. At the end of the study the researcher will send you a summary of the results. Again no individuals will be identifiable at all.

Who is organising and funding this research?
The research has ethical approval from the Tizard Ethics Committee. The University of Kent is funding this research and will hold the findings as well as the actual report of the current study.

What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. In the first instance you can speak to the researcher, Sarah Broadhurst or her supervisor Professor Glynis Murphy (contact details below) who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by completing the complaints form attached.

Contact
Please do not hesitate to contact the researcher (Sarah Broadhurst, email: sb793@kent.ac.uk tel no: 07824569466) or the supervisor of the research (Prof. Glynis Murphy, email: g.h.murphy@kent.ac.uk tel no: 01227 823960) if you have any queries.

If you wish to take part please complete the consent form attached.

Thank you for taking the time to read this.
Sarah Broadhurst

Comments Form

This form should be used for feedback involving sessions (workshops, interviews or observations) connected to the research on 'Understanding Resilience in family carers' conducted by Sarah Broadhurst. Every effort will be made to ensure confidentiality, consistent with a full investigation of any complaint.

1. Name	
2. Address for correspondence	
3. Research Study Title	Understanding resilience in family carers
4. Date and time of Session	
5. Principal/Chief Investigator	Sarah Broadhurst
6. Researcher(s)	Sarah Broadhurst

7. Comments (please ensure that all relevant details are provided, attach additional sheets if necessary).
8. Please summarise any informal action taken to resolve any issues or explain why informal action was not considered to be appropriate:

I understand that a copy of this form will be provided to any member of staff who is the subject of the comments, or who is otherwise involved.

I understand that a copy of this form will be provided to the Tizard Ethics Committee.

Signed_____ Date:_____

Completed forms should be returned to Glynis Murphy:

The Supervisor: Professor Glynis Murphy g.h.murphy@kent.ac.uk

Address: Tizard Centre, University of Kent, Canterbury, Kent, CT2 7LR

Tel. number: 01227 823960

The researcher: Sarah Broadhurst sb793@kent.ac.uk

The secretary of the Ethics Committee: Jo Ruffels

Address: Tizard Centre, University of Kent, Canterbury, Kent, CT2 7LR

The Head of School: Julien Forder

Address: SSPSSR, faculty of Social Sciences, Cornwallis North East, University of Kent, Canterbury, Kent, CT2 7NF

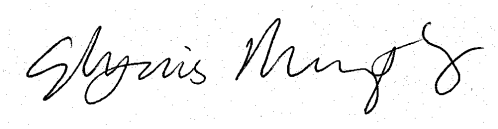
Tizard Ethics Feedback Form

Student Name:	Sarah Broadhurst
Supervisor:	Prof Glynis Murphy & Dr Nick Gore
Title:	*Understanding Resilience in Family Carers*

The Tizard Ethics Committee have received the amended proposal and confirm that this has ethical approval.

Signed: **J.Ruffels** **Date:** **22.03.18**

On behalf of Tizard Ethics Committee

Alterations approved by Supervisor	 15/2/18 **Signature** **Date**
Final approval On behalf of Tizard Ethics Committee	 **Michelle McCarthy** **Signature** **Date** **22.03.18**

Appendix Five: Letter to Ethics Committee and Approval Letter

38 Parkers Circus
Chipping Norton
Oxon
OX7 5LZ
4th April 2018

Dear Ethics Committee,

Student Name: Sarah Broadhurst
Research Study: Understanding Resilience in Carers

I submitted an application to the ethics committee in December 2017. The application requested approval to undertake two cost-benefit evaluations of Carer Centres. In the application I stated that:

All new referrals for a period of 2 months will be asked to complete the well-being questionnaire and to rate on a 5 point scale the degree to which they feel able to continue caring. The measures will be repeated 12 weeks later.

I had discussed this methodology with the carers centres and originally they felt it would be fine. However, due to their rerducing resources and hence capacity we have needed to shorten the period from 2 months to 2 weeks and measures will be repeated after 6 weeks not 12 as 6 weeks is when they do their usual follow-up calls and so it does not require extra resource.

Secondly, when the carers centres started using the well-being checklist they had a lot of negative reactions from carers in relation to a couple of the questions. Furthermore, the 5 point 'able to continue caring' scale did not seem to work well either. We therefore piloted the short well-being questionnaire[5] and the brief resilience scale[6] with a carer support workers and a few carers. The response has been very positive and therefore I would like to replace the original scales with these.

Yours Sincerely,



Sarah Broadhurst

[5] Short Warwick Edinburgh Mental Well-Being Scale (SWEMWBS) (2008) NHS Health Scotland, University of Warwick and University of Edinburgh

[6] Smith, B. W., Dalen, J., Wiggins, K., Tooley, E., Christopher, P., & Bernard, J. (2008). The brief resilience scale: assessing the ability to bounce back. International journal of behavioral medicine, 15(3), 194-200

Approval Letter

On 06/04/2018 18:56, Michelle McCarthy wrote:
Sarah,
I approve this change of questionnaire, as it has no ethical implications.

Jo,
Please can you keep this email on file, as a record.

Thanks.
Michelle

Appendix Six: Initial Findings from the first set of focus groups

This appendix summarises the direct responses carers gave to the questions outlined above. At this point no coding had been done. The audio recordings were transcribed and imported into NVivo. The researcher looked at each question and summarised the responses from all three focus groups. This was a way of checking for commonalties across focus groups.

- What tasks do you do as part of your caring role?

