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**Positive adaptation to Dementia: A
Realist Evaluation of family carers'
journey towards Resilience.**

Mark Parkinson

PhD

2018

**Positive adaptation to Dementia: A
Realist Evaluation of family carers'
journey towards Resilience.**

Mark Parkinson

A thesis submitted in partial fulfilment of
the requirements of the University of
Northumbria at Newcastle for the degree
of Doctor of Philosophy

Research undertaken in the Faculty of
Health and Life Sciences

April, 2018

ABSTRACT

Background: Prevalence of dementia and especially Alzheimer's disease (AD) is increasing exponentially, both in the U.K. and more globally. Reliance on family carers of people living with AD (FCOPWA) to provide the backbone of care remains critical and continued reliance on such carers also represents current governmental policy. However, carers are vulnerable to salient health inequalities and chronic variable stress in particular as a direct consequence of taking on the carer role. The numbers of those family carers whose own health and wellbeing might be affected has reached unprecedented levels which are set to increase further in future. **Aims:** This study therefore aims to investigate ways in which FCOPWA can be optimally supported to maintain and sustain family care over the course of the AD trajectory. **Research questions:** 'What works' 'when' and 'in what circumstances' to enable the FCOPWA?'

Design: this study adopted a scientific realist methodology to identify 'generative mechanisms' which support the long-term maintenance and sustenance of FCOPWA. A rapid realist review (RRR) is employed to investigate a comprehensive range of candidates for 'what enables the FCOPWA,' draw up a new conceptual framework based on 'what works' and formulate candidate Program Theories (CPTs) to be empirically tested. Testing comprised eighteen in-depth interviews with family carers to gather data which could be analysed to further investigate the CPTs. This led to the establishment of more specific and narrowly defined Program Theories (PTs). **Findings:** Five PTs emerged, presenting an adaptive carer pathway covering the three main stages of the AD trajectory. This adaptive pathway was underpinned by resilience as a key mechanism and facilitated by the adaptive and differentiated employment of a range of problem and emotion-focused coping approaches and strategies. Hope was also found to provide a pivotal positive and motivating influence throughout the FCOPWA. The pathway offered a way to promote the sustainability of FCOPWA.

Conclusions: The adaptive pathway outlined by this study may also prove useful in similar adult care contexts beyond AD and dementia. Additionally, the three main emergent strands: resilience, coping and salutogenesis might be usefully combined to represent an alternative paradigm to the traditional Medical model as part of the solution to the burgeoning question of how diseases which are chronic and life-limiting but not life-threatening such as dementia, but also other diseases with similar criteria, can be better served and supported in future by health and social care system.

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ACKNOWLEDGEMENTS

Many thanks to all the staff and carers who kindly gave up their valuable time and energy to take part in this study, without whom this thesis would not have been made possible.

To my supervisors who were always there for me to provide sound advice and stimulate deeper thinking. Many thanks to Professor Susan Carr who kept going alongside me throughout this voyage of discovery. To Dr. Clare Abley who likewise always went that extra mile to assist me in times of need and spurred me on. To Professor Rosemary Rushmer for inspiring confidence.

Indebted to you all, as testified by all the 'Many thanks' at the foot of my many E-mails which were always sincerely felt.

Thank you to Fuse for funding me and for making this whole venture financially viable.

Thank you Fuse also for providing excellent opportunities to attend conferences, seminars and discussions and to gain from many high quality professional development opportunities. Thank you to Northumbria University for yet again proving to be a superb provider of higher education at the highest level.

Closer to home, many thanks to my wife Alison who always maintained a belief in my ability to reach the finish line and who was always there to provide support through the good times, as well as the more challenging times.

Finally, a very large thank you to my parents Mary and Brian for their encouragement and support and my lovely sisters Celia and Rhonda for reminding me there's also sometimes a life beyond doing the thesis.

Dedicated to Alison.

DECLARATION

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Ethical approval was granted by the Faculty of Health and Life Sciences on 18th March, 2016

I declare that the Word Count of this Thesis is 98,287 words

Name: Mark Parkinson

Signature:

Date: 22nd November, 2018.

Glossary of terms

Abnormal neurofibrillary entanglements

Abnormal structures, composed of twisted masses of protein fibres within nerve cells, found in the brains of people with Alzheimer's disease (AD) (Gale Encyclopedia of Medicine, 2008).

Allostatic load

The biological response to stressors. This can be adaptive, e.g. the rapid production of adrenaline and cortisol can prepare us when we are confronted by challenges (McEwan, 2005). However, chronic stress can lead to these responses becoming maladaptive over time, leading to exhaustion, burnout and depression. This maladaptive response and its links with chronically accumulated stress that can lead to overload is often referred to as 'allostatic load' (ibid).

Amyloid hypothesis

Flaws in the processes governing the production, accumulation or disposal of beta-amyloid proteins in the brain are hypothesised to be the primary cause of AD. This theory is called 'the amyloid hypothesis.' Risk factors include age (particularly after the age of 65) (Hebert, Bienias & Aggarwal et al; 2010), heritability (Green, Cupples & Go et al; 2002) and the presence of the APOE e4 gene (Saunders, Strittmatter & Schmechel et al; 1993). Age represents the single largest factor associated with dementia prevalence (Plassman, Langa & Fisher et al; 2007). AD does not represent a 'normal' aspect of ageing and is classified under DSM-V (2013) as a major neurodegenerative disorder.

Apoptosis

Neuronal apoptosis refers to the death of neurons and subsequent neuronal loss in the brain in people with AD) (Niikura, Tajima & Kita; 2006). A main cause is the combined abnormal accumulation of amyloid plaques and tau neurofibrillary entanglements. Neuronal apoptosis is associated with neuro-degeneration in people with AD.

Assets and resources

'Assets' refers to: (a) those key resources which remain internal to the family carer such as carers' physical health status and psychological resources associated with resilience building.

'Resources' refers to: (b) those key resources that remain external to the family carer such as principal social assets and key service support resources associated with resilience building

Candidate Program Theory (CPT)

Candidate Program Theories (CPTs) or emergent CMOc's provide the starting point for a fuller Realist evaluation. As such they remain tentative and putative since they are generally based around secondary information which is usually derived from previous studies conducted by other researchers and their published reports. Realist syntheses and Rapid Realist Reviews (RRRs) '...reconstruct the Program Theories that have given rise to an intervention before going on to test those theories using...Primary research,' (Pawson, 2013, p.161).

Chronic variable stress (CVS)

While chronic stress is widely recognised for its potentially debilitating effects, carers face an even greater threat to their general health and wellbeing, identified in this study as 'chronic variable stress' or CVS. CVS represents a more profound form of chronic stress due its variability and unpredictability, provoked as it is by the irregular and highly variable frequency and magnitude of stressors associated with AD care. Inter alia CVS provokes the chronic over-production of 'stress hormones' or glucocorticoids by the hypothalamo-pituitary-adrenocortical system (HPA Axis), a physiological adaptation which in effect becomes maladaptive and potentially harmful for health (Herman, 2013). CVS in particular can result in a loss of homeostatic control over 'stress hormone' production in which carers oscillate unpredictably between states of over-production that leads to over-activation of the two principal stress circuits contained in the human body (HPA and SAM Axes) or under-production which leads to a 'blunted effect,' similar to that experienced in sufferers of depression. A main difficulty for family carers is that the unpredictability of CVS makes successful, adaptive habituation to such highly variable stressors problematic. In addition, CVS can render those exposed to it less resilient to novel, future stressors as these emerge (ibid).

Context

Mechanisms operate within a context that is often critical to the outcome that is generated. Realists are concerned therefore with how mechanisms are contingent on context and the extent to which context is conducive to mechanisms producing certain outcomes (Pawson & Tilley, 1997, p.216) i.e. whether specific contexts facilitate or hinder reasoned decision-making that leads to certain key outcomes. Knowledge of context is therefore deemed critical to how programs work, providing important specifics regarding 'who' 'when' and 'how' the program works. Such a level of understanding permits the further refinement of initial program theories. Underlying mechanisms, including people's assets, resources, reasoning and decision-making can give rise to discernible context-dependent patterns or demi-regularities ('semi-predictable patterns or pathways of program functioning') (Wong, Greenhalgh & Pawson, 2010, p.2). Different Contexts

may facilitate or hinder the operation of mechanisms, thereby influencing the outcome. The schematic below provides an illustration of how this might be applied:

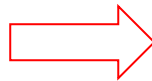
EXTERNAL MECHANISM

(Environmental mediator / moderator) + Context

+

INTERNAL MECHANISM

(Individual Reasoning)



Outcome
via the individual's response.
Where this response is in the desired direction intended by the program or intervention then it may be said to 'work.'

Illustration of how 'context' and 'mechanism' combine to generate causation ('outcome'), adapted from Pawson and Tilley (1997) and Dalkin et al.(2015).

CMO configurations (CMOc's) / Program Theories (PTs)

Realist methods strive to specify who the program works for and in which specific context. How context and mechanism combine to produce outcome is commonly referred to as a CMO configuration (CMOc) or Program Theory (Dalkin et al; 2015). Program Theories (PTs) are the underlying assumptions about how a program is meant to work and what impacts it is expected to have (Pawson, Greenhalgh et al. 2005). A candidate PT (CPT) or initial CMOc provides the starting point for a Realist evaluation with the CPT representing the unit of analysis (Pawson, 2013, p.188).

Critical Realism

A philosophical view of social science investigation which maintains that empiricism that seeks to infer causation by observing the relationship of events in conjunction is fundamentally flawed. Particularly so when it is applied to human affairs, since unlike physical phenomena, human / social phenomena are continually affected by the social structures that surround us, e.g. wider socio-politico-economic factors. In this, individual agency that can affect causation is recognised. However, the constraints imposed by social structures are also perceived to impose major constraints on individual agency.

Daily hassles

'Daily hassles' are events, thoughts or situations which, when they occur produce negative feelings such as annoyance, irritation, worry or frustration, and/or make you aware that your goals and plans will be more difficult or impossible to achieve (Conner, Fitter & Fletcher, 1999). A notable feature of daily hassles is the frequency of their occurrence at a proximal level on a daily basis which can accumulate over time to impact on health (Kanner, Coyne & Schaefer et al; 1981). Lazarus and Folkman (1987) contended that since our

more general experiences involve daily hassles these should be considered of importance in gauging the impact of stress.

Demi-Regularity / Outcome

An important point to note is that 'outcomes' in Realist terms does not refer to the kind of raw outcome data normally associated with 'outcomes' derived by other types of studies and approaches, e.g. RCTs (random controlled trials) (Pawson, 2013, p.40). Rather, 'outcomes' here refers to *change in individuals' reasoning* which is mediated by resources and context (Pawson & Tilley, 1997). This represents a more subtle and nuanced interpretation of 'outcomes' that arguably provides greater specificity regarding *how* the 'outcome' was achieved. In addition, the Realist interpretation recognises and makes explicit the fuller causal chain of events, i.e. rather than focus exclusively on the 'outcome,' Scientific realism (SR) strives to understand how 'context,' 'mechanism' and 'outcome' are all equally important to understanding causal processes. Moreover, that these three components should be interpreted according to how they each influence the other, i.e. as a context-mechanism-outcome configuration or CMOc. Indeed, a main strength of the SR approach is its emphasis on addressing complex research questions by examining the whole causal chain rather than viewing one component of it in isolation. When the same (or similar) outcomes can be explained by the same mechanisms, a regular pattern begins to emerge. Realists refer to these regular (though potentially changeable) patterns as 'demi-regularities.' Wong, Greenhalgh and Pawson (2010, p.2) define 'demi-regularities' as 'semi-predictable patterns or pathways of program functioning.' This definition acknowledges that 'outcomes' will always vary according to individual decision-making, as well as the specific context in which this occurs. Ultimately, the effect of this is to introduce a degree of unpredictability regarding which 'outcomes' will emerge. Hence the term 'demi-regularities' is used as opposed to 'regularities.' Demi-regularities and their identification are important in permitting some degree of predictability regarding the outcomes of certain patterns of events. These are often stated in realist terms as 'Program Theories.' In SR terms, 'outcomes' identify the recurrent demi-regularities associated with a program.

Mechanism

Mechanism refers to the reasoned response by a stakeholder to a Program or intervention, generally informed by the level of supportive personal assets and external resources available to them, which gives rise to certain outcomes (Dalkin et al; 2015). Mechanism therefore relates to causation, i.e. processes that produce events, otherwise referred to as recurrent patterns of events or 'demi-regularities.'

Middle Range Theories (MRTs)

'A unified theory to explain the overall observed patterns and uniformities in the data' (Merton, 1968). While individual CPTs or PTs may provide theoretical explanations for causation at a lower, underlying level, middle range theories (MRTs) can be employed to provide overarching explanations for the wider, combined and systemic effects of multiple CPTs or PTs. MRTs can therefore provide a more generalisable explanation of demi-regularities (Wong, Greenhalgh & Pawson, 2010). MRTs represent theories that are less specific than CPTs or PTs, but more specific than 'grand theories,' such as, for example, Marxism, Feminism or post-modernism. Hence, the term 'middle range.' The definition of MRT which is employed in this study is based upon that drawn up by Merton (1968, p.69) which in its full form reads: 'Theories that lie between the minor but necessary working hypotheses that evolve in abundance during day-to-day research and the all-inclusive systematic efforts to develop a unified theory that will explain all the observed uniformities of social behaviour, social organization and social change.' This definition fits well with the SR interpretation of 'outcomes' as demi-regularities or observed uniformities / patterns within a set of data.

Neuritic plaques.

A spheric mass primarily composed of amyloid fibrils and interwoven neuronal processes, frequently observed in AD (Farlex Partner Medical Dictionary, 2012).

Proteins amyloid and tau

The abnormal build-up of amyloid proteins or neuritic plaques in the brain has been referred to as the formation of 'amyloid plaques' (Bloom, 2014). Amyloid plaques operate in tandem with tau. Tau consists of micro tubular, neurofibrillary proteins which can accumulate abnormally in the brain alongside the formation of amyloid plaques. Tau can build up over time to produce neurofibrillary entanglements. The potent combination of: (a) the build up of amyloid plaques and (b) tau neurofibrillary entanglements leads either to synaptic dysfunction or neuron death (apoptosis) (Bloom, 2014).

Rapid Realist Review (RRR)

Rapid Realist Reviews (RRRs) represent a Realist review that is based on secondary information derived from previous studies conducted by other researchers and their published reports, rather than derived from primary data. RRRs provide a means gathering and analysing available evidence in order draw up CPTs. The CPTs can subsequently form the basis for a full Realist evaluation in which the CPTs are examined and reappraised against prima facie evidence, usually gathered during field work. RRRs represent an abbreviated form of the full Realist review or Realist synthesis that holds the advantage of accelerating the review

process from initial research question to publication of the findings, usually within a six month time frame or less (Saul, Willis & Bitz et al; 2013). The employment of a 'reference panel' of lay experts and an 'expert panel' of professionals / practitioners and academics who specialise in the field of inquiry as it relates to local contexts help to guide the review, focusing on the literature that is most relevant to the inquiry, i.e. addressing only those issues and topics contained in the literature which are of central importance to the research question based on the consensus views of a well informed group consisting of a good balance of lay experts to provide 'real world,' grass roots level experience, professionals / practitioners and academics who specialise in the field of research and who meet at frequent intervals throughout the review process. In the process, ensuring rigour is achieved in the findings via the selection of the most essential literature and lending robustness to the subsequent formulation of CPTs and CMOc's.

Resilience / resilience-building

No universal definition of 'resilience' currently exists. A main reason for this is not only the complexity of this construct, but also the fact that resilience tends to be highly 'context dependent' (Gilligan, 2004). Therefore how resilience operates may be largely dependent on the context in which it is set. This made it expedient to draw up an operational definition that fitted the aim of the present study and which corresponded well with how resilience is generally perceived within the dementia care related literature. This led to the following definition being applied: 'Resilience bolstered by assets and resources (Fergus & Zimmerman, 2005) that combine to provide a cumulative buffer against adversity (Schoon, 2006), as well as by supportive behavioural choices and actions.'

Retroduction

A form of logical inference in which recurring patterns of behaviour or action are observed in phenomena that may signal the emergence of demi-regularities. Demi-regularities are represented by 'outcomes' created by a change in stakeholder reasoning which is mediated by resources and context. Retroduction denotes the process by which these observed demi-regularities are examined in depth before inferences regarding causation are drawn from them. The application of deductive inference to the analysis of data can be limiting since emerging evidence is often only applied to a theoretical framework drawn up in advance (Meyer & Lunnay, 2013). A main difference between deduction and retroduction is the latter's focus on taking emerging evidence into account, even when it falls outside the original theoretical framework. Thus, fresh insights and revelations can be integrated with existing theoretical frameworks to permit a further expansion of original theory (ibid). Important to SR inquiry, retroduction can thus facilitate the development of causal explanations for phenomena by observing the demi-regularities which emerge. In this way, new information can emerge that can lead to theory development.

Scientific realism

A philosophical approach to social science investigation that seeks to move beyond the experimental approach denoted by empiricism and the latter's emphasis on linear 'input → output' formulae' that oversimplify how causation is generated. Scientific realism (SR) offers an alternative approach to the evaluation of social phenomena that attempts to overcome empiricism's deficiencies. It does so by holding to the fundamental tenant that an action is causal only if its outcome is triggered by a mechanism (the combination of human volition together with the personal assets and external resources available to facilitate this) operating in a specified context. SR acknowledges that in terms of how causation is generated context is key (Pawson & Tilley, 1997, p.215). SR promotes an approach to review, synthesis and evaluation that seeks to move beyond establishing whether programs or interventions work to provide explanatory accounts of causation, particularly how outcomes occur within social contexts, e.g. health, welfare, education, the environment, etc. (Pawson, 2013, p.90). It achieves this by providing a high level of specificity regarding which mechanisms and which contexts generate certain outcomes. In the process, revealing not only 'what' works within a program or intervention but crucially also: 'how' 'for whom' and in 'which circumstances.'

Stressor

Any stimulus that provokes the release of stress hormones (e.g. adrenaline, cortisol, noradrenaline etc.) Stressors can also be categorised as physical or psychological (Webster's New World Dictionary, 2010).

Synaptic dysfunction

Synaptic function is essential in permitting the transfer of chemical and electrical signals from neuron to neuron throughout the extensive neuronal networks contained inside the human brain. The impairment to synaptic function caused by AD leads to a constellation of symptoms. In addition to behavioural, physical and psychosocial symptoms, there are profound cognitive symptoms. These include: short-term memory loss, disorientation, language difficulties and increasing problems with planning and organising events.

The Transactional Model (Lazarus & Folkman, 1984, 1987).

This Model emphasises how stress is based on the interplay between individuals and their environment, in what is fundamentally a *transactional* relationship. Essentially, the Model maintains that this relationship can be mediated by a problem-focused approach (PFC) in which problems which can generate stress are addressed at their source and / or by an emotion-focused approach (EFC) in which individuals develop strategies to manage the emotional distress resulting from adverse events or encounter.

CHAPTER 1: INTRODUCTION

Dementia represented the leading cause of death in women in the U.K. five years ago (O.N.S., 2013) and Alzheimer's disease (AD) has since become the overall leading cause of mortality in England and Wales among males and females, overtaking ischemic heart disease (O.N.S., 2015). Current estimates have indicated that the number of those affected by dementia will rise to one million in the U.K. alone. Currently, there is a main reliance in the U.K., as well as more globally, on family carers to provide the bulk of care. A total reliance on formal care provision is estimated to amount to £119 billion (Carers UK, 2011) which represents almost the equivalent of the entire UK 2016/17 NHS budget, set at £120 billion (HM Treasury, 2017) and this makes alternative reliance on formal care provision untenable.

However, a key issue concerns the fact that the variability, unpredictability and long-term nature of dementia, coupled with its profound symptomatology, present unique challenges to family carers of people living with dementia (FCOPWD) that often lead to such carers experiencing chronic stress (Hirst, 2005). These challenges have come to be recognised as unique to FCOPWD and formidable, even in comparison to the care of adults with other chronic but non-dementia diseases (Kasper, Freedman & Spillman, 2014; Moise, Schwarzinger & Um, 2004; Wills & Soliman, 2001). Hirst (2004, 2005) identified these unique carer challenges as representative of salient health inequalities. Moreover, these health inequalities present a significant obstacle to current reliance on FCOPWD by increasing the probability of early cessation of family care (Argimon, Limon & Vila et al; 2004). Given these factors and the burgeoning reliance on FCOPWD in the U.K. it was recognised that there was a pressing need for research that examined how such carers might be better enabled to carry out the role.

These issues gave rise to the research question which is central to this study: 'What enables the FCOPWD?' This question was further refined as the study progressed to allow it to provide greater specificity and relevance by focusing on the most prevalent form of dementia which is represented by AD, which currently accounts for 62% of all cases of dementia in the U.K. (Alzheimer's Society, 2013). Implicit within this further refined research question: 'What enables family carers of people living with Alzheimer's disease (FCOPWA) to carry out the role?' is the underlying assumption that there are facilitating factors 'out there' to be found which may be pivotal to facilitating the longer term maintenance and sustenance of the FCOPWA. Moreover, that by extending this question to include not only 'what enables,' but also 'how it enables,' 'for whom,' and 'in what circumstances' a more substantial level of specificity might be achieved within this study's findings with regard to

potential answers to the research question. Crucially, a higher degree of specificity can be advantageous in terms of increasing the translational potential of the findings by providing greater clarity and precision with regard to ‘what enables’ that in turn permits more subtle and refined adjustments concerning how these are implemented. Greater specificity can also improve the potential research impact of the findings by facilitating their translation from research into practice. For these reasons the research methodology adopted in this study was scientific realism (Pawson & Tilley, 1997).

This study comprised four main phases (see Figure 1 below) with the initial phases (Figure 1, Boxes 1 & 2) concentrated on conducting a Rapid Realist Review (RRR) to glean information and derive hypotheses (candidate Program Theories) for ‘what enables carers’ from the available literature. As part of a Realist Evaluation, the subsequent phases (Figure 1, Boxes 3 & 4) were then focussed on testing these hypotheses against carers’ own lived experiences and what carers themselves found most enabling for them. The study culminated in the further refinement of Program Theories and their related context-mechanism-outcome (CMO) configurations to provide a comprehensive and explanatory account of ‘what enables the FCOPWD.’

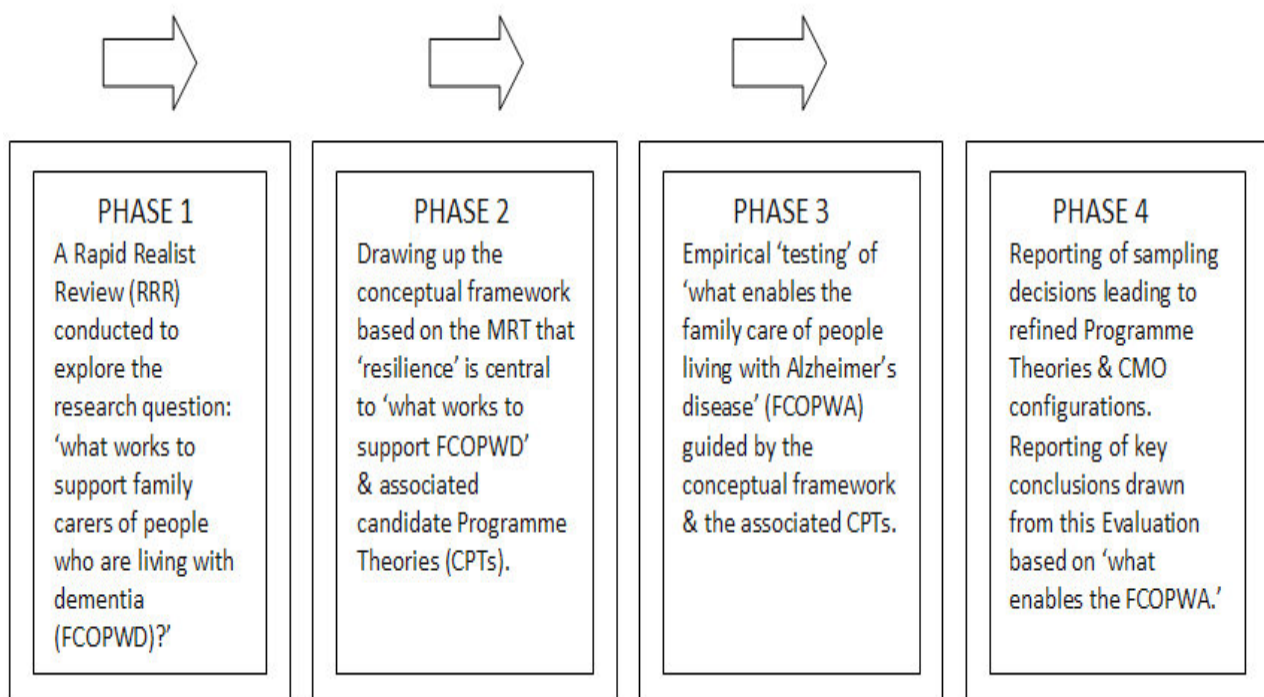


Figure 1. Four Phases of study to investigate ‘what enables the FCOPWA.’

The Chapters are arranged to reflect the chronological order outlined in Figure 1 above:

- Chapter 2 further explores the background context which provided the basis and rationale for this study;

- Chapter 3 outlines the methodology adopted and the principal advantages of employing a scientific realist approach;
- Chapter 4 describes how the RRR was carried out;
- Chapter 5 details the findings from the RRR and how the subsequent development of the conceptual framework for 'What enables the FCOPWD' and associated candidate Program Theories informed the remainder of the study;
- Chapter 6 provides details of the data collection phase of the study and how data collection, analysis and interpretation of data were carried out;
- Chapter 7 outlines this study's principal findings;
- Chapter 8 provides a detailed discussion of the findings, including further refinement of the Program Theories and CMO configurations informed by the literature. A new conceptual framework is also proposed with translational potential for improving carers' health and wellbeing more broadly;
- Chapter 9 outlines how the research aims were achieved, the translational potential and potential research impact of the findings and recommendations for future research in this key area of public health.

CHAPTER 2: BACKGROUND LITERATURE

2.1 Chapter introduction

This chapter explores the background literature which provided the basis of this study. Alzheimer's disease (AD) will briefly be examined in its broader context to highlight the exponential rise in the global prevalence of this disease and urgency of the response required to address this major pandemic health problem. The discussion then switches to a narrower focus on the U.K. as the prime focus of this study. This includes an examination of the alarming and unstoppable rise in disease prevalence that has made AD one of the most important public health issues of recent times.

The Chapter also explores the characteristics of AD which serve to highlight the unique nature of the challenges AD presents, not only to people living with AD (PWA), but also the family carers (FCOPWA) who provide the majority of their care. This includes an examination of the aetiology, risk factors and disease progression associated with AD and how these call for a bespoke, tailored response to the wide-scale public health issue represented by AD in the U.K.

The Chapter then moves to a discussion of how health and social care services and PWA in the U.K. remain critically reliant on FCOPWA and the implications of this for public health policy. The challenges FCOPWA currently face in the U.K. are explored and in particular how these may generate health inequalities as a serious hindrance to any principal reliance on FCOPWA unless they are adequately addressed as a matter of priority. These challenges are further explored against the backdrop of current U.K. policy and guidelines and in particular, how these currently fall short of meeting FCOPWA's needs.

The case is also presented for setting this research within a rival paradigm to the currently predominant Medical model and the rationale behind this.

This Chapter concludes with an explanation of how this background literature informed the focus and contribution intended to be made by this study. In addition, an outline is given for the rationale for selecting scientific realism (SR) (Pawson & Tilley, 1997) as the research approach and Realist Evaluation as the means of investigation in this study. Alternative approaches are briefly described and the reasons why these were not adopted for this study are explained. The aims and design of the study are also presented.

2.2 Alzheimer's disease: global prevalence

The global scale and rising prevalence of AD was recognised by the G8 summit held four years ago in the U.K. in which dementia, and the most common variant of the disease-AD-were given an international platform and declared a global health priority (Dementia G.A.A.; 2014). A main issue that was

addressed, and one which recurs throughout this Chapter, is that historically dementia research has been chronically under-funded (Luengo-Fernandez, Leal & Gray, 2015). Currently, the global prevalence of dementia stands at some 40 million people (Prince, Bryce & Albanese et al; 2013). However, this number is predicted to rise sharply, doubling every twenty years, at least until 2050 (ibid), potentially tripling global prevalence of the disease to 135.5 million people. Of these, up to 70% will receive the more specific diagnosis of AD (WHO, 2016). Much of this dramatic increase in dementia prevalence is due to a combination of medical advances and increasing longevity. For example, in the U.S. while as few as four percent of people living with AD (PWA) are aged 65, the risk factor increases sharply with age so that by the age of 75 the number affected rises more than tenfold (Ortman, Velkoff & Hogan, 2014). This is set to have a major impact on a sizeable number of families and family members who are widely expected to provide the bulk of AD care.

2.3 Alzheimer's disease: U.K. prevalence

Dementia represented the leading cause of death in women in the U.K. five years ago (O.N.S., 2013) and AD has since gone on to become the overall leading cause of mortality in England and Wales among males and females, overtaking ischemic heart disease (O.N.S., 2015). Advances in medicine have given rise to a paradox in which many more people are surviving life-threatening diseases but susceptible to life limiting diseases such as dementia (Ham, Dixon & Brooke, 2012). This is due in turn to an age effect in which the risk of dementia increases with age, particularly once people reach the age of 65 (Ortman, Velkoff & Hogan, 2014). A related factor which contributes to rising prevalence of AD in countries such as the U.K. and the U.S. is the post-war 'baby boom' generation who are now beginning to reach the critical age of 65. This means there are likely to be many more cases of AD in the near future (Davies, 2016). This prediction is supported by the recent figures that reveal that on average a new case of dementia in the U.K. arises every three minutes (Matthews, Arthur & Barnes et al; 2016) with AD representing the most prevalent form of dementia in the U.K., accounting for around 62% of all cases (Alzheimer's Society, 2013). Crucially, this outstrips the ability of formal services to meet the increasing demand for AD support, thereby placing even further emphasis on the need for family carers to bridge the gap. In the U.K. dementia currently constitutes one of the most serious challenges facing families and health and social care services (O.N.S., 2015).

There are currently some 850,000 cases of dementia in the U.K. (Prince, Knapp & Guerchet, 2014) with this number set to increase to over a million people affected by 2025 (ibid). Furthermore, longer term prevalence projections for the U.K. estimate that some two million people will be affected by dementia by 2050 due to the current demographic trend for increasing longevity which in turn gives rise to an increasingly ageing population (ibid). These dramatic changes are reflected in a 62% rise in the

number of people living with dementia (PWD) since 2007 (Prescribing & Primary Care Team, 2014). Overall, these statistics describe wide scale and seismic epidemiological and demographic changes that will place significantly greater reliance on family carers of people who are living with dementia (FCOPWD) and especially family carers of PWA. Reliance on family carers already stands at a sizeable 1:8 of the adult population (Carers UK, 2011) with this set to increase markedly in the future. A major question therefore concerns how such carers can be better enabled to carry out this important role both now and in the future.

2.4 Alzheimer's disease: aetiology and risk factors

The following section contains several references to more specialised terminology that is specific to the biological aspects of AD. Therefore a list of definitions is provided in the Glossary.

AD was first described over a century ago (Alzheimer, 1907), but it is only recently that it has become more clearly understood. AD does not represent a 'normal' aspect of ageing and is classified under DSM-V (APA, 2013) as a major neurodegenerative disorder. AD describes specific neurological changes brought about by the abnormal development of lesions, mainly caused by the build-up respectively of the proteins amyloid to form 'senile plaques' and tau to form 'neurofibrillary entanglements' (Laferla & Oddo, 2005) (see Figure 2).

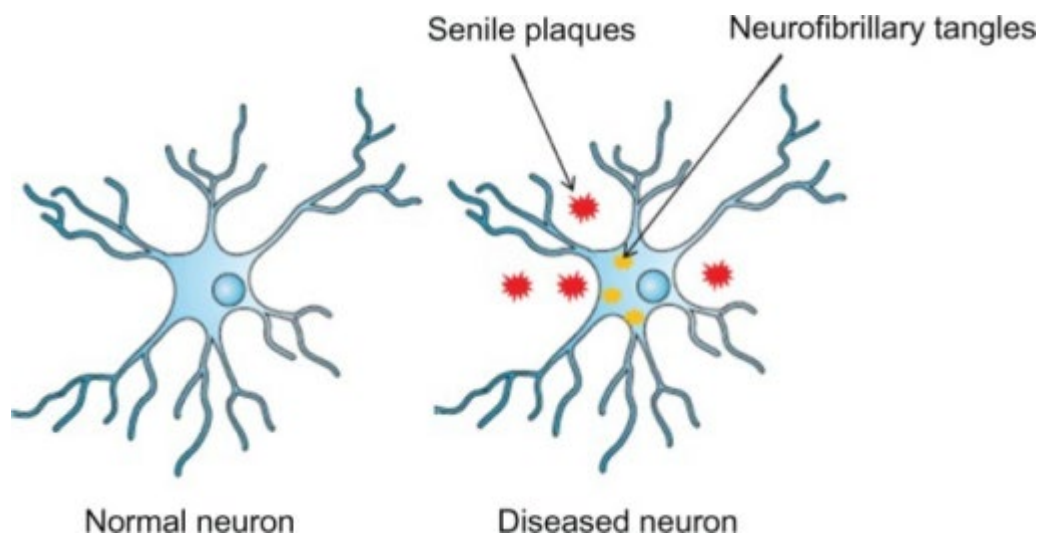


Figure 2. Alzheimer's disease describes specific neurological changes brought about by the abnormal development of lesions, mainly caused by the build-up of the proteins amyloid and tau to create senile plaques and neurofibrillary tangles respectively (Pub Med open-source, 2017).

Their abnormal accretion over time combine to impair neurological functioning as progressively more nerve cells become damaged (Figure 3).

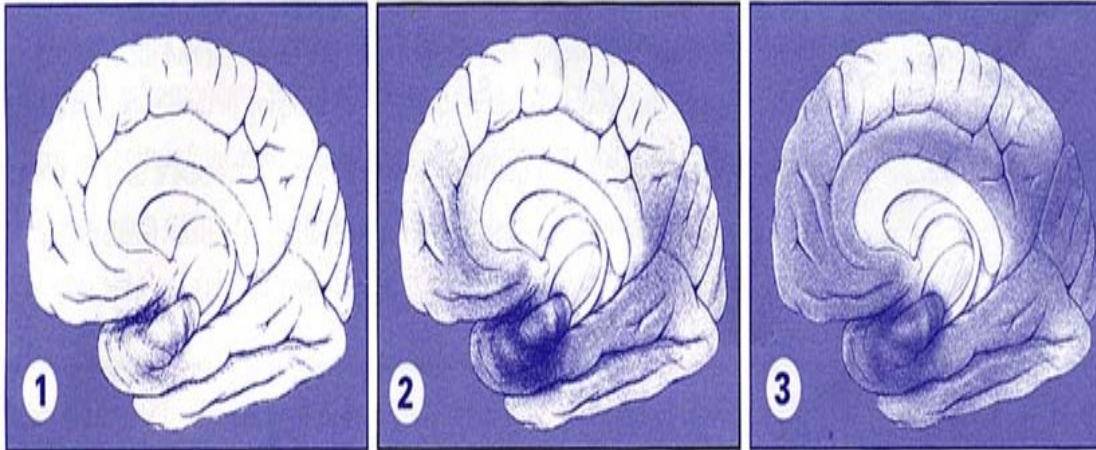


Figure 3. The accretion of amyloid plaques and tau neurofibrillary entanglements over time combine to impair neurological functioning as progressively more nerve cells become damaged (National Institute on Aging/National Institutes of Health, 2017).

Neuronal damage and neuronal depletion occurs via nerve cell ‘death’ or apoptosis (Jellinger, 2001). This damage includes impairment of normal synaptic function, leading to AD (Oddo, Caccamo & Shepherd et al; 2003). Synaptic function is essential in permitting the transfer of chemical and electrical signals from neuron to neuron throughout the extensive neuronal networks contained inside the human brain. The impairment to synaptic function caused by AD leads to a constellation of symptoms. In addition to behavioural, physical and psychosocial symptoms, there are profound cognitive symptoms. These cognitive symptoms include: short-term memory loss, difficulty recalling recent conversation or events, disorientation, language difficulties, inability to recall words for everyday things, increasing problems with planning and organizing events and a decreasing ability to communicate or recognize other people. The relatively prolonged physiological process by which these deficits occur is more commonly known as the Amyloid hypothesis (Glennner & Wong, 1984).

More recently however, there has been increasing emphasis on how biological causation also relies on the interaction with environmental factors and in particular lifestyle factors to mediate AD (e.g. Scheltens, Blennow & Breteler et al; 2016). Lifestyle changes, including self-improvements to important domains such as diet, exercise and frequent engagement in cognitively stimulating activities may combine to provide a protective factor against vascular-related dementias. However, whether such lifestyle changes can also provide protective factors against AD per se remains unclear. Crucially, the main causal factors remain unalterable, i.e. risk factors include age (particularly after the age of 65) (Hebert, Bienias & Aggarwal et al; 2010) representing the single largest factor associated with dementia

prevalence (Plassman, Langa & Fisher et al; 2007), heritability (Green, Cupples & Go et al; 2002) and the heritable presence of the APOE e4 gene (Saunders, Strittmatter & Schmechel et al; 1993).

The cumulative impact of AD towards the later stage of the disease is denoted by extensive neuronal degeneration which is manifest in pronounced brain shrinkage (see Figure 4 below).

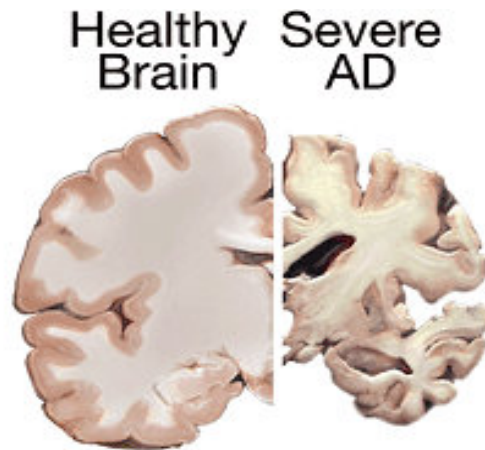


Figure 4. Right-hand image depicts the impact of Alzheimer's disease during the Later stage of the disease and the cumulative effects of neuronal degeneration which leads to extensive brain shrinkage (National Institute for Health, 2013).

2.5 Alzheimer's disease progression

AD is a neurodegenerative disease that gives rise to profound changes in the person affected by it. This also gives rise to a wide range of challenges for FCOPWA to overcome. Certain symptoms are relatively idiosyncratic (see Tables 1 and 2 below) and help to broadly define the dementia trajectory associated with AD (Alzheimer's Research UK, 2016).

Table 1. Typical early symptoms of AD.

- | |
|--|
| <ul style="list-style-type: none"> • Regularly forgetting recent events, names and faces. • Becoming increasingly repetitive, e.g. repeating questions after a very short interval. • Regularly misplacing items or putting them in odd places. • Uncertainty about the date or time of day. • Becoming disorientated or getting lost, particularly in unusual surroundings. • Problems finding the right words. • Becoming low in mood, anxious or irritable, losing self-confidence & becoming anhedonic. |
|--|

Table 2. Typical symptoms of AD as the disease advances.

<ul style="list-style-type: none"> • Deteriorating memory, cognition and decision-making. • Communication and language become more difficult. • Difficulty recognising household objects or familiar faces. • Day-to-day tasks become harder, e.g. using a TV remote control, phone or kitchen appliance. People may also have difficulty locating objects in front of them. • Changes in sleep patterns often occur. • Some people become sad, depressed or frustrated about the challenges they face. Anxieties are also common and people may seek extra reassurance or become fearful or suspicious. • Experiencing hallucinations. • Sense of balance may become impaired, increasing risk of falls. • Daily activities like dressing, toileting & eating become more difficult without support. • Regularly forgetting recent events.

AD progresses along a trajectory that usually commences well before clinical symptoms are officially diagnosed, possibly twenty or more years prior (Villemagne, Burnham & Bourgeat et al; 2013). Common symptoms include deficits to memory, language, problem-solving and other cognitive skills that affect a person's ability to perform everyday activities. These common symptoms eventually deteriorate to the extent that even basic bodily functioning becomes impaired, including feeding, bathing and walking (Alzheimer's Research UK, 2016). Importantly, many of the symptoms outlined in Tables 1 and 2 are not particularly amenable to the type of medical treatment normally associated with more physical ailments such as cancer. Arguably, this calls for AD to be handled differently to ailments that lend themselves to pharmaceutical intervention and this represents an important issue that will be returned to later in this Chapter.

AD has traditionally been subdivided according to the various stages that denote its trajectory. There have been several interpretations of this trajectory ranging from seven stages (Reisberg, Ferris & DeLeon et al; 1988) to three (Alzheimer's Association, 2017a). The interpretation of the AD trajectory as incorporating three broad stages remains consistent with how the AD trajectory was commonly referred to by the family carers who took part in this study, as well as in keeping with how the AD trajectory is normally referred to outside of clinical settings. It therefore represents how the trajectory will be viewed within this study. Hence, the disease trajectory can broadly be defined according three principal stages:

- (i) Early stage: (mild symptoms) typically lasting for the first few years;
- (ii) Mid-stage: (moderate symptoms) during the mid few years of the disease;
- (iii) Later stage: (severe symptoms) final three or more years or approximately 40% of the dementia trajectory (Arrighi, Neumann & Lieberburg et al; 2010). The average duration of AD for the majority of

people in the U.K. is typically around seven to ten years. However, a significant number of PWD in the U.K. (22%) live beyond ten years (NHS Digital, 2017), with some people living as long as eighteen years (Clark, 2000). For the purposes of the present study the AD trajectory will be referred according to these three broad stages and with this aggregate time-line in mind.