The range and number of tasks carers were doing with or for the person they cared for were enormous regardless of the condition the person they cared for had. Tasks included: cooking, shopping, cleaning, hairdressing, attending hospital/Drs appointments, administering medication, managing finances, supporting with homework, providing support to use the toilet, moral support, telephone chats, holding and containing the emotions, support to manage time, planning things to do, replacing activities when necessary. Sorting out benefits, advocating, teaching safety e.g. healthy eating, road safety. Providing entertainment, maintaining family links, sorting out crises, helping the care recipient to stay calm. Stoma care, wound dressing, peg feeding.

- What roles do you play as part of your caring role?

Regardless of who they were caring for participants reported performing multiple roles including nurse, doctor, teacher, advocate, financial advisor, friend, counsellor, coach, pastor, hair dresser, financial manager, gardener, cleaner, activities manager, driver, mother, personal care assistant, health and safety officer, healthcare assistant, negotiator, technical advisor, computer expert, finance officer, cleaner, diplomat, social skills teacher, taxi driver, PA, co-ordinator, sole decision-maker, psychologist, psychiatrist, dietician, occupational therapist, parent to your spouse who you shouldn't need to be a parent to.

- What skills do you need / have you learnt as part of your caring role?

Carers recounted a wide range of skills including: cooking, social skills, listening, patience, research skills, educating, juggling, knowing when to let go, IT skills, ability to remain professional and keep work life separate (if you have one), ability to remain calm, to care for themselves, sign language, study legislation and statementing, the need to and how to challenge social workers, learning the system, to be demanding, never to give up, never take no for an answer, social stories.

- How does your caring role leave you feeling? What emotions do you experience?

Feelings of isolation and a sense of losing one's own identity seemed to be common experiences. Participants reported a mixture of feelings that oscillated between anger, sadness, guilt, frustration, hopelessness and exhaustion to pride, fulfilment and love. Carers said they felt: drained, terrified, panicky, self-pity, bitter, powerless, head buzz because they were overwhelmed with everything there was to do and think of, violent, guilty, stressed, worried, lost, sense of loss, losing sense of belonging, loss of reality, isolated, confused, life was meaningless, losing self-esteem, lack of confidence. Pressure of being irreplaceable. More than one carer stated:

‘What happens when I am no longer here’.

Most carers said they either felt or had experienced depression and some recounted feelings of shame.

- What is the impact of your caring role on your life? What are the consequences for you?

The consequences of being a carer included, a reduction in financial resources due to decreased income from working less or not at all which went on to result in a decreased pension. A negative impact on physical and mental health, restricted family life, restricted holidays, restricted social life:
‘I am restricted in what I can do and when I can do it’.

Loss of friends, dealing with huge amounts of negative change, loss of job, loss of income, loss of profession/career, loss of time, loss of identity, all resulting in depression.

‘There is a negative impact on children and siblings, all your relationships with family and friends are put under strain because you get pulled in lots of different directions, often resulting in family breakdown on more than one level’.

‘You constantly have to think about the safety of the cared for person which results in lots of environmental consequences for example, the car you drive, the house you live in, where you go out’.

‘You face a lot of stigma, people being judgemental and unhelpful, they think they know better. Overtime you learn to avoid unhelpful people, but your support system starts to shrink as you avoid some people and others avoid you’.

Dealing with behaviour or the manual handling involved in personal care resulted in back and shoulder problems sometimes resulting in surgery. Some carers commented that the journey had been so harrowing that they experienced post-traumatic stress disorder.

Unanimously carers talked about experiencing one thing after another which led to them feeling like they had reached the end of their tether. Many of the participants recounted stories of being forced to continue their caring role because there was no alternative, no services, little support and no one else to do the job.

Some carers described that the sense of reaching the end of the road had resulted in them having a breakdown. In some cases, people had attempted to take their own lives.

Participants felt that positive consequences included learning more about themselves and strengths they didn’t know they had and learning to take pleasure in the small things in life.

- What does resilience mean to you in relation to your caring role?

When asked how they would describe resilience carers said it was the ‘the ability to keep caring’ which required the perseverance to keep fighting and:

‘The ability to keep repeating yourself’.

‘To keep applying yourself to the same situation again and again’.

‘To keep bouncing back from the set-backs’.

‘The ability to continue loving and to maintain hope’.

‘To survive on no sleep again and again’.

‘The ability to develop a thick skin and not sink under the unhelpful advice and lack of empathy from well-meaning friends, family and professionals.’

‘To have a strong internal sense of your own value and the value of what you are doing’.

Carers commented that they felt resilience was something that developed over time because there was no escape:

‘You have to go on caring, you have no choice.’

‘I would think thank god I have survived another day and then I would get up and do it all again’.

For some resilience was about their ability to keep caring by not allowing their spirit to be crushed.

- What does or would help you to be resilient?

A good support network, decent services, clear information and advice, knowing who and how to ask for help were all mentioned as factors that helped people to ‘keep going’. Carers also said:

‘ring fencing my own time’,

‘feeling like I might be able to get through – hope’,

‘accepting life and managing my life’,

‘maintaining and sustaining daily life’,

Some felt that resilience related to their ability to have some part of themselves that was not a carer and to be supported to keep that. Others stated that the ability to feel small rewards, coping with whatever the day brings, knowing that they had done the best that they could and coped the best they could without compromising themselves was what kept them going. Having inner strength, resourcefulness, and learning to cope one day at a time were all things carers mentioned as important in their ability to keep caring.

For some carers maintaining their resilience meant prioritising time to sleep. For others it meant understanding the law themselves so that they were better informed of their rights and those of the care recipient.

Carers also mentioned family, friends, sense of community, carers' centres, cognitive behavioural therapy, praise and positive feedback from the person they were caring for, loving and feeling loved, reminding themselves of everything they had achieved, writing things down, recognising their own individual strengths (important because of losing their identity in other ways), speaking to other carers who understood, having empathy, short breaks, walking, gardening, exercise, having other interests, feeling valued, laughter, being self-affirming, knowing their own limits were all important for maintaining resilience.