2.6 Critical reliance on FCOPWD in the U.K.

In the U.K. a central difficulty remains that formal care services are not equipped, either financially or logistically, to take over the responsibility for long-term care. This means that there is likely to be continued reliance on FCOPWD to provide the bulk of dementia care in the U.K. for the foreseeable future. A total reliance on formal care provision is estimated to amount to £119 billion (Carers UK, 2011) which represents almost the equivalent of the entire UK 2016/17 NHS budget, set at £120 billion (HM Treasury, 2017). Dementia already costs the health and social care sector almost £12 billion annually, more than cancer, stroke and heart disease combined (Lewis, Karlsberg & Schaffer et al; 2014). Yet despite the need for increased research to find ways to improve the efficiency of the systems and structures which support PWD and FCOPWD, dementia receives substantially less than each one of these other areas of health in terms of research investment (Luengo-Fernandez, Leal & Gray, 2015). Policy and practice that falls short of creating a more 'enabling care environment' represents false economy. For example, becoming a FCOPWD often means quitting work in order to meet the significant demands made by taking on the carer role. In the U.K. dementia already creates a substantial cost to the wider economy which is estimated to be around £26 billion annually (Lewis, Karlsberg & Schaffer et al; 2014). Up to 70% of FCPWD are female (Alzheimer's Research UK, 2017), with around 38% leaving full-time employment in order to carry out the carer role (ibid). This also creates financial repercussions and associated strain and stress for the carers themselves (WHO, 2016). Dementia is one of the costliest conditions to society with a disproportionately large impact on women in the U.K. Left unchecked this is an issue that is likely to be made worse by the growing prevalence of dementia in the U.K. that is set to make even greater demands in the future.

The argument for the financial feasibility or otherwise of replacing informal care should in any event not be conflated with the separate need to ensure FCOPWD receive adequate support. Family care largely represents the preferred method of care for the majority of PWD (Dowrick & Southern, 2014) and family members generally strive to accommodate this preference to the best of their abilities. Indeed, wholesale reliance on formal care provision is often perceived to be a last resort, to be postponed or avoided where possible (Ibid). A sense of responsibility and duty by families towards honouring PWDs' preference for continuing care in their own home tends to prevail in general. In addition, there are often significant financial considerations, as well as logistical issues and questions,

related to the PWD's projected quality of life, which need to be resolved before a decision to institutionalise a PWD can be made. However, an important point is that the financial impracticalities associated with increasing formal care provision, as well as PWDs' own preferences, should not lead to wholesale abnegation of responsibility for ensuring FCOPWD are adequately supported either.

Moreover, a more controversial issue is that at present the situation remains in the U.K. that families of people who have received news of a diagnosis of dementia are faced with little option other than for a family member to volunteer to become the primary unpaid carer. Whether this represents a decision which family carers enter into willingly or reluctantly remains a moot point. Ultimately however, family members are left with little choice. Current policy and guidelines which are ostensibly based on strengthening long-term, informal care provision via family care (H.M. Government, 2012) underscore the fact that there is a principal reliance on family carers and an implicit assumption is made that all such carers are readily equipped to carry out the role, despite the significant challenges this is likely to present. Such a policy raises a fundamental moral and ethical dilemma concerning whether it is permissible to restrict family members to a strictly limited choice that practically forces a family member to come forward to accept the role without first creating an 'enabling environment' in which to promote this. Finding sufficient resources to meet the needs of some predicted one million FCOPWD by 2025 in the U.K. presents a formidable challenge. Nevertheless, the unique challenges faced by FCOPWA that may even go beyond those experienced by carers of other chronic, but non-dementia diseases calls for a better compromise to be made. These twin challenges inform the discussion which follows in the next section and further underline the need in the U.K. for improved carer support throughout the course of the dementia trajectory.

2.7 Current challenges to the reliance on FCOPWA and FCOPWD

The subject of the following sections will be AD since this represents the specific focus of this study. In discussing AD there is therefore an acknowledgement that this disease can be broadly characterised by a repertoire of symptoms (see Tables 1 and 2 above) over a variable trajectory (see Figure 5 below). Nevertheless, the discussion which follows is likely to be also relevant to family carers of PWD in general, whose experiences are unlikely to differ markedly from carers of PWA.

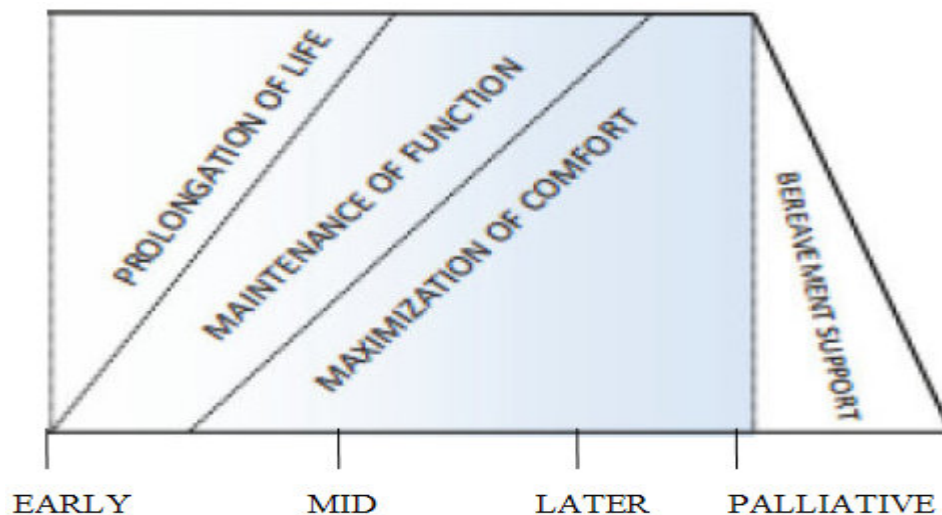


Figure 5. The three broad Stages of the Alzheimer's disease trajectory which can span up to 18 years (Clark, 2000), before palliative care becomes necessary (Adapted from van der Steen, Radbruch & Hertogh et al; 2014, p.206).

2.7.1 Erosion of the extended family

A key issue concerns the erosion of family support available to primary carers of PWA in the U.K. which has generally been diminished over recent decades. The current demographic trend in the U.K., as well as in many other developed countries, towards smaller family units and diminished contact with extended relatives also means that family carers face the prospect of being increasingly isolated, with a correspondingly larger share of the caregiving role (Windle, Francis & Coomber, 2011; Finn, 2007).

2.7.2 FCOPWA represent an ageing population

A further challenge is that many FCOPWA are aged 65 or over (Newbronner, Chamberlain & Borthwick et al; 2013) and therefore reaching an age where they are becoming more vulnerable to health problems themselves. This is borne out by a recent survey of carers in England revealing that around 44% of carers were already suffering from a long-term illness or disability at the outset of caring (Robbins, 2016).

2.7.3 AD variability, unpredictability and longevity

Although AD can be broadly divided according the three distinct stages (see Figure 5 above) with each stage denoting a further escalation in symptoms, AD can also present itself in highly individualised ways. Variability can be manifest in the range of different symptoms that emerge, the severity of symptoms,

changeability in symptom severity, individual differences regarding the duration of each stage of AD, the overall longevity of the disease and the relative impact on the PWA. Such variability and unpredictability over a long time course mean that AD presents unique challenges to family carers. Hirst (2005) highlighted how these challenges make FCOPWA especially vulnerable to chronic stress. However, while chronic stress is widely recognised for its debilitating effects and commonly associated with the experience of stress over long time courses, the unique variability and unpredictability that are additionally associated with AD may leave FCOPWA exposed to a particularly debilitating form of stress. Namely, chronic variable stress (CVS) (Katz, 1981; Herman, 2013). CVS is recognised as being distinct from other forms of stress such as 'acute' or 'chronic' stress, and generated by specific contexts in which there is a continual and chronic exposure to stressors which are highly variable and unpredictable. To summarise briefly from Herman (2013), this can result in the more comprehensive dysregulation of stress hormone production which can in turn lead to a general state that is similar to a 'blunted effect.' Importantly, this 'blunted effect' state has been found to share much in common with the symptoms of depression (ibid). This is significant given that the presence of depression-like symptoms in FCOPWA have previously been well documented in FCOPWA (Hirst, 2005) and moreover, such symptoms present a main trigger for the premature cessation of FCOPWA (Argimon, Limon & Vila et al; 2004). FCOPWA's vulnerability to exposure to CVS should therefore be a cause for concern, especially given the heavy reliance on such carers to provide the backbone of AD care in the U.K.

Although the scientific knowledge which underpins CVS has been around for a few years, to my knowledge this study represents the first to specifically document CVS as a fairly unique type of stress which may affect family carers' ability to maintain and sustain long-term care. Its applicability here stems from the relatively unique context and circumstances that generally surround the FCOPWA. In particular, the high degree of variability and unpredictability in symptomatology that is generally typical of AD may provoke a great deal of irregularity regarding the frequency and magnitude of stressors experienced by FCOPWA on a daily basis over the course of many years. A probable pathway by which chronic stress may exert its cumulative effects to disrupt family care can be derived from a number of studies in which (a) chronic stress and anxiety (Sadavoy & Wesson, 2012) leads to (b) sleep disorders chronic fatigue and burnout (Simpson & Carter, 2013), that culminates in (c) depression (Schoenmakers, Buntinx & Delepeleire, 2010), which in turn can trigger (d) the earlier cessation of FCOPWA (Argimon, Limon & Vila et al; 2004). Arguably, the increased severity of stress generated by contexts which are highly variable, unpredictable and persistent, i.e. CVS, can both exacerbate and accelerate these symptoms and their outcome.

Furthermore, females more than males may be most vulnerable to the impacts on health and wellbeing of chronic stress (Remes, Brayne & van der Linde et al; 2016), and this may well also include

increased vulnerability to CVS. This is significant given that up to 70% of FCOPWD are female (Alzheimer's Research UK, 2017). These factors further underline FCOPWD's health and wellbeing vulnerability and the potential repercussions of this for continued long-term reliance on the FCOPWA in the U.K.

Although the carer experience is likely to differ from individual to individual and the reasons for any cessation of family care may vary from the specific stages outlined in the causal chain outlined above, the pathway described nevertheless serves to emphasise the deleterious impact CVS can have on FCOPWA as well as the need recognise and address CVS as specific health inequality which may be fairly unique to FCOPWA. It is contended here that left unchecked CVS presents a key threat to the long-term maintenance of FCOPWA that could hasten the institutionalisation of PWA. At present, the cumulative challenges FCOPWA often face frequently culminate in crises points being reached, rather than being circumvented earlier through adequate family carer support systems (Newbrunner, Chamberlain & Borthwick et al; 2013).

2.7.4 Health inequalities faced by FCOPWD

The reality is that AD is a very complex and challenging terminal illness whose symptoms extend far beyond memory deficits to include more serious disabilities including impairments to speech, feeding and walking, as well as profound personality changes. This presents a paradox in which PWA become highly dependent on family carer support, but where the many challenges presented by the disease can simultaneously present significant challenges to the health of family carers themselves (Marques, Oliveira & Outeiro, 2010). The FCOPWD is uniquely challenging in comparison to the care of adults with other chronic but non-dementia diseases (Moise, Schwarzinger & Um, 2004; Wills & Soliman, 2001). The lengthy time course of AD, the inevitability of an irreversible decline in health for PWA, the unpredictability of how the disease will manifest itself from day-to-day and the high level of disability and dependence generally associated with AD combine to present novel and distinct challenges to family carers in comparison to other non-communicable diseases such as cancer (Murray, Kendall & Boyd et al; 2005; Murtagh, Preston & Higginson, 2004). Where FCOPWA provide the backbone of support for PWA in the U.K. despite unique and cumulative challenges, including the potential impact of CVS, it becomes essential that the unique health inequalities faced by FCOPWA are acknowledged and addressed. A potential consequence of any failure to provide consistent, adequate support, either locally or more widespread across the U.K., that is bespoke to FCOPWA is the potential to effectively *double* the problem by not only failing to safeguard the health and wellbeing interests of PWA, but also the FCOPWA who crucially provide the bulk of the care. That this remains a serious issue is amply demonstrated by the findings of multiple studies and it is to this telling evidence that we now turn.

FCOPWA are twice as likely as carers of people with other diseases to suffer emotional and physical difficulties that disrupt their emotional and psychological balance (Kasper, Freedman & Spillman, 2014). The chronic nature of these assaults means that their accumulated effects can threaten to compromise carers' own health (Fonareva & Oken, 2014). Recent studies have found that as many as 60% of carers of PWA report high or very high levels of emotional stress, with around 40% suffering from depression, while almost 75% of carers of PWA report concerns about their own health becoming jeopardised as a result of caregiving (Prince, Guerchet & Prina, 2013; Alzheimer's Association, 2016). Furthermore, a robust relationship has been demonstrated between dementia caregiving and its associated impact on psychological health (Gaugler, Roth & Haley et al; 2008; Campbell, Wright & Oyebode et al; 2008; Cooper, Katona, & Orrell et al; 2006; Clare, Wilson & Carter et al; 2002; Adkins, 1999), with rates of carer depression varying between 23% and 85% in developed countries such as the U.K. (Brodaty & Donkin, 2009).

In general, FCOPWA will experience significant health inequalities as a consequence of carrying out the carer role and this is evidenced in the additional health problems they encounter, which range from clinical levels of anxiety and depression to insomnia (Hirst, 2005). These symptoms are also often exacerbated by general fatigue and social isolation (Hirst, 2004). The health inequalities faced by FCOPWA may often exceed those experienced by carers of people with chronic, but non-dementia related diseases (Moise, Schwarzingler & Um, 2004; Vitaliano, Zhang & Scanlan, 2003; Wills & Soliman, 2001) and this extends the argument in favour of ensuring the availability of specialised external support throughout the course of the AD trajectory that creates a more 'enabling environment' for FCOPWA.

2.7.5 Current policy and guidelines affecting FCOPWA and PWA

A significant setback has been inertia in the global response to the dementia crisis until recently, some 40 years on from Katzman's (1976) ground-breaking research which first revealed AD as a 'major killer' within populations. Chronic oversight regarding the sizeable scale and projected impact of AD contained in such warnings resulted in other health priorities attracting greater attention instead. While this represents an endemic problem that is now finally beginning to be addressed, the focus appears to remain on future prevention and treatment of the disease with the goal of finding a cure by 2025, rather than on how those who already have the disease and the FCOPWA who currently support them may best be assisted. Arguably, this is an issue which is based around the medicalised perspective represented by the Medical model that is predominant in many Western-based societies, including here in the U.K.

In general, the Medical model (Engel, 1977) specialises in applying treatments and cures to physical ailments or symptoms. However, a central issue concerns the fact that at present AD is irreversible and

its amenability to pharmaceutical treatment strictly limited. Furthermore, AD symptoms result from cognitive deficits that may continue to go undetected for some time before becoming more pronounced, creating many challenges for PWA and prospective carers in the meantime before a diagnosis is eventually given. In many respects therefore, this makes the Medical model inappropriate as a main perspective or approach for intervention and support, both for FCOPWA and PWA. This point is underscored by the high emotional and psychological needs AD generates for FCOPWA and PWA that may often be overlooked by a predominantly, medicine-based approach to intervention that specialises in the treatment of physical disorders. Dementia is required to somehow co-exist incongruously and ill-fittingly within the existing health care and social care framework. This presents an argument for the creation of a separate health and social care system that is bespoke to dementia and tailored to the specific needs of PWA and FCOPWA. Discussion is warranted concerning the important issue of the Medical model's predominance in the U.K. and the repercussions of continued adherence to this model for dementia care. A more detailed discussion of this and key issues that relate to it are taken up in the next section.

The current and predicted figures for AD prevalence discussed in the opening sections of this Chapter uphold Silverstein and Flaherty's (2006) prediction and warning that dementia would become a 'social policy time-bomb.' However, while the need for urgency to act on dementia as a global health issue was demonstrated by the 2013 G8 summit on dementia, the formulation of effective policy in response has yet to be achieved in the U.K. Recent health policy changes such as The Care Act (2014) that provided new measures, including carers' access to a health assessment, fall well short of addressing PWA's and carers' wider needs, as testified by recent surveys which have found that only 50% of all family carers of PWD reported having ever been offered a carer's assessment of their own needs, let alone taking up the new service (Peel, 2014).

The 2014 Care Act has also attracted criticism for its large presumption that as a nation we already know what family carers need at specific times and within specific contexts. However, as previously discussed, the needs of FCOPWA are complex compared to the care required of other people with other diseases due to its unique characteristics. Such uniqueness means that family carers are rarely well equipped in advance to take on such a challenging role. On the contrary, a potential stumbling block is that the majority of family carers have not planned in advance to take on the role but have had to take on the role out of general necessity following a sudden crisis in which dementia is first diagnosed in a close family member or following a sudden deterioration in longer-term symptoms. As also previously discussed, FCOPWA may often have had little say in the important matter of whether they are best placed to take on such an important role. While The Care Act (2014) goes some way to recognise the fact that FCOPWA are themselves vulnerable to health inequalities as a result of becoming a carer, much

more needs to be done to make the FCOPWA sustainable than merely offering the opportunity (which is often not taken up) of a carer health check that monitors the impact of care challenges. Several years on from what was hailed as the 'seminal' 2013 G8 summit on dementia, most progress appears to have been made in terms of wider media coverage of the disease. While this has proved valuable in breaking down stigma, fear and misconceptions about dementia (Alzheimer's Research UK, 2016), it has achieved little to date that has had a more tangible impact for FCOPWD (ibid).

What is notably lacking to date is the creation of a more 'enabling care environment' that is pre-emptive in terms of supporting carers and PWA through the many challenges they face, proactive in safeguarding carers' health and wellbeing and viewed and practised as a collaboration between carers, PWA and professionals. A main impediment to achieving such a policy and practice change is that the current rise in dementia prevalence in the U.K. has taken place at an unfortunate time in its history during which the U.K. has witnessed dramatic cuts to health and social care stretching back almost ten years. Long-term governmental policy based on implementing 'austerity measures' due to fear of an irreversibly contracting U.K. economy has severely limited public health and adult social care spending. It remains a central paradox that at a critical time of exponential rises in AD prevalence in the U.K., funding of resources to support FCOPWA and PWA that reaches all parts of the country, be it Northern or Southern England or urban or rural-based communities, faces serious threats. Despite this, current governmental policy in the U.K. explicitly favours a continued reliance on unpaid family carers to provide the backbone of dementia care. This is a policy that is reflected in The Prime Minister's '2020 Challenge' (DOH, 2015, p.13) which identifies the following priorities:

- Better support for people with dementia and their carers following diagnosis;
- People with dementia being able to live in their own home independently for longer;
- Improved waiting times for diagnosis, applied consistently and country-wide;
- GPs ensuring continuity of care;
- All people with dementia being given the opportunity to plan ahead at the right time through advanced care planning.

Thus, there is a clear emphasis on (a) ensuring family-based care is extended for as long as possible (b) formal support only becoming more apparent as PWA approach the Later stages of dementia where palliative care / advanced care planning is likely to be required. However, arguably, this threatens to overlook the needs of FCOPWA over the course of a significant proportion of the dementia trajectory. Traditionally, palliative care / advanced care planning only become critical once PWA's physical symptoms become unmanageable. This can occur in the final three weeks' of family care, potentially ignoring any need for carer support throughout the majority of the FCOPWA which may extend for up to eighteen years (Clark, 2000). Again, a central issue is that palliative care models continue to be rooted in

the Medical model that is predominant in the U.K. (Elliott, 2011). This has the potential to overlook the many cognitive, affective and behavioural challenges PWA and family carers must often face during the course of a significant proportion of the preceding part of the dementia trajectory (see Figure 5 above), prior to palliative care becoming a necessity.

Furthermore, the '2020 Challenge' report identifies four main themes to be made a priority (DOH, 2015, p.19):

- (i) Risk-reduction;
- (ii) Research;
- (iii) Dementia awareness;
- (iv) Health and care delivery.

While progress has been made in relation to the third main theme: 'dementia awareness,' not least via the efforts of the voluntary sector, two further themes: 'risk-reduction' and 'research' remain primarily focused on prevention and finding a cure, underlining a governmental policy which is mainly focused on a medicalised approach to dementia and the FCOPWA. Only the fourth theme alludes to service delivery and support and its positioning at the bottom of the list provides some indication of how it stands in order of governmental priority. Indeed, its low priority is made explicit in this the report which goes on to concede there is much that remains to be done in terms of effectiveness and regional equality: '...in dementia care and support...' and that '...there is still more that needs to be done to improve the personal experience of people with dementia and their carers, and reduce regional variation,' (DOH, 2015, p.13).

First and foremost, family members who are faced with the prospect of caring for a relative who has been newly diagnosed with AD need to be entitled to a choice whether to become the primary carer or not. At present, there does not appear to be any real alternative given, leaving family members feeling compelled to take on the role. This implicit assumption is also often accompanied by a parallel presumption that all FCOPWA come readily equipped with the necessary knowledge and expertise to carry out the role. As outlined earlier in this Chapter, the unique challenges prospective family carers are likely to face means this is a decision which cannot be taken lightly or hastily and which deserves to be considered seriously, with sufficient time allowed to reflect carefully on what represents a major life decision. This is especially the case where prospective family carers are elderly and striving to manage their own health problems, which is not uncommon (NHS Digital, 2017). Importantly, at stake here is not just the health and wellbeing of the PWA, but also the carer. If current U.K. governmental policy regards it as universally ethical and fair to expect all family members to volunteer to become the primary carer almost without exception, arguably they should at least offer adequate support to enable this via a health and social care system which cultivates an 'enabling environment.' Furthermore, such support

should arguably be made available throughout the course of AD. That this represents a key issue to be addressed is underlined by a statement by Health Secretary Jeremy Hunt who declared that in the U.K. there is a pressing need to ensure that health care in relation to dementia become, 'human-centred and not system-centred,' (Thraves for Alzheimer's Society, 2016, p.10). In the same report Alzheimer's Society declared that, 'people with dementia are being failed by an NHS that is not person-centred enough,' (ibid). These criticisms come amid calls for a more equitable approach by the NHS towards dementia that directly addresses current policy and practice that currently exacerbate carers' health inequalities. For example, while carers of people with physical ailments such as cancer or heart disease can access social care which is free at point of use, family carers of PWA must first satisfy a means test. A significant number of FCOPWA fail to satisfy the stringent requirements of this test, meaning they must largely fend for themselves leaving FCOPWA a sizeable £5.8 billion out of pocket (Thraves, 2016, p.10). Such inequitable policies and practices prevail despite the fact that FCOPWA already face significant health inequalities compared to carers of people with non-dementia illnesses. More needs to be done to take full account of the uniqueness of AD that calls for specialised carer and PWA support across the full course of the dementia trajectory.

2.7.6 The need to challenge the Medical model

Much of this Chapter has up to this point necessarily focused on the potential challenges faced by FCOPWA and this covers some of the more negative dimensions and current deficiencies associated with the FCOPWA. However, there is arguably also an imperative to explore 'what enables FCOPWA.' In terms of ensuring that the unique needs of FCOPWA in the U.K. are adequately met, both now and in the future, there is a need to identify appropriate carer support measures that make the FCOPWA viable and sustainable. While there is documented evidence that some FCOPWA are able to employ strategies and approaches, backed by effective and enabling external support, that appear to facilitate successful long-term maintenance and sustenance of the FCOPWA (e.g. Gaugler, Davey & Pearlin et al; 2000), there is potentially much untapped knowledge that could be utilised to assist the much wider population of FCOPWA at large. This is of especial interest to this study.

At a fundamental ideological level, this may require some significant adjustment to the way in which the FCOPWA in the U.K. is perceived and dealt with by formal health and social care services. How disease is conceptualised is of importance and can determine '...the proper boundaries of professional responsibility and how they influence attitudes toward and behaviour with patients' (Engel, 1977, p.129), and family carers. Criticism of the Medical model stems from its focus on biology and how social, psychological and behavioural factors are often under-represented in terms of their influence on health

and wellbeing. Engel (1977) argued for a more holistic approach to health in which the predominant Medical model was superseded by a more inclusive biopsychosocial model that embraced a wholly different philosophy and approach. Engel viewed such a paradigm shift as an antidote to a Medical model that seemed impersonal, dehumanising and disempowering for those affected by disease (Borrell-Carrio, Suchman & Epstein, 2004, p.576). The biopsychosocial model by contrast offered a means to shift the emphasis from a focus on the clinical dimension of health care and on the disease toward a focus on the person and with this an acknowledgement of the critical influence of psychosocial factors. Such a perspective also goes further to take into account the broader complexity of health care, including recognition of the fact that health and wellbeing outcomes are often driven by multiple causal factors that may operate in non-linear ways (ibid, p.578). Part of the rationale for adopting a scientific realist (SR) approach (Pawson & Tilley, 1997) in this study stems from SR's awareness of this and its attempt to address complexity by investigating how causation in social contexts often involves the integration and interaction of several processes. These can include human resources and reasoning (Pawson & Tilley, 1997, p.68) and to avoid assuming that causation in social contexts is necessarily linear (ibid, p.69).

With specific reference to dementia care, current perceptions of the FCOPWA that are based on the Medical model remain at odds with the notion of such care remaining viable and achievable in the long-term. The Medical model frames dementia care within a sickness paradigm (Gilliard, Means & Beattie et al; 2005; Kitwood, 1990) with efforts directed more towards treatment of physical symptoms of the disease, rather than towards how the PWA and FCOPWA can best be supported to continue to achieve quality of life while still maintaining family care. Arguably, the medicalisation of dementia which is upheld by this model reinforces the notion of long-term and life-limiting diseases such as dementia being incurable 'lost causes' for which nothing can be done and within which family care is viewed as 'burdensome' and 'destined to be short-lived,' i.e. quickly superseded by formal care. While the 'burden of care' paradigm remains consistent with the dependency culture (Oldman, 2002; Swain & French, 2000) that has come to dominate medical care in the U.K. over the past seven decades, it remains incompatible with the notion of recognising and supporting the role of FCOPWA. The Medical model's speciality resides in its ability to provide life-prolonging intervention. However, what PWA and family carers require is support that is life-enhancing and which enables them to continue to enjoy as good a quality of life as possible for the remaining decade or more of their lives together. By contrast, deficit models of care that focus on 'care as burden' reinforce the Medical model, a message that is made explicit by the terminology employed. Specifically, that care is 'burdensome,' an encumbrance, an ordeal to be endured. This promulgates an ideology which is fundamentally based around the unsustainability of family care. Crucially, such models underestimate family carers' potential strengths

(Hirst, 2004). This is not to deny that family carers also require external support to create a more 'enabling environment' in which the long-term maintenance of FCOPWA is made more viable and the case for this has already been strenuously argued. Rather, it is a statement of carers' need to receive the right levels of timely support, resources and motivation if they are to be enabled to remain the primary caregivers in the long-term. Arguably, the depiction of 'care as burden' falls well short of achieving this. Similarly, highlighting the potential challenges FCOPWA may face should not become a reason for fatalism, but rather provide an opportunity to improve the type and levels of support available to sustain the FCOPWA.

In addition, the significant health inequalities FCOPWA are vulnerable to calls for future public health policy to address carers' needs more pre-emptively, i.e. before health problems arise. Again, this calls for a divergence from the Medical model and its emphasis on post-hoc diagnosis and treatment and a move towards the implementation of preventative measures to safeguard carers' and PWA's health and wellbeing. As well as representing a more equitable and humane approach to AD care, at a more pragmatic, governmental level this also makes economic sense. Indeed, it is becoming increasingly recognised that public health-based policies which are based on 'prevention rather than cure' carry the potential to be highly cost-effective (Cramer, Royal Society of Public Health, 2018; WHO, 2014).

In contrast, the current practice of framing dementia and dementia care within a 'burden of care' paradigm achieves the opposite by pathologising the carer role via an underlying assumption that the majority of family carers will follow an inevitable, fatalistic pathway that leads to the collapse of family caregiving. To this end, there is a burgeoning need for family carer research that recognises family carers' strengths and capabilities by framing their role within a positive paradigm, e.g. as demonstrated by Competency (Livingston, Katona & Roch et al; 2004) and Affirmation models of care (Swain & French, 2000). Ultimately, the framing of the FCOPWA within a more positive paradigm offers a more constructive alternative to the traditional Medical of dementia care and a firmer basis from which to promote the viability and sustainability of the FCOPWA.

2.8 The focus and contribution of this thesis

Implicit within a more positive approach to dementia care is the underlying notion of the potential to find ways and means to make the FCOPWA both more workable and more sustainable in the U.K., as well as more globally. The rising prevalence of AD means that there will be a predicted one million FCOPWA in the U.K. alone in the very near future. That the current system represented by formal health and social care appears to allow the health and wellbeing of FCOPWA to be placed in jeopardy, and by corollary, the longer-term maintenance and sustenance of FCOPWA also, current policy and practice needs to be urgently re-examined. It cannot be overstated that the current lack of consensus with

regard to 'what enables the FCOPWA' and the need for greater knowledge about this has become a matter of priority.

Moreover, the high degree of variability, unpredictability and longevity of AD means that 'what enables' the FCOPWA' is likely to also remain highly variable across the AD trajectory. There is therefore an urgent need to uncover not only 'what enables the FCOPWA,' but also more specifically 'how', 'for whom' and 'when.' FCOPWA already face significant health inequalities as a direct consequence of taking on such a challenging role. A high level of specificity is also required in order to increase the translational potential of the findings to similar population groups and to thereby increase this study's impact in terms of its ability to inform future policy and practice.

2.8.1 Research rationale and research question

With critical reliance on FCOPWA at an all-time high and set to increase exponentially over the next few decades, the need to find answers to 'what enables the FCOPWA' has never been more pressing. Gaugler, Davey and Pearlin et al. (2000) underlined the need for research concerning how FCOPWD can be optimised in ways that make it more manageable and sustainable. A disappointing feature of dementia-based research, particularly as it relates to family carers, is how the clarion calls by previous researchers for an urgent response to 'what enables the FCOPWD' have largely been met with scant affirmative action. Some eighteen years on, the need for such research has never been more vital nor the need to overcome inertia more pressing. The principal rationale for this study is to investigate the question which is overdue concerning 'what enables the FCOPWA.'

2.8.2 Research perspective

'What enables the FCOPWA?' Continued critical reliance on the FCOPWA in the U.K. means that it is expedient as well as vital that answers that lead to greater consensus regarding this question are found and quickly. Arguably, this also calls for research that is set within a more constructive, 'can do' paradigm that reflects the research question's focus on 'enablement,' as well as remaining consistent with the need which is pressing to find ways in which the FCOPWA can be made more sustainable over the long-term course of AD. This study therefore embraces a positive perspective in relation to the FCOPWA as an overarching philosophy. A key proviso is that this does not preclude the investigation of potential hindrances to 'what enables the FCOPWA,' since such knowledge is important in highlighting factors which may need to be overcome in order to facilitate a more enabling care environment.

2.8.3. Research approach

There is little consensus surrounding, 'what enables the FCOPWA' let alone the more specific details that concern 'how', 'for whom' and 'when.' Such a critical gap in knowledge has also been cited as a concern by previous researchers (e.g. Parveen, Morrison & Robinson, 2011; Jutlla & Moreland, 2009). At present, there also appears to be an implicit but misinformed assumption by policy-makers that current policy is adequately well informed by knowledge of 'what enables the FCOPWA' and that this knowledge is sufficient to ensure family carers' needs can be met. Important to correcting this oversight and bridging the gap in knowledge concerning 'what enables the FCOPWA' is the establishment of an evidence base which moves beyond syntheses of the findings from the available literature that are limited to more descriptive accounts based on 'outcomes' and instead towards a deeper analysis of 'process' via a focus on the underlying processes associated with 'what enables the FCOPWA' and 'how' these processes might be generated and facilitated. This deeper level of detail and specificity is urgently needed to increase the translational potential of the study's findings to other, perhaps similar population groups. It also lends itself to translatability from research findings into practice and to informing future decision-making regarding AD policy and practice.

These issues prompted a review of the methodologies and methods employed and the targeting of those that lent themselves well to (a) providing contextual specificity via richness of detail and sufficiency of depth concerning the evidence base for 'what enables the FCOPWA' (b) the ability to provide explanatory accounts based not only on 'what enables the FCOPWA,' but crucially also 'how,' 'when,' 'for whom' and 'in what circumstances.' These needs underpinned the rationale for the adoption of a scientific realist (SR) approach (Pawson & Tilley, 1997) and the employment of compatible methods in this study in order to draw up more detailed and specific guidelines regarding 'what enables the FCOPWA,' in keeping with the study's remit. More specifically, this study's reliance on Realist evaluation was supported by the capacity of such evaluations to narrow the gap that might develop between theory and reality. This is achieved through SR's dedication to empirical examination of program theory that seeks to validate or invalidate it. Empirical rigour is further strengthened by a dedication to capturing rich and detailed prima facie evidence and rigorous analysis via processes that are transparent and which permit iterative replication via successive trials of a program. This allows cumulative knowledge of a program to be developed that culminates in 'successful context-mechanism-outcome combinations' to directly inform policy-makers (Pawson & Tilley, 1997, pp. 219-220).

By occupying the middle ground between constructivism and positivism SR strives to avoid epistemological bias. While more positivist approaches may focus exclusively on observable phenomena, regard causation as generally linear and maintain that 'confounding variables' need to be controlled for, SR by contrast posits that the formulation of program theories which seek to unravel

social complexity must necessarily move beyond the scientifically 'observable.' Hence, SR maintains the view that the best scientific theories give 'true' or 'approximately true' descriptions of observable *and* unobservable aspects of the social world, with the 'unobservable' denoted by underpinning mechanisms that may not be overtly observable, e.g. human reasoning and decision-making that directly or indirectly influence causation and thus help to generate certain outcomes (these issues are further discussed in the succeeding Chapter). Moreover, what positivism might perceive to be 'confounding variables' may in fact prove pivotal to generating such outcomes. This represents an important point which SR acknowledges and takes into account via its coda of remaining receptive to the emergence of 'hidden,' underpinning mechanisms during evaluations. Program theory building provides a means to more precisely draw up theories of both the observable and the unobservable facets of social phenomena. Thus, SR is primarily theory-driven, with theory derived and informed by the best knowledge and information currently available in the literature. Moreover, by merging strong theoretical conjectures that are based around a sound evidence base or as sound as can be made possible and then 'testing' these empirically in their 'real world' context it becomes possible to achieve scientific rigour while avoiding the deficiencies associated with a purely positivist approach. Importantly, SR takes account of the fact that that human behaviour may be inherently unpredictable, prone to change, non-linear and not subject to rational laws. Furthermore, that how human behaviour is explored and examined requires a separate approach to positivism that acknowledges the complexity and unpredictability of social phenomena.

At the other extreme, SR avoids becoming biased towards more constructivist approaches that are generally data driven and which can threaten to overload the researcher with an over-abundance of theoretical propositions. Such a threat can become particularly salient for nascent areas of research such as that covered by this study where theory is protean and may direct the research along a multitude of different paths, not all of which may be the correct one to follow. Moreover, constructivist approaches can become overly interpretative with findings becoming more subjective and descriptive. By contrast, a key strength of SR lies in its ability to develop strong theoretical conjectures that are based around rigorous analysis of existing knowledge bases and then 'testing' these empirically in their 'real world' context with a focus on revealing potential underlying 'mechanisms.' Arguably, such an approach carries the potential to produce explanatory accounts that explicate how and in which contexts causation is generated that moves beyond merely descriptive accounts.

While it might perhaps be contended that critical realism (CR) (Bhaskar, 1978-1979, 1994) could provide an alternative approach in this study, this option was rejected on the grounds that CR risks undermining its own explanatory potential by deciding in advance of any social science research that people's capacity for any volition or rational decision-making as a major contributor to 'what works' is

fundamentally compromised by capitalist forces (Pawson, 2013, p.71). Theory-building ought to be a matter of striving to get closer to the 'truth,' and not about employing theory in a fixed, prescribed fashion that, irrespective of any other influences, preordains Marxist theory represents the predominant causative influence. SR argues that adopting such a biased political stance a priori, based on grand third tier theory, fundamentally undermines CR's attempts to achieve rigour and objectivity as an approach to evaluating social phenomena. As Collier (1994, p.171) points out, this means that CR has already decided in advance of any study that causation lies fundamentally within the institutions and market forces represented by a capitalist system. The main contention here is not the potency and influence of capitalism in Western societies. Indeed, whether one is of a Marxist persuasion or not, it is difficult to argue that capitalism exerts little influence over the lives of people within Western societies. Rather, the contentions made by SR (Pawson, 2013, p.64) are:

- (a) that this automatically generates a bias that permeates all subsequent investigation and compromises CR's claims for objectivity and pragmatism in the pursuit of scientific rigour;
- (b) it assumes that social programs are all equally constrained and equally limited by capitalist forces, irrespective of any other causal or contextual factors;
- (c) at an even more fundamental level, it denies that individuals have agency or determinism over the processes and events that regulate their lives. In short, the overriding mechanism becomes capitalism. All other contextual factors, together with the 'mechanisms' that accompany them, including human volition and facilitating resources, are rendered practically impotent in the face of capitalism. This undermines a main tenant of SR: that human volition accompanied by adequate resources and conducive contexts permit causation that can change outcomes (Pawson & Tilley, 1997).

A further fundamental issue is that CR regards 'resources' and 'reasoning' as separate factors associated with causation. By contrast, SR maintains the view that crucially it is how these two factors combine and interact that provides the 'action potential' or trigger for causative change / 'generative causation' (Pawson, 2013, p.5). Thus, SR maintains the view which this study supports that individuals can and do exercise agency alongside facilitative resources and contexts and can thereby play a pivotal role in determining the outcome of events.

On the basis of all this, SR was deemed to offer the most appropriate approach to meet the demands of this study.

2.8.4 Research aims

The current economic, demographic and political climate in the U.K. dictates that there will be increasing reliance in the future on family carers to provide the backbone of care for PWA. Therefore the main aims of this research revolve around this important premise. This underlines the need:

- To uncover ‘what works’ ‘how’ ‘for whom’ and ‘in what circumstances’ to enable the FCOPWA’ according to the carers’ own views. This includes investigating effective external support measures, but also ‘self-help’ measures FCOPWA may be able to implement themselves.
- To achieve this by acquiring specific knowledge of ‘what enables FCOPWA’ (*the mechanisms*) ‘for whom’ and ‘in what circumstances’ (*the context*), to enable family carers of PWA to maintain and sustain long-term family care (*the outcome*). To achieve this by employing a SR approach that is supported by SR methods of review, data collection, analysis and interpretation.
- To also expose ‘what does not enable FCOPWA’ by revealing potential hindrances that may need to be overcome or removed to facilitate ‘what enables the FCOPWA.’
- To uncover how carers’ needs may change over the course of the dementia trajectory and how this may require a differentiated response with regard to what enables them.
- To draw up recommendations based on explanatory accounts of the above that might help to inform future policy and practice and which may also possess wider translational potential to other contexts, in particular other family care-based contexts.

2.8.5 Research design

To assist the investigation of the research question and the related aims this study was divided into four phases (Figure 6):

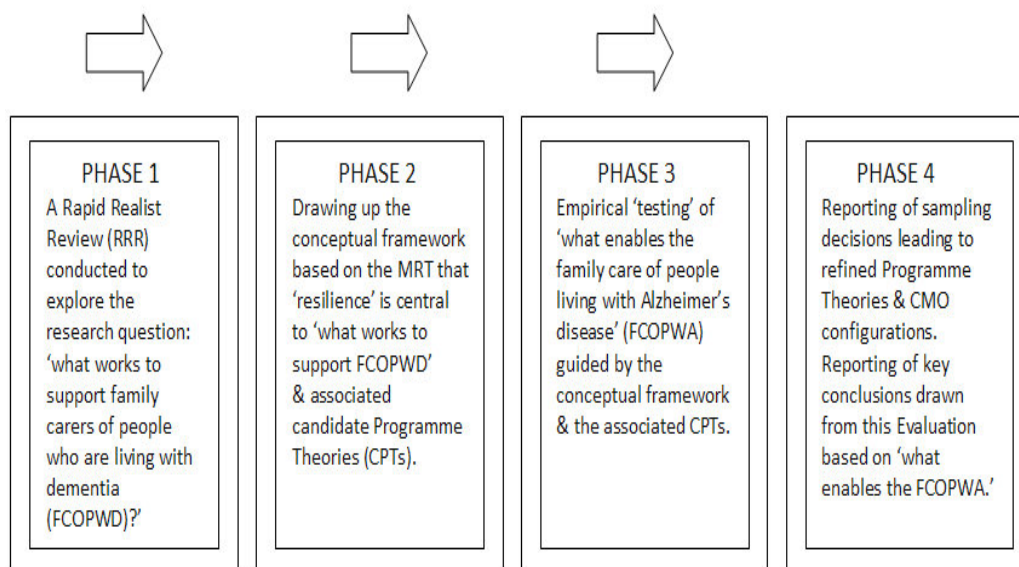


Figure 6. Four Phases of study to investigate ‘what enables the FCOPWA.’

Phase 1: A rapid realist review (RRR) was undertaken to provide a distillation of the theories that carry the most explanatory potential for ‘what enables the FCOPWD.’

Phase 2: Formulation of candidate Program Theories (CPTs) based on the findings from the RRR to provide hypotheses for ‘what enables the FCOPWD,’ ‘how,’ ‘for whom’ and ‘in what circumstances.’