- What services help (or would help) you to be resilient?

Carers mentioned a range of organisations and services that they felt had helped or could help them. Local carers' centres, Memory centre, Crossroads, Carers UK, Help the Aged, British Heart Foundation, MIND, other charities, Mental Health Services, Hospices, talking therapies, faith community, better co-ordination, partnership and co-operation between all parties including Local authorities and other services.

One carer stated: 'when dealing with a crisis we can't take things in physically, emotionally, mentally. It can take 6 weeks to feel like you are functioning again. Counselling and talking (provided by the carers' centre) helped me to contain each crisis. To keep it boundaried. It's crucial in finding a way forward.'

Finally, carers felt there was a need for better formal carer support so that carers didn't feel like they were the first or only person to do it. This needed to include better information and access to people who knew what they were talking about. Carers felt there was a need for advocates for carers who had a good understanding of employment law, carers rights and flexible working. Some would welcome a legal hotline. Carers felt that there needed to be more teaching and training for staff including medical / health staff. Carers wanted to experience a more holistic and family centred approach.

Appendix Seven: Example of line by line coding

Below is an extract from the transcript for the first focus group. It illustrates the verbatim transcript and the initial line by line coding.

Who	Comment	Initial Code
Facilitator	What are the tasks you do in your caring role?	
	Where do you start? (laughter)	All consuming
Facilitator	I guess, it's, it's huge isn't it? That's why I said hmmm simple, huh	All consuming
	Perhaps it's easier to say what we don't do	All consuming
	Supervision	Multiple roles
	Keeping people safe	Multiple roles
	It's things we do that we wouldn't do if we was doing a job	Scale of the caring task
Facilitator	Yes… keeping safe	Multiple roles
	Listening	Multiple roles
	Fighting for services and needs to be met	Fighting for services
	Prompting with hygiene	Multiple roles
	Making sure she's taken all her medication	Multiple roles
	Teaching new skills	Multiple roles
Facilitator	Can you give me an example?	
	Um, teaching my son to spread butter on his toast, put his trousers on, tie his shoelaces, have a shower, count to five, um, everything really	Complex tasks
Facilitator	Thank you	
	Life skills	Multiple roles
	Yeah	
	Feeding	Complex tasks
	Playing…	Complex tasks
	Toileting, sorry	Complex tasks
	Playing computer games, so you're sort of, um, you become a friend rather than a parent	Multiple roles
	Emotional support…	Multiple roles
	Full personal carer, washing, dressing, toileting, you know and…	Scale of the caring role
	Manual handling	Moving
	Manoeuvring	Moving
	Man-handling	Moving
	Manoeuvring, yeah	Moving
	Yeah	
	You mustn't let anybody see you do that	Hidden world
	You don't know what they're thinking	Hidden world
	Don't, don't do it…	Hidden world
	I won't even suggest doing…	Hidden world
	Helping with finances	Multiple roles
	Yeah, I was about to say financial support, i.e. paying, erm… well, just giving him money at the	Multiple roles

	moment, my eldest because he doesn't have a paid job	
	I've been specially trained, er, to be a carer to do this parenteral nutrition at home	Specific skills
	It's quite complicated the amount, I was said to undergo special training at the hospital	Specific skills
Facilitator	Well, that's actually, that brings us onto my next thing. What skills have you had to learn?	
	Put down PN, it's short for parenteral nutrition	Specific skills
Facilitator	Okay, thank you	
	plus, um, stoma care	Complex tasks
Facilitator	Stoma	Complex tasks
	Er, wound dressing and, er, before she had on, on a (not sure), she had, erm, what they call peg feeding (?) so dealing with an artificial feeding through a, what they call a peg tube	Complex tasks Specific skills
Facilitator	Okay	
	Before all those I was, I had to undergo a course of training at the hospital, er, for all those	Specific skills
	Signing another alternative communication	Specific skills
	Psychology, how to outwit (laughter)	Multiple roles
Facilitator	And was that something, is that something you got, like, input or is it something you've had to learn	
	It's something I've had to learn	Learn
	It's also, er, the same thing, er, getting them to do something, you know, to actually move and do some exercise and stuff like that	Motivate
	Patience	Patience
	Oh, good one	Patience
	Definitely	Patience
	Reassure	Reassure
	Reassurance and motivational skills	Reassure Motivate
	Um, and dealing with…	
	Exercising	Exercise
	Intellectual stimulation	Stimulate
	We'll be here all morning	All consuming
	Yeah, how long have we got?	All consuming
	Yes	All consuming
	Stamina, is one thing, you know it's very easy if you're not looking after somebody to lounge around and enjoy yourself but you have to have stamina	Stamina
	Yeah, the ability to survive on no sleep	No sleep
	Stamina can get some sleep (laughter)	Stamina

Appendix Eight: Example Memos

Below is a memo written after the first focus group.

011215

Summary of the Roles Carer's play for the cared for person: Safety and safeguarding, counsellor, coach, friend, pastor, hair dresser, financial manager, gardener, cleaner, activities manager, driver, mother, personal care assistant, advocate, teacher, healthcare assistant, health and safety officer, negotiator, technical advisor, computer expert, finance officer, cleaner, diplomat, social skills teacher, taxi driver.

My Reflections:

Every area of life.

All consuming.

So many different hats.

The need to swap in and out of the various roles quickly and seamlessly.

If you are playing so many different roles for another person when do you have a chance to play the role of you?

The roles they play for the cared for person increases but the number of roles they have within their network / community and the wider society decreases.