Phase 3: Data collection via 18 x in-depth interviews with primary family carers of PWA using a semi-structured interview schedule based around the CPTs derived from the RRR. Subsequent analysis and interpretation of the data to establish causal explanations (Program Theories) concerning ‘what enables the FCOPWD,’ including evidence to identify underlying causal mechanisms and their contexts. Thereby addressing the deeper question, ‘what works (enables) for whom under what circumstances,’ rather than limiting the findings of the study to a more general descriptive account of ‘what works (enables).’ The formulation of context-mechanism-outcome configurations (CMOC’s) linked to the Program Theories and based on the overall findings, including further consideration of the supporting literature to offer further validation.

Phase 4: Write-up of this 90,000+ word Realist Evaluation.

2.9 Chapter Summary

This Chapter examined the global context of AD to highlight the dramatic rise in the global prevalence of this disease and how AD has emerged to become one of the most serious health issues encountered by human populations on this planet and among the most important public health issues the U.K. has ever faced.

The unique characteristics of AD were explored which emphasised the unique nature of the challenges AD presents, not only to PWA but also to the family carers who provide the majority of the care. This included an examination of the aetiology, risk factors and disease progression which remain highly specific to AD and which call for a bespoke, tailored response to the public health problem AD presents. Moreover, a response that also calls for the positioning of the FCOPWA within an alternative, more constructive paradigm than that which is currently provided by the Medical model and its subsidiary ‘the burden of care’ paradigm.

The Chapter then moved to a discussion of how PWA in the U.K. remain critically reliant on family carers and the implications of this for public health policy. The challenges such carers currently face were explored and this underlined the critical point that while the U.K. is becoming increasingly reliant

on family carers of PWA, such carers face significant challenges via serious health inequalities. Moreover, that these health inequalities may be more severe than previously reported, i.e. they may be manifest in an especially debilitating form of stress-chronic variable stress (CVS).

Current U.K. policy and guidelines were also critically appraised and assessed and found to fall short of meeting FCOPWA's needs and by association PWA's needs also, particularly regarding enabling the long-term sustainability of family care.

The Chapter concluded with an explanation of the focus and contribution intended to be made by this study, as well as the study's main rationale, perspective, research question, approach, aims and design. The next Chapter will explore the methodological basis of this study.

CHAPTER 3: METHODOLOGY

3.1 Chapter introduction

Research methodology refers to the purpose of methodology, i.e. its role and function in the research process: how researchers go about finding out knowledge and conducting research (Wainright, 1997). Fundamentally, it is the strategic approach adopted for a study, rather than the methods per se (ibid). Methodology incorporates the means by which evidence might be found to verify a particular theory or proposition. Methodology also refers to the overarching research philosophy. The decision to adopt one methodology over another cannot be taken lightly therefore. As Pawson observed, 'social science is rather febrile...In Kuhnian terms...pre-paradigmatic-unable to settle on a definitive set of first principles,' (Pawson, 2013, p.xii). However, this means that social inquiry is able to draw upon a myriad of methods and approaches in order to attempt to address a wide range of social phenomena. This can leave the researcher with a bewildering choice when it comes to selecting methodology. Ultimately, the 'acid test' that decides between a sound methodological basis or otherwise and the main criterion applied here is its 'fit for purpose' to meet the requirements of the research question to be addressed by it. Thereafter, it is matter of ensuring the methodological approach selected is effectively adapted to meet the particular requirements of the individual study (Pawson, 2013, p.xii).

This chapter explores the scientific realist methodology which underpins this study and which forms the basis for the realist evaluation which follows. Subsequent to Chapter 9 there is a Glossary containing some of Realist terms employed in this Chapter that may assist the discussion which follows.

An important point to note is that historically, scientific realism (SR) has represented 'a methodological approach' and overarching guide to carrying out research rather than a prescribed protocol per se. This allows flexibility in terms of the methods employed as part of a SR approach. However, flexibility should not be confused with laxity and in recent years initiatives such as the RAMASES (Realist and Meta-Narrative Evidence Synthesis-Evolving Standards), updates such the RAMASES training materials (e.g. Wong, Westhorp & Pawson et al; 2013) and RAMASES publication standards guidelines (e.g. Wong, Greenhalgh & Westhorp et al; 2013) form part of an ongoing, rigorous attempt to introduce clearer guidelines regarding how SR inquiries can be conducted.

The principal approach to realist research is based around realist evaluation and this represents the main approach adopted for this study. The Chapter will proceed to explore the ontological and epistemological bases of SR, including their strengths and advantages. The origins of SR will be examined before proceeding to provide a summative rationale outlining the reasons for adopting SR as an appropriate approach for this study. The theoretical framework employed to carry out the realist

evaluation in this study will be described. The Chapter will conclude with a rationale for framing this study within a positive perspective.

3.2 Ontological basis of scientific realism (SR)

Ontology is concerned with the form and nature of reality and what can be understood about it (Hudson & Ozanne, 1988). Closely related to this, 'ontological position' deals with the fundamental nature of existence (Dilts & DeLozier, 2000), as well as the particular 'lens' through which the researcher views existence, nature, reality. In social science, ontology is specifically concerned with the nature of social reality (Dillon & Wals, 2006; Ramey & Grubb, 2009) – the kind of things that exist, the conditions of their existence and the relationships between these things (Blaikie, 2007). Ontology also helps to define the characteristics of the paradigm in which the research is set (Guba, 1990), e.g. realist, critical realist, SR, etc.

To avoid any sources of confusion the brand of Realism espoused by Pawson and Tilley (1997), often referred to as 'scientific realism' (SR), will be the approach taken in this study. SR maintains that all knowledge of the real world is subject to individual outlook and perspectives and also influenced by the contexts in which the world is viewed: environmentally, temporally and situationally. As such, our understanding of the world can never be complete or absolute. Science never furnishes us with irrefutable 'facts,' but instead produces what Pawson (2013, p. 188) refers to as 'partial truths.' Therefore, the best we can hope to achieve is to try to narrow the gap between our subjective perceptions of the world and the reality as it actually exists outside these perceptions. Essentially, SR holds that there exists a world around us that is external to and thus independent of the mind (Chakravartty, 2017). According to realism, claims about scientific objects, events, processes, properties, and relations, whether they be observable or unobservable, should be construed literally as having truth values, whether true or false (ibid). Pawson and Tilley (1997) refer to this as, 'the black box enigma' that characterises the workings or mechanisms that underpin a program or intervention. This requires a resolve by researchers to delve deeper to uncover not only 'whether' programs or interventions 'work,' but also to investigate 'how,' 'for whom' and 'in which circumstances' they work. Moreover, this requires the formulation of theories that move beyond the scientifically 'observable.'

3.2.1 The ontological position of SR regarding subjectivity and objectivity in research

Ontology is associated with the central question of whether social entities need to be perceived as objective, i.e. whether they have a reality that is external to people. Alternatively, whether they

should be perceived as subjective, i.e. whether they are social constructions based on people's own perceptions (Bryman, 2008). A main tenant of SR is its attempt to produce syntheses and evaluations that move as close as possible to 'the truth' or social reality of the social phenomena being investigated. There is no better way to highlight this key point and emphasise how this represents a cornerstone of SR than to draw attention to how the word 'realistic' and its contingency 'striving to capture social reality' became incorporated into the title of Pawson and Tilley's (1997) book, *'Realistic Evaluation.'*

SR employs a wide of range of measures in its attempt to narrow the gap between our subjective perceptions of the world and the reality as it actually exists outside such perceptions. These include:

- avoiding basing program theories upon gross presumptions or received wisdom. To use an often cited example: just because someone has never seen a black swan does not mean such a swan does not exist. This requires the adoption of a neutral stance towards the program theories that have been drawn up and the avoidance of holding on to hypotheses too preciously. Hence, researchers must be prepared to accept evidence that may be counter-factual where such evidence possesses strong validity;
- avoiding epistemological bias by striving to achieve a balance (rather than a polarity) between constructivism and positivism;
- eschewing theoretical bias by avoiding the adoption of approaches or perspectives that may contain an inherent bias a priori, e.g. postmodernist, Marxist etc. Any reliance on third tier level of theory or grand theory that may favour a particular world view is set aside (Westthorp, 2013) in favour of reliance instead on program theory as a basic unit of analysis at more local levels. Where required, middle range theory (MRT) can also provide a further level of abstraction that helps to provide a unified explanation that accounts for overall causation;
- avoiding methodological bias by selecting the most appropriate methods suitable for uncovering (as far as possible) 'the truth' with regard to the research question under investigation. As opposed to arbitrarily avoiding certain methods on the grounds that they are in some way incompatible with the underlying philosophy associated with a particular methodological approach;
- acknowledging that 'reality' and 'the truth' remain in a constant state of flux. Thus, SR stresses the fundamental importance of clearly identifying context and its importance in mediating outcomes;
- acknowledging that 'real world' contexts and circumstances, be they political, economic, social, temporal etc., do not remain static. Therefore, all we can hope to achieve is to capture as fully as possible the demi-regularities (or partial realities / 'partial truths') at work, i.e. emergent patterns, common threads, social regularities, behavioural patterns etc. within causative chains (Pawson,

2013, p.8). These demi-regularities remain inherently variable depending on changing context, including the fluid context denoted by time itself. Hence, the terms ‘demi’ or ‘partial’ regularities are deliberately employed (as opposed to ‘regularities’) to convey the important concept that no ‘real world’ regularity exists. Particularly so while the context in which the social world is situated remains in an ever-changing, constant state of flux. This also presents a further argument in favour of adopting an iterative approach to evaluation in social science (as SR does), to take account of contextual changes as well as to gain the benefits of cumulative knowledge;

- seeking to obtain the viewpoints and perspectives of a wide range of stakeholders in order to arrive at more balanced and well-informed conclusions. Rather than to accept more narrow or singular perspectives, particularly those which may be exclusively derived from ‘upper stream’ sources that may otherwise lead to practitioner-led program theories and ignore ‘grass roots user level’ / principal stakeholder-led program theories;
- taking fuller account of the potential for underlying processes to give rise to causation, rather than automatically treating these as confounding variables or treating them in an arbitrary, post-hoc fashion (Pawson & Tilley, 1997, p.54) that ignores or underestimates their potential importance. Within SR these are also sometimes referred to as ‘invisible program mechanisms’ that may make crucial contributions to how a program works (Pawson, 2013, p.122).

The points enumerated here served to provide important guidelines that directed the course of this study. Guidance included: the need to attempt to avoid bias a priori; to attempt to base initial program theory on the best that available knowledge from the existing literature could offer; to consider whether there was a need in this study to develop MRT; to remain open-minded regarding how program theory might change in the light of empirical evidence; the need to ensure that the views of end-users were taken fully into account etc. Such guidance proved critical given that the family care of people who are living with Alzheimer’s disease (FCOPWA) represented a nascent topic for research and there was a lack of consensus regarding the research question: ‘what works to support FCOPWA.’

3.3 Epistemological basis of SR

Epistemology can essentially be defined as the theory of knowledge, especially with regard to its methods, validity, and scope, and the distinction between justified belief and opinion (Oxford Living Dictionary, 2018). Epistemology concerns how we make justifiable claims about our knowledge of things we wish to study (Johnson, 2017). The epistemological basis of a study and the epistemological assumptions which follow are important in social research because they influence

the research design that is adopted (*ibid*), i.e. the overarching approach represented by methodology and methods and how these are applied to address the research question and what we claim to be valid knowledge in response to the research question (*ibid*). It also represents sound practice to make clear the perspective and approach that has been adopted to facilitate subsequent testing that may challenge the original findings. In addition, the epistemological basis of a study is important from a translational viewpoint, i.e. ensuring that any findings which might subsequently inform policy and practice are justified in terms of what the researcher claims to be a valid version of the reality that has been studied.

SR represents, 'a commitment to the idea that our best theories have a certain epistemic status: they yield knowledge of aspects of the world, including unobservable aspects,' (Chakravartty, 2017). Epistemologically, SR is committed to the idea that theoretical claims (interpreted literally as describing a mind-independent reality) constitute knowledge of the world (*ibid*). The fundamental basis of realist evaluations and realist reviews is 'realism.' This is based on the assumption that the world in which we live can be represented as an external reality that can be assessed via the formulation and examination of program theory. The subsequent theoretical claims derived from such evaluations are argued to reflect 'real world' phenomena and scenarios. This is in contrast to alternative epistemological perspectives (notably anti-realism) that remain doubtful whether scientific investigation is epistemologically powerful enough to yield such knowledge (Chakravartty, 2017). A fundamental tenant of SR therefore is the maintenance of the view that the best scientific theories give true or approximately true descriptions of observable and unobservable aspects of a mind-independent world. Crucially, a SR approach can permit a fuller exploration of phenomena that may be initially based around intuitions, hunches and inferences to construct theories which can have important implications and which may never have come to light without some 'leap of faith.' Arguably, remaining 'shackled' to scientific inquiry that insists on examining only that which is observable is too self-limiting and does not permit sufficient leeway for developing new theories that may potentially lead to significant insights and breakthroughs in our understanding of social phenomena.

In general, evidence concerns the observable while theories often refer to the unobservable and while there is inevitably some tension between the two, there is also scope for these two processes to complement each other, i.e. more explicit and overt *prima facie* evidence may be complemented and enriched by exploring what SR sometimes refers to as 'invisible program mechanisms' that lie beneath (Pawson, 2013, p.122). 'Invisible program mechanisms' can make a crucial contribution to our understanding of how a program works (Pawson, 2013, p.123), e.g. the impact on crime reduction made by merely announcing, but not yet implementing, security patrols (*ibid*). Often,

these 'invisible program mechanisms' are related to the individuals' underlying reasoning and decision-making processes, as well as by the factors that motivate and mediate these processes, e.g. in the above example the resources and logistics required to mount an advertising campaign and some understanding of the subliminal, persuasive power of effective advertising.

However, 'invisible mechanisms' can also be driven by important contextual factors which can become overlooked in social research. A key point here is that social phenomena in particular often involve a complex combination of factors and frequently these may influence outcomes in subtle and nuanced ways. Experimental-based science that may focus on a single, observable variable and its outcome may all too easily overlook the primary cause. 'Invisible mechanisms' necessarily rely on some degree of inference or abstraction to provide the best explanatory account of phenomena. In SR terms, this is generally based on the observable evidence, but also on theories that seek to move understanding of causation beyond the observable.

A SR approach can permit a fuller exploration of phenomena that may be initially based around intuitions, hunches and inferences to construct theories. While this may necessarily involve hypothesising about mechanisms that may not be directly observable, this approach represents much more than a 'blind leap of faith.' Rather, research rigour and robustness is achieved initially via the attempt to draw from the best theories available from within the current literature and the subsequent collection and analysis of primary data to confirm, deny or call for modification of initial theory. Furthermore, SR inquiry relies on remaining as reliable and informative as possible through its dedication to capturing richness and detail, including important contextual detail derived from primary data, during subsequent empirical 'testing' and validation of theory, (Wong, Greenhalgh & Pawson, 2010, p.8). To this end, this study involved the collection and analysis of a comprehensive range of available literature to provide a sound basis on which to develop candidate program theories (CPTs) which could subsequently be tested empirically in 'real world' settings.

A further main tenant of SR is its adherence to the notion that knowledge is cumulative, seeking to build on what has gone before, rather than a terminus (Pawson, 2013, p.84). This also upholds Karl Popper's view that, 'Science grows with the cumulation of explanation,' (Popper, 1992, p.94). Thus, the robustness of program theory (PT) is established by drawing up hypotheses which are then iteratively 'tested' and 'retested' to admit their subsequent refinement according to cumulative evidence. As opposed to theory becoming an 'established' fact on the basis of a single study. Thus, SR attempts to narrow the gap between unobservable phenomena and the establishment of more robust theory concerning phenomena via collaborative evidence (Eronen, 2015). In practical terms, this often means: (a) detecting the phenomena via a variety of means, rather than adopting a more singular approach, and in doing so increasing the probability that the theory or interpretation arrived

at approximates to 'the truth' (b) employing an iterative approach to theory-building in which it is fully anticipated that follow-up research and studies, including those conducted by other researchers, will likely give rise to the need for further refinement and modification of existing theories that bring it closer to 'the truth.' Hence, SR inquiry is mainly theory-driven (Wong, Greenhalgh & Pawson, 2010, p.7), enabling theory and theorising that ultimately allows more insights to be revealed and knowledge and understanding to move forward.

SR perceives the danger of adopting a polarised view, recognising that there are also strengths and advantages contained in both positivism and constructivism and instead, striving pragmatically to occupy the middle ground between these two positions (Pawson, 2013). This arguably enables it to capitalise on the strengths which are inherent to both positivism and constructivism:

- the capacity to derive meaning about the world around us via the senses to provide a grounded interpretation of events;
- employing doubt and scepticism to achieve rigour in scientific analysis by moving away from subjective interpretation;
- inviting consideration of counter-factual evidence that may disprove theory;
- taking into account the ways in which people construct their worlds, including how knowledge and meaning-making are socially constructed.

There is therefore an awareness of the importance of finding some middle ground between emotional perceptions, instinctive responses and logical assumptions. This also acknowledges the inherent complexity of the social world and social phenomena, rather than falling into the trap of reductionism represented by wholesale reliance on positivism.

Furthermore, SR argues that even the hard sciences such as physics often relies on placing theory upfront, i.e. a theoretical proposition is stated first and foremost, with subsequent observation and investigation employed to prove or disprove the theory. In short, SR maintains the view that both the physical and the social sciences are constrained by the need to place theory upfront, to observe emerging patterns or demi-regularities associated with physical and social phenomena respectively and then to draw up conjectures, guesswork and informed judgements (Pawson, 2013, p.64).

Therefore the goal should not be to ensure social science evaluations are relatively 'closed systems' in which all important variables are somehow isolated as critical realism (CR) seeks to do, since this is fundamentally impossible due to the complexity and dynamic nature of social phenomena and is difficult enough to achieve in the physical sciences. Rather, social science should seek to establish the best that theory can provide in order to draw up initial hypotheses for potential generative mechanisms and contexts and the outcomes they may give rise to (PTs). Then to explore and examine these as rigorously as possible via iterative investigations that generate cumulative

knowledge and understanding (Pawson, 2013, p.65). In this SR recognises that in this we can only achieve 'partial closure' since it is impossible to achieve absolute, unequivocal knowledge and understanding of social phenomena. However, SR attempts to offset the deficiency inherent in 'partial closure' through its dedication to iterative inquiry and evaluation which actively seeks to accumulate knowledge and understanding of a subject, rather to remain fully satisfied with initial findings. Indeed, a key difference between CR and SR is the former's somewhat misguided insistence that social science is capable of establishing 'closed systems' in which to explore social phenomena.

3.4 Advantages of a SR approach from an ontological and epistemological viewpoint

In summary, from an ontological and epistemological viewpoint SR holds several advantages. SR attempts to narrow the gap between our subjective perceptions of the world and the reality as it actually exists outside such perceptions. This is achieved via a comprehensive range of means that include:

- avoiding epistemological bias;
- acknowledging that 'reality' and 'the truth' remain in a constant state of flux and the fundamental importance therefore of specifying contexts in research;
- taking fuller account of the potential for underlying processes to give rise to causation, including human volition and reasoning, that may not be overtly observable but may nonetheless be highly influential in terms of their causative influence;
- permitting a deeper investigation of complex social phenomena that helps to uncover not only 'whether' programs or interventions 'work,' but also 'how,' 'for whom' and 'in which circumstances.' Crucially, this moves research beyond being merely descriptive to permit explanatory accounts, i.e. accounts that take fuller account of how causation is generated;
- program theory building providing a means to more precisely draw up theories of both the observable and the unobservable facets of social phenomena. Thus, SR is primarily theory-driven, but arguably the gap that might develop between theory and reality is narrowed through SR's dedication to empirical examination of program theory, i.e. objective testing in the 'real world' to validate or invalidate theoretical propositions;
- further strengthening empirical rigour via a dedication to capturing rich and detailed prima facie evidence and subjecting this to rigorous analysis via processes which are transparent and which permit replication;
- adherence to an iterative approach to theory-building that encourages subsequent research and studies, including those conducted by other researchers. This facilitates further theory

refinement and modification to compensate for ‘partial closure,’ bringing successive findings closer to ‘the truth.’

3.5 The origins of Realism

The philosophical origins of realism that eventually led to the development of CR (Bhaskar, 1978-1979) which in turn, spawned the emergence of SR (Pawson & Tilley, 1997; Pawson, 2006; 2013), stem from Hume’s ideas concerning causality which date back to the 18th Century. A contention raised by Hume in relation to scientific investigation was the problem of ‘constant conjunction.’ Namely, that scientific investigation frequently inferred causation where two events occur in succession, even where the two events may be unrelated. The repercussions of this assertion for empiricism were profound, prescribing significant boundaries within which empiricism could explain causation and draw inferences from outcomes alone. Empiricism is defined here as, ‘the theory that the origin of all knowledge is gained via sensory experience’ (Encyclopaedia Britannica, 2017). The term ‘empiricism’ is etymologically derived from (a) the Greek word for ‘experience’ and (b) from Greco-Roman usage of the term ‘empiric’ in reference to physicians whose skills are derived from practice rather than rooted in theory (ibid). Hume’s argument was that this represented a serious flaw in the philosophical foundations of science and scientific study. A contemporary example of the problem of constant conjunction is illustrated by the received wisdom that for decades stress was perceived by the medical establishment to be the main cause of stomach ulcers. This premise was largely based on the observation that these two factors commonly appeared in conjunction. However, it relied on a radical change of theoretical approach to closely examine alternative, counter-factual arguments for causation which led to the discovery that the actual mediator / mechanism was helicobacter pylori (Marshall & Warren, 1984).

During the 1920’s ‘Logical empiricism’ emerged as a philosophical movement in Vienna and was characterized by the view that scientific knowledge is the *only* kind of factual knowledge and that all traditional metaphysical doctrines are to be rejected as meaningless (Encyclopaedia Britannica, 2017). Proponents included Bertrand Russell, David Hilbert and Gottlob Frege who became collectively known as members of the ‘Vienna Circle.’ They sought to formulate ‘a logic of the sciences’ that would be analogous to the logic of pure mathematics (ibid). Logical empiricism also expanded on Hume’s ideas to state that causation could only be defined by observation of phenomena that could be perceived via the senses. However, this view attracted criticism since these ideas rested on the premise that any phenomena which are unobservable are not amenable to empirical study. This view also maintained that what is knowable must be based on public, experimental observation rather than upon personal experience (Encyclopaedia Britannica, 2017). All

this had serious repercussions for the emerging social sciences. In particular, it presented a significant challenge to the ability of the social sciences to apply scientific rigour in the analysis and interpretation of human behaviour since arguably, much of human thinking, rationalisation and behaviour is not always easily observable, i.e. it remains implicit and hidden, at times it is even unconscious or subconscious to individuals.

Ultimately, criticism of 'Logical empiricism' and the ideas which underpinned it led to theorists such as Kuhn (1970), Popper (1974) and Hesse (1974) to contend that all observation was in fact 'theory-dependent.' This view challenged even empirical science's ability to explain all physical phenomena via observation alone, particularly as science moved inexorably towards the study of phenomena at molecular, inter-cellular, sub-atomic and inter-stellar levels. Thus, 'Hypothetico-deductive' method emerged from this, in which empirical observation was deemed to provide the 'gold standard' in terms of scientific rigour, but nevertheless, these observations were acknowledged to be reliant on theory. This closer bond between theory and logic, between observable and less visible phenomena, essentially paved the way for admission of the implicit social and psychological nature of science and of scientific observation and reasoning. Most notably, how social and psychological factors impinge on how we observe the world and how these in turn influence and bias our interpretations or reconstructions of how the world and those who populate it function. At the heart of all this lies the philosophical question of the relationship between natural science and social science and more particularly, where their respective boundaries meet.

Bhaskar (1978) took this debate further by stating that while there is an 'objective' world containing structures or agencies that give rise to causation, how these are interpreted cannot escape the inherent observational biases contained in our contemporary culture and the era in which these interpretations are set. In 1979 Bhaskar extended these views to incorporate the further notion that the same general process of science can be applied to both natural and social science, but that the subjective bias imposed by the social world, including customs, norms and culture, inevitably place certain limits on the degree of empirical rigour that can be achieved. Moreover, that these constraints are not only imposed on the social sciences, but also the study of the physical sciences. Bhaskar originally referred to these ideas as 'critical naturalism,' later changing the terminology to 'critical realism' (CR) (Collier, 1994). A main tenant of CR is that social science and physical science share the same explanatory structure, i.e. both attempt to explain the complexity and flux of real world events by reference to some underlying mechanism (Pawson, 2013, p.61).

3.6 The challenge of achieving ontological depth

With regard to the research question at the heart of this study is the issue of how to address the complex question: ‘what works to support FCOPWA?’ In particular, how do we uncover the often latent, hidden or even dormant underpinning mechanisms that work to bring about improved outcomes for such carers? Especially, where carers themselves may possess only a partial meta-cognitive or conscious self-awareness of ‘what works’ themselves? If this problem calls for theory-building to help to account for these unobservable underpinning mechanisms, a main question concerns how such theory bring us closer to reality, to realism, without succeeding in achieving the opposite, i.e. theory driving a wedge between unobservable phenomena (e.g. social phenomena) and the reality as it actually exists.

The iceberg metaphor (see Figure 7 below) represents a useful way in which to perceive the challenge of achieving ontological depth in this study. Where ‘what works to support FCOPWA’ is likely to involve deep-seated and underpinning psychological factors and biological factors as well as existing within a volatile context that contains influential social factors, different levels of resourcing, differential impacts of socio-politico-economic factors and central to all this: a dementia care context that remains in constant flux in response to unpredictable symptomatology. A contention made here is that SR can provide much needed focus to guide this study. Merging strong theoretical conjectures that are based around a sound evidence base or as sound as can be made possible and then objectively ‘testing’ these empirically in their ‘real world’ context with a focus on potential underlying ‘mechanisms’ providing the potential to produce explanatory accounts of causation. Thus, SR offers a means to narrow the gap between theory and the reality as it actually exists.

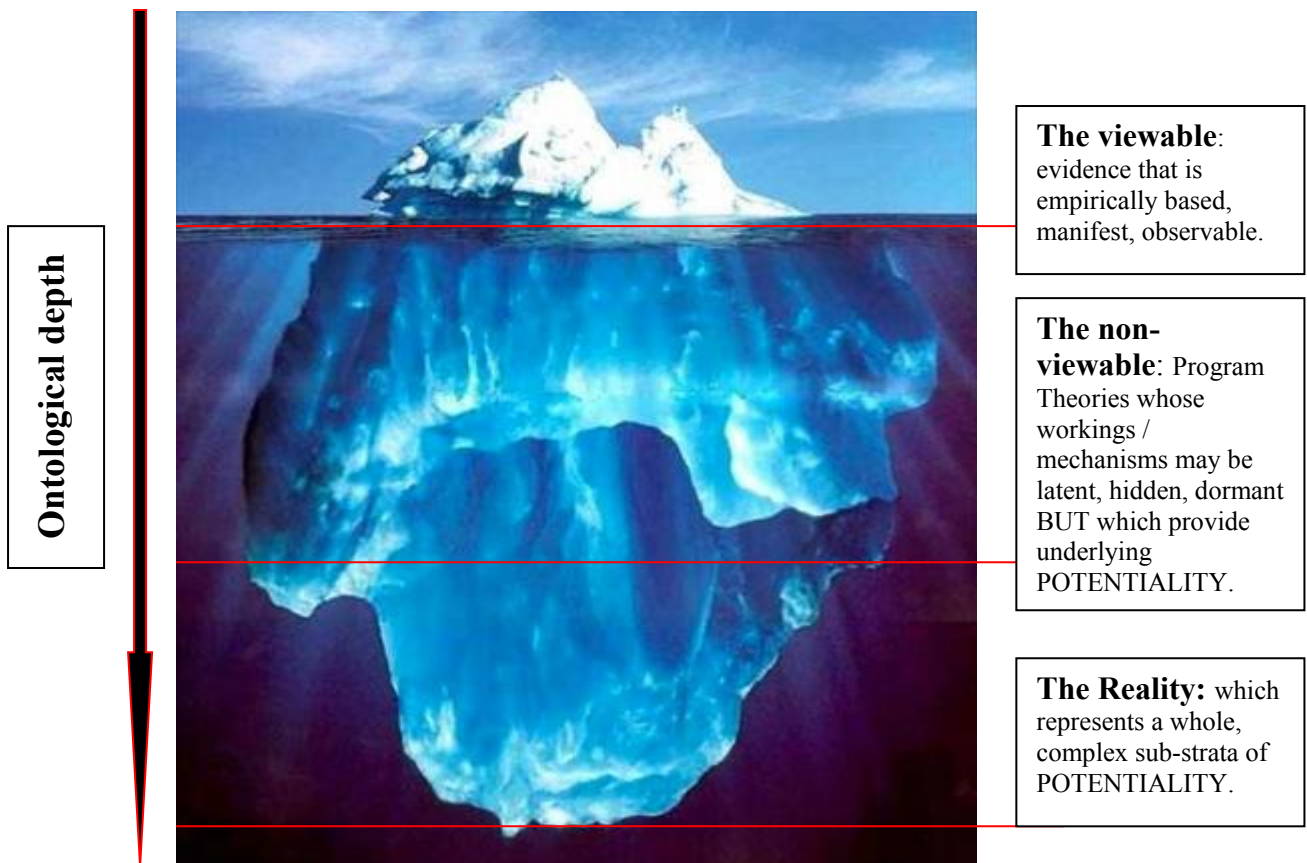


Figure 7. The iceberg metaphor representing the challenge faced by both the natural sciences and social science in examining complexity in sufficient ontological depth. Adapted from Jagosh (2015).

The origins of SR (Pawson & Tilley, 1997) stem from CR developed by Bhaskar (1978-9, 1986, 1989, 2013). At a fundamental level, both approaches represent an attempt to understand how structures and mechanisms operating within the social world give rise to causation that is manifest in recurring patterns of events or ‘regularities.’ Both approaches also recognise that the human world is different from the physical world, i.e. that that human behaviour may be inherently more unpredictable, prone to change, non-linear and not subject to rational laws. Further, that how human behaviour is examined requires a separate approach to positivism that acknowledges its complexity and unpredictability.

SR maintains that crucially, it is how individual reasoning and resources combine and interact that provides the ‘action potential’ or trigger for causative change or to use SR terminology: ‘generative causation’ (Pawson, 2013, p.5). Generative causation is deemed to occur where main stakeholders and communities exercise their underlying causal powers within contexts that are conducive to enabling this (Pawson & Tilley, 1997, p.215).

Pawson (2013, p.27) refers to ‘mechanisms’ as ‘specific treatment modalities’ in much the same way as the independent variable might be identified in empirical science. However, an important difference is that in social science the ‘mechanism’ may be less easily observable and only made

clearer at all by focusing on how ‘mechanism’ (M) combines with specific ‘contexts’ (C) to bring about certain ‘outcomes’ (O). The SR position maintains therefore that ‘mechanisms’ operate via a combination of:

- (i) influential contextual factors;
- (ii) availability of external resources;
- (iii) client reasoning and decision-making (Pawson & Tilley, 1997; Dalkin et al; 2015).

In this, the relationship and interactions between these three components (as a CMO configuration or CMOc) is therefore crucial. Moreover, the ‘mechanism’ is only more reliably validated once its operation has been detected over a range of instances, i.e. there is sufficient evidence to be able to identify demi-regularities (recurrent patterns of causation) at work across several instances.

Arguably, this enables SR to take fuller account of how human volition, in combination with the external resources available at the time and given the right context generates causation. Arguably also, this provides an analytical approach which contains greater explanatory potential by incorporating the crucial determining element-‘human volition’ as an integral component and agent of causation.

3.7 SR’s attempt to remain objective and pragmatic

As the philosophical approach adopted for this study, SR helped to provide the level of objectivity that this study demanded. This was achieved by continually striving to establish a robust evidence base both at the outset via the initial Rapid Realist Review (RRR) to generate strong theoretical propositions (CPTs) and subsequently via rigorous empirical testing and validation of these propositions. SR is fundamentally a theory-driven approach. As Pawson and Tilley (1997, p. 155) make clear: ‘...the researcher’s theory is the subject matter of the interview, and the stakeholder is there to confirm, to falsify and, above all, to refine that theory.’ This means that SR is not data-driven and does not rely on overly interpretivist accounts which can generate dense, descriptive accounts of events (Gephart, 2004), rather than focus on actual causative influences.

SR instead adopts a more pragmatic approach in which stakeholders’ views need not be ‘second-guessed’ but actively sought and treated as crucial prima facie evidence with regard to validating candidate Program Theories (CPTs). This is illustrated in the later Findings Chapter 7 which demonstrates transparency between: (a) the CPTs (b) evidence derived from stakeholders to confirm, deny or call for their amendment (c) the rationale for any judgements made in relation to (a) and (b).

An important issue that emerged early on in this study and which is related to all this was how to overcome the almost unavoidable subjectivity provoked by such a potentially emotive subject as the

FCOPWA. It was contended that while it would likely be difficult to circumvent this, particularly during face-to-face interviews with FCOPWA, it was nevertheless paramount that the CPTs drawn up remain the main focus throughout and to allow the evidence gleaned in relation to the CPTs to as transparent and objective as possible, avoiding becoming overly interpretative. Clearly, achieving complete objectivity with regard to analysing and interpreting any social phenomena remains fraught with difficulty and challenges, e.g. individual reasoning that leads to certain outcomes may sometimes be irrational and unfathomable. Thus, in common with the majority (if not all) methodologies, SR is limited to providing 'partial' rather than 'full closure' in terms of our theoretical understanding of social phenomena. Indeed, it remains central to the difference between CR and SR and also the juncture at which a fundamental schism opens up between these two methodological approaches that SR goes much further to recognise the limitations of social science inquiry and evaluation, but simultaneously strives to compensate for this inherent deficiency via a strict adherence to ensuring:

- (a) CPTs are based upon the 'best' that the available literature, including grey literature to provide relatively robust and ecologically valid theory;
- (b) CPTs are empirically 'tested' via field work to subject them to objective, 'real world' testing;
- (c) program theories (PTs) are refined and modified, accepted or rejected on the basis of the above;
- (d) PTs undergo further iterative scrutiny and refinement, acceptance or rejection via additional research and further studies, including by other researchers, in a progressive (rather than a repetitive) manner.

Arguably, such an approach represents the attempt to achieve as much methodological rigour as possible, to cumulatively and constructively add to and increase our existing knowledge of social phenomena. As Pawson (2013, p.107) points out: '...evaluation cannot hope for perfect objectivity but neither does this mean it should slump into rampant subjectivity.' Arguably also, SR offers a more objective approach than many alternative approaches, including CR. Arguably also, the ability of SR to provide a research approach focused on achieving objectivity via a reliance on robust evidence bases and adherence to rigorous methods of investigation means it is well served to deliver findings that are sufficiently robust and well specified to permit its translation from research into policy and practice.

and by doing so narrowing the gap between social science theory and objective scientific inquiry

3.7.1 Advantages of adopting an iterative approach to evaluation

SR promulgates an iterative approach that encourages 'demi-regularities,' often embodied with PTs, to be 'tested' and 'retested.' This is achieved by carrying out subsequent studies as part of a

continual process of refinement, adjustment and modification and possibly also- rejection (e.g. where contextual changes as well as other factors that may influence client reasoning become significant enough to render the existing CMO configuration no longer valid).

3.7.2 Advantages of employing a theory-driven approach

Theory-driven approaches such as SR can help to avoid the pitfalls associated with the continual and burgeoning search for more theory encouraged by more data-driven approaches that risk becoming theory-laden (Pawson & Tilley, 1997, p.26). Arguably, data-laden research can too easily become labyrinthine and opaque, rather than explanatory and revealing. By contrast, theory-driven approaches such as SR can provide the means from the outset to determine where the researcher might look and what the researcher might look for. Moreover, by anchoring the evidence in the search for 'mechanisms' that may be pivotal to bringing about change, SR allows research to remain focused on causative influences and thus more objective.

3.8 Theoretical framework: Realist evaluation

The conceptual approach adopted in this study is realist evaluation (Pawson & Tilley, 1997). Realism is not a research method but a methodological orientation; an approach to constructing and selecting research methods (Pawson et al; 2005). At its core, it promotes an approach to synthesis and evaluation that seeks to move beyond establishing whether programs or interventions work to reveal 'how' 'for whom' and in 'which circumstances.' Essentially, this enables in-depth analysis of interventions via the formulation of PTs and their subsequent empirical examination. Analysis highlights the specific contexts (C) which need to be present to permit the triggering of the relevant mechanisms (M) to produce certain observed outcomes (O) (Pawson & Tilley, 1997, pp.21-22).

Mechanism (M) refers to the reasoned response by a stakeholder to a program or intervention, generally informed by the level of supportive external resources available to them, which gives rise to certain outcomes (O) (Pawson & Tilley, 1997; Dalkin et al; 2015). Mechanism therefore relates to causation, i.e. processes that produce events or patterns of events (demi-regularities).

Mechanisms (M) operate within a context (C) that is often critical to how the outcome (O) is generated. Realists are concerned therefore with how mechanisms are contingent on context and the extent to which context is conducive to mechanisms producing certain outcomes (Pawson & Tilley, 1997, p.216), i.e. whether specific contexts facilitate or hinder reasoned decision-making. Knowledge of context is therefore deemed critical to how programs work, providing important specifics regarding 'who' 'when' and 'how' the program works.

An important point to note also is that 'outcomes' in Realist terms does not refer to the kind of raw outcome data (Pawson, 2013, p.40) normally associated with 'outcomes,' i.e. derived by other types of studies and approaches, such as RCTs (random controlled trials). Rather, 'outcomes' here refers to change in individuals' reasoning which is mediated by resources and context (Pawson & Tilley, 1997; Dalkin et al; 2015). This represents a more subtle and nuanced interpretation of 'outcomes' that arguably provides greater specificity regarding how the 'outcome' was achieved.

The activation of mechanisms is dependent on the specific characteristics and circumstances associated with context and situation, including the availability of key external resources, and how these contribute to stakeholder reasoning to either facilitate or hinder the emergence of certain outcomes. This study is principally concerned with how external resources combine with FCOPWA's reasoning to support and facilitate the long-term family care of PWA. SR maintains that how context (C) combines with mechanisms (M) is critical to the outcomes produced (Pawson 2006). Therefore, identifying how these two main variables combine to support the long-term FCOPWA and presenting these as CMO configurations represents a critical aspect of the realist evaluation conducted as a main part of this study. Essentially, the resulting CMOc's contribute to elucidation of the specific conditions and circumstances in which FCOPWA are best supported, responding to the research question: 'what enables the FCOPWA.' To evaluate this research question, the theories within a program must be made explicit, by developing clear hypotheses about how, and for whom, programs might work in advance of any field work. This is achieved by identifying context (C), mechanism (M) and outcome (O) configurations (CMOc's) because causal outcomes following from mechanisms acting in contexts provide the basis upon which all realist explanation builds (Pawson & Tilley, 1997). Realist methods therefore strive to specify who the program works for and in which specific context.

How context and mechanism combine to produce outcome is commonly referred to as a CMO configuration (CMOc) or PT (Pawson & Tilley, 1997). PTs are the underlying assumptions about how a program is meant to work and what impacts it is expected to have (Pawson, Greenhalgh et al. 2005). A CPT or initial CMOc provides the starting point for a realist evaluation with the CPT representing the unit of analysis (Pawson, 2013, p.188). CPTs or emergent CMOc's generally provide the starting point for a fuller realist evaluation. As such they remain putative since they are generally based around secondary information usually derived from previous studies conducted by other researchers and their published reports, as well as grey literature. CPTs only become more substantive and deserved of the full title PT once they have undergone empirical examination against prima facie evidence.

With regard to this study, the purpose of conducting a realist evaluation was to develop a deeper understanding of 'what enables FCOPWA' in the U.K., in the absence of any real consensus

regarding this question. In doing so, realist evaluation strives to capture how causation is generated by a combination of context, external resources and human reasoning (see Figure 8 below). This follows a main tenant of realist evaluation: that social evaluations need to pay close attention to how context and mechanisms combine to give rise to outcomes in order to fully appreciate how causation is generated (Pawson & Tilley, 1997, p.215). The overarching aim of realist evaluation is to provide explanatory accounts of causation that include a sufficient level of specificity to directly inform wider policy and practice and in this to offer decision-support. Realist evaluation has, ‘a different cause from other social sciences, namely to have realistic ambitions to inform real-world policy and practice’ (Pawson, 2013, p. xix). Particularly so within social contexts such as health, welfare, education, the environment, etc. (Pawson, 2013, p.90) and in this study-public health.

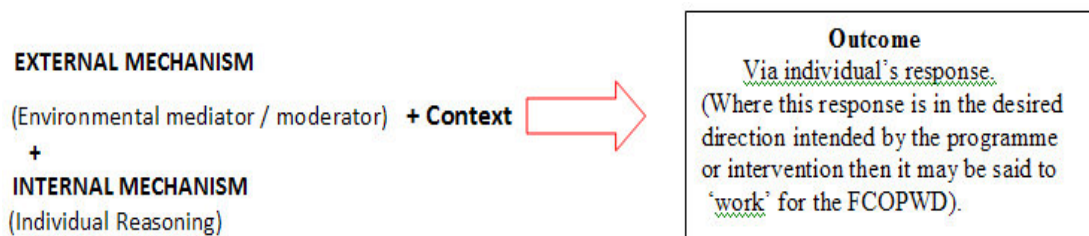


Figure 8. How mechanism (M) and context (C) combine to generate causation denoted by outcome (O) in this study. Adapted from Pawson & Tilley (1997); Dalkin et al; 2015).

3.8.1 The progress of SR

SR is rapidly gaining momentum as a research method of choice, particularly in key areas of research such as public health (Porter, 2015). The rise of SR in recent years has been due in no small part to its growing reputation as an approach capable of addressing complex social issues and evaluating these in a rigorous manner. This has met a burgeoning need in areas of research such as public health for evaluative approaches capable of providing evidence-based accounts not only of ‘what works,’ but importantly also, ‘how, for whom and in which circumstances’ (Pawson, 2013). SR has continued to benefit from a continual process of refinement and adjustment via the RAMASES project and its open engagement in ongoing discussion, debate and cross-validation to further improve the robustness of its methodology.