Feels like there is a spotlight on the cared for person and the carer dances around the edges of the spotlight - sometimes darting into the centre - as the spotlight becomes more focused the area the carer has to 'dance' in becomes more and more restricted. What happens in the background - in the shadows - no one knows.

Emerging Themes:

The enormity of the caring role.

The complexity of the caring role.

Carer as 'the skilled helper'.

The hidden life of the carer.

Below is a memo from the positional mapping in part 1, study 1

WHAT?
This positional map maps out the positions related to caring being the default position versus a choice and the carer being hidden and not valued versus visible and highly valued.

SO WHAT?
Analysing the various positions surfaces some other themes around commitment to invest in carer support services or not and whether being able to continue to care is simply down to personal skills, attitudes and knowledge or where the community support plays a part.

Other themes that run through the discourses linked to emotions. Positions where the caring role is not recognised and the focus is on the relationship there is a sense of expectation that it is one's duty to undertake the caring role. That it is something you should want to do and should be capable of doing with little support. This leads to experiencing feelings of guilt, shame, sense of duty and resentment.

Where the role of carer is recognised but not the relationship there again is a sense of expectation that because you've chosen to do this you should be able to do it well and with little support. Therefore as a carer if you're struggling it feels impossible to admit it and there is no sense of who to ask for help. Again this could lead carers to feeling despairing as there may be no light at the end of the tunnel. This position is likely to leave carers who are struggling fighting to maintain their self-esteem.

In positions where both the relationship and the caring role are recognised there can still be a sense of blame and control as position 4 demonstrates.the impact on carers of this position is again likely to be a mixture of anger, frustration, despair, and low self-esteem.

Position five does suggest some investment in carer support services but there is still a tendency to oversimplify the support that is required. That said the recognition of both relationship and the carer role probably help in supporting the carer to access help when they need it.

Position six provides recognition of both relationship and the carer status but crucially it also recognises that there should be some choice involved and that family carers should have some options around how much care they provide and the nature of that care. this position recognises the need for investment in carer support and an investment in services for the care recipient.

WHAT NEXT?
What are the discourses around investment in carer support versus not in carers ability to keep caring being about them versus community support?

What happens when family carers choose to stop or reduce their caring role?

Below is a memo written during the social arena mapping for part 1, study 3

WHAT IS THE FOCUS OF THIS ARENA?
Social arena identifies the social worlds that are relevant to the former carer.

WHAT SOCIAL WORLDS ARE PRESENT AND ACTIVE?
the social worlds of the community are still present and active but it can be difficult for the former carer to re-engage with them depending upon how disengaged with them they became through the carer journey.
Likewise the social worlds of family friends and neighbours are also still present and active but again if the carer has struggled to maintain those relationships throughout the carer journey and it can be difficult for them to re-engage.

Finally the social world carers often begin to access more as the social world of health services and many former carers have an increase in health issues after the death of a loved one.

WHAT SOCIAL WORLDS ARE NOT PRESENT?
The social worlds connected to the care recipient are often all lost. These include the social world of paid carers, care homes and other professionals. It can also include the social worlds of some voluntary and community organisations if the carers access was dependent upon the care recipient.

AHAT ARE THE HOT ISSUES / CONTESTED TOPICS?
there is an assumption that the burden lifted when the care recipient dies and so former carers after a period of mourning do not require further support and in fact should regain their ability to thrive. However, both previous literature and the findings from the focus group suggests that this is not the case and that there are a number of carer legacies that leave former carers experiencing poor quality of life outcomes.

ARE THERE ANY SURPRISING SILENCES?
There is a lack of support for former carers and a lack of specialist bereavement services to support former carers to what is often complicated grief.

WHAT ELSE SEEMS IMPORTANT THAT THIS ARENA?
Social worlds change throughout the carer journey and are linked to roles people play and their sense of identity. And the reduction, loss of and difficulty re-engaging with a large amount of social worlds resonates with Larkins description of former carers entering a void.

Appendix Nine: Audit Tool

Domain	Standard	Carers' Centre Activities
Relationship with the care recipient Logic model – Activities – staff workshop and ethnographic observations. Outputs – performance management data.	Carers are supported to recognise and navigate (emotionally and practically) their (changing) relationship with the person they care for.	▪ Awareness raising to support identification of carers at the start of their journey ▪ Easily accessible information, advice and guidance ▪ Opportunity to talk to a carer support worker in a community setting e.g. GP surgery ▪ Peer support groups ▪ Counselling ▪ Free courses e.g. 'Introduction to Caring'
	Carers are supported to manage their sense of loss and feelings of guilt or shame.	
	Carers are supported to understand their caring role and the impact it does or might have on them their relationships and their quality-of-life now and in the future.	
Empowered to manage the condition, symptoms and behaviours of the care recipient Logic model – Activities – staff workshop, observations. Outputs – performance management data. Context – interviews.	Carers are supported to better understand and cope with the condition, behaviour and symptoms of the person they care for.	▪ Information, advice and guidance for carers on managing symptoms and behaviours ▪ Support to develop emergency plans ▪ Peer support groups
	Carers are supported to feel confident in their caring role and safe in terms of emergency and/or future planning.	

	Carers are supported to manage stress, their sense of loss and any mismatch between their hopes, dreams, expectations & current reality.	▪ Courses on specific conditions, managing behaviour etc. ▪ Stress management courses e.g. mindfulness ▪ Provide access to and support to engage in therapeutic activities e.g. art classes ▪ Provide access to and support to engage in healthy living e.g. healthy diets/cooking and exercise ▪ Provide access to and support to help run the house e.g. cleaning, shopping, gardening, personal admin etc. ▪ Provide access to financial advice ▪ Provide support to navigate the system, the form filling, etc.
A positive sense of self. Positive roles and identities other than carer Logic model – Inputs – workshop. Activities – workshop, observations, review of marketing information. Outputs – performance management data.	Carers are supported to maintain other roles and identities.	▪ Coaching to support carers in finding the solutions that will work for them ▪ Provide access to groups or community organisations that facilitate other roles and enable carers to contribute e.g. carers choir, volunteer schemes, faith groups, etc ▪ Support to secure flexible care for the care recipient leaving the carer 'free' to engage in other activities ▪ Work with employers to enable carers (if they want to) to continue working and care
	Carers are supported to end their caring role and move on, if and when they want or need to.	

Positive relationships with friends and family that help to meet practical and emotional needs Logic model – Inputs – workshop. Activities – workshop. Context – interviews.	Carers are supported to navigate their relationships with extended family and friends.	▪ Carer support workers work with the whole family ▪ Encourage carers to use technology to improve communication among family members ▪ Coaching to support carers to maintain relationships and build new ones (particularly if emotional needs are not being met) ▪ Access to family systems counselling
	Families are empowered to understand and support each other.	
Empowered to access and valued by the community they live, work and socialise in Logic model – Context – interviews. Inputs – workshop.	Carers are valued, listened to and involved.	▪ Involve carers in the governance and running of the carers centre ▪ Collate, share and learn from feedback from carers on their experience of support from the carers centre and the outcomes it has resulted in. ▪ Engage in campaign activities with the aim of influencing national and/ or local policy
	Carers experience and access carer-friendly communities.	▪ Raise awareness of carer's issues ▪ Work with stakeholders to improve local policy and practice e.g. GP surgeries, housing, community equipment services, social care, hospitals, leisure centres, high streets, etc.
	Carers work for carer-friendly employers.	▪ Raise awareness of carer's issues ▪ Work with local employers to improve local policy and practice.

	Carers are supported to manage experiences of oppression and/or discrimination.	▪ Information about carers rights ▪ Provide access to legal advice ▪ Provide advocacy for carers
	Carers are supported to connect with others in their community to reduce isolation and loneliness.	▪ Information and signposting ▪ Social media forums ▪ Peer support groups ▪ Working with other community services to reduce isolation and loneliness
Empowered to work in genuine partnership with professionals (individuals and organisations) Logic model – Inputs – workshop. Context – interviews.	Carers are signposted to appropriate professionals and organisations.	▪ Work with primary and secondary health care, social services and providers of care and support to better identify and support carers to get their own needs met. ▪ Contacting appropriate professionals and organisations on behalf of the carer (with their consent)
	Carers are seen as experts in their own situation and that of the care recipient	▪ Support and training for other organisations/professionals on valuing and involving carers
Measuring Carer resilience and wellbeing Logic model – Outcomes – standardised measures and online survey with impact scale.	Carer resilience is measured at first point of contact with carers centre and at appropriate, regular intervals afterwards. Carer wellbeing is measured at first point of contact with carers centre and at appropriate, regular intervals.	▪ Measure changes in carer resilience. ▪ Measure changes in wellbeing.

Appendix Ten: Short Well-being Scale (SWEMWBS)



The Short Warwick–Edinburgh Mental Well-being Scale (SWEMWBS)

Below are some statements about feelings and thoughts.
Please tick the box that best describes your experience of each over the last 2 weeks

STATEMENTS	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been feeling close to other people	1	2	3	4	5
I've been able to make up my own mind about things	1	2	3	4	5

Short Warwick Edinburgh Mental Well-Being Scale (SWEMWBS) © NHS Health Scotland, University of Warwick and University of Edinburgh, 2008, all rights reserved.