SR also offers a workable approach to conducting evaluations in terms of how it can be applied, i.e. at a more practical and pragmatic level it is assisted by regular methodological updates by RAMASES (Realist and Meta-Narrative Evidence Synthesis-Evolving Standards), as well as updates such the RAMASES training materials (e.g. Wong, Westhorp & Pawson et al; 2013) and RAMASES publication standards guidelines (e.g. Wong, Greenhalgh & Westhorp et al; 2013). Arguably, these continuing efforts have helped SR establish its place among some of foremost social science research approaches of recent times.

The decision to adopt SR as the methodological approach in this study also stemmed from the success of previous health-based studies which had already employed it. This included SR studies which have explored such public health-based topics as how to facilitate health literacy to promote public health (Willis, Saul and Biz et al; 2014); how to improve the health of traveller communities (Carr, Lhussier & Forster et al; 2014); evaluation of a new model of emergency department based mental health nursing practice (Wand, White & Patching, 2010); the role of communities of practice in changing healthcare practice (Ranmuthugala, Cunningham & Plumb et al; 2011). These studies represent just a few examples among the many which have been conducted to date and further highlight the burgeoning confidence of employing SR as the methodology of choice in public health-based research. As the SR approach becomes progressively more clearly clarified and more widely practised so has the frequency of its selection as the methodology of choice among commissioners of public-based research and reports. A recent review by Porter (2015) noted the rapid momentum being gained by SR and its ready selection by public health research commissioners, not least for its great potential for translation potential to similar contexts and similar population groups and its translatable potential from research into policy and practice. Advocates find that SR meets a current need for a research approach which is capable of providing the level of specificity required to: (a) unravel social complexity (b) tailor solutions to meet the needs of specific population groups (c) deliver research findings which are sufficiently well specified to permit translational potential to further population groups.

3.8.2 Rationale for adopting SR as the approach in this study

The 'acid test' that determines whether a study contains a sound methodological basis rests on its 'fit for purpose' to meet the requirements of the research question which is to be addressed by it and its capacity to meet the particular requirements of an individual study (Pawson, 2013, p.xii).

Applying this fundamental 'fit for purpose' criterion to this study, the decision to adopt a SR approach was based on:

- (a) its adoption of a theory-driven approach that strives to establish 'the best' that theory has to offer, that crucially also includes evidence derived from the grey literature to ensure that theory also possesses an ecological basis in 'real world.' In this study FCOPWA's experiences and views to support CPTs which can then be empirically 'tested' and validated;
- (b) the ability of such a theory-driven approach to narrow the ontological gap between unobservable phenomena that often lie at the heart of social phenomena and human interactions with their environment and phenomena which may be more overt and observable. Crucially, this presents the opportunity to take fuller account of the potential for underlying processes to give rise to causation,

rather than automatically treating these as confounding variables or treating them in an arbitrary, post-hoc fashion (Pawson & Tilley, 1997, p.54) that ignores or underestimates their overall importance. Within SR, these are also sometimes referred to as ‘invisible program mechanisms’ that may make crucial contributions to how a program works (Pawson, 2013, p.122) (Figure 9):

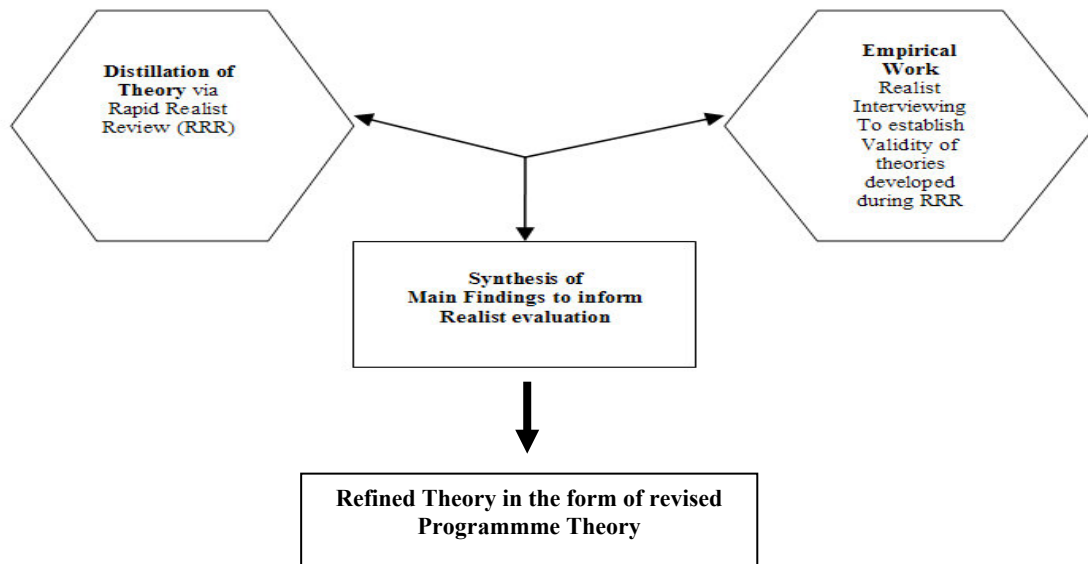


Figure 9. The importance of adopting a theory-driven approach in this study and its contribution to the overall realist evaluation.

- (c) SR focuses on the causative influences that generate certain outcomes to derive explanatory accounts, rather than rely on a more data-driven approach that risks producing overly interpretivist and dense descriptive accounts of social phenomena (Gephart, 2004);
- (d) SR’s ability to specify the contexts that are most conducive to ‘what works to support FCOPWA.’ A significant gap in the available literature was found to be that in the majority of studies which have examined FCOPWA, few make specific reference to the contexts in which family carer support works best. Mechanisms operate within a context that is often critical to the outcome that is generated. SR is concerned therefore with how mechanisms are contingent on context and the extent to which context is conducive to mechanisms producing certain outcomes (Pawson & Tilley, 1997, p.216). Knowledge of context is deemed critical to how programs work, providing important specifics regarding ‘for whom’ ‘in which circumstances’ the program works;
- (e) SR’s ability to uncover at a deeper level the underpinning ‘mechanisms’ that explain ‘how’ particular types of support ‘work’ for FCOPWA. SR offers an analytical approach capable of identifying the significant determining factors and influences that might explain how certain outcomes occur in specific contexts. Thus, SR provides a high level of specificity, but also of abstraction that takes underpinning and sometimes ‘hidden mechanisms’ also into account;

- (f) SR's great value in facilitating translational research, i.e. the same general principles found in certain program theories may be usefully applied to other, perhaps similar situations (Pawson, 2013, p.89). In this study 'what enables FCOPWA' may also usefully inform 'what enables' the long-term care people with other chronic conditions. This widens the potential research impact of such studies. By contrast, 'outcome-driven, quasi-experimental approaches imported from clinical trials' and 'constructivist' approaches generally fall short of delivering this (Pawson (2013, p.xii);
- (g) SR's ability to provide explanatory accounts based around the contexts and mechanisms that combine to produce certain outcomes. This transcends the limitations inherent to many alternative methodologies that instead focus on producing descriptive accounts that are mainly based on a focus on 'outcomes,' e.g. traditional review methods such as systematic review and meta-analysis (Pawson, 2002);
- (h) SR's ability to provide useful tools for synthesizing complex and wide-ranging evidence from the diverse sources to address the inherent complexity contained in many social phenomena. This includes the complex and potentially wide-ranging research question investigated here: 'what enables FCOPWD?' Where complex social issues are investigated causation may often be non-linear and generated by factors that are unobservable, making such studies unsuitable for more traditional scientific modes of inquiry. 'Realist reviews and evaluations are best suited for making sense of complex interventions where context is thought to influence outcomes and answer questions that ask some or all of what works, for whom, in what contexts, to what extent, how and why?' (Wong, 2018, p.2);
- (i) SR's ability to capture and examine social complexity via '...a gradual, progressive, cumulative process of inquiry' (Pawson, 2013, p.112) that is wholly reliant for its effectiveness on (i) the adoption of an iterative approach in which theory is further refined (ii) the critical scrutiny of other researchers, including further investigation, that leads to further refinement of theory (iii) striving to ensure that these processes remain cumulative and progressive rather than creating cyclic theoretical 'cul-de-sacs;'
- (j) SR's ability as a methodology to remain method neutral, rather than adopting the stance held by alternative methodologies that may arbitrarily reject certain methods, despite their potential utility, where they are not aligned with underlying philosophy;
- (k) SR's attempt to narrow the gap between social science theory and more traditional scientific approaches via its attempt to achieve empirical rigour;
- (l) SR's burgeoning growth as a research methodology of choice, particularly within health-based research.

3.8.3 Rationale for framing this study within a more positive perspective

The rationale for framing this study within a more positive perspective was presented earlier in Chapter 2. Therefore it is sufficient here to briefly reiterate the deliberate attempt to do so and to acknowledge this as part of this study's adherence to the SR principle of transparency. This rationale was based on:

- (a) the research question's focus on investigating 'what enables FCOPWA' made the implicit positive assumption that there are 'enabling factors' out there to be uncovered;
- (b) reliance in the U.K. on the FCOPWA to provide the backbone of AD care remains crucial, therefore it is expedient and necessary to explore more positively 'what enables FCOPWA';
- (c) the Medical model and the 'burden of care' paradigm that accompanies it which are predominant in the U.K. automatically predict poor carer outcomes irrespective of any carer support that may be provided. Framing the FCOPWA within such a paradigm remains wholly incompatible of the notion of investigating ways to enable the FCOPWA over the long-term. While the Medical model remains important in terms of dementia diagnosis, there is a need thereafter to shift the focus away from a biomedical preoccupation with the pathology associated with the disease and undue emphasis on decline and health deficits (Clarke & Wolverson, 2016). Such an emphasis might be more appropriate where it is applied to terminal illnesses that are potentially treatable, such as cancer. However, their appropriateness for AD where those affected by the disease may continue to enjoy a reasonable quality of life for several years after diagnosis remains highly questionable (see Chapter 2).

Previous efforts aimed at presenting the FCOPWA within a more positive perspective inspired the adoption of a similar outlook in this study. Such a stance also meets the burgeoning need at present, both in the U.K. as well as more globally, for family carer research that recognises family carers' strengths and capabilities given the exponential rises in AD prevalence and critical reliance on an ever greater number of family carers to provide the backbone of care. Among those influences which inspired the adoption of a generally positive approach in this study were: the salutogenic paradigm (Antonovsky, 1996), The Affirmation Model of Care (Swain & French, 2000) and Competency Models of Care (Livingston, Katona & Roch et al; 2004).

3.9 Chapter Summary

This chapter explored the SR methodology and approach which underpins this study and which forms the basis for the realist evaluation which follows. The Chapter then explored the ontological and epistemological bases of SR, their strengths and advantages and the appropriateness of employing SR as the approach in this study.

The origins of SR were examined, before moving on to explore the theoretical framework employed to carry out this realist evaluation. The Chapter concluded with a rationale for framing this study within a positive perspective.

Historically, SR has represented 'a methodological approach' and 'overarching guide' to carrying out research, rather than a prescribed protocol per se. However, attempts have been made recently to more clearly define how SR studies might best be conducted and these will be explored in the Methods Chapters which follow. The next Chapter will explore the method of review that was employed-rapid realist review-and how this was carried out.

CHAPTER 4: METHOD-RAPID REALIST REVIEW

4.1 Introduction

This chapter will explore the review and evaluation methods and procedures employed to address the research question: ‘what works to support family carers of people living with dementia (FCOPWD)?’ based around a Rapid Realist Review (RRR) (Parkinson, Carr & Rushmer et al; 2016). How these methods fit into a scientific realist (SR) approach and how they led to the construction of a framework from which to explore the research question will be examined, including the subsequent development of context-mechanism-outcome (CMO) configurations to represent hypotheses for the specific contexts and mechanisms that facilitate positive outcomes for FCOPWD. Additionally, how the CMO configurations led to the formulation of candidate Program Theories (CPTs) representing theoretical propositions which could be empirically tested and validated during the remaining phases of this multi-phase study.

4.1.1 The focus of this review

This review investigated the key factors, strategies, interventions, contextual factors and mechanisms that relate to the research question: ‘What works to support FCOPWD?’ A key challenge for family carers is that the lengthy time course of dementia, the inevitability of an irreversible decline in health for people living with dementia (PWD) and the unpredictability of the disease’s day-to-day manifestation mean that dementia and the FCOPWD is unique, presenting novel and distinctive challenges to family carers in comparison to other non-communicable diseases such as cancer (Murtagh, Preston & Higginson, 2004; Murray, Kendall & Boyd et al; 2005). These challenges give rise to salient health inequalities for many FCOPWD (Hirst, 2004). Despite this, a recurring theme in family care research is the polarity of carer response to the challenges of taking on the role (Gaugler, Davey & Pearlin et al; 2000). While some carers may struggle with the challenge of being a FCOPWD, others appear to not only maintain stability, but may even report improvements over time (ibid). A main question therefore concerns, ‘what works’ for those carers who appear to navigate the challenges of dementia care more successfully than others. Moreover, how such knowledge can be applied more universally to benefit other adults, particularly those who face prolonged periods of adversity.

4.1.2 Rationale for a review of the current literature

A relatively wide range of literature, including published papers and grey literature, currently exists that explores how FCOPWD might be supported in what is generally recognised as a challenging role. However, what is largely absent is any real consensus or coherence concerning, ‘what works.’ This

prompted the need for a comprehensive review of the current literature to examine this question in further depth.

4.1.3 Rationale for employing a Rapid Realist Review (RRR)

The rationale for employing a RRR as the review method was based on its ability to provide the following advantages:

- More traditional meta-analyses or systematic reviews tend to focus on ‘outcomes’, i.e. whether a program or intervention ‘works.’ Such methods can be limited to proving more general, aggregate accounts of ‘what works’ (Pawson, 2002) that lack specificity and which may ignore important details such as ‘how, for whom and in which circumstances’ a particular program works.’ RRRs by contrast attempt to provide a more comprehensive account of causation, i.e. by exploring not only ‘what works’ but also ‘how, for whom and in which circumstances.’ This greater level of specificity enhances the translational potential of such reviews.
- Public health research is often time critical, therefore review methods that shorten the timescale to allow results and findings to be utilised earlier hold a distinct advantage over more time-consuming methods. RRRs typically take around six months to complete (Saul et al; 2013), far quicker than more traditional review methods. This enhances their translatable potential from research into practice.
- RRRs are especially useful during the initial phases of multi-phase projects where research findings need to be rapidly adapted and iteratively refined to take account of emerging evidence. Essentially, the RRR facilitated the speedy transition of the review’s findings into a workable theoretical framework based around ‘what works to support FCOPWD,’ as well as candidate Program Theories (CPTs). These provided the basis for subsequent empirical testing in a timely manner which enabled overall completion of this study within the time allotted to it at the outset, a feat which would not have been possible otherwise.
- RRRs can benefit from on-going guidance and advice from multiple stakeholders, including professionals, end-users and academics to provide a range of expertise and experience to help maintain a clear focus and direction for inquiry that is well informed.

4.2 Method

RRRs represented a relatively novel approach to conducting reviews at the outset of this study. They have since become increasingly ubiquitous. Their growing popularity owes much to their utility

in terms of providing explanatory accounts based on ‘what works, how, when and for whom’ that transcend the limitations imposed by more descriptive methodological approaches that focus mainly on ‘outcomes,’ e.g. meta-analyses and systematic reviews. Moreover, while these latter approaches may take up to three years to complete, RRRs can be achieved within much shorter time-frames, typically within six months. This is particularly useful for time-limited research where answers to research questions need to be found and implemented speedily and where there is also a need to produce findings which to go further to explicate the processes by which certain outcomes are generated.

Standard SR presentation protocol was adhered to with regard to how the RRR was presented, guided by the Realist Publications Standards guidelines laid down by Wong, Greenhalgh and Westhorp et al. (2013). In particular, close adherence was made to the ‘19 point’ checklist on page 4 of those guidelines. This helped to ensure the standards required for publication of an SR based review were maintained.

Meanwhile, the methods employed to conduct the RRR closely adhered to the most recently published protocol available at the outset of this study, as established By Willis, Saul and Bitz et al. (2014). This protocol denotes a five step review process (Willis et al; 2014, p.517) which is organised as follows:

Step 1: Developing and refining a purpose statement and research questions;

Step 2: Searching and retrieving information;

Step 3: Appraising the evidence;

Step 4: Synthesising information;

Step 5: Interpreting information.

However, as Wong et al. (2013, p.4) point out, although the steps involved in SR inquiries may be set down in a chronological and sequential manner for ease of reference and overall guidance, the realist process is often non-linear and iterative, meaning that some steps may need to be revisited. This proved to be the case in this study, as will be demonstrated in the summary which follows.

4.2.1 Step 1: Developing and refining a purpose statement and research questions

The basis and rationale for the research question that is the focus of this study was outlined earlier in Chapter 2.

4.2.2 Step 2: Searching and retrieving information

1st Literature search: Scoping review

The search process involved an initial scoping review based on the Google and Google Scholar search engines (see Appendix 1) to identify relevant abstracts related to the research question: 'What works to support FCOPWD?' This provided initial confirmation and support for the contention that the research question had not been comprehensively addressed previously and justified the decision to proceed further with inquiries in relation to it.

2nd Literature search

A comprehensive 2nd search of the literature via electronic data bases (including grey literature) was deemed essential in order to derive sufficient evidence to formulate more substantive hypotheses. Grey literature, including administrative grey literature, can prove especially useful in providing less formal but potentially revealing evidence, i.e. from family carers who represent the focus of the study. Grey literature can also prove invaluable in adding additional knowledge that helps to resolve a lack of consensus regarding the research question.

The 2nd literature search was conducted using more refined search terms and guided by inclusion criteria (see Table 3 below). This included filtering of articles to achieve breadth of coverage, relevance and depth and was also guided by the inclusion criteria. The 2nd search was filtered to only include those articles dating from 1st January, 2005 to December, 2014. This time frame provided the opportunity to focus on articles published during the previous ten years in order to achieve breadth of coverage while also attempting to ensure that any findings remained relevant to contemporary population groups. The ten year interval was intended to provide a guideline only in the search for articles and did not preclude the inclusion of pre-2005 findings where these were gauged to be critical to the present research. This included seminal papers such as Kitwood (1990) that were somewhat ahead of their time and still highly relevant to this study.

Five key databases were interrogated for relevant evidence as part of the purposive sampling strategy employed, using the search terms contained in Table 3 below. Four of these databases focused mainly on peer reviewed published papers and were also selected for their ability to yield relevant results based on the essentially scientific, medical, sociological and psychological dimensions of the research question. The psychological dimension of dementia care was deemed important since it is well established that the majority of carers of PWD will encounter psychological challenges (Hirst, 2005). The fifth database included NORA (Northumbria University Research Articles database) to ensure grey literature coverage of the research question. Grey literature has particular value in terms

of providing useful and highly relevant information gleaned directly from the principal stakeholders who represented the subject of this study. Its inclusion also satisfies a recommendation made in SR studies to ensure principal stakeholders' views are taken into account (Pawson & Tilley, 1997).

Additional databases (e.g. Cochrane Reports data base, Department of Health, N.I.H.R. and Voluntary sector Reports such as Alzheimer's Society U.K. and Carers U.K.) were also interrogated to ensure comprehensive coverage of relevant databases and to add to the rigour of the review. Some of these databases included supplementary grey literature to ensure this important dimension of the review received sufficient coverage.

Articles meeting any of the inclusion criteria (see Table 3 below) were retrieved for full text screening. Full text articles meeting inclusion criteria proceeded to full extraction. Articles not meeting any of the above criteria were excluded.

Table 3. Search process, search terms and number of abstracts selected per database to be assessed against the inclusion criteria as a precursor to selection for extraction.

<p>Scoping Review based on the Google & Google Scholar search engines to glean background information concerning the research question: 'What works to support family carers of PWD?' This confirmed the initial contention that there was a relatively narrow data base surrounding this question.</p>	<p>2nd string search of more bespoke databases related to the scientific, medical, physical, psychological and social science bases of the research question. Principally, this included any documents relating to the family care of PWD or Alzheimer's disease; any efforts or interventions designed to support family carers; barriers to support & current health policies relating to this.</p> <p>Search Results: 428 articles from Northumbria University Research Articles database (NORA) 146 articles from Applied Social Sciences Index and Abstracts (ASSIA) 30 articles from Social Services Abstracts 110 articles from PsycARTICLES 484 articles from ISI Web of Science</p> <p>Search Terms Family carers* of 'people with dementia' Scholarly article-peer-reviewed Content Type: Any Subject Terms: dementia Subject Terms: caregivers Filtered from 2005 to 31st December, 2014</p>
<p>* Inclusion criteria descriptions</p> <ol style="list-style-type: none"> 1 Article discusses dementia within the context of family care, informal care, unpaid care 2 Article discusses Alzheimer's disease within the context of family care, informal care, unpaid care 3. Article discusses what works to support the care of people with dementia / Alzheimer's disease 4 Article discusses potential barriers to the care of people with dementia / Alzheimer's disease 5 Article discusses potential interventions employed to support the care of people with dementia / Alzheimer's disease 6. Article discusses the health policies surrounding the care of people with dementia / Alzheimer's disease 7. Article discusses the health policies surrounding the care of people with dementia / Alzheimer's disease and offers recommendations for the future based on research evidence and stakeholders' experiences. <p>*Articles meeting <i>any</i> of the above criteria were retrieved for full text screening, even where only one criterion might be met. Full text articles meeting inclusion criteria proceeded to full extraction. Articles not meeting any of the above criteria were excluded from the Results, but where relevant helped to inform the background and introduction to the review.</p>	

4.2.3 Step 3: Appraisal and validation of the evidence.

Data extraction from 2nd literature search

Synthesis of the findings focused in realist terms on the broad ‘mechanisms of change’ relative to ‘what works to support FCOPWD.’ ‘Mechanism’ is defined here according to the SR interpretation of ‘mechanism’ as being reliant on the context in which causation occurs, together with individuals’ internal reasoning and actioning, as well as the availability of key external resources in order to causally influence ‘outcomes (Pawson & Tilley, 1997, pp. 216-217; Dalkin et al; 2015) (see Figure 10).

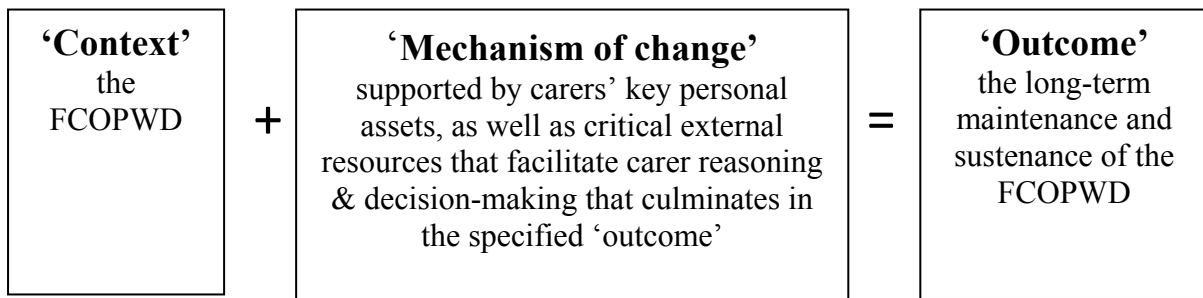


Figure 10. SR interpretation of ‘Mechanism’ and how it is contingent on certain factors, including context, to generate specific outcomes.

Uncovering the broad ‘mechanisms of change’ relative to ‘what works to support FCOPWD’ involved analysing each of the documents selected from the 2nd literature search for:

- (i) the broad context in which ‘what works’ was situated;
- (ii) the broad mechanism of change associated with ‘what works;’
- (iii) a potential area of intervention or improvement to ‘what works’ within each context and mechanism.

At this stage, synthesis was focused on developing a broad scaffold as part of an ongoing effort to bring greater coherence to the multiple findings derived from the 2nd Literature search. To this end, five broad, overarching contexts and mechanisms were identified that might be most instrumental in ‘working to support FCOPWD.’ However, there remained an outstanding need to bring further internal cohesion to the findings that would also assist in identifying potential links among these five broad areas. In sum, a unified theory was needed to further explain all the observed patterns and uniformities in the data and to bring cohesion to the main findings by:

- (a) examining the possibility that a common denominating factor might connect the five broad areas;
- (b) reappraisal of what the five areas all more specifically achieved in terms of broadly supporting FCOPWD.

This led to the search for a middle range theory (MRT) (Merton, 1968) concerning how the five broad areas might be linked by an overarching Context-Mechanism-Outcome (CMO). Having explored a range of potential MRTs and considered their respective strengths and weaknesses, a strong candidate MRT emerged which presented a plausible explanation for all the observed patterns and uniformities in the data. The ‘outcome’ (O) which was originally defined by ‘what works to support FCOPWD’ was also further refined and clarified as: ‘what works to support the maintenance and sustenance of FCOPWD.’ A fuller discussion of how the MRT was arrived at is contained in the next Chapter which explores the RRR’s findings.

4.2.4 3rd literature search investigating links between proposed MRT and the FCOPWD

It was essential to establish the strength or weakness of the evidence base in support of the proposed MRT by re-engaging with the literature via a 3rd literature search with the focus this time on how the MRT might be related to the support of FCOPWD (see Table 4 below). The searches were filtered from October, 2005 to May, 2015 since this step of the RRR was conducted during May, 2015.

Table 4. 3rd Literature search to establish how the MRT might be related to the support of FCOPWD.

Search Platform	Search Results	Search Terms
PubMed	28	‘Family carers’ ‘dementia’ ‘resilience’ Scholarly article-peer-reviewed, Conference papers & proceedings, dissertations & Theses Content Type: Any Subject Terms: dementia Subject Terms: caregivers Filtered from 2005 to May, 2015 Age Range: 18 years or over Language: English Filtered from October, 2005 to May, 2015
PubMed	152	‘resilience’ Scholarly article-peer-reviewed, Conference papers & proceedings, dissertations & Theses Content Type: Any Subject Terms: carers Subject Terms: caregivers Filtered from 2005 to May, 2015 Age Range: 18 years or over Language: English Filtered from October, 2005 to May, 2015

Essentially, the 3rd literature search substantiated the contention that the MRT was related to each of the five broad areas and might also represent the cornerstone supporting those factors that might 'work to support FCOPWD.'

4.2.5 Step 4: Synthesising information

Having found evidence within the 3rd literature search to support the plausibility of the MRT, it was then necessary to re-examine of all the review evidence gathered so far in further depth and detail. This included reappraisal of the main findings from the earlier 2nd literature search, informed now by the evidence for how the MRT 'worked' derived from the 3rd literature search. Essentially, this evidence could now be viewed with the different 'lens' provided by the MRT which provided a main hypothesis for the process which underpinned 'what works.' This recursive process of revisiting data represents a fundamental attribute of SR inquiry and remains consistent with the iterative approach that is encouraged when employing such a SR approach to the exploration of data. Hence, initial theory acts as a 'starting point for evaluation' with subsequent trials and analyses permitting further opportunities for theory to be 'fine-tuned' (Pawson & Tilley, 1997, p.217). Re-examination of the findings from the earlier 2nd literature search enabled the analysis to go further by identifying the salient underlying sub-Themes or sub-categories within each of the five broad areas already revealed. This shed further light on 'what works to support FCOPWD.' The analysis also revealed certain clear links between these underlying sub-Themes and the MRT. Synthesis of the findings culminated in the development of a theoretical framework for 'what works.'

4.2.6 Step 5: Interpreting information

The theoretical framework facilitated the process of retroductive inference-making employed during Step 5. Inferences can be viewed in terms of 'thought operations' and therefore as 'different ways of reasoning and thinking in order to proceed from something to something else,' (Habermas, 1972, p.113). Essentially, this involved moving from a theoretical account of 'what works to support FCOPWA' based on the conceptual framework produced by the RRR to the formulation of context-mechanism-outcome (CMO) configurations associated with each sub-Theme within each of the five broader areas identified at the outset of the RRR. CMO configurations represent '...a proposition stating what it is about a program which works for whom in what circumstances,' (Pawson & Tilley, 1997, p. 217). Meyer and Lunnay (2013) note how retroduction denotes the process by which these observed demi-regularities are examined in depth before inferences regarding causation are drawn

from them. In realist terms, this involves examining the demi-regularities represented by ‘outcomes’ and exploring how these ‘outcomes’ might be mediated by a combination of:

- (i) the availability of external and internal assets resources;
- (ii) individual reasoning and decision-making;
- (iii) within conducive contexts.

Crucially, retroductive inquiry’s focus on taking emerging evidence into account can permit fresh insights and revelations, including the formulation of CMO configurations relating to each sub-Theme. Drawing up the CMOs was guided by three main principles of SR, paraphrased from Pawson and Tilley (1997, p.114):

- (i) Identify which specific mechanisms achieve change in the desired direction.
- (ii) Pinpoint the context(s) in which the mechanism is most likely to be triggered.
- (iii) It should become possible to draw up certain predictors that presage likely health outcomes for the intervention given certain circumstances and for specific population groups.

The resulting CMO configurations provided hypotheses for the specific contexts and mechanisms that lead to outcomes which support the maintenance and sustenance of FCOPWA, as well as how these related to and were supported by the underpinning MRT.

A draft analysis of the CPTs was circulated to the Supervisory Team (in lieu of the Reference Panel and Expert Panel that would normally form part of a RRR research team) for feedback, guidance and further refinement before being operationalised. Crucially, the Supervisory Team provided a unique balance of academic knowledge of the research topic provided by two professors who specialised in this area of public health; practical knowledge drawn from current employment as a Nurse Consultant in the area of vulnerable older adults, including adults with dementia and family carers of PWD; lay experience by two team members of actually carrying out the role of FCOPWD. This provided an ideal aggregate of academic, practitioner and lay expertise and experience. Furthermore, the Supervisory Team all had experience of employing SR methodology and although this methodology is now beginning to become more widespread, at the outset of this study it represented a unique skill-set. Moreover, strong links had already been established with the Supervisory Team and communications between members was rapid and efficient. All these factors combined to speed up the review process and ensure that the RRR achieved a principal aim of accelerating the review process. Thus, the majority of the RRR was completed within seven months, allowing several weeks following the main work for further consultation, discussion, revision and refinement of the CMO configurations and the formulation of Program Theories based on these which could be further examined via fieldwork during the succeeding phases of the study. The full RRR process is outlined in Figure 11 below.

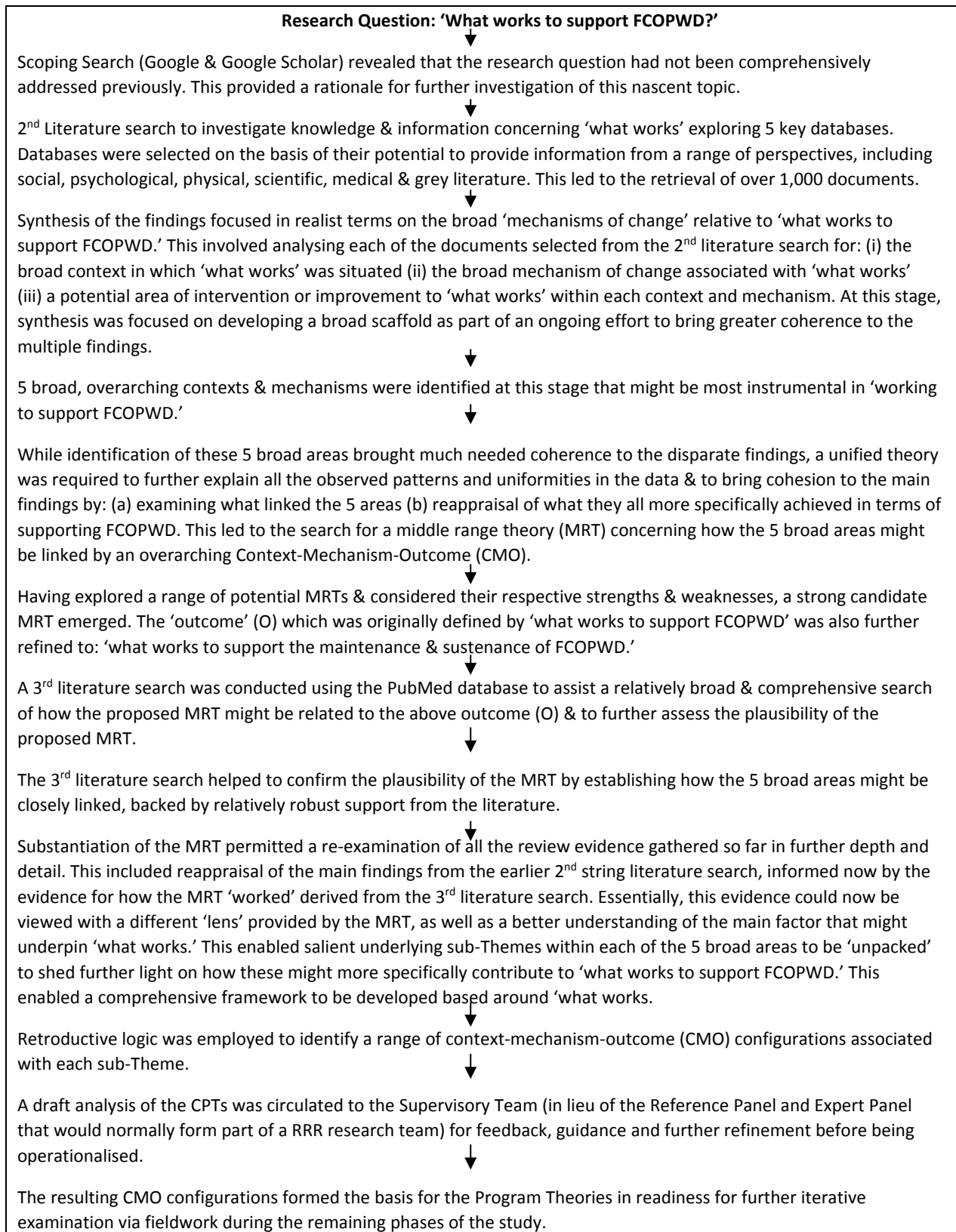


Figure 11. The RRR process in full.

4.3 Summary

RRR was chosen as a research method capable of detailed investigation of ‘what works to support FCOPWD’ as well as ‘how, for whom and in which circumstances.’ In doing so, RRRs can assist in moving beyond descriptive accounts centred around whether programs or interventions ‘work’ to additionally provide fuller explanatory accounts that examine the processes by which certain outcomes are achieved. RRRs can also assist in accelerating the process by which reviews are completed in order to achieve timeliness. This was particularly important to the present study where the focus of the research revolves around a burgeoning public health issue that is in urgent need of address, but which represents a complex issue that must nevertheless be investigated within a strictly delineated time period.

Procedurally, the RRR followed the protocol established by Willis, Saul and Bitz et al. (2014, p.517). Meanwhile, the protocol for how the RRR was presented was guided by the Realist Publications Standards guidelines laid down by Wong, Greenhalgh and Westhorp et al. (2013).

The RRR was based on a comprehensive search of the published literature spanning the past decade, including grey literature. The findings from some earlier documents, including seminal studies and accounts, were also utilised where these represented key contributions to the research question. The RRR drew some coherence among the disparate findings related to ‘what works to support FCOPWD’ by identifying five broad areas derived from the literature which appeared to be focal to ‘what works.’ A unifying theory or MRT was developed to establish how the five main areas might achieve the overarching outcome: ‘the long-term maintenance and sustenance of FCOPWD’ to bring further internal cohesion to the findings.

The MRT was substantiated by a further literature search to examine the potential links between the five broad areas identified as potentially key to ‘what works.’ Subsequent synthesis of all the main findings from all the literature searches culminated in a comprehensive framework depicting what was hypothesised to ‘work to support FCOPWD.’ This included main sub-Themes within each of the five main areas. Development of this expansive framework directly influenced and informed the eventual formulation of CMO configurations representing propositions stating ‘what works, how, when and for whom.’ From these a set of candidate Program Theories (CPTs) were formulated which would provide the basis for further empirical investigation of the research question.

The RRR relied on a Theory-driven analysis which permitted a deductive approach in which theories concerning, ‘what works to support FCOPWD’ led to hypotheses which could be subsequently verified, validated, rejected or refined through empirical ‘testing.’ A deductive approach based on theory proved essential given the lack of consensus concerning the principal research question, as well as a paucity of information concerning the underlying mechanisms that might support FCOPWD. This

also remained consistent with the SR approach adopted in this study which denotes a mainly theory-driven approach.

Retroductive logic was employed to identify 'mechanisms' that may have produced the patterns or demi-regularities observed in the review's findings. Retroduction is important in enabling fresh insights and revelations to emerge to drive inquiry forward and also crucial to informing the subsequent formulation of CPTs. The empirical investigation conducted during the subsequent phases of the study permitted the gap that might develop between theory and reality to be narrowed via SR's dedication to empirical examination-objective testing in the real world- of CPTs that seeks to validate or invalidate them. The next Chapter outlines the main findings from the RRR before moving on to an account of the empirical 'testing' phase of this study.

CHAPTER 5: RAPID REALIST REVIEW RESULTS

5.1 Introduction

This Chapter will explore the findings from the Rapid Realist Review (RRR). To briefly recap, the research question was based around a recurring theme in family carer research, namely the polarity of carer response to the challenges of taking on the role (Gaugler, Davey & Pearlin et al; 2000). While some carers may become overwhelmed by the experience, others appear to not only maintain stability but may even report improvements over time (ibid). The Chapter therefore outlines the factors identified by the RRR which were found to be associated with ‘what enables the family care of people who are living with dementia (FCOPWD).’ This includes details of potentially enabling strategies, interventions and theories derived from the existing literature. To remain relevant and contemporary the findings were based around a search of the available literature mainly spanning the past decade. This included peer reviewed published articles, but also information from the grey literature in order to gather more informal, but no less relevant information from end-users to derive insights from as wide a range of stakeholders as possible to deepen the working hypothesis (Pope & Mays, 2006).

This study involves researching social phenomena and this can present a particular challenge since the interplay between people and their environment introduces multiple levels of complexity. Increasingly, this has led to the need to find new and more refined ways to try to meet this challenge. Not least to ensure that policy and decision-making avoid oversimplification and over generalisation, as well as to ensure that public health research moves towards the production of findings that lend themselves to their translation from theory to practice. It is becoming increasingly commonplace in many disciplines, including social science, to try to respond to the need to capture how multiple components, multiple contexts and multiple agencies combine to generate certain outcomes for specific population groups. This can demand comprehensive coverage to ensure research findings take these multiple factors into account. Additionally, the scientific realist (SR) position clearly states that research which strives to unravel social complexity needs to focus not only on outcomes per se, but also to consider in some depth the processes by which such outcomes emerge. This calls not only for comprehensive coverage, but also depth of coverage. Responding to these needs, the RRR and its findings were comprehensive and detailed, representing the aggregate findings from over 1,000 published documents.

However, the breadth and depth of coverage achieved by the RRR meant there was insufficient space here for the full inclusion of all the results from all five broad areas or Themes associated with ‘what enables the FCOPWD’ in this Chapter. The Chapter therefore explores one Theme out of the five identified by the review as an exemplar for how the literature findings were analysed and

consolidated. The example used represents Theme 1 and was selected on the basis of its ordinal position as the first broad area identified. The remaining four Themes represented as Themes 2 to 5 inclusive remain of equal importance to Theme 1, but to economise on the length of the thesis the full results of the RRR are contained in Appendix 3. To the same end, a summary table to present the candidate Program Theories (CPTs) for all five Themes associated with 'what enables the FCOPWD' is included in Appendix 4. This, together with the conceptual framework which was drawn up, provides an insight into the conclusions drawn from the RRR.

How 'Resilience' was developed as the middle range theory (MRT) hypothesised to be pivotal in underpinning 'what enables the FCOPWD' is also elucidated. This includes an exposition of how the MRT assisted in identifying the sub-Themes contained within each of the five broader Themes.

The rationale is presented for why it was necessary to develop a new conceptual framework based around carer resilience. In addition, the six-step deductive process by which each of the sub-Themes is examined, including how this led to the formulation of CPTs based around 'what enables the FCOPWD' representing theoretical propositions to be empirically tested during the subsequent phases of the study.

5.2 Results of the Rapid Realist Review

5.2.1 Initial findings

The RRR search process involved an initial scoping review based on the Google and Google Scholar search engines to identify relevant abstracts. This indicated that the research question had not been specifically examined previously and might present an opportunity to investigate an important dimension of dementia. This prompted a comprehensive 2nd string search of the literature via electronic data bases (including grey literature) in order to derive sufficient evidence to formulate reasonable hypotheses. The 2nd search revealed that literature related to 'what enables the FCOPWD' coalesced around five Themes / demi-regularities (recurrent patterns): (a) social factors critical to supporting the carer (b) carer's physical health status (c) key psychological factors associated with the carer (d) carer's quality of life (e) the availability of key external resources to support the carer (see Figure 12).

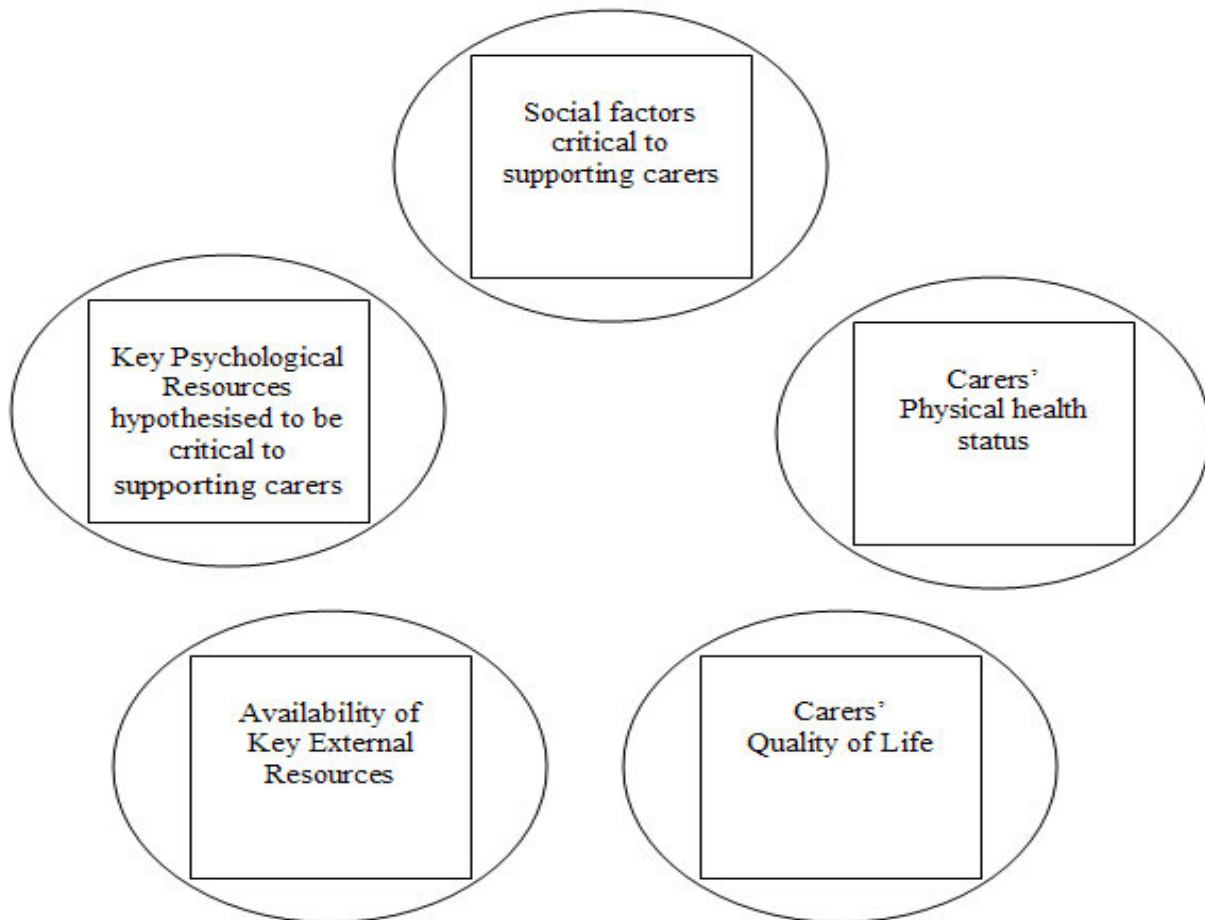


Figure 12. Five broad areas or Themes identified by the 2nd Literature search found to be closely associated with 'what enables the FCOPWD,' representing the key demi-regularities (recurrent patterns) observed within the findings.

While identifying these five broad themes / demi-regularities lent some much needed coherence to 'what enables the FCOPWD,' the need remained to bring further cohesion to the findings. The 2nd Literature search yielded a wide range of strategies, interventions and practices that might 'enable the FCOPWD,' but what was notably lacking at this stage was any coherence among the findings. In addition, there was no real means at this stage to establish which of these factors might be most critical, particularly in order to prioritise those factors which warranted further investigation. Ultimately, a unified theory was required to explain all the observed patterns and uniformities in the data, i.e. an overarching middle range theory (MRT) (Merton, 1968).

Theory is important to...telling us where to look as well as what to look out for during an evaluation (Pawson, 2013). This is particularly the case where it is MRT, where such overarching theory can exert a major influence on the overall direction and outcome of a study. In order to assist the process of finding a plausible MRT to help guide this study it was necessary to re-examine the research question to determine more precisely how 'what enables the FCOPWD' might be more specifically qualified in terms of its

perceived ‘outcome’ for carers. This required further consideration of what in SR terms the principal ‘outcome’ was intended to be regarding to the majority of factors associated with enabling the FCOPWD explored by the RRR. These considerations led to the ‘outcome’ of ‘what enables the FCOPWD’ being more clearly operationalised as ‘those measures designed to augment carers’ capacity to maintain and sustain the longer-term family care of PWD despite the challenges this may present.’ Having clarified this important point, there remained a need to find the common denominating factor which facilitated this ‘outcome’ for FCOPWD. Focus for finding a unified theory to bring cohesion to the initial RRR findings relied on exposing the underpinning ‘mechanism’ by which the long-term maintenance and sustenance of the FCOPWD might be achieved. To this end, retroductive inquiry involving the exploration of a range of potential MRTs was conducted to establish the most plausible MRT to account for how this outcome might be generated.

5.2.2 Selecting the MRT

This involved the systematic consideration of a range of candidate factors whose association with maintaining the family carer role despite adverse circumstances had previously been reported in the literature. The interpretation of MRTs is necessarily subjective and other teams may arrive at different MRTs to explain the findings (Wong, Greenhalgh & Pawson, 2010, p.7). However, what is important is that the MRT can be substantiated by evidence and shown to have greater explanatory power than alternative MRTs (ibid). The use of MRT to help to explain emerging data is also commonplace among SR studies and has been incorporated into a process which has been referred to as ‘progressive focussing’ (Wong, Greenhalgh & Pawson, 2010, p.3). Progressive focussing can involve distinct phases (see Figure 13):

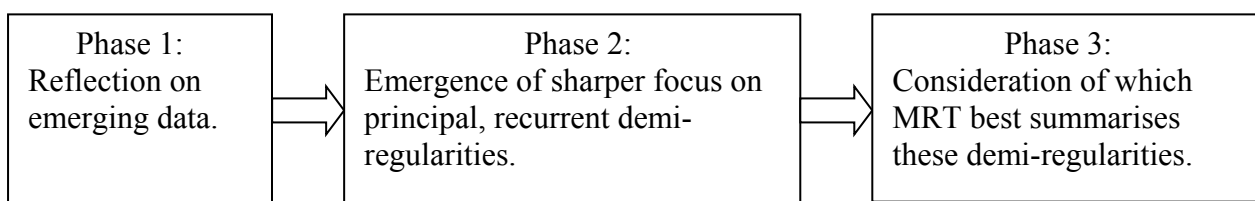


Figure 13. Progressive focussing in SR research to arrive at middle range theory (MRT). Adapted from Wong, Greenhalgh & Pawson, 2010).

Reflecting on the emerging findings from the literature led to five principal, demi-regularities (recurrent emergent patterns) being identified. Namely, that ‘what works’ appeared to coalesce round five main areas or Themes, as depicted in Figure 12. What remained as the next step of progressive focussing was to consider further which MRT might best summarise these demi-regularities (see Box 3 of Figure 13 above).

5.2.3 Consideration of which MRT best summarises the demi-regularities observed

(i) Frequently cited in the literature are the overarching influence of a range of distinct personality factors on maintaining and sustaining the longer-term family care of PWD, despite the challenges this may present.

Among the most notable of these are:

1. extraversion (Melo, Maroco & de Mendonça, 2011);
2. optimism (Carter & Acton, 2006);
3. hardiness (Garrosa, Moreno-Jimenez & Liang et al; 2008).

However, a drawback is that personality traits are widely believed to be relatively stable in later adulthood (Costa & McCrae, 1994) and not therefore amenable to interventions designed to support adults, including FCOPWD. Furthermore, placing the focus on carers' personality traits carries the imputation that dementia care outcomes are largely dependent on biological inheritance and therefore somewhat already predetermined. This also suggests that carers are dependent on an inheritance 'lottery' and that care outcomes are therefore mainly determined by chance. The research was seeking answers to the question of 'what enables the FCOPWD' that might ultimately be applied to improve how the majority of FCOPWD are supported in future. Personality traits did not appear to contribute to any unified theory that might draw together the RRR findings in support of this wider-reaching and more inclusive goal.

Moreover, there appeared to be no discernable link between specific personality factors and the five broad Themes (see Figure 12 above). For these reasons personality traits were rejected as candidate MRTs in this study. This is not to deny that carers' personality traits can potentially exert some influence on the long-term care of PWD, but rather to state that their fixity and lack of modifiability in adulthood rules them out as potential moderating factors that might underpin 'what enables the FCOPWD.'

(ii) A further MRT that was considered was 'fear' and in particular fear of the consequences of cessation of family care and subsequent institutionalisation of the PWD. A contention was that 'fear' of such an outcome might provide an underlying motivational impetus that drives family carers towards the maintenance and sustenance of FCOPWD. However, it seemed doubtful that the chronic experience of 'fear' would provide any long-term solution to 'what enables the FCOPWD,' particularly given that 'fear' would likely contribute to the chronic stress that is so frequently linked with the FCOPWD and a main contributor to the early cessation of family care (Hirst, 2005). Thus, 'fear' seemed more likely to derail the FCOPWD in the long-term, rather than underpin 'what enables it.'

(iii) A relatively recent study by Kraijjo, Leeuw and Schrijvers (2014) led to speculation regarding a further candidate MRT: 'perseverance.' Wagnild (2009, p.106) defines 'perseverance' as 'the ability to keep going

despite setbacks,' while the OED (2018) defines 'perseverance' as 'doing something despite difficulty or delay in achieving success.' In Kraijo et al.'s study, the authors had explored the possibility of differentiating FCOPWD according to their 'level of perseverance' as a main mediating factor that could be measured along a spectrum. This spectrum served to differentiate between carers who appeared to manage the FCOPWD reasonably well at one extreme against those who barely seemed to cope at the other. However, a limitation of 'perseverance' as a candidate MRT was that it can also connote 'stubbornness' that can even border on 'bloody mindedness.' This represents more than a semantic argument since how the MRT is defined can have significant repercussions for how the mechanism hypothesised to underpin 'what enables the FCOPWD' is interpreted.

Furthermore, the selection of the MRT becomes important since it provides a crucial guide for the remainder of the study. Thus, recognition that 'perseverance' can connote 'trying to stay the course, but at any cost,' potentially remaining too inflexible to realise when a set course of action might represent the wrong one made it unsuitable as a candidate MRT. Ultimately, 'perseverance' might prove to be maladaptive rather than adaptive in the context of the FCOPWD.

Moreover, 'perseverance' is more often viewed as a sub-component of 'resilience' (Wagnild, 2009; Greeff & Ritman, 2005). Thus, while 'perseverance' seemed to hold out some initial promise as a MRT, it was revealed to be a concept that is generally regarded as subordinate to 'resilience,' with resilience denoting the super-ordinate factor (Wagnild & Young, 1993). Ultimately, this led to speculation that 'resilience' might represent a stronger candidate MRT (see Figure 14).

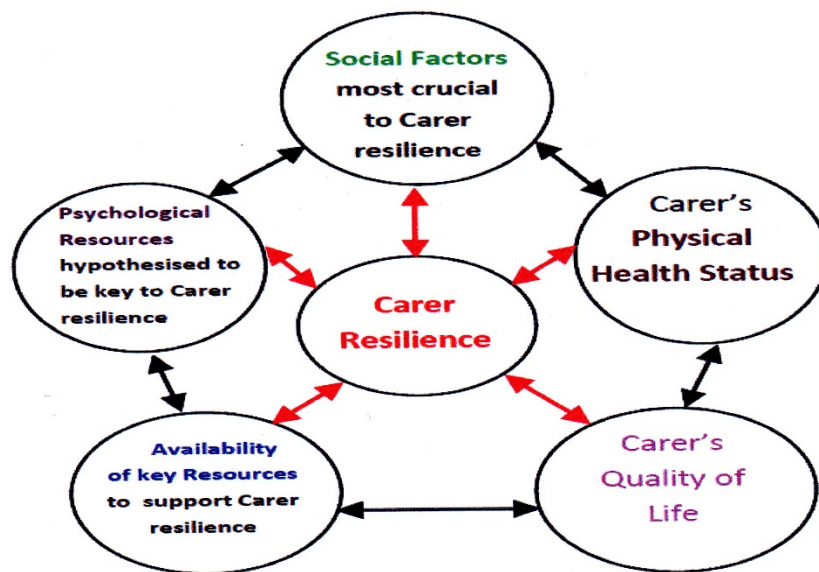


Figure 14. Initial Model outlining 5 main areas or Themes for family carers support based around the middle range theory that resilience underpins 'what works' to support the long-term maintenance and sustenance of family care.

'Resilience' was operationalised as, 'Resilience bolstered by assets and resources (Fergus & Zimmerman, 2005) that combine to provide a cumulative buffer against adversity (Schoon, 2006), as well as by supportive behavioural choices and actions.' How resilience was envisaged to 'enable the FCOPWD' is illustrated by Figure 15 below.

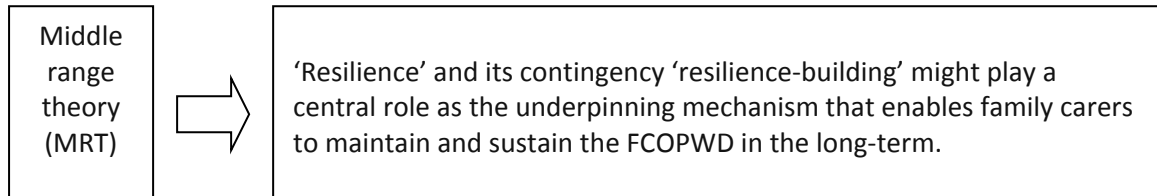


Figure 15. The hypothesised central role of 'resilience' and its contingent 'resilience-building' as the underpinning mechanism which enables family carers to maintain and sustain the FCOPWD in the long-term, representing a plausible candidate MRT.

The establishment of the MRT represented a breakthrough. However, this contention needed to be substantiated via further progressive focussing. This required re-engagement with the literature via a 3rd literature search to investigate how 'resilience' might be related to each of the five broad Themes / demi-regularities and support the MRT. In addition, re-examination of all the findings from the RRR guided by the MRT 'resilience' identified several key sub-Themes within each of the five Themes. The deductive process which led to the identification of the sub-Themes, including an inventory which references the publications used to help identify each sub-Theme, is contained in Appendix 2. This deductive process was assisted by the more specific interpretation of 'what enables the FCOPWD' provided by the MRT and the sharper focus it provided on those factors that lend themselves to carer resilience and resilience-building. This also endorsed the observation that MRTs can make the task of evaluating complex systems (including the FCOPWD) simpler by assisting in drawing up the conceptual boundaries around systems (Westhorp, 2012). Broadly, these boundaries are represented here by the five broad themes and their sub-themes which were uncovered by the RRR. Consolidation of all the findings from the RRR led to development of a conceptual framework for 'what enables the FCOPWD' underpinned by resilience and its contingency resilience-building (see Figure 16 below).

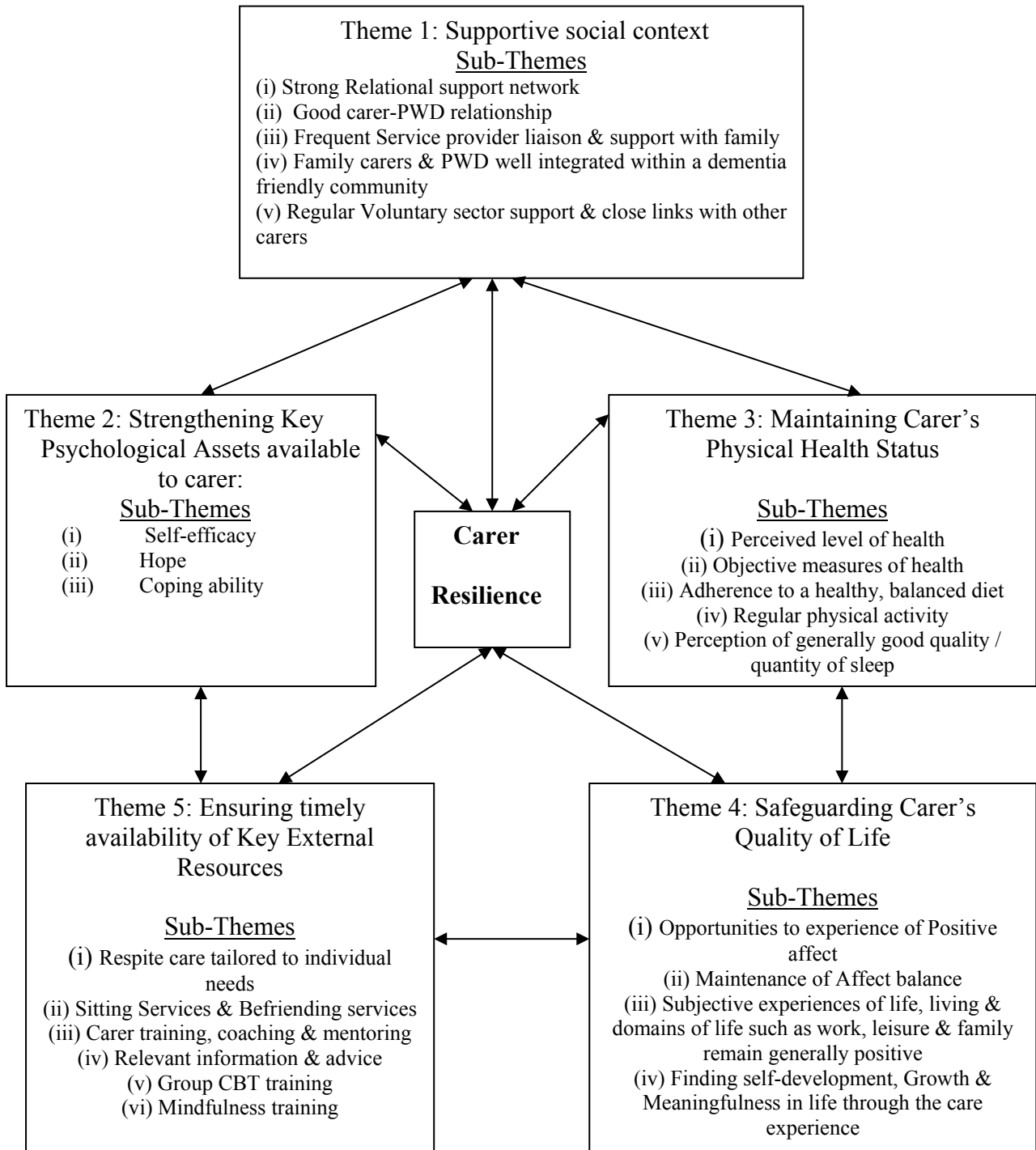


Figure 16. Conceptual framework for 'what enables the FCOPWD' underpinned by resilience and its contingency resilience-building, derived from the RRR findings.

5.2.4 Rationale for developing a new resilience framework

Pawson (2013, p.92) advises strongly in favour of employing existing conceptual platforms or frameworks which can be made re-usable, i.e. these can be built upon or refined to match the needs of a current investigation, avoiding unnecessarily 'reinventing the wheel.' However, based on the findings of the RRR it became clear there was a notable lack of consensus with regard to the research question. Furthermore, the only directly relevant conceptual framework which existed at the outset of this study was the 'Resilience Framework' produced by Windle and Bennett (2011) (see Figure 17).

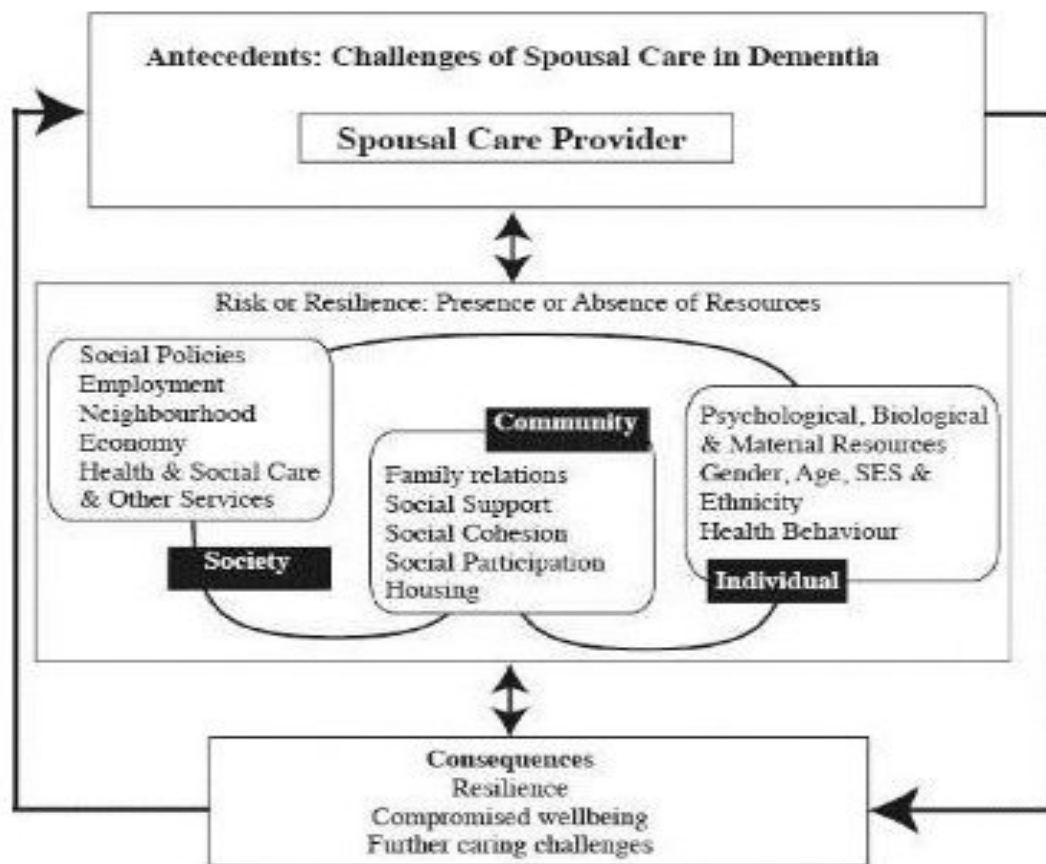


Figure 17. The Resilience framework, Windle and Bennett (2011).

While Windle and Bennett's (2011) framework provided a summary of some of the broad factors that might be important to carer resilience, there was a lack of specificity regarding precise factors that might generate resilience, particularly details of potential underlying mechanisms and contexts.

Moreover, their resilience framework did not clarify the relative importance and impact of each component of the framework, how they might be related to each other or, at a more fundamental level, how they 'worked' to promote carer resilience. Arguably, this was not the authors' intention. Rather, the framework was intended to provide a broad and generic overview that encompassed a

strata of influences, including broader, macro level factors (e.g. employment, the economy), consistent with an Ecological Systems Theory (EST) approach (Bronfenbrenner & Ceci, 1994). Such an approach leads to frameworks that tend to identify broad levels of influence between individuals and the environment, providing a general descriptive account of how environmental factors may impinge on individuals to influence the course of actions they follow.

Conceptual frameworks which are based around EST such as Windle and Bennett's are intentionally holistic in their attempt to capture complexity, but crucially they lack any detailed explication of the actual mechanisms at work and how they work to provide greater specificity. For example, it is difficult to state which specific hierarchical spheres of influence are most instrumental in determining individual decision-making or even whether individuals are more or less constrained by environmental factors. There is an implicit, a priori assumption made by EST and those approaches which are based on it that individuals possess very limited agency or determinism over their own actions. This is also reflected in the fact that 'resilience' is not a dimension that was included in the Bronfenbrenner (1979) original EST model and some have argued for its integration within EST to restore some balance, i.e. by reaffirming individuals' ability to exercise some influence over events, even where contexts and circumstances may be unfavourable or adverse (Engler, 2007). For these reasons, models which are based on EST can be difficult to implement and this directly impacts on their translatable potential from theory to practice and their overall research impact.

Pawson (2013, p.47) explicitly advises caution against using such Systems perspectives to tackle complexity in evaluations, stating there is a danger of making such evaluations too remote and too abstract by losing sight of context, particularly at the level of the individual within the study. While Systems perspectives can sometimes prove useful in identifying the wider strata of social influence that surround a program, Pawson warns that this should not detract from the main focus of most realist evaluations-the principal stakeholders. As outlined in the earlier Methodology Chapter, investigations that rely on scientific realism (SR) as the research approach tend to focus more on events at the micro and meso level, i.e. much closer to the sphere of individual reasoning and rationalisation to pinpoint the pivotal decision-making and individual actions that tip the balance towards individual behaviours and how these help to generate certain outcomes. Such an approach arguably moves us much closer to explaining how causation is generated at the level of the individual carer with regard to instilling resilience, i.e. producing explanatory accounts based on actual causative processes rather than more descriptive accounts of carer resilience that are more limited regarding their translation from theory into policy and practice.

Arguably also, the somewhat pessimistic view of individual agency inherent in EST, made explicit in the portrayal of resilience as a means to 'reduce carer burden' (Windle & Bennett, 2011, p.224)

largely reduces carer resilience to providing some form of ‘damage limitation’ against ‘carer burden.’ This presents a strictly limited view regarding resilience’s potential that is rooted in ‘care as burden’ and by association the Medical model of care. Such a stance stands in contrast to SR which maintains the more optimistic view that individual reasoning and decision-making are at least theoretically possible and therefore potentially significant in terms of generating causation to influence the course of events in our lives: ‘...even the simplest initiative will offer subjects considerable compass for decision-making,’ (Pawson & Tilley, 1997, p.216).

Further research has been conducted since that utilises and expands on Windle and Bennett’s resilience framework, including by Donnellan, Bennett & Soulsby (2015). Several issues were raised by this more recent study which this study also endorses, including concerns regarding how resilience is interpreted and measured as a construct that take fuller account of its complexity. Several commentators have remarked that quantitative measures using numerical scales may not be appropriate to capture the complexity of this construct (e.g. Aburn et al, 2016). Standardised assessments of resilience such as the complete and brief versions of the Resilience Scale developed by Wagnild and Young represent the most frequently used form of assessment. However, such measures remain rooted in the somewhat outmoded methodological tradition of assessing resilience via personal psychological attributes, i.e. as if resilience solely represented a personality trait. More recently, Dias, Santos and De Sousa et al. (2014) reiterated the importance of adopting a more holistic view of that takes fuller account of resilience as a dynamic process involving psychological, biological and environmental factors.

A further issue that is raised is the need for a more tempered interpretation of carer resilience in which it is underlined that, ‘carers do not flourish or become ‘super functioning’ (Donnellan et al; 2015, p.5). This updated interpretation debunks the notion that resilience is only attainable for a minority few who possess some super-human level of functioning, as well as the misconception that carer resilience means not only managing but actually ‘flourishing.’ By corollary, that this represents the benchmark by which the successful achievement of carer resilience should be measured. The authors are rightly at pains to point out that carer resilience is potentially available to all carers and this represents an important point, particularly in terms of the research impact of resilience research.

Donnellan et al. focus not only on what facilitates resilience but also on what hinders it. The present study adopts a similar position, acknowledging that there is much that can be gleaned about mechanisms and how they operate by examining those factors and their contexts which hinder their operation: ‘Program Theory represents a hypothesis that a particular factor ‘works’ because of the action of some underlying mechanisms, which only come into operation in particular contexts’ (Pawson, 2013, p.21-22). This statement recognises that there are likely to be contexts which hinder

the operation of causative mechanisms as well as alternative contexts which are facilitative.

Knowledge of both can prove to be critical in understanding how carer resilience can be enabled. The key findings reported by Donnellan et al. (2015) share much in common with some of those uncovered by the present RRR (see Tables 5 and 6 below):

Table 5. Factors which facilitate carer resilience uncovered by Donnellan et al. (2015) and based on Windle & Bennett's (2011) carer resilience framework and those identified by the present RRR (Parkinson et al; 2015).

Factors found to facilitate carer resilience by Donnellan et al. (2015)	Factors found to facilitate carer resilience by the RRR (Parkinson et al; 2015)
The authors highlight the importance of resilience that is strengthened from without as well as from within, including via appropriate support services.	The operational definition of resilience employed in this study similarly emphasises how resilience is Resilience bolstered by assets and resources (Fergus & Zimmerman, 2005) that combine to provide a cumulative buffer against adversity (Schoon, 2006), as well as by supportive behavioural choices and actions.'
Resilient carers can be encouraged to share their knowledge and expertise with those who are not resilient. The ideal forum for this is the support group setting.	Peer support: In general, there appears to be robust support for the benefits to carers and PWD of becoming involved with local Voluntary sector support groups. Much needed emotional and practical support may be found in local, informal support groups.
Formal services could step in to help potentially at risk individuals, such as those who are not resilient and/or those without knowledgeable peers.	The need to move towards shifting the emphasis away from a reactive medical approach based on dealing with the effects of illness and a radical re-orientation towards a preventative approach to health care.
Maintaining continuity, but the emphasis is placed on the context-dependent, i.e. it becomes easier to achieve where the care context remains relatively stable which may be unlikely to be the case for the majority of carers.	It is more a question of carers remaining adaptive and moving forwards. That the fluid nature of the FCOPWA means that there is no going back, no returning to a default position. Rather, that the care situation remains in flux due to changing symptomatology and so too therefore must family carers in order to keep pace with constant changes.
Staying positive.	This dove-tails with the RRR's finding that (i) Hope instils a positive attitudinal orientation towards goals & daily challenges fosters a belief in & motivation to achieving goals; (ii) Hope encourages positive reframing of the carer role which acts as a buffer against depression; (iii) Carers who proactively seek out the positives gained from the care experience report higher levels of overall satisfaction & low perception of care as 'burden.'
Downward comparison with those that are 'worse off' may be an important way of increasing self-efficacy and the carer's confidence.	Self-efficacy is highlighted as an important psychological asset that, inter alia, can increase confidence to carry out care role via a growing belief in one's ability to manage the care situation.
The acquisition of knowledge supports existing dimensions of resilience such as favouring challenge and garnering control.	Information and advice can empower FCOPWD to make their own decisions, take control of their lives & improve self-efficacy to increase resilience.
Facilitating factors emerged at a community level, including friendships with common experience and social participation.	Facilitate socialisation within the community to encourage wider social support & wider engagement in social activities to enhance quality of life.

Table 6. Factors which hinder carer resilience uncovered by Donnellan et al. (2015) and based on Windle & Bennett's (2011) carer resilience framework and those identified by the present RRR (Parkinson et al; 2015).

Factors found to Hinder carer resilience by Donnellan et al. (2015)	Factors found to Hinder carer resilience by the RRR (Parkinson et al; 2015)
Negative outlook	Lack of understanding regarding how a more positive outlook can be instilled & maintained in carers over the long-term. It remains unclear how hope might be inculcated & applied in practice. A need to comprehend how underpinning mechanisms work to promote hope / positive outlook. The need to manage & maintain positive affect. Negative mood states such as anger, depression, anxiety and worry can generally be categorised as examples of negative affect. Carers may need to ensure they cultivate a mindset that is predisposed towards engagement in pleasurable activities from the outset of dementia care and remain actively involved in creating opportunities for these.
Common for family carers of PWD to suffer the effects of social isolation	The current demographic trend in many developed countries, including the U.K. towards smaller family units and diminished contact with extended relatives. Common for family carers of PWD to suffer the effects of social isolation.
Reticence to accept informal support	The demographic shift towards nuclear families and greater social mobility make it increasingly the case that it cannot be assumed that primary carers will be supported by family and friends.
<p>Respite care is valuable but some participants feel that they are not ready for it or are unaware of its availability. Thus, access to resources is not always sufficient; carers must wish to use them.</p> <p>The timing of certain external services such as respite care needs to be right for the carer.</p>	Carers who remain passive and who largely anticipate that services will be advertised to them when they become available are likely to be limited in terms of the formal services they receive. Inertia towards carer services uptake, particularly by minority groups in the U.K. who may feel there is a lack of inclusion reflected in existing policies and practices designed to offer external support. This includes recognising & catering for carers of PWD represent as a very diverse group of people, i.e. tailored respite care that meets carers' personal needs. Lack of integration that exists between external services to facilitate relatively seamless accessibility of external resources by family carers. Use of the term 'carer' can prove inappropriate in terms of capturing the role actually performed by family in relation to PWD. 'Carers' often do not self-identify as 'carers' & this can present a hindrance to services uptake. The need for a clear mandate for how temporary support such as respite care can be achieved for carers. Many carers only receive respite care support once they have reached crisis point. There needs to be stricter guidelines regarding the quality & affordability of respite care available.
Few societal resources emerged from their analysis.	Isolation and its adjunct loneliness represent potentially crucial concerns in the North East of England due to the wide geographical dispersion of populations, including to rural areas. In general, carers of PWD living in rural areas are more susceptible to the negative effects of social isolation than their urban or suburban counterparts. The need to differentiate between rural and urban carers in order to take better account of their differing needs.

However, as will be revealed in greater detail as this Chapter progresses, the RRR uncovered a much more comprehensive range of factors, both facilitative and potentially a hindrance to ‘what enables the FCOPWD,’ which centred around a range of key demi-regularities and which led to the identification of specific Themes and their sub-Themes hypothesised to enable carer resilience. Moreover, identification of these demi-regularities paved the way for more specific and detailed CPTs to be formulated. Such a significant departure from Windle and Bennett’s framework warranted the development of a new conceptual framework in order to capture all the core elements uncovered by the RRR, particularly the many factors not explicitly included in Windle and Bennett’s (2011) conceptual framework or the subsequent revisions to it (e.g. Donnellan et al; 2015).

In addition, there were several difficulties identified with Windle and Bennett’s (2011) framework, including more recent investigations and interpretations of it that curtailed its utilisation in the present study. For example, Donnellan et al. (2015) attempt to overcome some of the difficulties associated with how such a complex construct as resilience can best be captured and assessed by laying down context-specific criteria. This remains consistent with SR which similarly emphasises the importance of taking the context of the research fully into account, including utilising context to assess how causation is generated. Thus, the authors employ general criteria to gauge whether or not carers are resilient (Donnellan et al; 2015, p.4). However, a fundamental concern raised here is whether resilience should be perceived as a binary ‘all or nothing’ disposition or whether it would be more accurate to depict it as operating along a continuum. ‘Our participants are classified as either resilient or not using the criteria above’ (ibid). The alternative view which this present study upholds is that where carer resilience is perceived to operate along a continuum, this importantly takes account of the fact that resilience may be more variable and changeable, i.e. dependent on the varying availability of carer assets and resources at any given time, as well as how challenging the current care context is perceived to be and carers’ perceived ability to overcome these challenges.

In addition, some contentions might be raised with regard to the criteria utilised by Donnellan et al. (2015, p.4) to establish whether carers are resilient or not (see Table 7 below):

Table 7. Criteria utilised by Donnellan et al. (2015, p.4) to establish whether carers are resilient or not.

- | |
|---|
| <ul style="list-style-type: none"> a) There must be a significant challenge: caregiving; b) No sign of (di)stress; c) Maintaining a life of meaning and satisfaction (a sign of bouncing back); d) Actively participating in life (a sign of managing); e) Current life seen as positive (a sign of adaptation). |
|---|

In particular, the second criterion employed by Donnellan et al. (2015, p.4) might be questioned, particularly in light of the health inequalities experienced by FCOPWD which are primarily manifest in stress (see Chapter 2). It is doubtful given the saliency of such inequalities whether it is indeed possible to have a complete 'absence of stress' in the context of the FCOPWD. While resilience can provide supportive assets and protective factors that can assist individuals to counteract the stress that is generally inherent to the FCOPWD, it does not make carers somehow invulnerable or immune (Cowan, Cowan & Schultz, 1996). Other authors (e.g. Ollson, Bond and Burns et al; 2003) have also warned against using such criteria to measure resilience.

Furthermore, several studies confirm that resilience can be manifest in a high level of functioning despite the existence of stress (e.g. Kralik et al. 2006, Bonanno et al. 2007). Indeed, most definitions of resilience emphasise that the presence of adversity represents an essential feature and contingency in order for resilience to be truly present and testable, e.g. 'Resilience refers to patterns of positive adaptation in the context of significant risk or adversity,' (Masten & Powell, 2003, p.4). 'Significant risk or adversity' is likely to generate stress. Therefore resilience is not about eradicating stress, but rather moderating or attenuating it to a level where it can be manageable. An important point here is that FCOPWD who continue to experience stress should not automatically regard themselves as somehow lacking in resilience or to have in any way 'failed' to maintain resilience. This latter view which is upheld in this present study endorses the 'protective model' view that resilience provides a protective buffer against stress rather than complete immunity.

A further point is that the criteria for carer resilience given in parentheses (see Table 7 above): 'Maintaining a life of meaning and satisfaction (*a sign of bouncing back*)' and 'Current life seen as positive (*a sign of adaptation*)' appear to contradict one another. Arguably, 'bouncing back' involves returning to a previous default position whereas 'adaptation' generally entails change and moving forwards, evolving in response to a changing context. The fluid nature of the FCOPWA context means that there is no going back, no returning to a default position. Rather, that the care situation remains in flux due to changing symptomatology and so too must family carers adapt and move forward in order to keep pace with these constant changes. Indeed, the authors themselves endorse this key point earlier in their report, that a feature of resilient carers is their predisposition towards embracing challenge over stability (Donnellan et al; 2015, p.2).

On the basis of all these arguments, there was an imperative to develop a new conceptual framework. However, similar to Windle and Bennett's framework, there is an important need to ensure such conceptual frameworks are examined empirically via objective testing in 'real world' situations before they can be further substantiated.

5.3 Exploring the new conceptual framework based around carer resilience

An example of how each of the five Themes associated with ‘what enables the FCOPWD’ and their related sub-Themes were explored via a six-step deductive process (see Table 8 below) is contained in the next section. As explained earlier in this Chapter, only the first main area is illustrated by virtue of it being first in terms of the chronological order in which it was originally documented. How the remaining four main areas were similarly explored using this six-step deductive process is contained in Appendix 3.

Table 8. The six-step deductive process which was followed in order to further explore each sub-Theme identified by the RRR.

<p>1. What could enable the FCOPWD, including details of strategies, interventions and theories associated with ‘what works’ based on the existing literature.</p> <p>2. What could hinder the FCOPWD, including potentially important contextual factors identified by previous research that may need to be addressed in order to facilitate ‘what enables the FCOPWD.’ By definition, a Program Theory represents a hypothesis that a particular factor ‘works’ because of the action of some underlying mechanisms, which may only come into operation in particular contexts (Pawson, 2013, p.21-22).</p> <p>3. Specific evidence, where this could be found, for the links between each sub-Theme and the MRT resilience.</p> <p>4. General evidence, in the absence of more direct evidence, for factors associated with resilience relating to FCOPWD: this section provides details of evidence uncovered by the RRR relating to how the sub-theme might be more generally linked to resilience, i.e. based on evidence from related fields of inquiry such as cancer care.</p> <p>5. CPTs drawn up based on the RRR evidence: this section provides the tabulation of the principal context-mechanism-outcomes (CMOs) (Pawson, 2013; 2006) which are hypothesised to facilitate resilience in order to generate the main outcome ‘the long-term maintenance and sustenance of the FCOPWD.’ The CPTs outlined here directly informed the formulation of the interview schedule which formed the basis for exploring these hypotheses via subsequent field-work during the remaining phases of the study.</p> <p>6. The Context-Mechanism-Outcome configuration (CMOc) for each sub-Theme, drawn up from the CPTs.</p>
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5.3.1 Conducting the six-step deductive process for Theme 1: Supportive social context

5.3.2 Theme 1 Sub-theme (i): Strong relational support network

(a) 'What could enable the FCOPWD'

A great deal of evidence demonstrates that a key factor in long-term health and mental wellbeing is level of social isolation experienced by people (Walters, Cattan & Speller et al; 1999). This is especially relevant to FCOPWD who are susceptible to the problems associated with social isolation, particularly as the intensity and duration of care increases as dementia symptoms deteriorate (Mittelman, Haley & Clay et al; 2006). Closely linked to these findings is evidence that family-based interventions aimed at improving social support have proved effective for carers (ibid). More specifically, larger social networks have been found to be a protective factor against chronic stress and caregiver depression (Kim & Knight, 2008; Gallagher, Ni Mhaolain & Crosby et al; 2011). Meanwhile, Walmsley and McCormack (2013) cite the need to maintain high levels of communication between those with dementia and family members. Cattan (2002) recommended that isolation in older populations that could include carers needs to be tackled via quality support that includes practical support and assistance with transportation. Group activities that include educational or recreational content or physical activity have also been found to be particularly effective (ibid).

Gallagher et al. (2011) found that the adaptive emotion-focused coping strategies of receiving emotional support from others combined with acceptance and positive reframing were independent predictors of reduced caregiver depression.

(b) 'What could hinder the FCOPWD'

The current demographic trend in many developed countries towards smaller family units and diminished contact with extended relatives (e.g. Finn, 2007) also means that family carers are more likely to face the prospect of isolation with a correspondingly larger share of the caregiving role (Windle, Francis & Coomber, 2011). The demographic shift towards nuclear families and greater social mobility make it increasingly the case that it cannot be assumed that primary carers will be supported by family and friends (Leinonen, 2011).

A further issue is that relational networks rarely remain unchanged over time and cannot always be relied on to provide care needs (May, Eton & Boehmer et al; 2014). Moreover, it is not uncommon, especially for older carers whose links with family or friends have lapsed over time, to have no relational network to support them (Barnett, Mercer & Norbury et al; 2012). It is relatively common for family carers of PWD to suffer the effects of social isolation (Mioshi, Foxe & Leslie et al; 2013). Indeed, a recent Carers U.K. report (2015) found that as many as 83% of carers reported feeling lonely

or isolated. In terms of ‘what enables the FCOPWD,’ initiatives which address the problem of social isolation represent an important avenue to explore.