Appendix Eleven: Brief Resilience Scale

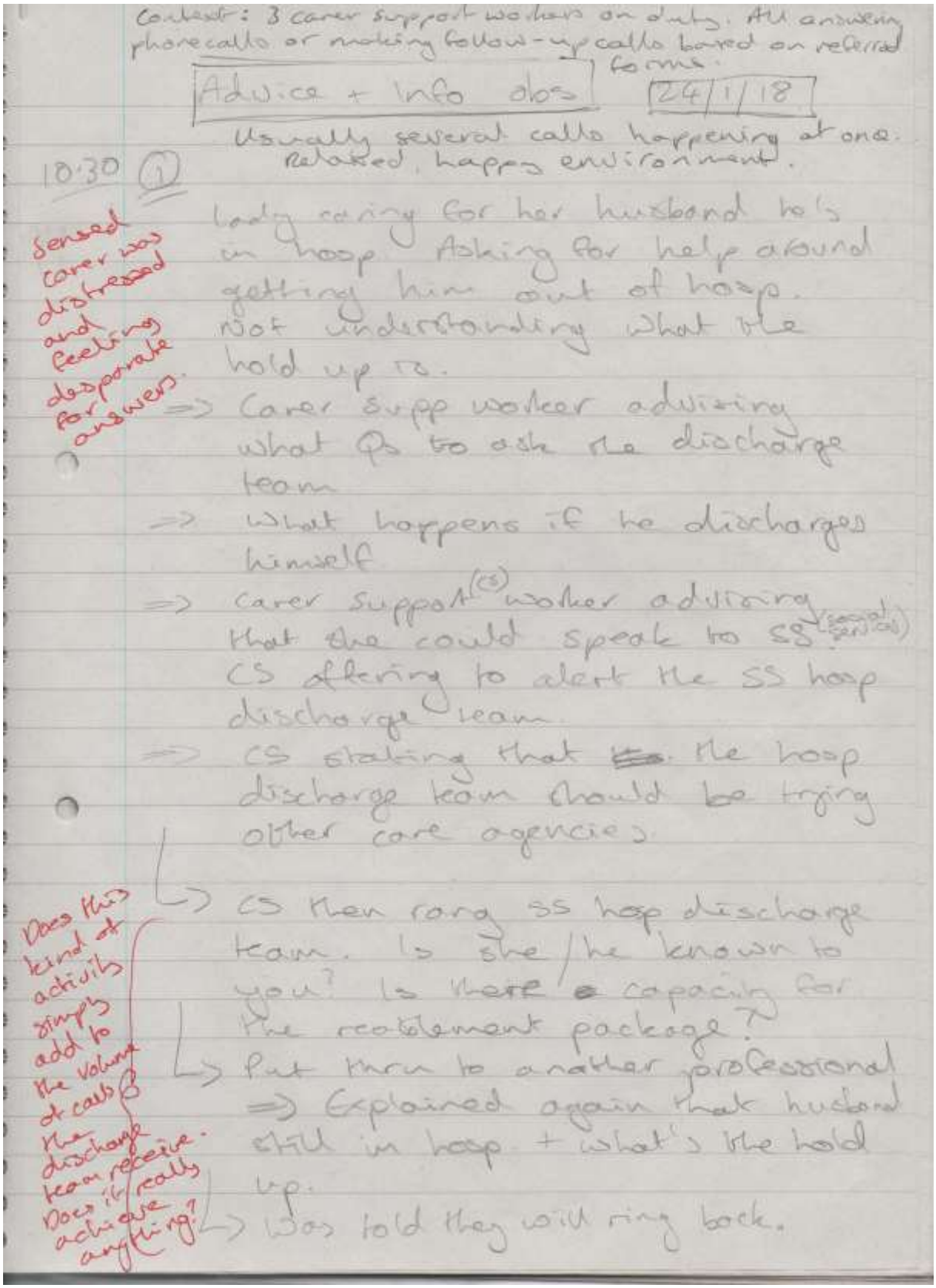
Brief Resilience Scale

Instructions: Use the following scale and **circle** one number for each statement to indicate how much you disagree or agree with each of the statements.

1 = Strongly Disagree 2 = Disagree 3 = Neutral 4 = Agree 5 = Strongly Agree

1. I tend to bounce back quickly after hard times..	1	2	3	4	5
2. I have a hard time making it through stressful events.....	1	2	3	4	5
3. It does not take me long to recover from a stressful event.....	1	2	3	4	5
4. It is hard for me to snap back when something bad happens.....	1	2	3	4	5
5. I usually come through difficult times with little trouble.....	1	2	3	4	5
6. I tend to take a long time to get over set-backs in my life.....	1	2	3	4	5

Appendix Twelve: Example of 'Day in the life of…' field notes



Context: 3 carer support workers on duty. All answering phonecalls or making follow-up calls based on referral forms.

Advice + Info days 24/1/18

Usually several calls happening at once. Relaxed, happy environment.

10:30 (1)

Sensed carer was distressed and feeling desperate for answers.

Lady caring for her husband he's in hosp. Asking for help around getting him out of hosp. Not understanding what the hold up is.

=> Carer supp worker advising what Qs to ask the discharge team

=> What happens if he discharges himself

=> carer support (CS) worker advising that she could speak to SS (social services)

CS offering to alert the SS hosp discharge team.

=> CS stating that the hosp discharge team should be trying other care agencies.

CS then rang SS hosp discharge team. Is she/he known to you? Is there capacity for the reablement package?

Put thru to another professional

=> Explained again that husband still in hosp + what's the hold up.

Was told they will ring back.

Does this kind of activity simply add to the volume of calls the discharge team receive. Does it really achieve anything?

(2) lady rang in because her husband has just come out of hosp. She had previously called in bcoz she needed care for him on a Friday so that she could go shopping.

NB Some confusion among CS about what reablement is and what it offers + who its for.

CS did not seem to have clear info about reablement offer + so could not give clear info + advice to carer.

=> Self funders: SS can arrange the care but they will charge £250 fee for arranging it

=> Contact details for community stroke coordinator

Update was that she had managed to arrange for a friend to sit w him on fridays. Now he's come been in hosp + now coming out. Trying to establish whether reablement team are involved

Previously given her the contact details for the care agencies but Carer feels they are too expensive

CS gave 2 more contact names

Eg - the community stroke coordinator
- the stroke association
To ring to get some support. If that doesn't work ring us back

When CS finished the call she spoke to one of her colleagues in a very judgemental way about the carer. Demonstrated a lack of understanding about carers + personal resilience