(c) Specific evidence for factors associated with carer resilience

Social support is defined here as, ‘any type of informal relational support offered to carers by family members, friends, neighbours and the wider community.’ In their review of biopsychosocial factors associated with carer resilience, social support was found to be a moderating factor (Dias, Santos & de Souza et al; 2014). Social support networks can provide the resources to assist carers to manage the care situation (Pinquart and Sörensen, 2007). Moreover, the social system that surrounds the carer represents an important factor with regard to resilience (Vanistendael, 2007). More specifically, Walsh (2003) found that family beliefs that focus on strength via teamwork are more likely to achieve resilience. Payne (2007) cited the availability of a supportive family and kinship networks among those factors which are associated with resilience. Resilience requires an inner strength that can come from relationships that are affirming (Purves, Savundranayagam & Kelson et al; 2011). Importantly also resilience and social support have been linked with corresponding health benefits (Reppold, Mayer & Almeida et al; 2012). However, in their review of social support and resilience in dementia care, Dias et al. (2014) noted the lack of consistency between studies regarding how social support should be defined, e.g. ‘network size,’ ‘frequency of contact,’ ‘quality of support’ etc. Earlier studies indicate that it may be the quality of support that is the single most important factor (Luthar, 2006; Roth, Mittelman & Clay, 2005).

(d) More general evidence for factors associated with carer resilience

More general evidence that links social support with resilience comes from a range of studies (e.g. Farran, Gilley & McCann et al; 2007; Sorenson, Duberstein & Gill et al; 2006; Nolan, Ingram & Watson, 2002; Masten, 2001).

(e) Candidate Program Theories drawn up based around the RRR evidence

Main Area	Sub-theme	Potential Mechanisms & How they may operate to instil Resilience
Theme 1: Supportive Social Context	Sub-theme (i) Strong Relational support network	<ul style="list-style-type: none"> • Reducing social isolation removes a potential trigger for carer depression; • Reliable alliance support reinforces ability to cope; • Division of labour reduces number of hours engaged in daily care by a single family member to alleviate the intensity of care for each individual; • Shared responsibility permits contingency plans to be made & duties reorganised to allow adaptation to meet sudden changes to the carer situation, facilitating carer recovery from adverse events; • Adaptive emotion-focused coping (including emotional support from others, acceptance & positive reframing) provide a protective factor against carer stress.

(f) Context-Mechanism-Outcome configuration (CMOc) drawn up from the CPTs

Strong relational support networks provide carers with a supportive social context (C) which can facilitate the longer-term maintenance and sustenance of FCOPWD (O) by a variety of means or mechanisms (M), including reducing social isolation, offering emotional support, division of labour, shared responsibility and reinforcing carers' ability to cope.

5.3.3 Theme 1 Sub-Theme (ii): Good relationship between the carer and the PWD

(a) 'What enables the FCOPWD'

Positive strategies carers may adopt for coping with dementia care have been found to include acceptance of the disease by the primary family carer and the fostering of a non-blame culture in which the family carer acknowledges that however unfortunate it might be, it is not the family member's fault they have dementia (Nolan, Ingram & Watson, 2002). Several studies have found that the provision of behavioural management skills as an intervention may help maintain good relations (Farran, Gilley & McCann et al; 2007; Sorenson, Duberstein & Gill et al; 2006). In addition, adaptive coping strategies such as positive reappraisal of carer events can promote a positive carer-PWD atmosphere (Hildon, Montgomery & Blane et al; 2009).

(b) 'What could hinder the FCOPWD'

It should not be automatically assumed that carers possess the requisite interpersonal skills and coping strategies to maintain a good relationship with the PWD. Dementia symptomatology can include behavioural changes that may include profound changes to personality brought about by cognitive decline. These changes can significantly challenge carers' efforts to maintain a good relationship with the PWD. Interventions that include taught strategies, e.g. behavioural management skills, may prove beneficial in helping FCOPWD to maintain a good relationship with the PWD therefore.

(c) Specific evidence for factors associated with carer resilience

Purves, Savundranayagam and Kelson et al. (2011) found that interventions designed to facilitate and support communication and the development of good relationships between FCOPWD and PWD (e.g. Storycorps) also promote resilience. Windle and Bennett (2011) highlighted the potential of strengthening carer-PWD relationships to enhance carer resilience and called for more interventions to enhance this potential.

(d) More general evidence for factors associated with carer resilience

Hodgkinson, Butow & Hunt et al. (2007) reported that in cancer care a high-quality marital relationship was found to increase resilience, both for carer and care recipient.

(e) Candidate Program Theories drawn up based around the RRR evidence

<p>Theme 1: Supportive Social Context</p>	<p>Sub-theme (ii) Good relationship with PWD</p>	<ul style="list-style-type: none"> • Reduce potential social tensions alleviates anxiety / stress; • Maintaining a stronger rapport & mutual trust supports a more harmonious atmosphere around the care situation; • Reduce likelihood of misunderstandings leading to behavioural management issues that can otherwise promote high levels of stress; • Positive reappraisal of carer events promotes a positive carer-PWD atmosphere.
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(f) Context-Mechanism-Outcome configuration (CMOc) drawn up from the CPTs

Maintaining a good relationship with the PWD provides carers with a supportive social context (C) which can facilitate the longer-term maintenance and sustenance of the FCOPWD (O) by a variety of means or mechanisms (M), including reducing potential social tensions, maintaining a strong rapport and encouraging the positive reappraisal of potentially adverse events.

5.3.4 Theme 1 Sub-theme (iii): Fostering effective service provider support for carers

Profound changes were made to the organisations responsible for commissioning health services in England in 2013 meaning that Clinical commissioning groups (CCGs) are now responsible for the majority of the NHS budget, with NHS England sharing these responsibilities with CCGs in most parts of the country through co-commissioning arrangements since 2015. A report by The King’s Fund (Holder et al; 2015) described these changes and the delivery of a sustainable health care system as a formidable challenge. Particularly so given the organisational restructuring and financial constraints currently faced by the NHS. The report warns of significant unmet needs and threats to the quality of care. The report also calls for a fundamental change to the way in which the burgeoning needs of an ageing U.K. population and increased prevalence of chronic diseases within it are addressed. The number of people with chronic conditions is predicted to rise by a third over the next decade (Department of Health, 2012). Principally, by shifting the emphasis away from a reactive medical approach based on dealing with the effects of illness and a radical re-orientation towards prevention. Arguably, this is very relevant also to family carers of PWD, as well carers more generally.

(a) ‘What could enable the FCOPWD’

Since the U.K. is highly dependent on family carers and this is likely to be even more the case in the future and given also that family carers, including those who care for PWD, are especially vulnerable

to health inequalities via the inherent stress associated with long-term care (Hirst, 2004), prevention of illness in such populations remains paramount.

CCGs have a legal duty to consider health inequalities (Holder et al. for The King's Fund, 2015). The King's Fund (2015) also called for more systematic and proactive management of chronic disease to improve health outcomes, reduce inappropriate use of hospitals, and have a significant impact on health inequalities. If service providers are to base future policies on prevention of ill health in carer populations, closer liaison and support will be required. Voluntary sector organisations such as Alzheimer's Society also draw attention to the additional need for dementia liaison and support to extend across the full course of the dementia trajectory rather than to be sporadic.

Meeting carers' needs is not only a matter of providing practical support and a frequent finding is that support should include emotional support (Benbow, Ong & Black et al; 2009). Such support is likely to become essential to counteract the emotional aspects of dementia care, including dealing with the PWD's progressive cognitive decline and later, towards the final stage of dementia, coming to terms with the terminal nature of the disease and how to cope in the aftermath of this event.

Initiatives based on an outreach approach, including relatively low-cost interventions designed to improve the delivery of emotional support to family carers of PWD, such as telephone support services, have previously demonstrated success (Salfi, Ploeg & Black, 2005). Outreach represents an important issue, particularly the extent to which formal health and social care services should continue to be primarily reactive rather than proactive in reaching out to meet the needs of carers (and PWD). Arguably, the Voluntary sector, via its expanding network of contacts with carers and PWD, is perhaps better placed to fulfil the role of intermediary between end-users and formal health and social care services.

(b) 'What could hinder the FCOPWD'

In their report commissioned by Alzheimer's Society, Dowrick and Southern (2014) cited the need for quality services provided by well trained staff to deliver consistent, personalised carer and PWD support that meets clients' needs. Improved care co-ordination can have a significant effect on the quality of life of older people with multiple long-term conditions (Hofmarcher, Oxley & Rusticelli, 2007).

Although family carers may anticipate some emotional support from service providers to deal with some of the more challenging circumstances and events they may encounter, there is a history of such support not always being forthcoming (Cascioli, Al-Madfai & Osborne et al; 2008; Innes, Blackstock & Mason et al; 2005). Arguably also, there is an intrinsic expectation of healthcare providers that PWD and their carers can rely on a relational network to help support their needs (May, Eton & Boehmer et

al; 2014). However, it should not be assumed that carers will be supported by family and friends (Egdell, 2012; Leinonen, 2011). Arguably, interaction with carers by service providers may also demand a predominantly proactive approach that takes fuller account of the average age of family carers of PWD in the U.K. which is 65+ years of age (Newbronner, Chamberlain & Borthwick et al; 2013) and a culturally and generationally based expectation that formal care services will come to them rather than carers to have to do all the running. This represents a key point alluded to by Livingston et al. (2010) who emphasise the decisive role a G.P. can play in persuading carers who, in general may be largely passive rather than proactive in their approach to formal services to follow guidelines that encourage greater carer-services interaction (Livingston, Katona & Roch et al; 2004). Hence, formal care services may need to differentiate their approach to family carers to accommodate family carers' generally deferential attitude and higher responsiveness where formal services present a more authoritative and lead-taking style.

A further issue concerns the population distribution in the North East of England that means large swathes of the population live in relatively remote areas with limited means of access to support services (Egdell, 2012). More generally, Winterton and Warburton (2011) found that those who lived in more rural settings had varying needs that were often unmet, particularly 'flexible, joined-up services that were responsive to changes in need.'

(c) 'Specific evidence for factors associated with carer resilience

Service provider support is defined here as, 'support offered to FCOPWD via formal social and health care services.' Specific evidence for the link between resilience and effective service provider support was lacking. A report by Seddon, Robinson and Tommis et al. (2009) concluded that fewer than 3% of carers receive emotional support via formal health and social care providers and that their main contribution is limited to practical support.

However, there was indirect evidence of link between such services offering FCOPWD with effective emotional support and there are direct associations between this and resilience. Examples found included telephone support (Salfi, Ploeg & Black, 2005). Meanwhile, additional emotional support has been shown to provide an extra buffer against carer depression (Benbow, Ong & Black et al; 2009). Emotional support has also been identified as a potentially important factor in supporting FCOPWD resilience (Windle & Bennett, 2011).

(d) General evidence for factors associated with carer resilience

The general evidence did not add anything further to the discussion.

(e) Candidate Program Theories drawn up based around the RRR evidence

<p>Theme 1: Supportive Social Context</p>	<p>Sub-theme (iii) Fostering effective Service provider support for carers</p>	<ul style="list-style-type: none"> • Foster the notion of the caregiving role as being family oriented approach by health professionals & inclusive of family members who are seen as valued for their contribution; • Closer integration between formal services & carers to ensure practical Advice, information & signposting can be made available without much delay to permit a rapid response to carers' & the PWD's needs • A proactive policy by formal service providers to try to ensure carer health & wellbeing remain paramount, including emotional support.
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(f) Context-Mechanism-Outcome configuration (CMOc) drawn up from the CPTs

Fostering effective service provider support for carers offers carers a supportive social context (C) which can facilitate the longer-term maintenance and sustenance of the FCOPWD (O) by a variety of means or mechanisms (M), including fostering the notion of the caregiving role as being a family oriented approach in which family members are seen as valued, closer integration helping to ensure practical advice, information and signposting can be made available without much delay and carers can receive emotional support.

5.3.5 Theme 1 Sub-theme (iv): Carers and PWD well integrated within dementia friendly community

(a) 'What could enable the FCOPWD'

Supportive local communities represent a great asset to dementia care (Blackstock, Innes & Cox et al; 2006), a factor recognised by the steady growth in the number of 'dementia friendly' communities, shops and cafes that provide a means to address the societal problem of the stigma that is attached to dementia.

The wider community acceptance of dementia and the gradual replacement of stigma with acceptance help to provide an environment in which carers, PWD and the wider community can better co-exist (Mc Gown, 1993).

Establishing wider community acceptance of PWD during the early stages of dementia can help to set a precedent that encourages carers and PWD to continue to socialise despite the disease. It is not difficult to perceive how this can also help to offset the problem of isolation which can later befall carers and PWD. This represents an important issue since a lack relational network that can include family, friends and neighbours to provide social support can exacerbate the situation for carers of PWD (May, Eton & Boehmer et al; 2014). Moreover, FCOPWD are particularly vulnerable to experiencing social isolation and this in turn has a well established link with poorer health outcomes (Mittelman, Haley & Clay et al; 2006). Social isolation, as distinct from loneliness, refers to the number

of social contacts someone has as well as the frequency of interactions with these (Age UK, 2010). However, physical isolation exacerbated by social isolation may be most closely associated with the subjective perception of feeling lonely that is more closely linked with compromised health and wellbeing in the long-term (ibid).

(b) ‘What could hinder the FCOPWD’

Isolation and its adjunct loneliness represent potentially crucial concerns in the North East of England where the wide geographical dispersion of populations and establishment of many rural communities creates issues of proximity and access to public transport that may exacerbate difficulties in accessing support (Egdell, 2012). An unsurprising but nonetheless pertinent fact is that, in general, carers of PWD living in rural areas are more susceptible to the negative effects of social isolation than their urban or suburban counterparts. Blackstock et al. also (2006) highlighted the need to differentiate between rural and urban carers in order to take better account of their differing needs, including access to transport, health services, voluntary health care services, community networks and relational networks.

(c) Specific evidence for factors associated with carer resilience

While there was no specific evidence to link carer resilience with community integration there was nevertheless a reasonable amount of more general evidence, particularly in relation to community integration providing valuable social support (e.g. Milnac, Sheeran & Blissmer et al; 2011; Yates & Masten, 2004).

(d) General evidence for factors associated with carer resilience

The general evidence did not add anything further to the discussion.

(e) Candidate Program Theories drawn up based around the RRR evidence

<p>Theme 1: Supportive Social Context</p>	<p>Sub-theme (iv) Carers & PWD well integrated within dementia friendly community</p>	<ul style="list-style-type: none"> • Remove social stigma attached to dementia encourages acceptance of carers & PWD within the community reducing potential anxiety / tension; • Facilitate socialisation within the community to encourage wider social support & wider engagement in social activities to enhance quality of life.
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(f) Context-Mechanism-Outcome configuration (CMOc) drawn up from the CPTs

Integrating carers and PWD within a dementia friendly community offers carers a supportive social context (C) which can facilitate the longer-term maintenance and sustenance of the FCOPWD (O) by a

variety of means or mechanisms (M), including removing social stigma and facilitating socialisation that enhances quality of life.

5.3.6 Theme 1 Sub-theme (v): Regular Voluntary sector support and close links with other carers

(a) 'What could enable the FCOPWD'

In general, there appears to be robust support for the benefits to carers and PWD of becoming involved with local Voluntary sector support groups, e.g. Egdell (2012) found that interventions involving peer support organised by voluntary groups is valued by FCOPWD and can alleviate social isolation to in turn improve carer health. Meanwhile, McLaughlin and Jones (2011) reported that much needed emotional and practical support may be found in local, informal support groups.

(b) 'What could hinder the FCOPWD'

The availability as well as the value of such Voluntary sector services may need to be promoted more widely to improve uptake by more FCOPWD, e.g. a recent systematic review of family carer access to services, including Voluntary sector support, found that insufficient service information was frequently emphasised as a barrier (Greenwood & Smith, 2015). Further barriers to access include reluctance to use services because of a sense of duty and limitations to service use brought about by cost or lack of availability (Greenwood, Habbi & Smith et al; 2015; Brodaty, Thomson & Thomson et al; 2005).

Adequate funding to support the Voluntary sector support of FCOPWD also needs to be addressed. Although dementia is now becoming a higher public health priority, the costs involved in maintaining Voluntary involvement are substantial. This point has been further highlighted since writing up the RRR with a recent Alzheimer's report revealing that in order to deliver the necessary changes required to meet carers' and PWDs' needs adequately the organisation would need to raise £1 billion in voluntary income over the next decade (Alzheimer's Society, 2017b).

(c) Specific evidence for factors associated with carer resilience

Dias et al. (2014) drew attention to the potential for peer support organised by the Voluntary sector to augment carer resilience and the need for a more concerted effort designed to strengthen carer resilience. Meanwhile, resilience might also be promoted less directly by encouraging social support organised by the Voluntary sector, e.g. The Meeting Centres Support Program (Dröes, Meiland & Schmitz et al; 2006) which offers a comprehensive program of activities that includes information and social support to both carers and PWD by means of a social club within community centres. Older carers who may have no relational network may rely more on the Voluntary sector for social support

(Barnett, Mercer & Norbury et al; 2012). This can alleviate social isolation as a means to improve carer health (Egdell, 2012).

(d) More general evidence for factors associated with carer resilience

People’s integration within a supportive community has been found to strengthen resilience (Hildon, Montgomery & Blane et al; 2009).

(e) Candidate Program Theories drawn up based around the RRR evidence

Theme 1: Supportive Social Context	Sub-theme (v) Regular Voluntary sector support & close links with other carers of PWD	<ul style="list-style-type: none"> • Provide a less formal & potentially more inviting pathway to access information, advice, support & training relevant to both the carer & the PWD; • Reduce social isolation & increase emotional support to remove potential triggers for carer depression; • Promote resilience of carer via mutual support, camaraderie & carer solidarity; • Increase the potential for rapid dissemination of new or emerging advice.
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(f) Context-Mechanism-Outcome configuration (CMOc) drawn up from the CPTs

Regular Voluntary sector support and close links with other FCOPWD offers carers a supportive social context (C) which can facilitate the longer-term maintenance and sustenance of the FCOPWD (O) by a variety of means or mechanisms (M), including providing a less formal and more inviting pathway to access up-to-date information, advice, support and training, reduce social isolation and increase emotional support.

N.B.1: Examination of the remaining four Themes identified as potentially critical to ‘what enables the FCOPWD’ is contained in Appendix 3. This follows the same 6-step process outlined in the example which is presented for Theme 1 above.

N.B.2: A full list of all the CPTs from all 5 Themes is contained in Appendix 4.

N.B.3: The deductive process which led to the identification of the sub-Themes, including an inventory which references the publications used to help identify each sub-Theme, is contained in Appendix 2.

5.4 Summary

Based on the findings from the RRR, this Chapter provided an account of how the identification of five emergent demi-regularities led to the eventual development of a new conceptual framework based on ‘what enables the FCOPWD.’ The emergence of the MRT ‘resilience’ and its contingency ‘resilience-building’ were discussed, including their role in providing a potentially pivotal mechanism

underpinning 'what enables the FCOPWD.' How the MRT assisted in uncovering the sub-Themes within each of the five Main areas was also discussed. A rationale was also provided for why it was necessary to develop a new conceptual framework based around carer resilience.

The six-step deductive process by which each of the sub-Themes were further examined was also explicated, using Theme 1 as an exemplar for how this process was carried out. It was made clear that details of the findings for the four remaining Themes were included in Appendix 3 in order to economise on space within the thesis. There was a need to ensure the RRR and the hypotheses derived from it remained broad and comprehensive. This reflects the growing need in social science research and also in public health-based research to unravel the complexity inherent in research questions that affect relatively large populations by capturing how multiple components, multiple contexts and multiple agencies combine to generate certain outcomes within these populations. Particularly so where the study is based around emerging evidence within a nascent area of research and there is a lack of consensus regarding the research question. While researchers must generally decide what is important to investigate versus that which must be left untouched, the decision was made to attempt to examine a broad range of factors to shed light on a previously under-researched area of research and to ensure that factors which might later prove to be crucial were not left out. This study was also mindful of the need to be comprehensive in terms of investigative coverage to ensure this important research topic was addressed as fully as possible. Particularly so given the background of an ever increasing reliance on the FCOPWD both in the U.K., as well as more globally, due to exponential increases in dementia prevalence and the accompanying urgency to find ways in which the FCOPWD can be made more maintainable and sustainable.

This Chapter concluded with an account of how the development of a new conceptual framework informed the formulation of a range of CPTs and CMOc's based around 'what enables the FCOPWD.' These provided the basis for the empirical testing of hypotheses related to the research question during the subsequent phases of the study. A full list of the CPTs derived from the RRR was included in Appendix 4. The next Chapter outlines how the empirical testing phase of this study was organised as part of the further investigation of the CPT

CHAPTER 6: DATA COLLECTION METHOD

6.1 Chapter Introduction

While the RRR represented phases 1 and 2 of this 4-phase study, this 3rd phase (see Figure 18 Box 3 below), represented the theory ‘testing’ phase, in which the theories developed during the earlier phases were subjected to empirical investigation (objective testing in the ‘real world’).

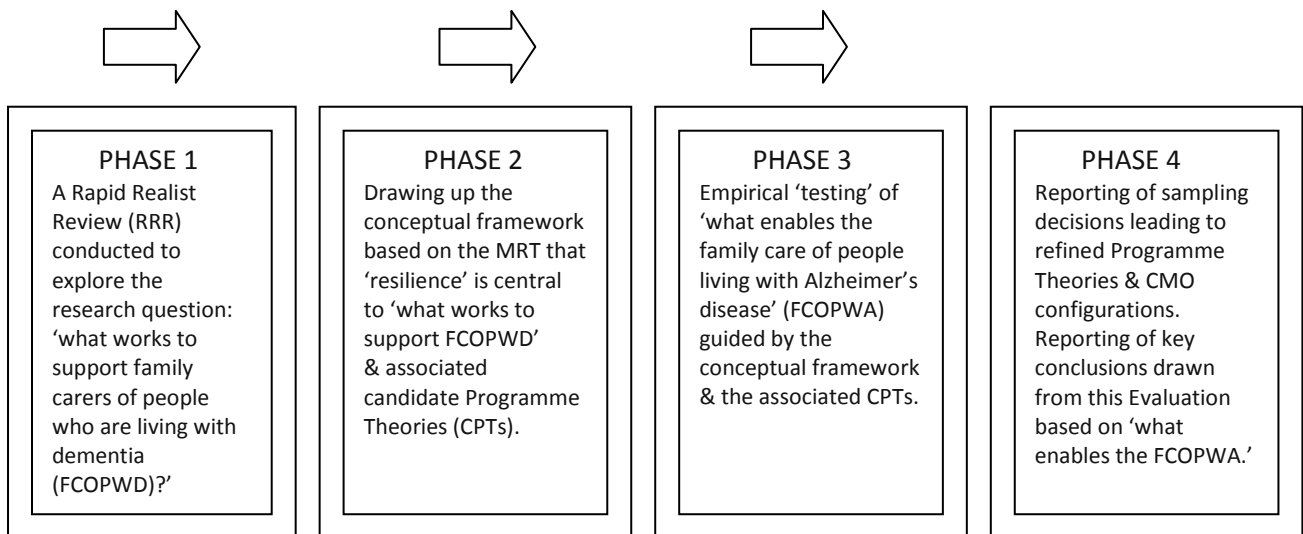


Figure 18. Four Phases of this study to investigate ‘what enables the FCOPWA.’

This Chapter provides details of how this 3rd phase of the study was conducted, including the important questions which remained to be addressed. How the method selected fits with scientific realist (SR) theory and the rationale for selecting qualitative methods as part of this Realist evaluation are discussed. The Chapter then expounds the rationale for focusing specifically on family carers of people living with Alzheimer’s disease (FCOPWA), as opposed to carers of people living with dementia (FCOPWD).

The rationale for employing qualitative methods is explained, including why there was a need to employ in-depth interviewing as the method of data collection. How sampling and participant recruitment was carried out is then explored, including the rationale for the sampling approach employed. Brief vignettes and descriptive statistics are presented to provide a rounded overview of participants. Considerations that were made with regard to the selection of study site are also examined. Sampling limitations are discussed, before moving on to address how ethical considerations including safeguarding were dealt with.

The procedures employed for data collection are explained, including how richness in the data was achieved, before moving on to explore how the interview schedule was drawn up. This includes

the rationale for incorporating a wide range of candidate Program Theories (CPTs) within the schedule. The criteria used to gauge when data saturation was deemed to have been reached is explained.

The Chapter then moves to a discussion of how the three broad phases of conducting interviews in SR studies (Monzano, 2016) were achieved, using examples of the data analysis that was conducted to illustrate how this process was carried out and how this culminated in the development of more substantive Program Theory (PT). The Chapter concludes by providing details of how the most salient findings were highlighted and why data that was extant to these salient findings was 'parked' rather than purged.

6.1.1 From theory-building to theory 'testing'

To recap, the Rapid Realist Review (RRR) initially addressed the question, 'what enables the FCOPWD?' This led to the development of the middle range theory (MRT) that 'resilience' and its contingency 'resilience-building' might provide the underpinning mechanism that facilitates the outcome of interest to this study: 'the long-term maintenance and sustenance of FCOPWA' and how this might best be better enabled. The RRR also culminated in the construction of a conceptual framework based around five main areas:

- (a) social factors critical to supporting the carer;
- (b) carer's physical health status;
- (c) key psychological factors critical to supporting the carer;
- (d) carer's quality of life;
- (e) the timely availability of key external resources.

Within each of these areas, sub-Themes were identified as potentially important factors that might contribute to carer resilience. The resulting conceptual framework and associated CPTs which formulated from the RRR required further empirical 'testing' against primary evidence. The CPTs were derived from a close examination of the literature associated with each of the identified sub-Themes to determine the mechanisms and their contexts (where context was specified) hypothesised to generate carer resilience. Essentially, a series of questions emerged from the RRR which needed to be addressed during the succeeding 3rd phase of this study. These included:

- (i) Determining the validity of the MRT 'resilience' and its contingency 'resilience-building';
- (ii) Determining whether additional MRT (s) might supersede or be conjoined with the existing MRT;
- (iii) The validity of the CPTs derived from the RRR;
- (iv) Determining which factors contained in the CPTs remained most critical the long-term maintenance and sustenance of the FCOPWA;

(v) Determining how these factors might alter over time in response to the different demands created by a dementia care context that is in flux. Establishing this was also crucial to providing the right level of specificity required to ensure this study's findings carried translational potential, i.e. in SR terms not only identifying 'what enables,' but also 'when.'

These considerations were informed by Schoon's (2006) concern for the need for resilience research that appreciated the complexity of this construct and how potentially multiple factors may combine to mediate an individual's capacity for resilience. They were also informed by the need to consider how those factors which mediate resilience might change over time, particularly in response to different contexts and circumstances. Indeed, a recent review makes clear that to date no studies have previously examined how carer resilience changes over time (O'Dwyer, Moyle & Taylor et al; 2017, p.8) and this represents a significant gap in knowledge.

6.1.2 Making the decision regarding methods selection in Realist evaluation

Ultimately, the decision regarding which methods to select should be based on their utility in addressing the research question. SR therefore maintains a method-neutral stance with regard to methods selection in which any method bias is set aside in favour of a meritocratic approach that favours the method's 'fit for purpose.' 'The golden rule being that...the method is justified for the study,' (Pawson, 2013, p.14). Thus, SR perceives the importance of both qualitative and quantitative methods in the collection of data with the final arbiter concerning which methods to select being decided by the specific needs and requirements unique to each study.

6.1.3 Rationale for selecting qualitative methods in Realist evaluation

Pawson (2013, p. 19) draws up a useful heuristic to help guide researchers towards a clearer decision based on a more pragmatic and utilitarian approach: that in general, the investigation of 'mechanisms' tends to demand qualitative evidence, while the observation of 'outcomes' tends to warrant the extraction of quantitative evidence. That is not to say that 'outcomes' were not of importance to this study. Indeed, finding a yardstick by which to gauge whether a particular factor might be considered to be enabling or not in terms of the research question 'what enables the FCOPWA' was crucial and also formed part of the process of selecting the MRT 'resilience.' Specifically, that in order to determine that resilience and resilience-building might underpin 'what enables the FCOPWA,' it was first necessary to establish what the MRT achieved for carers. This required further consideration of what in SR terms the principal 'outcome' was intended to be with regard to the majority of interventions explored by the RRR. Thus, 'outcome' was more clearly operationalised as 'those

measures designed to augment carers' capacity to maintain and sustain the longer-term family care of PWD despite the challenges this may present.'

However, this study's adoption of a SR approach and focus on explicating not only 'what enables' but also 'how,' 'for whom,' and 'in which circumstances' meant that there was a need to explore mechanisms. This provided a main rationale for the adoption of qualitative methods in this study. Qualitative methods can prove especially useful in explicating 'how' real world phenomena 'work,' (Sayer, 1992).

6.1.4 Rationale for focusing on exclusively on FCOPWA

The need for a wider forum for family carers' voices in which their own views can be fully taken into account remained central to the data collection process. In general, there is an absence of carers' voices within many dementia-based studies, a deficiency which led Oldman to describe family carers as 'the hidden army that operate resiliently in the background,' (Oldman, 2014, p. 26). If persistent carer health inequalities are to be addressed, arguably the need to listen to and act upon carers' own views based on their lived experiences of FCOPWA needs to be a high priority. Of continued importance is 'ensuring all voices are heard, especially those who have found it harder to make their opinions felt and suffered greater health inequalities as a result,' (NHS England, 2016, p. 49). A related issue concerns the lack of a carer voice in the discussion of 'resilience' as a potential mediator for 'what enables the FCOPWA.' For example, O'Dwyer et al. (2017) recently reported that despite a growing interest in resilience in FCOPWD, carers' voices are noticeably absent from such studies and as few as three previous studies (Deist & Greeff, 2017; Donnellan, Bennett & Soulsby et al; 2015; Ross, Holliman & Dixon et al; 2003) have sought to elicit FCOPWD's own views concerning resilience via more informative means, such as in-depth interviewing. O'Dwyer et al. (2017) emphasise the need to go to 'the source' in order to address the research question by gathering prima facie evidence, rather than trying to 'second guess' this via second-hand accounts from non-carers.

Furthermore, in Scotland concerns surrounding the issue of FCOPWA lacking any real say in how care dementia policy and practice was formulated led to the formation of the Scottish 'Dementia Carer Voices' ALLIANCE (Health and Social Care Alliance Scotland, 2018). This continues to highlight the vital role of FCOPWD and the contribution their views can make to wider policy and practice. These reasons justify the rationale for ensuring that a wide range of views were collected from as many FCOPWA as possible during this 3rd phase of the study and from a wide spectrum of different types of FCOPWA (see Sampling sections later in this Chapter). Ultimately, such an approach helped to address the research question in a very direct way, i.e. by going straight to the source for answers. The time and energy invested in compiling a substantial data base that comprehensively explored carers'

own views with regard to the research question was crucial in enabling the eventual conclusions cited by this study to be reached. While certain parameters may often be set to narrow the focus of studies, this can be more problematic for nascent areas of research such as this where a wide spectrum of views exist, but where there is little consensus.

In addition, while the inclusion of others' views regarding 'what works', e.g. service providers, policy-makers and practitioners, might be perceived to provide a 'more rounded view,' it is questionable how such views would have made any real significant contribution to addressing the research question. As stated earlier, the existing literature is already replete with non-carer views. What is saliently lacking is primary stakeholders' own views and this is where a significant gap lies in terms of current knowledge. For the purposes of this study the views of non-carers are arguably supernumerary in comparison to carers' own views and insights. If this is perceived to be a 'trade-off' in terms of concentrating this study's resources more fully on primary stakeholders' views, rather than the views of non-carers then this can be justified on the grounds that this study is about family carers as the primary stakeholders at the hub of the FCOPWA and represents an opportunity too seldom taken up in AD related studies for their voices to be made central. These reasons provided an important justification for the study's design and how the study was conducted. Arguably, once a firmer basis has been established regarding 'what enables the FCOPWA' founded on carers' own views, then future studies become well placed to explore how these views can be further translated into policy and practice. However, arguably the former should first be established via thorough consultation with family carers before subsequent meaningful and well informed action can be achieved via changes to current policy and practice.

6.1.5 Investigating the new conceptual framework and implications

Some necessary limitations needed to be imposed on this study's overall agenda in order to accommodate a comprehensive investigation of the new conceptual framework for FCOPWA resilience derived from the RRR within the time-scale set for this study's completion. To recap, the lack of consensus regarding the broad and expansive research question 'what enables the FCOPWA' meant that a comprehensive review of the existing literature was demanded. This identified five key areas associated with what enables the FCOPWA.' Further reviewing enabled the sub-Themes within these areas to be identified. Arguably, this represented tangible progress, particularly when viewed against the start-point of this study where it was apparent that a multiplicity of different views, findings, recommendations, policies and interventions vied for position in terms of 'what works / enables' without presenting any clear, coherent way forward.

However, the position of this study following the RRR also meant that the carer resilience framework which was developed and the range of CPTs formulated still left a great deal that remained to be investigated empirically. At this stage there was no sure-fire way of determining which aspects of the conceptual framework or which CPTs might prove to be most critical, without first 'testing' them against prima facie evidence derived from the carers themselves. The decision was therefore made to empirically 'test' all the CPTs first and thereby placed in a position to state more objectively which factors proved most critical to 'what enables the FCOPWA.' This represented a sizeable task in its own right, but arguably one that needed to be carried out given the lack of consensus concerning the research question, its basis in a nascent area of research and the imperative to obtain carers' own views in order to address this issue. While this decision meant that potentially much was set to be gained from this study by investigating all five main Themes bound by the MRT resilience and the CPTs related to them, it also meant there would be insufficient scope to elicit non-carers' views.

Nevertheless, on balance this represented a comparatively small concession to make, given the opportunity to more fully and comprehensively address the primary demands of the research question via the thorough investigation of the newly developed conceptual framework. Ultimately, the main remit of this study and one that was met was to provide family carers with a 'voice' that is seldom permitted an open forum in which to speak candidly on such an important issue as 'what enables them' over the long and challenging course of AD. That this meant setting certain parameters to balance the time and resources available to this study in order to focus on the research question, and in doing so address the urgent need to uncover carers' views as the foremost need and most salient gap in knowledge, justified the decision which was made to leave the views of non-carers concerning the conclusions reached by this study to subsequent studies and research.

6.2 Rationale for selecting interviewing as the main method of data collection

The rationale for selecting interviewing as the method of data collection was based on the need to address the gap in knowledge concerning, 'what enables the FCOPWA.' This gap has been created by the general absence of carers' voices within many dementia-based studies. The SR approach and its deliberate attempt to capture the 'reality' of how causation is generated by identifying the generative mechanisms (contexts and reasoning) that naturally exist, highlight the importance of extracting primary stakeholders' own views based on their lived experiences as a critical basis for empirical evidence. Essentially, providing an insight into 'the real' (Angus et al; 2006).

Kvale (1996) also noted that interviewing provides a means to capture social phenomena that may otherwise not be easily detected. Pawson and Tilley (1997) similarly acknowledged the value to

certain SR inquiries of employing interviews as the principal method. In particular, that interviewing in SR studies should be focused on garnering rich, detailed evidence, e.g. from principal stakeholders, in order to validate PTs or CPTs. Importantly, the employment of interviewing within SR studies can provide a way to explore theory-driven propositions to be tested and refined (Monzano, 2016). Interviewing therefore represents a useful means to validate, refine or refute the theory-driven propositions represented by MRT and CPTs and to shed further light on the mechanisms at work, as well as their contexts and outcomes, including emerging evidence of other mechanisms perhaps not previously considered.

Additionally, where they are semi-structured as in this study, interviews permit some leeway that allows the opportunity for interviewees to voice additional views that constitute further, relevant, emerging evidence that may not have been foreseen but which may be important and need to be highlighted.

Furthermore, the employment of in-depth interviews in this study and the subsequent analysis of transcripts was selected for its capacity to accurately capture carers' own lived experiences of caring and to learn at first hand 'what enables them,' as well as 'how,' 'when' and 'in what circumstances.' In-depth interviews have the potential to glean rich and detailed information (Weiss, 1994). This can be particularly useful where the area of research represents a nascent area, such as in this study, and where there is therefore a need to address salient gaps in the evidence base created by an absence of knowledge concerning 'what works' for population of interest in a study. In addition, in-depth interviewing can assist in deepening the working hypothesis by asking principal stakeholders for their views (Pawson, 2013, p.18).

Moreover, 1:1 interviewing avoids the potential for distraction or bias that might be associated with focus group meetings where the focus may more easily digress from the research question and / or dominant group members may leave insufficient opportunity for everyone to express their views. 1:1 interviewing also lends itself well to asking follow-up questions, probing for additional information, and revisiting key questions to garner a rich understanding of participants' lived experiences and perceptions of events.

6.2.1 Three broad phases of conducting interviews as part of a Realist evaluation

Realist interviewing involves adherence to three key steps, as outlined by Monzano (2016):

- Phase 1: Theory gleaning;
- Phase 2: Theory refinement;
- Phase 3: Theory consolidation.

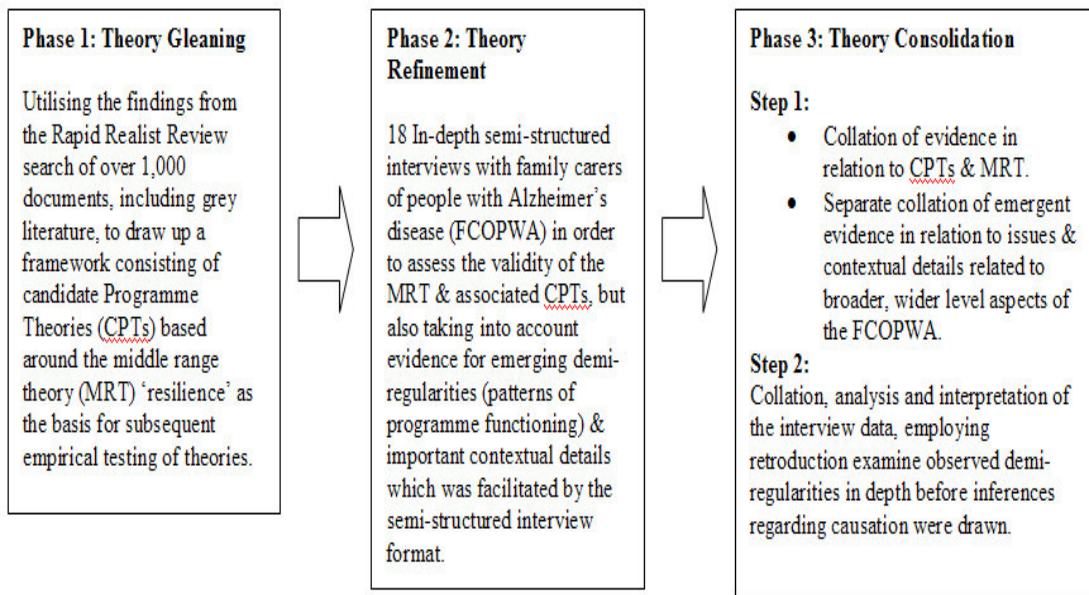


Figure 19. Flow diagram summarising the phases and steps involved in conducting the interviewing within a SR study.

The flow diagram (see Figure 19 above) provides a summary of the phases and steps involved in conducting interviewing as part of a Realist evaluation and how these were executed in this study:

Phase 1: Theory Gleaning

Utilising the findings from the RRR search of over 1,000 documents, including grey literature, a conceptual framework was drawn up based around the MRT 'resilience,' alongside a range of associated CPTs. These provided the basis for subsequent empirical testing of theories.

Phase 2: Theory Refinement

This phase can sometimes commence prior to empirical 'testing' where there is a sufficiently robust consensus regarding the research question and the hypotheses associated with this. However, as described earlier in this Chapter, the nascent nature of this topic, the lack of any real consensus found by the RRR meant and insufficient rich and detailed evidence derived from principal stakeholders meant that prima facie need to be gathered first before theory refinement could be reliably carried out without shedding potentially important hypotheses prematurely. Thus, eighteen in-depth semi-structured interviews were carried out with FCOPWA in order to derive sufficient evidence to permit hypotheses selection / shedding; assess the validity of the MRT and associated CPTs and refine the salient CPTs in order to formulate more definitive Program Theories (PTs). Sufficient data was also gathered regarding emergent demi-regularities (recurrent patterns of program functioning), as well as important contextual details.

Phase 3: Theory Consolidation

This represents the phase that is most relevant to how the interview data was analysed.

Theory consolidation included:

- Examination and reappraisal of the evidence to support the CPTs;
- Examination of the emerging evidence not previously explored by the CPTs that was obtained from the interviews and which was facilitated by the semi-structured interview style adopted;
- Selecting the most salient demi-regularities which emerged from the data, i.e. those recurrent patterns in the data which provided the most explanatory account of ‘what enables the FCOPWA;’
- Examination and reappraisal of how the interview evidence supported, refuted or called for amendment of the MRT ‘resilience;’
- The formulation of revised PTs in the light of the above analysis.

How this third phase was achieved is discussed later in this Chapter, following the discussion of how the carer interviews were conducted.

6.2.2 Purposive sampling: defining the number of participants

The first criterion that needs to be considered prior to conducting in-depth interviews is to establish the number of such interviews gauged to be sufficient to address the research question (Francis, Johnston & Robertson et al; 2010). Although this is likely to vary depending on the specific needs of the study, several yardsticks exist to act as a ‘rule-of-thumb’ guide. These include Guest, Bunce and Johnson’s (2006) recommendation that twelve interviews should serve as the minimum to enable data saturation, i.e. the point at which no new information emerges from the data. Meanwhile, Mason (2010) provides a more stringent yardstick of twenty interviews to define common professional practice. More specific to this study, Monzano (2016, p.8) advises that Realist evaluations should aim to collect large amounts of data to ensure that sufficient data can be obtained from it to be able to provide a plausible explanation of how causation is generated. A minimum sample size was established as fourteen interviews at the outset of this study. This was slightly below Mason’s more stringent guideline, but importantly met most other criteria including those established for SR studies.