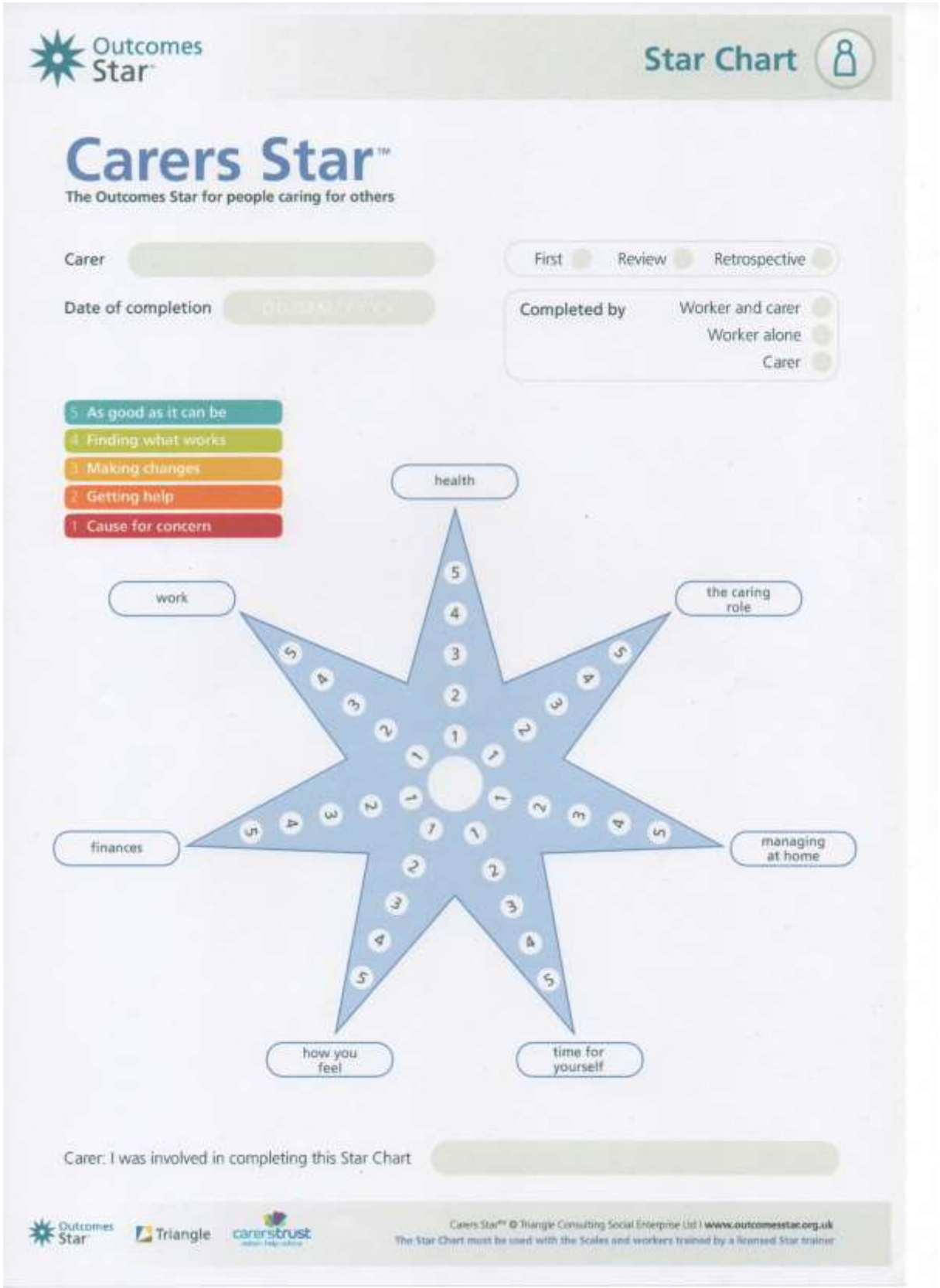
NB Some judgement about the fact that this lady was getting the full package from reablement. That she doesn't want to pay. Doesn't want to be a carer. She wants to go out + get her hair done → as if this is somehow not acceptable. She is going to have to get her head round being a carer!!

(3) Carer calling for advice about how to move their situation along. Previously known to us. Talking through the difficulties of getting her husband to accept that they need some help. (self funding)

=> Is your husband SF? Does he have savings of more than ---? Helped her work out that they were financially eligible.

=> CS said that she will make an urgent referral to the front door of adult social care.

Appendix Thirteen: Carer's Outcome Star



Carers Star™ Scales

The Outcomes Star for people caring for others

In each of the seven questions, circle the description that best fits for you now.

1 **cause for concern** 2 **getting help** 3 **making changes** 4 **finding what works** 5 **as good as it can be**

1 Health

Managing physical and mental health; healthy lifestyle; doctors and other health services



5 I am healthy enough and look after my health well

4 My health and lifestyle are mostly OK but there are a few changes needed

3 There are no immediate concerns but I need to look after my health a lot better

2 My health is poor or at risk. I have some support with this

1 My health is poor or at risk. There is no support available or it wouldn't help

2 The caring role

Skills; understanding; practical caring; legal issues; planning ahead; communicating with professionals



5 I mostly have the skills, understanding and information I need and can plan ahead

4 I have a good idea about my caring role, but still would like to learn more

3 Things are difficult but I'm starting to get to grips with my role

2 I'm finding it hard to cope. I get some support but am not confident it'll really help

1 It's hard. I don't know if I can carry on as things are or how anyone could help

3 Managing at home

Day-to-day tasks and the suitability of your home – or that of the person you care for if you don't live with them



5 Our/their home is suitable and we can manage day-to-day tasks well enough

4 Mostly we can manage day-to-day tasks at home but some areas need to be addressed

3 We're getting by but it's hard to stay on top of day-to-day tasks or changes are needed to our/their home

2 We're not coping with many of the day-to-day tasks or our/their home isn't suitable. I'm getting help to sort this out

1 We're not coping with many of the day-to-day tasks or our/their home isn't suitable. There's no support available or it wouldn't help

4 Time for yourself

Social life; activities; breaks from hands-on caring



5. Things are as good as they can be. I have breaks and balance caring with other things
4. I have some time for myself, and some activities or social life outside my caring role, but things could be better
3. I'm trying to get some time for myself, and some activities or social life outside my caring role, but it's difficult and often doesn't work out
2. Caring has taken over my life but I'm getting some help to see if I can change this
1. Caring is my whole life. I can't see how it could be any other way

5 How you feel

Feeling supported; dealing with anxiety or stress; managing any difficulties in a key relationship



5. I mostly feel calm and positive enough and can deal with the pressures of being a carer
4. I'm finding what helps me feel OK or to manage stress, anxiety or difficulties in a relationship but things could be better
3. I'm trying things that might help me manage stress, anxiety or difficulties in a relationship
2. Stress, anxiety or difficulties in a relationship are getting me down but I have some support with this
1. I experience high levels of stress, anxiety or difficulties in a relationship and have no support with this