However, it was also recognised that there was a need to remain flexible and above all, to ensure that the research question was fully addressed. This second criterion relies on conducting a sufficient number of in-depth interviews to achieve data saturation in which there is no new emergent evidence (Francis, Johnston & Robertson et al; 2010). As Mason (2002) points out, sample size may increase as part of ‘organic’ sampling and this recognises that predicting sample sizes ahead of investigation is

inherently problematic because how data collection unfolds is often unpredictable. This proved to be the case in this study where variation between participants (different ages, relationships with PWA, duration of caregiving etc.), coupled with a wide assortment of interview questions based on a range of CPTs, meant that emergent evidence continued to be forthcoming beyond the fourteenth interview. Hence, data saturation was not achieved until completion of the eighteenth interview, by which time much confirmatory evidence had been gathered with regard to the research question and more specifically the MRT and CPTs that related to this. Theoretical saturation was reached at this juncture with no newly emergent insights forthcoming. Thus, any continuation of interviewing was unlikely to bring additional incremental gains to theory development. As Strauss and Corbin (1998) note: this often provides a signal to cease data collection which was also the case here.

6.2.3 Purposive sampling: Recruiting participants from non-clinical settings

Dr. Clare Abley, Nurse Consultant for Vulnerable Older Adults at a local NHS Trust Hospital, was consulted to obtain valuable advice and expertise concerning the most suitable and sensitive means by which participants might be recruited to this study. Among the range of options which were considered for participant recruitment were to recruit (a) via a hospital consultant list (b) a G.P. list or (c) via a voluntary sector association. However, it was decided that recruiting from a clinical setting might introduce a sampling bias in which only family carers who had already registered with a hospital consultant or G.P. would become available. In particular, Dr. Abley recommended that recruitment take place via voluntary sector organisations from which a wider range of family carers could be recruited covering the fuller dementia trajectory (excepting the palliative stage of care). This included those carers who had been in the role for twelve months at one end of the scale, to carers who had been carrying out the role for ten+ years at the other. This helped to solicit a wider selection of carers' views than might have been possible had this study focused on recruitment within clinical settings.

Moreover, the voluntary sector offered the prospect of a more relaxed and informal setting in which carers might feel less inhibited in terms of speaking candidly about their experiences, including their views concerning the more formal areas of carer support. In addition, voluntary sector organisations tend to have gained access to relatively large numbers of FCOPWA and this factor would help to overcome some of practical and logistical issues surrounding the potential recruitment of people who were likely to experience certain difficulties in arranging time away from the dementia care environment. A key point that needs to be underlined was the inherent difficulty that needed to be overcome in attracting participants from what is an especially vulnerable group who are likely to

have many more concerns and challenges to contend with and whose time is valuable, without having to devote half a day to a research study.

A criticism that might be raised is that the selection of participants from the voluntary sector might be viewed as convenience sampling. However, to counter such criticism participants were selected to include a mixed group, with some regularly attending the Alzheimer's Society branch, but also others who rarely made any contact. Hence, recruitment ensured a mixture of carers, some of whom attended the Alzheimer's Society branch fairly regularly and some who rarely renewed contact following initial contact. Convenience sampling tends to be based around a 'first come, first selected' basis. This is not how the participants in this study were selected and a main aim was instead to achieve sample diversity rather than too much sample homogeneity.

6.2.4 Sampling criteria

In general, the more clearly the sample population is described the more transparent and valid the conclusions drawn become and this can also increase generalisability (Robinson, 2013). Explicit detail concerning sampling methods assists transparency that adds to the robustness of research. This in turn can assist a study's impact and importance, i.e. the extent to which the research contributes to theory and practice (Robinson, 2014). The employment of sampling criteria (see Table 9 below) narrowed the focus of the research to more specific FCOPWD groups. Sampling becomes arguably of even greater importance where the data will be mainly derived from a few dozen or fewer participants. The following sampling criteria therefore guided participant recruitment:

Table 9. Purposive sampling criteria employed for participant recruitment.

- Carers were selected who were aged 50 to 79 years of age. This excluded carers aged 80 or over. This age limit allowed comparability between participants, but without making the age restriction so rigid it prevented recruitment of sufficient numbers of participants. It also ensured some heterogeneity in the sample.
- Family carers of PWA were selected to provide greater specificity regarding the context of care, rather than make the study too generic by focusing on the broader area defined by 'dementia.' However, since AD represents the most common form of dementia in the U.K. accounting for some 62% of all cases of dementia (Age UK, 2015), selecting carers from within this population group would facilitate the generalisability of the findings.
- Volunteers were sought via their contact details which were held by the Alzheimer's Society branch based in the South Tyneside area of the North East of England. Recruiting FCOPWA from a similar geographical area helped to ensure that the range of services available might be comparable between participants to achieve homogeneity in the sample.
- Carers were required to have been caring for a minimum of 12 months at the time of interview to ensure that they had gained sufficient experience of caregiving to be in a position to provide rich and detailed feedback during interviewing.

In general, inclusion criteria serve to delineate the target population and this in turn tends to increase sample homogeneity. Achieving sample homogeneity is important since it lends itself to analytical processes by ensuring that the context surrounding participants is relatively well specified as opposed to being more generic (Smith, Flowers & Larkin, 2009).

However, providing too many sample criteria can also impose constraints, some of which may be unwarranted. In particular, they can limit the degree to which a study's findings permit wider abstraction to wider contexts, i.e. restrict generalisability. Moreover, sample heterogeneity also needs to be taken into account. In particular, it is important that any demi-regularities (semi-predictable patterns or pathways of program functioning) identified in a population group represent more than an artefact that is unique to the sample population (Mason, 2002). Allowing some heterogeneity by including some population diversity can increase the likelihood that the demi-regularities observed are generalisable rather than a unique, chance occurrence. Essentially, all this means that when drawing up a study design there is a need to consider how a homogeneity / heterogeneity trade-off can be achieved (Robinson, 2014).

6.2.5 Sample characteristics

The study design took into account how a homogeneity / heterogeneity trade-off could be achieved in which there would be some balance between achieving sufficient sample variability to permit wider generalisability of the findings, but at the same time sufficient sample homogeneity to allow valid comparisons to be drawn between participants. This balance was achieved via an agreement with the Alzheimer's Society centre manager who in the role of gatekeeper would help to guide participant selection and select as wide a possible range of carers who met the sampling criteria. Hence, sample variation was achieved via diversity in terms of:

- Carer Age
- Carer Gender
- Relationship to PWA
- Duration of care
- Stage of dementia
- Age of PWA

This arrangement led to the inclusion of participants with a wide range of demographic characteristics, (see Tables 10 and 11 below). An attempt was made to achieve a balance between the recruitment of females and males, however consistent with the general demographic trend associated with AD care in the U.K., the majority of FCOPWA who took part in this study were female. Despite the need for and use of purposive sampling methods, some heterogeneity was introduced into the sample to ensure to

the evidence base was not too narrow. At the same time, the use of purposive sampling helped to ensure the representativeness of the sample to similar demographic groups and to thereby ensure their translatable potential from research findings to policy and practice.

6.2.6 Summary statistics and descriptive statistics

Table 10. Wide-ranging sample characteristics to introduce some heterogeneity into the sample to ensure the evidence base was not too narrow.

Participant	Age of carer	Gender of carer	Relationship to PWA	Duration of Family care	Age of PWA
1	73	F	Spouse	3 years	78
2	70	F	Spouse	5 years	89
3	75	F	Spouse	3 years	78
4	54	F	Daughter	3 years	80
5	60	M	Son	5 years	85
6	73	M	Spouse	10 years	70
7	78	F	Spouse	5 years	78
8	62	M	Son	1 year	92
9	56	F	Daughter	3 years	75
10	62	F	Spouse	1 year	78
11	53	M	Son	1 year	80
12	78	F	Spouse	9 years	83
13	73	F	Spouse	8 years	76
14	75	F	Spouse	3 years	76
15	70	F	Spouse	4 years	71
16	63	F	Daughter	5 years	91
17	68	F	Spouse	3 years	74
18	50	F	Daughter	1 year	90

Table 11. Descriptive statistics illustrating the wide-ranging sample characteristics achieved via purposive sampling to introduce some heterogeneity into the sample.

<p>Mean Age of family carer: 66.28 years S.D.: 9.00 years</p> <p>14 Female carers 4 Male carers</p> <p>11 spouses 4 Daughters 3 Sons</p> <p>Mean duration of care: 4.06 years S.D.: 2.69 years Mean age of PWA: 80.22 years S.D.: 6.73 years</p>
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6.2.7 Vignettes of participants to provide contextual background to the study

Overview

This section provides several vignettes of the carers who participated in the study to assist in contextualizing the study. All the carers resided in the North East of England in a sub-urban area known as South Shields. This was formerly the site of much heavy industry, including ship-building that has now largely disappeared. Relative affluence and poverty co-exist in the area today with the decline of heavy industry creating a need for social mobility resulting in more transience and changeability in terms of housing occupancy. This has also led to some fragmentation of formerly close-knit communities and an erosion of the stability once created by several generations of one family residing in the same locality.

Participant 1: PT 1 is female, aged 73 and her spouse is aged 78. She has been married to her spouse for 57 years. PT 1 has previously suffered two heart attacks, but has made a good recovery. She has been caring for her spouse for 3 years, but AD symptoms had commenced much earlier than this. Symptoms of AD were first recognised when her husband suddenly became withdrawn and uncommunicative with family and friends, which was uncharacteristic. His G.P. was reluctant to issue a diagnosis of AD in case he was later shown to have been incorrect. Eventual diagnosis came as a relief because PT 1 assumed it would open up doors to receive help and support, but the primary support has been for physical problems related to cardiovascular issues. Social services provided a good service regarding falls prevention, but little else. PT 1 demonstrates reluctance towards seeking formal support and is mainly reliant on the voluntary sector to provide this instead. PT 1 emphasises the need for closer collaboration between formal services and family carers to support the FCOPWA.

PT 1 is especially wary of ending up on a path that leads to respite care, seeing this very much as the last resort. PT 1 cites the introduction of the voluntary sector, specifically the local Alzheimer's Society branch, as instrumental in changing her perception of the FCOPWA from one of despair to one of strength. Learning to handle the role of carer has been a steep learning curve with even basic information such as AD being a form of dementia proving revelatory. PT 1 perceives AD to be more challenging than physical diseases such as cancer because of the absence of a cure and the inevitability of a terminal decline.

Her husband had been a ship's captain. PT 1 has two sons, one living in the area and the other living and working in Portsmouth in the South of England, making it difficult to visit often. The grandchildren also live in the South of England. PT 1's husband's family are conflicted in their attitude to supporting them with his sisters keeping very much at arm's length, but his brothers taking him out

each Sunday. PT 1 relies more on her sister-in-law who goes on holiday with them each year and helps to care for her husband while they are away. At one time PT 1 could name every neighbour on the estate, but now it is only the few who live close by who are known to her. Many are of working age with families with their own busy lives to lead. The long-standing neighbours who continue to live in the locality provide a welcoming atmosphere that encourages PT 1's husband to go out occasionally. PT 1 also relies on her long-standing neighbour, a nurse, who helps her with chores such as shopping. The many years her spouse spent away at sea meant PT 1 developed a great deal of independence and this was invaluable to her as a carer, giving her the confidence to run the household without her husband's assistance. Her spouse has limited independence and relies heavily on PT 1, issuing him with instructions on how to carry out daily activities.

Participant 11: PT 11 is male, aged 53 and has opted to live with his mother who has AD and is aged 80 to make the FCOPWA more manageable. He has been caring for his mother for one year. AD symptoms first began with memory loss about 3 years previously. PT 11 believes that societal issues persist regarding the ability to make a clear distinction between AD and 'normal ageing.' PT 11 was able to devote more time to caring for his mother, including seeking a full diagnosis of AD, once his father whom he was also a carer for had passed away and he no longer had to divide his time between caring for both parents.

PT 11 is unemployed and receives a nominal amount as his mother's full-time, live-in carer. PT 11 felt compelled to move in with his mother once she commenced nocturnal wandering. He has encountered problems with the local Job Centre who have been unsympathetic regarding his status as a full-time carer. This has resulted in him taking them to court over monies and benefits owed. PT 11 also encountered problems regarding his carer application which left him in limbo for 4 months waiting for this to be approved.

The voluntary sector has been 'a God-send' to PT 11, providing much needed support, advice and direction to facilitate the FCOPWA. Without such support PT 11 states the carer role would be far more stressful and difficult to manage. PT 11 utilises the local Day care centre for an afternoon each week, but sometimes has to bring his mother home when she becomes agitated and unsettled. Social services assumed the carer would prefer to place his mother in a residential home and they seemed reticent to accept his veto of this until he firmly asserted this option was unacceptable to both he and his mother. A pattern of mistrust of formal health care services has built up over several years due to PT 11's experience of health professionals' errors and covering up these up that has led to an ongoing police investigation of alleged medical negligence regarding his late father.

Sorting out the lengthy and abstruse legalities regarding will and testament and power of attorney, have led to much frustration and financial difficulty for PT 11. PT 11 emphasises the need to be assertive, proactive and persistent in securing formal support to enable the FCOPWA.

One of PT 11's brothers lives and works in London and can visit only occasionally. His brother initially had difficulty comprehending the situation, underestimating the severity of the AD symptomatology his mother experienced. The other brother keeps at arm's length and does not make contact. However, there is a close local neighbourhood and neighbours who have known each other for half a century frequently come round to check on PT 11's mother, keep her company or invite her into their home.

PT 11 has far fewer opportunities now to go out and socialise, but thanks to neighbours can still enjoy his martial arts training twice a week which helps him to meet friends and importantly also release some of the tension that can accumulate due to stress which can otherwise impact on his diabetes symptoms. Caregiving has not been without its challenges and PT 11 has been suffering from the effects of sleep deprivation, constantly maintaining vigilance in case his mother tries to leave the house in the middle of the night. Chronic fatigue has also exacerbated his diabetes symptoms, including an incident in which he blacked out for several hours and almost did not regain consciousness. Dealing effectively with stress is clearly important and PT 11 has taken on board the advice of the voluntary sector and other carers to carefully manage it, including seeking external support. PT 11 is cognisant of the fact that where stress is allowed to make the carer ill, then the FCOPWA is placed in jeopardy, but is aware that not all carers fully comprehend the need which is paramount for carers to ensure their own health and wellbeing is preserved. This includes carers encouraging PWA to remain independent for as long as possible, rather than assume responsibility for every task or chore.

PT 11 describes learning to be a FCOPWA as akin to an apprenticeship, but that voluntary sector assistance including peer support can prove invaluable. PT 11 describes the FCOPWA as a situation and context that is in flux, leaving the carer the challenge of adapting to constant changes. Moreover, that wider public awareness of the challenge of being a carer is only now becoming recognised as increasing prevalence of the disease means more people have direct or vicarious experience of its full impact.

Participant 16: PT 16 is female, aged 63 and spent the last 5 years caring for her mother who is 91. PT 16 suffered a major stroke 5 years ago which she attributes to the level of stress she was under at the time, juggling a full-time career with being a carer. PT 16 maintains that she has made a full recovery following the stroke, but suffers from diabetes. PT 16 describes it as a generational tradition

and part of the North East's cultural heritage among the women of the family to look after elderly parents. PT 16 therefore feels a sense of duty and pride in following in her mother's, grand-mother's and great-grand-mother's footsteps.

PT 16 receives minimal support from family and her closest relative-her son-lives over 2 hours' drive away. Most of her mother's friends are now deceased. She receives most support from a long-term, close friend who is retired. This friend has been 'a lifeline' to her, providing support that includes arranging opportunities for the carer and PWA to go out together, enhancing their quality of life. PT 16 is very aware of the isolation and loneliness that can befall carers and carees and actively strives to avoid this happening. However, social life has waned due to the number of caregiving commitments PT 16 needs to address daily, including a gap opening up between herself and contact with extended family.

PT 16 describes the caregiving as intensive, very tying and becoming increasingly heavy. PT 16 has to closely monitor her health and how caregiving affects this because of her diabetes. The principal form of formal support is provided by a private company who ensure paid carers come briefly three times each day to assist with dressing and meal preparation. PT 16 rates the service they provide as 'very good,' but needed to be assertive with the company's manager at the outset to resolve early issues of incompetence. Obtaining additional support has proved to be difficult with social services placing a lot of bureaucratic 'red tape' in P16's way that denies access. This has exacerbated the decline in PT 16's ability to enjoy a social life. Respite care is described as difficult to arrange, even for just a few days, and needs to be planned for some 6 months' in advance which presents a hindrance to its uptake. PT 16 has also encountered obstacles to services in the NHS, including access to treatment for her mother in the absence of a Power of attorney. PT 16 has also been trying to contact the 'Bowel Nurse' for over 6 weeks without success to arrange intervention for her mother's incontinence. PT 16 finds it baffling that Social Services, the NHS and the voluntary sector fail to 'work hand in glove' as an integrated team. PT 16 also found it anomalous and inappropriate that the Mental Health Service should have most jurisdiction over the monitoring of AD cases.

Although she lives only 5 minutes away, PT 16 would prefer to move in with her mother to be able to provide 24 /7 support but cannot do so because her mother lives in a single-bedroom council bungalow. Her mother's neighbours are elderly and frail and don't mix socially and this points to a key flaw in a system based on a housing policy of pooling the elderly together.

PT 16 is dissatisfied with council cuts to public spending for AD and implies that the council is ignorant of family carers' needs. Community Practice Nurses are cited as being overstretched with 600 caseloads to deal with.

The voluntary sector, particularly Alzheimer's Society, has proved to be important not only in providing advice but also in organising pleasurable activities involving both carers and carees. Peer group meetings organised by the local branch offer support and allow the carer to view her own situation in a more favourable light compared with other carers who face greater challenges. The Carers' Association also arranged for a Befriending Service for the carer for a few hours per week which was greatly appreciated.

Over time, PT 16 has had to learn how to manage and cope with the FCOPWA and to overcome earlier doubts about her capabilities. This has involved a gradual process of adaptation which remains ongoing in order to deal with fresh challenges wrought by changing AD symptoms.

6.2.8 Considerations regarding participant recruitment / selection of study site

Following discussions with a range of voluntary sector organisations I was granted co-operation in this study by the Alzheimer's Society's North East of England Regional Manager. This led to my being introduced to the Manager of the South Tyneside branch of Alzheimer's Society to discuss the possibility of using the branch as both a recruiting site and venue for conducting in-depth interviews with FCOPWA. Importantly, this meant that: (a) a voluntary sector member of staff already known to the prospective participant could act as a gatekeeper and intermediary, offering reassurance and emotional support if required to prospective participants (b) by utilising the voluntary sector organisation's own premises, a less formal, familiar and safeguarded venue for the interviewing could be organised (c) the venue was situated outside the local Metro train station and bus station with good transport links.

In all these arrangements I was mindful of the fact that in-depth interviewing of FCOPWA could potentially cause some discomfort or distress to participants as they related their experiences of caring for someone who is living with AD. This issue could at least partly be addressed by ensuring interviews took place in an environment that participants would find comfortable. The venue also proved ideal in providing a secure environment in which participants felt sufficiently at ease to engage in candid discourse concerning their caregiving experiences. Even despite the strong emotions this might elicit. Participants were also given the option of a home visit by the interviewer where this proved more convenient. Four participants agreed to this option. It was made clear that where interviews were conducted in FCOPWA's own home the simultaneous presence of the PWA be avoided to ensure confidentiality.

6.2.9 Limitations

It is acknowledged that the sampling procedures excluded carers who did not have any contact with the voluntary sector since successfully recruiting sufficient numbers of participants who were already registered with the voluntary sector presented a significant challenge on its own. Although 'snowball sampling' was considered an option that might overcome this sampling limitation, it was deemed untenable due to the strictly limited time and logistics available to this study. However, a recommendation for future studies is that carers who have no contact with the voluntary sector be specifically targeted to ascertain whether there are any notable differences between carers who do. In particular, to establish whether such carers consider themselves already sufficiently resilient or whether there may be some other hindrance to accessing voluntary sector support.

It is further acknowledged that there is an inherent socio-economic and cultural bias in the sample selected in this study which meant all the participants were Caucasian, had lived in a sub-urban area of the North East for the majority of their lives and belonged to a working-class or lower middle-class background. However, the sample selected was representative of general U.K. population and this met the remit established at the outset of the study: to maximise the generalisability, and by corollary the translational potential, of the findings to other, perhaps similar groups.

Nevertheless, future studies might usefully target FCOPWA groups not specifically included in this study, including BAME communities. This would help to establish whether any significant differences exist regarding 'what enables the FCOPWA' within such communities, e.g. BAME communities may demonstrate a very different family care dynamic, i.e. one in which a more collectivist approach is applied to the FCOPWA that promotes greater collective responsibility for care provision. However, a disadvantage is that BAME communities appear to be more vulnerable to health inequalities due to poorer access to formal services (Moriarty et al; 2011). There is a dearth of robust research on the impact of ethnic background on AD and caregiving (Botsford et al; 2011) that future research might importantly address.

A further limitation concerns the fact that the sample selected in this study was derived from a specific sub-urban region in the North East of England. Carers' experiences in other parts of the country may well be different, particularly where there is better access to social and health care services. Regional variations can be dramatic, e.g. carers in some areas of England may be fifteen times more likely to receive Local Authority support than in others (Nomis Database, 2016). Similarly, differences have been found in carers' experiences in rural versus more urban settings, including access to transport, health services, voluntary health care services, community networks and relational networks (Blackstock et al; 2006). Future studies might usefully focus more specifically on regional and urban / rural comparisons therefore.

The 'gold standard' in terms of sampling is often regarded as random sampling which seeks to select an unbiased representation of the total population by ensuring there is an equal probability of an individual from a larger group being selected. However, the sampling technique employed in this study-purposive sampling-represents a non-probability sampling technique. While this prohibits complete randomisation of participants, it compensates for this by ensuring the sample selected has been purposively chosen to attract participants whom the researcher is especially interested in and who are therefore of most relevance to the study and addressing the research question. In general, for researchers pursuing qualitative or mixed methods research designs the employment of purposive sampling is not considered to be a weakness.

This study strived to achieve a balance between sample homogeneity and heterogeneity. When drawing up a study design there is often a need to consider how a homogeneity / heterogeneity trade-off can be achieved (Robinson, 2014) since both approaches can offer distinct advantages.

(a) Sample variation was controlled by applying sampling criteria (see Table 9 above) to achieve a level of homogeneity within the sample. This included focussing on FCOPWA as opposed to adopting a more generic approach that included FCOPWD. This took account of the fact that dementia represents a broad constellation of diseases, with each sub-type exhibiting differences including: rates of disease progression, symptomatology, symptomology and duration. For example, survival rates for AD have typically been recorded as nine years versus eight years for Frontotemporal lobe dementia (FTD) (Rascovsky, Salmon & Lipton et al; 2005). There is also a more rapid deterioration of basic functional abilities in patients with FTD than in those with AD (ibid). This was important since it lent itself to analytical processes by ensuring that the context surrounding participants was well specified as opposed to being too generic (Smith, Flowers & Larkin, 2009). In homogeneous sampling, units are selected based on their having similar characteristics because such characteristics are of particular interest to the researcher. Inclusion criteria serve to delineate the target population of interest to the study and this can in turn increase sample homogeneity. Sampling becomes arguably of even greater importance where the data will be mainly derived from a few dozen or fewer participants in order to avoid having too much sample variation, which can in turn limit the level of specificity applied to a study and thereby reduce its translational potential to other, perhaps similar groups. By contrast, clearly specifying context (including sample) lends itself to greater precision in SR studies by providing greater specificity regarding, 'what works for whom in what circumstances.' Context is perceived to be an integral component of a program (Pawson, 2013, p.36) and therefore needs to be well defined. Such specificity also lends itself to the translational potential of a study's findings.

(b) However, it was also useful to simultaneously achieve a level of heterogeneity within the sample in terms of capturing a wide range of perspectives related to the research question and avoiding

selecting samples which may be unique and / or narrow and whose experiences may represent artefacts, rather than more generalisable findings. Essentially, allowing some heterogeneity within the sample was important in ensuring that the evidence base was not too narrow and could permit greater insights regarding the research question by facilitating its examination from multiple carer perspectives. This can also assist in identifying common themes / demi-regularities that are evident across the sample: a particularly important consideration in SR studies where insights regarding such demi-regularities can be pivotal to explicating causation.

A degree of heterogeneity was achieved via the selection of carers of AD who represent carers of the most prevalent form of dementia in the U.K., comprising 62% of all cases (Alzheimer's Society, 2013). Heterogeneity was further achieved by ensuring the sample selected was representative of FCOPWA in general in the U.K., including being comparable in terms of:

- (i) average of carer (U.K. mean age = 65 years / sample mean = 66 years);
- (ii) carer gender (U.K. ratio of approximately 3 female FCOPWA: 1 male FCOPWA / sample = approximately a 3:1 ratio);
- (iii) carer ethnicity (In the U.K. most FCOPWA are Caucasian / sample = Caucasian);
- (iv) carer locality (In the U.K. most FCOPWA live in sub-urban areas / sample = a sub-urban);
- (v) carers were selected to cover all three key Stages of AD, taking account of the different challenges faced by carers due to changing symptomatology across the AD trajectory.

Additionally, the sample criteria ensured the inclusion of participants with a wide range of demographic characteristics to further increase the generalisability of the findings to a wider range of carers who similarly met the sampling criteria.

This study sought to achieve a balance between sample homogeneity and heterogeneity, recognising the distinct advantages offered by each to achieve the best overall balance. Specificity that is achieved via purposive sampling ensured the target population of most interest to the study was clearly delineated and not too generic. Purposive sampling is only a disadvantage when criteria are set and judgements made that are ill-conceived or poorly considered, i.e. not been based on clear criteria. But also achieving a level of generalisability by allowing some sample heterogeneity that ensured the evidence was not too narrow, i.e. by including a wide range FCOPWA views.

While the sampling decisions employed in this study held certain key advantages it is acknowledged that it inevitably excluded certain FCOPWA sub-groups and that future studies may be necessary to separately examine the research question in relation to these different carer sub-populations.

6.3 Ethical approval

Ethical approval for this study was granted by Faculty of Health and Life Sciences Research Ethics Committee on 18th March, 2016 (see Appendix 5). Permission was granted to contact the South Tyneside Alzheimer's Society branch by the North East Alzheimer's Society regional manager, John Buttery in January, 2016. Agreement to act as the study's gatekeeper and for the South Tyneside Alzheimer's Society branch to act as the principal venue for interviewing was agreed with the Centre manager Liz Williams in February, 2016. Participants read a comprehensive information sheet which provided full details of the study (see Appendix 6) before giving their written consent to participate (see Appendices 7 and 8). Contingencies were made in advance to cover issues such as safeguarding (see Section 6.3.5 below). However, no significant ethical dilemmas emerged during the course of data collection.

6.3.1 How ethical issues were addressed

6.3.2 Anonymity

The Centre Manager of the Alzheimer's Society branch in South Tyneside acted as the gatekeeper in the recruitment of participants. Participants' confidentiality and anonymity was maintained via 'the golden triangle' arrangement in which participants were invited to partake in the study by the gatekeeper, but thereafter only required to contact the researcher if they wished to volunteer. This ensured the gatekeeper need not know who responded to the request to participate and who declined.

Participants' actual names were replaced with anonymised numbers during all stages of data collection so that they could only be identified by the researcher. Similarly, the actual names of people referenced in the interviews were replaced with an 'X' in the transcripts to prevent participants being identified by their relationship to individuals.

6.3.3 Confidentiality and storage of data, including voice recordings

Participants consented to the interviews being recorded by MP3 voice recorder (see Appendix 9). Participants were reassured that any information they provided would remain anonymous and confidential. Also that the information they provided would be used /stored /destroyed in accordance with the current Data Protection Act. A Northumbria University approved MP3 recorder was used to ensure the data was secure. Participants were only identifiable from the audio recordings by their designated participant number to preserve anonymity. All collected audio data was securely stored electronically. All data retained on the MP3 recorder's own storage drive was securely deleted once this had been transferred to a more secure data storage location. Information was stored by the

researcher on a password protected, non-portable home computer. The computer was scheduled to be backed up regularly to prevent data loss. All identifiable paper records were stored in a locked filing cabinet, accessible only to the researcher. Electronic Information was stored by the researcher on Northumbria University's own hard drive storage facility (the 'U' drive) which is very secure, password protected and regularly backed up.

6.3.4 Retention and disposal of data

Participants were made aware that raw data would be stored for up to one year from the completion of this study in April, 2018, before it was securely destroyed. Paper copies of raw data would be securely shredded. In addition, that there was a possibility that this study's findings / thesis may be published in a scientific journal or at a conference and that in such an event their data may be stored for up to seven years before being destroyed. Participants were informed that such personal information / data would not be identifiable and also notified that should they decide to withdraw from the study before the study had been completed, then all electronic and paper records related to them would be immediately destroyed.

6.3.5 Safeguarding measures

FCOPWA represent a vulnerable population group due to the challenges and health inequalities they face. There was therefore a need to remain mindful of this and well prepared for the fact that the interviews would necessarily delve into sensitive aspects of carers' lives that might be emotionally challenging. A comprehensive range of precautionary steps were taken. These included:

- A full risk assessment was carried out in advance and approved by the University's Ethics Committee, including: (a) Lone interview risk assessment (b) Lone worker risk assessment (see Appendices 10 and 11);
- Safeguarding carers against pre-interview anxiety by making the arrangement to contact participants a few hours ahead of any scheduled interview to check they were still able to attend. This provided participants with the option to change their mind / postpone the interview to a more suitable time should they see fit to do so. This also helped to take into account the unpredictability of FCOPWA;
- The venue most frequently selected by participants was the Alzheimer's Society branch in South Tyneside which offered a comfortable, familiar and secure environment. Interviews were conducted in a private room which offered privacy, but which was annexed to a main office staffed by Alzheimer's Society personnel to offer participants a sense of personal security;

- The interviewer and the interviewee signed in at the Alzheimer's Society reception desk before being escorted to the separate interview room and signed out once interviews were concluded. This also ensured staff were fully aware of when interviews were in progress;
- Principal Supervisor was notified when and where interviews were taking place and when they were concluded to ensure safety and safeguarding;
- At the outset of each interview, participants were reminded of the purpose of the interview and their right to pause or take a break at any point if they felt uncomfortable;
- Participants were reminded that they could exercise their right to terminate the session at any point, including their right to withdraw from the study and refuse to permit the use of any data collected;
- It was emphasised prior to each interview that my role was as a researcher to record carers' responses to questions, that I did not possess any formal medical training and could not offer specialist advice;
- An informal and relaxed atmosphere was established at the outset between interviewer and interviewee by ensuring carers felt at ease, including offering them tea, coffee or water and talking more generally about their journey to the centre;
- A respectful and sympathetic attitude towards participants was maintained throughout and carers' statements received with sensitivity to the very personal nature of these. This included not pressing carers for information when it was clear they did not wish to continue to discuss a topic;
- Carers were reminded they had given consent to the interview being recorded (see Appendix 9) and the reasons why it was necessary to record to the data. Also that the data would be securely stored and only accessible to the researcher;
- Interviews generally lasted no more than 100 minutes and participants were reminded of the approximate duration (90 minutes) prior to commencing. This took account of the fact that FCOPWA may be constrained for time. The time allowed was sufficient to obtain the information required by the study, but not unreasonable. Carers were reminded they could halt the interview at any time;
- A contingency plan was put in place so that if carers felt they needed immediate emotional support, e.g. on completion of the interview, there was a strategy in place for helping them to deal with this involving meeting the Centre Manager for informal counselling. This was made explicit in a letter which was presented to each participant immediately upon the conclusion of the interview (see Appendix 12).

6.3.6 Procedures for participants

Participants were asked to take part in a 1:1 interview lasting approximately 90 minutes. The interview was based around the CPTs drawn up by the RRR concerning the research question: 'what enables the

FCOPWD?’ and this was made clear. Examples of the format and type of questioning employed are illustrated in Figures 20 and 21 below. Transcripts were made from the MP3 voice recordings. These were to be analysed to extract evidence which might confirm, deny or refine the CPTs, including details of potential hindrances to ‘what enables the FCOPWA.’ Consent was also obtained to note down any salient points, including emerging demi-regularities made during the course of each interview. The semi-structured format of the interviews permitted this. A participant debrief form was prepared to be issued to participants upon completion of each interview (see Appendix 13).

6.3.7 Conducting the interviews

Qualitative Methods were employed via in-depth interviews and subsequent analysis of transcripts to elicit authentic accounts based on the lived experiences of FCOPWA. A full version of the interview schedule is contained in Appendix 14. An example taken from the full version is provided here to indicate how the schedule was drawn up (see Figure 20 below). The example includes the CPTs which formed the bases for the interview questions. They are provided here for illustration purposes only and were omitted from the actual interview schedule in case they were accidentally presented in lieu of the intended questions. The CPTs were not directly stated to participants verbatim since explicit reference to them might have prompted a response bias. Furthermore, the majority of the CPTs were derived from academic studies and based around theory that would have required a great deal of additional explanation for which there was insufficient time. Particularly given that time also need to be allowed to admit some leeway provided by the semi-structured format of the interviewing to pursue emergent demi-regularities.

Theme 3: Maintaining Carer's Physical Health Status

Q1: How well do you feel in general, on a day-to-day basis?

Prompt: Has this changed since you became a carer? In what ways?

Potential Mechanisms & How they might work to support FCOPWD

- Moving beyond the mind-body dichotomy, perceptions of health provide important determinants of physical health, e.g. low perceptions of stress may provide a protective factor against carer depression;
- Emotion-regulation may provide a means to mediate perceived health;
- Improving perceptions of health can contribute to a more salutogenic approach to carers' health & wellbeing.
- Higher carer resilience is associated with reduced psychosomatic symptoms that may be partly determined by health perceptions.

Figure 20. A full version of the interview schedule is contained in Appendix 14. The excerpt presented here provides an illustration of how the interview questions were organised. Their basis in the CPTs derived from the RRR is also shown in this example. However, the CPTs were omitted from the actual interview schedule that was employed in case they were accidentally presented in lieu of the intended questions.

Interviews were conducted over a period of five months between early May, 2016 and late September, 2016 and ceased once data saturation was reached and sufficient evidence was gleaned to:

- (a) address the research question;
- (b) address the validity of the MRT;
- (c) validate, refine or reject CPTs
- (d) allow detailed exploration of emerging evidence;
- (e) formulate PTs based around a substantial evidence base.

Data saturation was reached by the eighteenth interview and sufficient information and insights had been garnered to satisfy the specific need of Realist evaluation (Pawson, 2013) to permit rigorous analysis of the data and ensure the relevance of the data to confirming or denying the original CPTs. Interviews lasted on average 100 minutes and provided over 30 hours' of data, much of it directly relevant to 'testing' the theoretical propositions represented by the CPTs and MRT, as well as providing insights into emergent demi-regularities. The volume of data collected for analysis remained in keeping with Monzano's (2016, p.8) recommendation that a sufficiently large amount of data be obtained to provide a plausible explanation of how causation is generated. Ultimately, sufficient evidence was accumulated that related directly to the CPTs and the MRT to be put forward for analysis. In addition, the opportunity was utilised to confirm and clarify participants'

responses throughout to ensure the accuracy of the recorded statements made in relation to the research question.

Furthermore, the frequent consensus that was found between different participants concerning their views of the same CPT and by corollary, the MRT ‘resilience,’ together with the regularity with which similar salient points and perceptions were raised by different respondents inspired confidence in the data. Rigour is achieved when sufficient information relevant to the research question has been gathered to provide a comprehensive analysis (Yardley, 2000).

6.3.8 Achieving richness via the data collection method employed

Questions and prompts were composed and structured according to the format recommended by Monzano (2016) (see Figure 21 below), i.e. they were designed to probe deeper to elicit explanatory accounts of ‘what enables the FCOPWD,’ via specific, searching questions, rather than be limited to descriptive accounts derived from highly generalised or relatively vague questioning.

- How do you think...
 - Could you talk to me about...
 - What ideally should happen when...
 - What sort of things help you with regard to...
 - What sort of things get in your way when you...
 - Thinking about X, what do you think works well / not so well...
 - In your opinion, how useful would it be to have...

Figure 21. Examples of how questions and prompts were structured and presented during the interviews to probe deeper to elicit explanatory accounts of ‘what works to support FCOPWA,’ rather than be limited to descriptive accounts. Adapted from Monzano (2016).

What qualifies as ‘good data’ relies on the quality, depth, detail and relevance of the data, as well as a sufficient amount of quality evidence to be able to justify the conclusions reached in Realist evaluation. Achieving good quality data relies on the richness of the data garnered. In this study this richness was achieved via a range of means:

- (a) Questions were designed to be clear and concise and free from jargon to avoid ambiguity;
- (b) Questions based on insights, particularly with regard to how causation might be generated, tend to yield richer responses (Ogden & Cornwall, 2010, p.1068). This was achieved here by basing questions on the CPTs and MRT;
- (c) Frequent use of open questions and prompts (see Figure 21 above) allowed the interviews to probe deeper to elicit explanatory accounts of ‘what works to support FCOPWA,’ rather than be

limited to descriptive accounts. Ogden and Cornwall (2010) note that open questions, especially where these draw upon respondents' past and present experiences as they did in this study, tend to elicit rich data;

(d) Frequent use of personal pronouns by respondents (ibid) that reflect deeper personal insights and reflections;

(e) The interviewer maintained the position of 'Program Theory expert,' arriving at the interview fully furnished with a detailed understanding of the MRT which lay at the heart of the investigation, as well as the CPTs which related to this. This remained consistent with Monzano's (2016, p.10) recommendation that the Realist interviewer maintain the role of PT (or CPTs) and mechanisms 'expert.' This necessarily meant the relationship between interviewer and interviewee was somewhat contrived in order to steer the interview towards the CPTs and elucidation of the mechanisms which may underpin these. Dahler-Larsen (2011) note that this represents no natural relationship, but rather one that is necessarily 'special', ensuring as it does that primary focus is crucially maintained on gathering evidence for or against the CPT and the underpinning MRT. Questions relating to causation, including participants' reasoning, decision-making, intentions, actions, inner thoughts, reflections, feelings and perceptions also tend to elicit rich data (Ogden & Cornwall, 2010; Charmaz, 2003, pp. 88-89). The SR approach adopted in this study very much lent itself to this by focusing on such potentially important causative factors, as well as their contexts, with a view to elucidating 'what works, how, when and in what circumstances;'

(f) With the passing of each interview it was possible to build up a clearer picture of the FCOPWA and the contexts, including local, geographical, cultural, services etc. in which these were set. Thus, CPTs could be viewed in more nuanced contextual detail. With the completion of each interview it was also possible to observe a pattern in which certain salient CPTs or elements of the MRT could also be seen to gain prominence. Emergent demi-regularities could also be noted and consistent with the iterative nature of Realist inquiry, it was possible to be mindful of their recurrent emergence during succeeding interviews;

(g) The generous allotment of interview time meant data could be gathered regarding all the CPTs drawn up from the RRR. This ensured each CPT was interrogated across all 18 interviews and allowed sufficient data to be gathered with regard to each CPT to be able to make a judicious decision regarding selection of salient hypotheses during the subsequent analysis of the data;

(h) It also allowed time to clarify responses and to probe further where more information about questions was required;

(i) The five months' span of time spent interviewing proved useful in allowing time to reflect deeply on the main findings as they emerged;

(j) It also allowed me to become well established among the staff and clients at the Alzheimer's Society branch as someone who could be trusted and genuinely cared about the needs of FCOPWA and PWA. This assisted in building a good rapport with respondents and in breaking down any barriers which might have prevented a more candid exposition of carers' frank, personal and insightful views of their caregiving experience. Full disclosure of lived experiences based around deeply personal topics tends to yield rich data (Ogden & Cornwall, 2010);

(k) The interviews were conducted in a comfortable, familiar and safe environment that was conducive to encouraging carers to be more relaxed and open regarding sharing their views and opinions.

The testament to achieving richness in the data rests with the richness, detail, level of insightfulness, cogency and explanatory power demonstrated by the eventual PTs and hopefully this is ultimately achieved by the end of this study.

6.3.9 Rationale for delaying announcement of the MRT to participants

The rationale for delaying full disclosure of the MRT 'resilience' and 'resilience-building' as the underpinning (though at this stage still tentative) theory for, 'what enables the FCOPWA' until the post-interview debrief was based on the following rationale:

- (a) The need for sensitivity regarding unwittingly conveying to carers the notion that family carers *should be resilient / should do* more to achieve resilience and failure in this regard denoted inadequacy on their part;
- (b) The need to avoid response bias based around an expectation that carers would provide answers which demonstrated carer resilience;
- (c) The need to keep an open mind about the MRT 'resilience' and to allow respondents the opportunity to voice their own views concerning what was critical to enabling the FCOPWA.

Although the potential importance of 'resilience' is recognised in academic circles, it remains a somewhat esoteric term. O'Dwyer et al. (2017) also recently conducted in-depth interviews with FCOPWD to try to elicit their views regarding resilience and how it might operate. The authors found that FCOPWD possessed a notable lack of meta-cognitive awareness of their own levels of resilience until this was pointed out to them by the researcher. This discovery forced the authors to deviate from their original study design by abandoning their plan to directly question carers about resilience per se. Carers' more forthcoming responses based on questions about the CPTs and the related conceptual framework based around carer resilience could still be interpreted at a more academic level during post-hoc analysis. This follows Meyer and Lunnay's (2013) advice that lay accounts often

differ from sociological conceptualisations but this does not mean they are incorrect, rather that there is a need to unveil a distinction between the lay and sociological understandings.