6 Finances

Benefits; debts; managing money; legal issues



5. I'm managing financially and know where to go if I need support
4. My financial situation is mostly OK but there are some issues related to caring
3. I'm trying to sort out financial matters related to caring but it's hard
2. There are financial problems as a result of my caring role but I have some support to address them
1. There are financial problems as a result of my caring role but I prefer not to discuss them

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7 Work

If you're retired or a full-time carer there's no need to do this scale – simply place yourself at 5 to complete your Star



5. I'm a full-time carer or retired, or I'm in work or training and managing well enough
4. I'm in work, or training or volunteering as a way in to it, but there are some problems
3. I'm trying to sort things out with work or to move towards finding work but it's hard
2. I need to find work and I have some support with how to balance work with my caring role
1. I need to find work but I can't see how due to my caring role and I have no support with this

Now mark on the Star Chart where you are on the Journey of Change for each of the areas. If you join the points on the Star, you will see an overall shape of how your life is right now. Use that as a basis to talk to someone about how you can make things as good as they can be for you, in your caring role, with support.

Appendix Fourteen: Unit Cost Calculation for Carers' Centre A

Direct labour per day = £105
Direct materials per day = £0

Indirect costs per year (e.g. premises, equipment, IT, expenses) = £260,000

Total number of available days for all adult carer support workers per year = 1352

Overhead recovery rate = $\frac{\text{Indirect costs per year}}{\text{Total days per year}}$

$= \frac{260000}{1352}$

= £192

Unit cost/per day for one adult carer support worker = overhead recovery rate + direct labour per day + direct materials per day

= 192 + 0 +105

= £297

[Atrill, P., and McLaney, E. (2009) *Management Accounting for Decision Makers (6th Edition).* Harlow: Pearson Education Limited (page 142)]

Appendix Fifteen: Unit Cost Calculation for Carers' Centre B

Direct labour per day = £110
Direct materials per day = £0

Indirect costs per year (e.g. premises, equipment, IT, expenses) = £126,000

Total number of available days for all adult carer support workers per year = 708

$$\text{Overhead recovery rate} = \frac{\text{Indirect costs per year}}{\text{Total days per year}}$$

$$= \frac{126000}{708}$$

= £178

Unit cost/per day for one adult carer support worker = overhead recovery rate + direct labour per day + direct materials per day

= 178 + 0 +110

= £288

[Atrill, P., and McLaney, E. (2009) *Management Accounting for Decision Makers (6th Edition).* Harlow: Pearson Education Limited (page 142)]

Appendix Sixteen : Rationale for SROI Evaluation of Carers' Centres

Social Return on Investment (SROI) has its roots in cost-benefit analysis and social accounting. The approach (which was brought to the UK by the new economics foundation) can be used with private, public sector and community organisations and is appropriate for both large and small scale evaluation projects aiming to identify both the 'merit' and 'worth' of service level interventions (New Economics Foundation, 2007).

SROI incorporates social, environmental and economic costs and benefits, and helps to understand better the value a service level intervention provides by assigning a monetary value to all these factors. SROI is underpinned by seven principles that are core to the approach:

- Involve stakeholders
- Understand what changes
- Value the things that matter
- Only include what is material
- Do not over claim
- Be transparent
- Verify the result

There are six stages to SROI. These are listed below and alongside comments are made about how this would apply to a SROI evaluation of carers' centres.

SROI Stage	SROI Evaluation of Carers' Centres
Establish scope and identify stakeholders and how to involve them.	The majority of carers' centres are members of the Carers Trust. It would be advantageous to undertaken the research in partnership with Carers Trust. There would be benefit in carers being co-researchers. There would also be benefit in having a research team that included commissioners and carers' centre managers. A mix of qualitative and quantitative data collection would ensure that the voice of stakeholders is heard and that quantifiable data is collected.

Map outcomes – linking the relationship between inputs, outputs and outcomes.	This would involve building on the logic model to create a full theory of change model (Coryn et al, 2011).
Evidence outcomes and give them a value – find data to show what outcomes have been achieved and decide what value they have.	This would involve using standardised measures for wellbeing, resilience and carer quality of life at first point of contact, 6 weeks, 12 weeks and perhaps 6 months later across all the carers' centres involved in the SROI evaluation.
Establish impact – and clarify which aspects are directly related to the intervention.	One of the weaknesses of this thesis was that the impact measure was not a standardised tool. SROI analysis provides a method for taking into consideration what would have happened anyway ('deadweight'), any unintended negative consequences, displaced benefits ('displacement'), and the extent to which outcomes are the result of the intervention as opposed to other factors ('attribution'). This ensures that the SROI is a robust and rigorous process.
Calculate the SROI – consider both negative and positive benefits to arrive at a total value.	SROI methodology for calculating this is outlined in the New Economics Guide. There are also a network of SROI evaluators trained in using and applying the methodology. It would be beneficial if the research team included an evaluator trained in using this methodology.
Reporting, using and embedding the results.	Increasingly dissemination is an important part of research. The commissioners, carers' centre managers and even policy makers I work with rarely look at peer reviewed journals. Creating change will involve disseminating findings in an accessible way through the mediums used frequently by these stakeholders rather than simply through the traditional academic routes of papers and conferences.

As with all research methods SROI evaluations do have their limitations. For example it can be difficult to translate some benefits and outcomes into a monetary value e.g. increased resilience. The approach can be very resource intensive, particularly if outcomes data isn't already available which the scoping review

suggests it isn't as carers' centres do not typically collect data on carer resilience, wellbeing or quality of life. However, the scoping review also indicated that undertaking a large scale SROI evaluation of carers' centres across England could help to develop carers' policy, facilitate decision-making and strategic planning and improve the case for funding and investment in support for carers.