6.4. Rationale for incorporating a wide range of CPTs into the interviews

The analytic framework advocated by Pawson (2013) was followed in order to explore the complex issue represented by the research question. Pawson advises that in exploring complex issues such as public health there is an important need to remain selective (Pawson, 2013, p.30). Pawson recommends two main ways to achieve the selectivity required of Realist evaluation:

- (i) Draw up a map of the complexity of the situation you are trying to address in your research, e.g. what are the key elements that help to build resilience in FCOPWA. In this study this was achieved by drawing up the conceptual framework based around the CPTs and MRT 'resilience.'
- (ii) Basing theories to be tested on the conceptual map or framework, but being selective with regard to the number of Program Theories you select for scrutiny since only a finite number of Program Theories can be interrogated in one research study.

However, a central difficulty with achieving the second point was the fact that this study is based around a nascent area of research and it was therefore difficult to know at the outset which components of the conceptual framework produced as a result of the RRR remained most critical to 'what enables the FCOPWA.' Hence, the subsequent investigation of a wide range of CPTs via Realist interviewing became a practical necessity to be in a well informed position via the interview evidence garnered to then narrow the focus to the specific CPTs most critical to 'what enables the FCOPWA' which would form the bases for eventual PTs. Unquestionably, this required much work, particularly for the data analysis and synthesis of the main findings. However, this arguably provided the better option given the alternative which would have been to arbitrarily reject a number of CPTs derived from the RRR for the sake of expediency, thereby risking jettisoning theories that might subsequently be revealed to be crucial.

For the present, this calls for many questions to be answered before further headway can be made. Pawson likens this to emerging from the 'swamp' of complexity and advises that there is 'no exact formula to be followed in exiting the swamp,' (Pawson, 2013, p.161). A main skill in research is to be able to gauge which hypotheses might carry more weight in terms of their relevance to the research question than others. However, there were a range of factors which hindered making this judgement, including the nascent state of this area of research, the lack of consensus in the literature regarding the research question, the plausibility of the five main areas or Themes identified by the RRR, their apparent symbiotic relationship to each other that led to the initial judgement that they carried more potency working in combination than when kept separate, the need for empirical

evidence first to substantiate those factors which might be most critical and to then be in a sufficiently well informed position to begin the process of ‘hypotheses shedding’ (Pawson, 2013, p.161). Pawson recommends four strategies for exiting the ‘swamp’ of complexity:

(i) *‘Situate the review on an existing conceptual platform.’* As described earlier in this Chapter, the principal conceptual platform that existed at the outset of this study (Windle & Bennett, 2011) held several limitations that necessitated the development of a new conceptual platform based on the RRR findings.

(ii) *‘Engage in a continuous process of hypothesis selection and hypothesis shedding.’* In the absence of any real consensus regarding the research question, hypothesis selection and hypothesis shedding relied first on ‘testing’ the CPTs in order to then be in a better informed position to deduce which were most critical. An alternative to this approach was mooted early on in this study. This involved curtailing the study to the investigation of a single main Theme, rather than attempt to address all five. However, there were several key reasons why the study maintained its focus on all five Themes:

- This study is investigative but also exploratory, covering a wide range of themes and ideas within a nascent area of research and within a context that remains in continual flux;
- The situation remained far from clear once the RRR was concluded which of the Themes was the most important. This made any decision to select one Theme over another problematic;
- The RRR highlighted how all five Themes appeared to complement each other and contribute to a more holistic, integrated framework, rather than each Theme operate separately. It did not therefore seem logical to dissociate them at this point in the study.

(iii) *‘Focus the selection of theories on points of policy discord.’* Arguably, there is much debate already concerning the adequacy or otherwise of certain policies in relation to the FCOPWA. However, as stated earlier in this Chapter, what was lacking was the ‘carer voice’ in all of this; a discrepancy which this study sought to address. Moreover, this study was primarily concerned with ‘what is enabling’ as opposed to ‘what is not.’ Hence, there was a greater focus on gathering carers’ own views on points of accord rather than discord.

(iv) *‘Develop lines of inquiry, breaking each theory down into themes and sub-themes.’* This course of action was duly followed leading to the development of the new conceptual framework for FCOPWA based around ‘resilience.’

No doubt, as more becomes known about, ‘what enables the FCOPWA,’ future research will become more crystallised and narrowly focused, guided by robust conceptual frameworks which can benefit from their further refinement and validation via repeated testing, particularly involving more substantive evidence garnered from carers themselves to address a critical gap in knowledge regarding what they find enables them to maintain the long-term care of PWA. However, for the

present, a key remit of this study was to provide a point of origin in which to anchor future studies based around the research question. Arguably, this could only be achieved with a degree of rigour via a comprehensive investigation of ‘what enables the FCOPWA’ that at least initially demanded a broader conceptual focus that could be later narrowed via ‘hypotheses shedding.’ This aim was deemed critical to making further headway with the research and therefore became the priority, eclipsing other considerations that could be met by future studies, including further empirical testing and hypotheses verification among a wider selection of stakeholders.

The true function of Realist evaluation is to provide ‘decision support,’ rather than to conjure up immutable truths or laws (Pawson, 2013, p.107). Ultimately, this represents what this study set out to achieve and arguably the resulting conceptual framework, together with the PTs and MRT associated with it, achieved this crucial aim (see Findings Chapter 7). While some research designs seek to achieve a ‘more rounded’ view by seeking the opinions of non-carers to ‘add’ to a study’s findings, a robust case was presented here for the omission of the latter in this study. Essentially, it would not have ‘added’ anything further in terms of addressing the research question. Rather, the greater challenge was in eliciting family carers’ comprehensive, candid and deeply personal views regarding the research question and ensuring a substantial data base was compiled that captured this. This represented the study’s main challenge and arguably it represents a challenge which was duly met.

6.5 How theory consolidation was achieved from the CPTs to produce Program Theory

6.5.1 Theory consolidation Step 1

- (A) All interviews were transcribed verbatim from the original MP3 Voice recorder recordings;
- (B) Line-by-line analysis was conducted for each transcript, since each piece of data represents a fragment or fraction of the whole story. This demands in-depth analysis of each fragment (Emmel, 2013);
- (C) The systematic collation and tabulation of data evidence relating to each sub-Theme and its associated CPT for each of the five Main areas derived from the RRR: (i) Supportive social context (ii) Psychological assets (iii) Carer’s physical health status (iv) Quality of life (v) Ensuring timely availability of key external resources;
- (D) Noting evidence that supported the MRT ‘resilience;’
- (E) Noting evidence that might support an alternative MRT.

How this information was collated and initially analysed is illustrated by the example in Table 12 below. Since there is no set or fixed protocol to guide the analysis of Realist interviews, analysis followed a logical course based on Monzano’s (2016) guidelines, with particular attention paid to the following:

- (i) ensuring that analysis was thorough and rigorous;
- (ii) remaining mindful of the need to avoid creating constructivist-based and therefore mainly descriptive accounts of the data;
- (iii) adhering to the principles of SR inquiry by focusing on generating explanatory accounts based on ‘what enables the FCOPWA,’ as well as ‘how, for whom, when and in what circumstances.’

Table 12. Excerpt to illustrate the systematic collation of FCOPWA interview data evidence that related to each of the sub-Themes within each of the five main Themes derived from the RRR: (i) Supportive social context (ii) Psychological assets (iii) Carer’s physical health status (iv) Quality of life (v) Ensuring timely availability of key external resources. The data for each sub-Theme was recorded separately. This example illustrates some of the evidence and its initial analysis for the main Theme: ‘Psychological assets’ and within this the sub-Theme: ‘Hope.’ A separate Table similar to that which is depicted was drawn up for each sub-Theme.

Main Theme	Sub-Theme	Candidate Program Theories & How these may operate to instil Resilience
Theme 2: Strengthen Key Psychological Assets available to carer	(ii) Hope	<ul style="list-style-type: none"> • Hope has a moderating role in alleviating carer stress to help protect carers’ psychological wellbeing; • Hope instils a positive attitudinal orientation towards goals & daily challenges fosters a belief in & motivation to achieving goals; • Hope encourages positive reframing of the carer role which acts as a buffer against depression; • Hope helps mobilise resources to adapt to changes; • Hope promotes problem-solving and growth seeking behaviours.
<p>What works</p> <p>P16: Positive attitudinal orientation towards goals & daily challenges: I talk to some people and they are really resentful of their life, and I can understand it, but you have to hope and pray it passes. Carer suggests that this positive attitudinal orientation is linked with a focus on each day as it comes. This makes rational sense-rather than catastrophise ahead of time, to just gauge each day as you experience it & with luck, it may turn out better than you’d hoped: That’s why I have got into the habit of taking each day as it comes, I don’t project. But this comes at a cost both to longer-term strategic care planning & to ensuring opportunities for high QOL activities: They (carers’ friends) are all booked to go to Venice next year, I would love to be doing that but you can’t. Don’t think that far ahead and you’ll be alright. But this also harks back to a certain superstition carers seem to avoid provoking, i.e. booking events too far in advance while not knowing how the dementia will progress in the interim: tempting fate as it were.</p> <p>P17: Positive attitudinal orientation towards goals & daily challenges: I just carry on really, just carry on. Evokes something of the spirit of the aphorism, ‘Keep calm and carry on.’</p> <p>P18: Positive attitudinal orientation towards goals & daily challenges fosters a belief in & motivation to achieving goals: I can say positive as I have already experienced it and I know what’s on the cards. I know it was a while ago and I was in my teens when it happened, but it’s coming back through my dad and I just have to think positive. We’ve been there, done that. We’re just going to do it again...</p> <p>P10: Hope may be more important early on for carers as they adjust to this new role and come to terms with the disease and its impact on the PWD: I think in the beginning it’s obviously very important, like I said I just thought we’d be okay, things would change but we’d have a good few years, we’d be okay. However, as the dementia advances & symptoms deteriorate then perhaps this hope necessarily gives way to Acceptance-based coping as a means to then adjust to the harsh reality of the situation: When things started to change dramatically I think I don’t hope that things are going to improve, I just accept now...</p> <p>P10: Ability to envision & strive for the best possible future despite the circumstances: Positive attitudinal orientation: in the beginning it’s really important to be positive and that’s what we both tried to do.</p> <p>What does not work</p> <p>P2: I looked forward and I thought this is going to be brilliant, we can just go away any time of year at the drop of a hat. We only had a couple of years and everything changed and now we’ve never been abroad since 2009. Highlights the major impact on Quality of life that dementia can bring-that a lifelong ambition to have both the time & money to</p>		

finally enjoy holidays whenever you want them becomes completely undone by the disease. It's not only disappointment but a loss of hope that can result from such a profound setback. And when you make your plans, and you think we'll be able to do this, that and the other, it's disappointing. You think what a shame, we should have done it. I always say to people, "do it while you can." That's my motto now. Here, as evidenced elsewhere in other interviews, this concept of 'carpe diem' becomes far more central to carers than it might have done at any previous point in their lives: do it when you can because you don't know what's around the corner.

As illustrated in Table 12 above, each sub-Theme Table separately chronicled the interview evidence that related to that sub-Theme. The example depicted here represents a short excerpt which was taken from a much fuller analysis, but provides sufficient detail to convey how the initial analysis was conducted. Notably, this included the collation and analysis of evidence for 'what works' or 'enables the FCOPWA,' as well as 'what does not work.' Although the primary focus was on 'what works,' Pawson (Pawson, 2013, p.96) points out that the identification of who a Program will 'not work' for and 'why' is important in gaining further insights into Program Theory development, including identifying those contexts which are most conducive to 'what works.'

Each carer statement was prefixed by its unique participant number identifier and placed in inverted commas to distinguish this from my own annotated remarks. These annotations documented my own initial analysis of each separate piece of data. In this I was principally focused on:

- (i) Evidence to support the CPTs associated with each sub-Theme;
- (ii) Evidence to challenge the CPTs associated with each sub-Theme;
- (iii) Further insights and inferences that might emerge with regard to the CPTs associated with each sub-Theme;
- (iv) Evidence for the specific contexts and circumstances surrounding 'what enables' or 'does not enable the FCOPWA;'
- (iv) Evidence to support the MRT 'resilience' as central to 'what enables the FCOPWA;'
- (v) Evidence that might point to an alternative MRT as central to 'what enables the FCOPWA.'

The aim of this initial analysis was to identify causative processes that might provide an explanatory account of 'what enables the FCOPWA.' Rather than to derive more limited descriptive accounts that focused solely on 'outcomes,' i.e. where the focus is on 'what enables the FCOPWA,' but where specific and important details regarding, 'how, for whom, when and 'in what circumstances' might be absent.

In tandem with the above, broader, emergent potential demi-regularities were also chronicled. This represented a process that was ongoing and cumulative, building steadily as the analysis progressed to reveal potentially key recurrent patterns in the data (see Table 13 below).

Table 13. Summary Table chronicling broader, emergent potential demi-regularities.

Potential emergent demi-regularities recurring frequently from one carer data set to the next.
1. The need for earlier diagnosis of dementia.
2. The prevalence of carer isolation.
3. Day Care as a less drastic solution than Respite Care in terms of reducing carer workload & making provision for more time to complete care-related tasks, as well as facilitating 'down-time' in which to relax.
4. Predominance of the Medical Model of services provision Versus the need for more personalised, tailored carer support.
5. The power imbalance between carers and service providers.
6. Systemic problems with carer service delivery.
7. Service providers being obstructive to carers.
8. Variability in the quality of service provided to carers by their local G.P.
9. The need to differentiate between different FCOPWA to take differential levels of health inequality into account.

6.5.2 Theory consolidation Step 2:

(A) Employing retroductive inference-making

Considerable time and effort was dedicated to the task of collating, analysing and interpreting the interview data, as illustrated by Figure 13 above and bearing in mind this represents a brief excerpt taken from a fuller analysis and that a similar degree of analysis was applied to every Theme and their associated sub-Themes. Inferences and inference-making represent a critical part of Realist evaluation. Inferences can be viewed in terms of 'thought operations' and therefore as 'different ways of reasoning and thinking in order to proceed from something to something else,' (Habermas, 1972, p.113), i.e. moving from a theoretical account of 'what enables the FCOPWA' based on the conceptual framework produced by the RRR to the new conceptual framework outlined in the Findings Chapter and informed by the empirical investigation of that framework. Deductive inference is commonly used in the analysis of qualitative theory-driven research (Meyer & Lunnay, 2013). However, solely applying deductive inference-making to the analysis of data can be limiting since emerging evidence is often only applied to a theoretical framework which has been drawn up in advance (ibid). Therefore it was important that as well as making deductive inferences based on the original CPTs and the MRT, a crucial further dimension to the analysis was retroductive inquiry.

Retroduction can facilitate the development of causal explanations for phenomena by observing patterns or demi-regularities that emerge. Retroductive inquiry's focus on taking emerging evidence into account moved the theoretical propositions developed by the RRR forward, beyond the original conceptual framework, permitting fresh insights and revelations that extended theory in this study. Engaging in the analytical process of retroduction allowed fresh insights and inference-making to mediate between existing theoretical frameworks and emerging evidence. Important to SR inquiry,

retroduction explores the circumstances, conditions or contexts in which such causation occurs (Danermark et al; 1997). Ultimately, this led to the refinement of the CPTs and the formulation of more substantive PTs based on a narrower focus on more specific factors found to be most critical to 'what enables the FCOPWA' (see Figure 22 below). Thus, the use of retroductive inquiry permitted a further expansion of original theory.

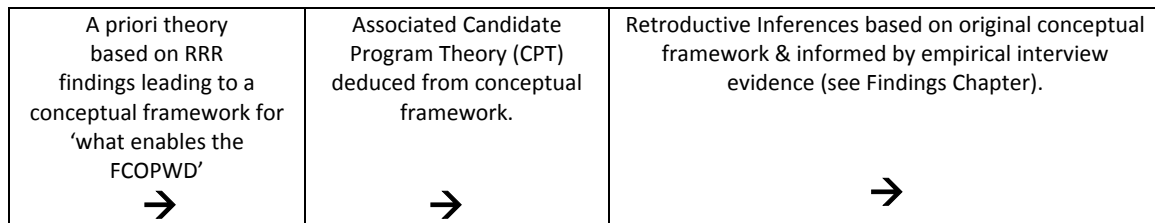


Figure 22. The retroductive inference-making process which was employed.

6.5.3 Theory consolidation Step 2

(B): Employing abstraction and abductive inference-making

The resulting PTs were based around the selection of those CPTs and their refinement through empirical testing against the primary evidence collected and analysed which ultimately possessed the most explanatory potential in terms of addressing the research question to account for 'what enables the FCOPWA,' 'how, when, for whom and in what circumstances.' This included the pinpointing of those CPTs which were gauged to contain the most significant determining, causal factors at different stages of AD. This process also involved the abstraction of some key concepts, e.g. adaptation, flexibility, control, caring style. Where this process leads to a new conceptual framework for 'what works' / 'what enables' the inference-making process becomes abductive by allowing new ideas to be introduced (Habermas, 1978). A main distinction between retroductive and abductive inference-making therefore is that the theoretical frame is the starting point at which retroductive inference can be employed, whereas abductive inference-making can serve to move theory towards new conceptual frameworks (Meyer & Lunnay, 2013). While deduction is capable of confirming or refuting a theory, abduction goes further to introduce new possibilities and new theories based on findings that were not evident or obvious previously, particularly prior to empirical testing. Objective testing of initial theory in the 'real world' can thus extend beyond initial conceptual frameworks (ibid). Crucially, this allows the researcher to formulate new ideas beyond the original theoretical premise (Danermark et al; 1997).

Abductive inference-making is fundamental to theory-driven research, enabling research to move beyond the initial theoretical frame of reference (Meyer & Lunnay, 2013), thus allowing theory to

advance and hopefully also with it, our knowledge and understanding of social phenomena. Essentially, theory-driven research that involves abductive reasoning moves beyond simply ‘testing’ theory drawn up a priori to take fuller account of any significant findings that may emerge, even where these are extant to initial theory.

Abductive and retroductive inferences are complementary tools which allow for a more comprehensive analysis of theoretically-driven data (Meyer & Lunnay, 2013). Where retroductive and abductive inference are used in conjunction, these forms of inference can lead to the formation of a new conceptual framework or theory (Danermark et al; 1997). The process by which this was achieved in this study is outlined in Figure 23.

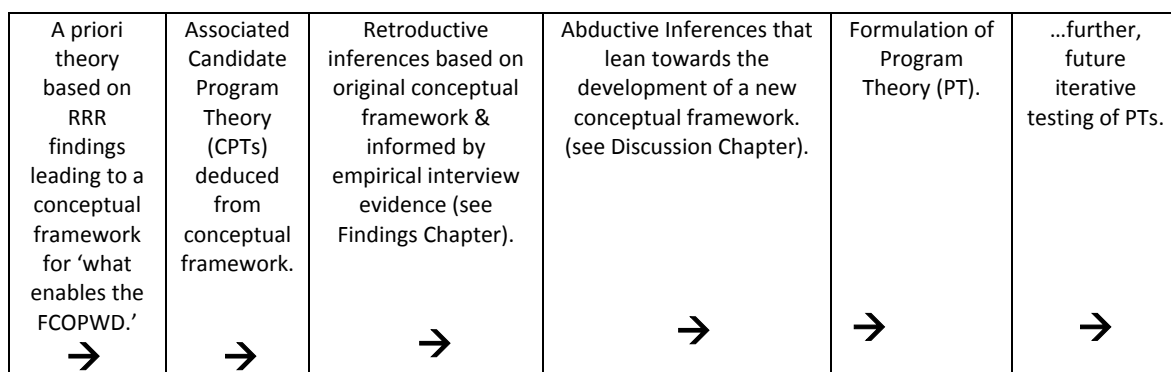


Figure 23. The theory-driven process employed by which Program Theory was developed, empirically tested, then refined and modified in this study.

How this process was applied in this study is further illustrated in Table 14 below which demonstrates how the conceptual framework developed by the RRR led to a new conceptual framework for ‘what enables the FCOPWA.’

Table 14. How the theory-driven process outlined in Figure 22 above was applied to this study to assist the development of a new conceptual framework for ‘what enables the FCOPWA.’

A priori theory based on RRR findings leading to a conceptual framework for ‘what enables the FCOPWA.’ →	Associated Candidate Program Theory (CPT) deduced from conceptual framework. →	Retroductive Inferences based on original conceptual framework & informed by empirical interview evidence (see Findings Chapter). →	Abductive Inferences that lean towards the development of a new conceptual framework. →	Formulation of Program Theory (PT). →	...Further, future iterative testing of PTs. →
The association between hope and psychological health, particularly its role in moderating psychological	‘Hope helps mobilise resources to adapt to changes.’	Carers adapt to accommodate new dementia challenges. How carer goals are achieved may often need to be revised at short notice. Carers often lack the necessary resources to remain flexible at short	Adaptability rather than Flexibility per se that is important to building resilience for FCOPWD. ‘Flexibility’ implies the ability to return to a previous state following	PT1: ‘Carer hope forms part of a wider, collective belief in the potential to learn, adapt to and overcome the challenges presented by dementia, as carers evolve to remain	

<p>distress (Rustøen, Cooper & Miaskowski, 2010).</p> <p>Donovan and Corcoran (2010) highlighted how hope can instil a positive, 'can-do' attitude and mindset.</p> <p>'Hope' is defined as 'a future goal orientation, the belief that goals can be attained' (Snyder, 2000)</p>		<p>notice and this presents a main impediment to carers exercising 'flexible goal adjustment.'</p> <p>Flexibility appears to become limited, particularly as carers advance towards the mid-stage of dementia, as carers increasingly come to rely on scheduling activities and events on a more ad hoc basis.</p> <p>What carers found <i>more</i> useful was remaining adaptable to changes within the care situation.</p> <p>Carers perceive the dementia care situation as one which is continually evolving and changing. This requires adaptation and growth on their part in order to accommodate the evolving situation and move forward.</p> <p>'Remaining hopeful' at their own individual, localised level forms part of the more collective global effort to overcome dementia.</p> <p>Adaptation provides a positive adaptive response to a wide range of circumstances and changing contexts: e.g. carers adapting to fundamental contextual changes that mean adapting to a slower pace of life.</p> <p>Carers perceive relevant care information that is specific to their local environment as a powerful tool that can facilitate learning and adaptation to meet fresh challenges. Having personal control over the access to this data is also important and perhaps also empowering.</p> <p>'What works for family carers,' often has to be newly acquired as part of an adaptive skill-set and therefore represents a learning curve for most carers is also highlighted.</p>	<p>an adverse event or challenge as in 'flexing back into shape.' However, carers' testimonies suggest they may go further than this. By being adaptive and making positive adaptations that enable them to cope with the challenges of caregiving, carers appear to move forwards by building on the experience and learning gained from adverse events. This is indicative of growth, progression and personal development. So long as the care context remains in a relatively constant state of flux, it makes sense for carers to learn to continually adapt and progress in close parallel with dementia's inexorable advance.</p> <p>In terms of 'What enables the FCOPWA' the difference between 'flexibility' and 'adaptation' represents more than a semantic one therefore.</p> <p>Carers will need to embark on a journey of learning and discovery to develop the requisite skills and knowledge to deal with such care. This journey forms part of an ongoing adaptive process that often begins in the pre-dementia diagnosis stage when dementia-like symptoms are first observed and adjustments are made to accommodate them and this continues throughout the course of dementia trajectory.</p> <p>Achieving carer resilience therefore moves beyond</p>	<p>resilient despite these challenges.' While resilience is recognised as an important developmental pathway (Hawley, 2000), a main concern is that at present 'no single trajectory exists...that practitioners can recommend' (McCubbin et al; 2002). Where Hope is implicated in this process and its promotion during the Early stages of dementia (identified as potentially critical to how the FCOPWA eventually plays out), it represents an important factor in terms of equipping FCOPWA with the right mindset to adapt to changes as they follow the dementia trajectory & to thereby maintain resilience.</p> <p>Peer support can provide vital first-hand advice & strategies during these Early stages of dementia.</p> <p>Voluntary sector can provide carers with an invaluable source of advice, strategies and guidance also.</p> <p>There is also a strong inference that is made here that the adoption of a mindset that is positive predicates successful carer adaptation.</p> <p>In developmental research Hope has been identified as a fundamental characteristic of a resilient mindset (Brooks in Golstein & Brooks, 2013). However, arguably this can be extended to include older adults.</p> <p>Hope also shares close links with Locus of control (LOC) (Farone</p>	
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		<p>Practical, first-hand advice and information appears to be a high priority in order to enable adaptation that restores some necessary control over the care situation. In this, Peer support that is organised by the Voluntary sector is an invaluable source of first-hand advice.</p> <p>Importance of the voluntary sector in offering advice & support that is directly perceived to reduce and Minimise carer stress.</p>	<p>adjustment that helps regain equilibrium within the care environment and reinstating the status quo. Rather, resilience is achieved by moving forward, i.e. by learning new knowledge and skills and acquiring further resources, including external support at each stage.</p> <p>The early stages can create great uncertainty (O'Shaughnessy et al; 2010). This therefore denotes a critical period during which carers need to establish receptivity and amenability to adaptation. Hope can provide a crucial state of mind that is biased towards achieving successful adaptation. This goes further than Donovan and Corcoran (2010)'s assertion that hope can instil a positive, 'can-do' attitude and mindset by stating 'how' hope achieves this for FCOPWA.</p> <p>Similarly, Rustøen et al's (2010) assertion that there is a strong association between hope and psychological health may be founded in hope's role of encouraging adaptability that meets with success in dealing with the changes & challenges brought about by dementia. Essentially, early adapters who build a solid foundation early in the care journey benefit from having (i) a sound platform for resilience to become well established (ii) an openness to adaptation based on earlier successes that serves</p>	<p>et al; 2007) & this is important re: the other PTs. The resulting PT attempts to capture the qualities cited here: 'Carer hope forms part of a wider, collective belief in the potential to learn, adapt to and overcome the challenges presented by dementia, as carers evolve to remain resilient despite these challenges.'</p>	
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			<p>them well later by facilitating further adaptation (iii) later adaptations become reduced in magnitude and easier to achieve since they may rely at least partly on earlier adaptations, meaning that those carers who need to adapt <i>the least</i> in order to successfully maintain family care of PWD may be more resilient (Donnellan, Bennett & Soulsby, 2014).</p> <p>The most relevant CPT here is 'Hope helps mobilise resources to adapt to changes.'</p>		
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A further great value of abstraction is its transferability to other similar health situations and health contexts (Pawson, 2013, p.89). 'Deductive inference is limited in the guidance it provides on how we can gain knowledge about what makes events, lived experiences or phenomena possible' (Danermark, 2002). However, engaging in the processes of retroduction and abstraction can assist in producing novel insights about known phenomena and contribute to the development of more comprehensive theoretical explanations of events or experiences (Meyer & Lunnay, 2013). Deductive inference is often complementary to retroductive and abductive inference but on its own may be limited in terms of explaining how specific contexts, individual assets and external resources combine in complex, multi-faceted ways to bring about causative effects. 'Social research, in its simplest terms, involves a dialogue between ideas and evidence' (Ragin, 1994, p.55) and arguably, retroductive and abductive inference expand that dialogue, particularly where the researcher is cognisant of the fact that knowledge cannot be simply reduced to observable events (see Chapter 3).

6.5.4 Hypotheses selection

Pawson warns that the process of abstraction inevitably involves engagement in hypothesis selection and hypothesis shedding (Pawson, 2013, pp.164-165). As stated earlier, this represents an important part of the process and journey of emerging from the 'swamp' of complexity (Pawson, 2013, p.161). However, 'hypotheses shedding' perhaps represents too strong a term where it is applied to this study. Rather than apply the more radical binary action of 'accepting' or 'rejecting' the initial hypotheses based in the CPTs, the RRR recognised the multiple ways in which FCOPWD might be enabled to carry out the role and the merit and benefits of each, be it relational support, regular

exercise, information, sitting services etc. It would be more accurate to state that the interview analysis highlighted the central importance and saliency of certain CPTs which were gauged to be most critical to 'what enables the FCOPWA.' This does not indicate an outright rejection of all the extant CPTs, but rather it provided a means of prioritising what were deemed to be the most important CPTs and developing these into PTs. Ultimately, decisions regarding hypotheses selection and the robustness of the PTs which were finally formulated relied on:

- (a) the strength of the evidence base which supported them;
- (b) the cogency with which the PTs were argued;
- (c) their plausibility;
- (d) their explanatory power in relation to the research question;
- (e) their translational potential.

Hence, carers' need to establish independence and autonomy due to a perceived lack of formal health and social care support; to control their own health and wellbeing by regulating stress; to remain adaptive in terms of the strategies they employed in order to maintain control over the care situation; the close links between exercising control over AD care and building and maintaining carer resilience: these became key areas that were writ large in terms of their importance to carers according to the data, culminating in the formulation of five PTs adjudged to be most instrumental to and offer the greatest explanatory potential for 'what enables the FCOPWA.'

The decision regarding which CPTs to highlight also relied on the 'Trust: Doubt' ratio which in turn can only be borne out by:

- (i) how accurately the original CPTs reflect the review (RRR) findings;
- (ii) how well the refined CPTs which provide the bases for the eventual PTs are supported by the interview evidence;
- (iii) how well the PTs are then supported by a re-examination of the literature;
- (iv) further down the line: how well the PTs stand up to future investigation by other researchers and further studies.

This follows Pawson's (2013) advice to apply Campbell's (1988) 'Trust: Doubt' ratio during hypothesis selection. As Pawson points out, sometimes a wealth of information and data might be gleaned, but it only becomes practicable and realistic given the constraints often imposed on single research studies to focus on and explore what appear on balance to be the most important and most salient aspects (Pawson, 2013, p.164). This can result in around 90% of the data findings being 'parked' in favour of highlighting those findings which offered the most explanatory potential in terms of accounting for the 'what enabled the FCOPWA' and addressing the research question.

6.6 Chapter Summary

This Chapter provided details of how the 3rd phase of the study was conducted, including how the method selected provided a good fit with SR theory. The Chapter proceeded to outline the rationale and implications for focusing specifically on FCOPWA. The rationale for selecting qualitative methods and in-depth interviewing as the method of data collection for this Realist evaluation was also discussed.

How sampling and participant recruitment was carried out was then explored, including the rationale for the approaches employed. Brief vignettes and descriptive statistics were presented to provide an overview of participants. Considerations that were made with regard to the selection of study site were also examined. Sampling limitations were discussed, before moving on to address how ethical considerations including safeguarding were dealt with.

The procedures employed for data collection were described, including how richness in the data was achieved. How the interview schedule was drawn up was discussed, including the rationale for incorporating a wide range of CPTs. The criteria used to gauge when data saturation was deemed to have been reached was also explained.

The Chapter then moved to a discussion of how the three broad phases of conducting interviews in SR outlined by Monzano (2016) were achieved, using examples of the data analysis that was conducted to illustrate how this process was carried out. Finally, the criteria by which hypotheses selection was achieved was discussed. The next Chapter will provide an overview of the key findings from this 3rd phase of the study.

CHAPTER 7: FINDINGS CHAPTER

7.1 Introduction

This Chapter will present the findings from the interviews conducted with family carers of people who are living with Alzheimer's disease (FCOPWA), based upon the candidate Program Theories (CPTs) drawn up following the Rapid Realist Review (RRR). Analysis of the data revealed five salient Program Theories (PTs) underpinned by carer resilience which combine to create an adaptive pathway by which family carers can build and maintain resilience across a dynamic and fluid Alzheimer's disease (AD) trajectory. The time course of AD is broadly depicted here according to three stages which can extend for up to 18 years (Clark, 2000), before palliative care becomes necessary towards the end (see Figure 23 below). This represents how non-clinicians and FCOPWA tend to perceive the trajectory and it therefore provides an appropriate way of depicting it throughout this study. The three stages include: (i) Early stage (mild AD symptoms) (ii) Mid-stage (moderate symptoms) and (iii) Later stage (severe symptoms).

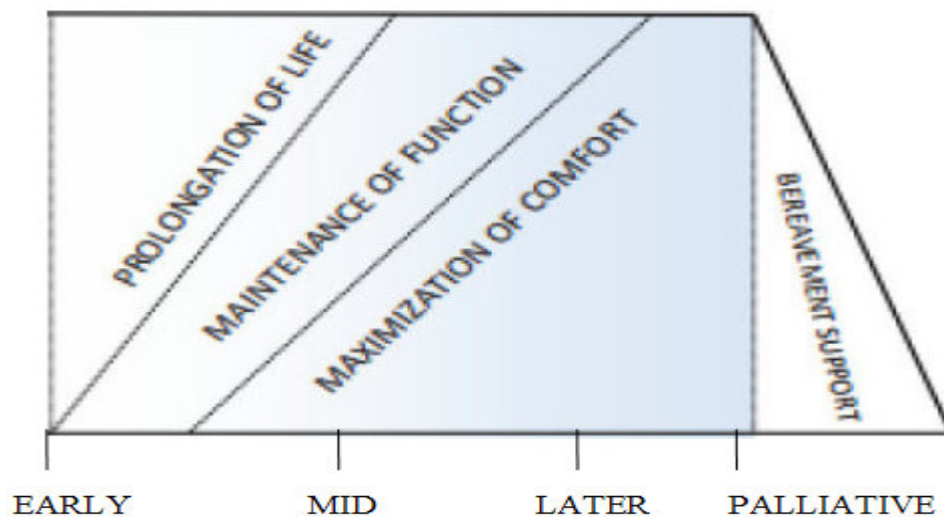


Figure 24. The three broad stages of the Alzheimer's disease trajectory which can span up to 18 years (Clark, 2000), before palliative care becomes necessary. (Adapted from van der Steen, Radbruch & Hertogh et al; 2014, p.206).

Meanwhile, the key findings associated with each PT will be presented in five sections with each section introducing:

- the principal CPT derived from the RRR;
- how this CPT was further refined in the light of the interview data;
- a summary of 'what works, for whom and in what circumstances;'
- the formulation of the PT;

- the formulation of a context (C), mechanism (M), outcome (O) configuration or CMOc to represent each PT and to provide an explanatory account of ‘what works,’ ‘how,’ ‘for whom and ‘when’ in relation to FCOPWA and where the principal outcome (O) is represented by ‘the successful long-term maintenance and sustenance of the FCOPWA.’

Schematics will also occasionally be employed where the operation of some PTs requires additional clarification.

7.2 Brief overview of the PTs

PT1: Hope identifies how carer ‘Hope’ as an **Emotion-focused Coping (EFC)** (Lazarus & Folkman, 1984, 1987) approach forms part of a wider, collective motivation and belief in the potential to learn, adapt to and overcome the challenges presented by AD, as FCOPWA evolve to remain resilient despite these challenges. Furthermore, how the maintenance of ‘Hope’ is important in promoting a positive outlook.

PT2: Problem-focused Coping (PFC) (Folkman & Lazarus, 1980) defined as, ‘actions taken to address the source of a stressor to reduce or remove it’ (ibid) represents an adaptive coping approach identifies how carer resilience can be significantly enhanced throughout the Early Stage of AD and thereafter where carers increase internal Locus of Control (ILOC) via the application of problem-focused coping (PFC) to mediate the effects of a form of stress which is arguably specific to the FCOPWA-Chronic Variable Stress (CVS).

PT3: Emotion-focused Coping (EFC) (Lazarus & Folkman, 1984, 1987) and how it is specifically applied by family carers to deal with the stressors associated with care-based challenges on an ad hoc basis. The EFC approach outlined by PT3 provides an adaptive coping approach which can make a significant contribution to carer resilience as FCOPWA approach the Mid-stage of AD. It achieves this by enabling carers to increase ILOC, particularly over stressors, via the adaptive implementation of a dual process coping approach in which PFC continues to be applied to deal with solvable problems, but works in conjunction with EFC to help regulate stressors which are not amenable to problem-solving.

PT4: Caring Style identifies how carer resilience can be significantly enhanced as family carers advance towards the Mid-stage of AD where carers adopt a ‘**Pragmatic caring style.**’ The effectiveness and adaptiveness of different caring styles and their differential contribution to ‘what enables the FCOPWA’ has been largely overlooked to date and represents a significant gap in the existing literature. Therefore, the PT developed here represents the first time such a Pragmatic caring style has been introduced. In addition, how this caring style is complemented by and assisted by the

adaptive employment of EFC and PFC approaches is explored here for the first time, including how these adaptations can combine to enhance carers' ILOC and in turn, increase carer resilience.

PT5: Social coping and Acceptance as further adaptive EFC strategies: identifies how as FCOPWA approach the Later stage of AD, resilience is maintained by adapting to fresh challenges via the EFC strategy of 'Social Coping' (Folkman & Moskowitz, 2004). Social coping encourages support-seeking behaviour as the intensity and duration of care increases in response to deteriorating symptomatology and challenges becoming increasingly driven by AD symptomatology that may be less amenable to a PFC approach. 'Social coping' is defined here as, 'seeking emotional support and seeking practical support from others,' as a specific EFC coping strategy (ibid).

In addition, PT5 identifies how the separate employment by FCOPWA of the EFC strategy 'Acceptance' can adaptively replace avoidance-coping strategies as the person who is living with Alzheimer's disease (PWA) approaches the Palliative stage of the disease. 'Acceptance coping' is defined here as, 'accepting that a difficult situation is real and must be addressed' (Carver, Scheier & Weintraub, 1989).

7.3 PART 1 PT1: Hope

The RRR identified that in terms of 'what enables the FCOPWA' the need to remain adaptive as part of maintaining carer resilience might represent a primary need. This contention made intuitive sense since carer adaptation seemed likely to be a key requirement where carers were faced with the inherent unpredictability and variability which characterises the FCOPWA. Moreover, adaptation has been strongly linked with resilience (Dias, Santos & de Sousa et al; 2014). However, there remained a need to empirically 'test' the validity of this contention, as well as to uncover the actual mechanism that facilitates carer adaptation.

Candidate Program Theory 1

In terms of factors likely to be important to 'what enables the FCOPWA,' the RRR identified the CPT: *'Hope helps mobilise resources to adapt to changes.'*

Interview data

Hope as a motivator towards adaptation and maintaining a positive outlook

The implication that is made clear by the interview data is that carers perceive the FCOPWA context as one which is continually changing and evolving over time. Moreover, that this requires adaptation and growth on their part in order to accommodate these constant changes and to move forward.

Self-development and personal growth feature strongly in this need. The twin themes 'evolution' and 'adaptation' are recurrent here. There is also a strong element of inherent hopefulness surrounding carers' perceived ability to successfully make these adaptations. This also stems from the need to maintain the positive belief in the human capacity to somehow instinctively find ways to overcome challenges, no matter how taxing these may sometimes be. P17 is 68 years old and has been caring for her spouse for three years. She has multiple sclerosis (MS), but continues to work as a primary FCOPWA as well as a local councillor. P17 is also Chair of the MS Society. P17: "*We think we are using the ability to find other ways around it. Your brain is a clever thing, it looks for other ways around it, every obstacle that's in your way-it finds a way around.*"

A similar view is shared by P4 who is 54 years old and has been caring for her mother for three years. P4 took voluntary redundancy from her profession in education in order to attend to the carer role full-time: P4: "I think it's important to remain hopeful, I think you have to as a human being, because if you lose hope what good are you to yourself and anyone else."

FCOPWA can draw hope and meaning in their present actions from knowing that they are part of a larger, galvanised effort trying to address AD and moving inexorably forward towards eventual solutions. P2 is 70 years of age and has been caring for her spouse for five years. P2 and her husband retired to the Coast at South Tyneside ten years' earlier from their occupations in Blaydon near Gateshead as a secretary and a technician respectively. P2: "I know there's research going on all the time and they seem to be a little bit nearer, a little bit nearer. It's going to get there eventually."

P7: "They are talking about some sort of injection...I read all the literature on it and listen to the programs just in case I hear anything that would be relevant...there is a lot of research going on. By the time you get to that age it's going to be not cured, but more controllable and that's what you want."

P18 is 50 years old and has been caring for her father for one year, but also provides care for her elderly mother who is crippled with arthritis. P18 feels as though she has been left to fend for herself as a carer and is finding the learning curve involved somewhat steep. P18: "Well I think it's there. You've just got to hope everything is going to work out, hope everything is going to work out the way you want it to work out-and for the best."

Hope as quintessential to maintaining resilience despite adversity

P13 is 73 years old and has been a carer for her husband for eight years. She continues to work part-time as a Scheme Manager for sheltered housing. Work plays an important part of P13's life,

providing socialisation and a sense of normality beyond the context of the FCOPWA. P13: “Well you keep hoping things will get better...You keep hoping there’s always somebody there, somebody on your side. You don’t always find them like, but I think you’ve got to keep your hopes up because if you don’t you’ll just go under, completely under.”

Importantly, Hope can also help to provide a ‘positive outlook’ and reinforce a positive state of mind more globally, at any point during the care journey, even during periods of adversity. P3 is 75 years old and has been caring for her husband for three years. She and her husband have lived at the same address in South Shields for forty years, but her husband is beginning to struggle to remember this fact and is experiencing increasing difficulty comprehending the world around him. P3: “If you start thinking, ‘I cannot manage and I cannot manage that,’ you would be away you know. But as things are now I feel I can cope at the minute and I wouldn’t like to see him going away...As long as I can do it, I’ll look after him...Positive, most definitely.”

Adaptation

Adaptation as a relatively steep and necessary learning curve for carer from the outset of the FCOPWA due to minimal formal services’ involvement: P18: “You are chucked in at the deep end when they are first diagnosed. You think “where do I go from here? Where do we go now?” So you are finding out for yourself, what to do and how. It’s a learning curve and you are left to your own devices to get on with it.”

The need for carer Adaptation to a highly novel set of circumstances and challenges from the outset is underlined by the finding that it may be very seldom to find carers who come readily equipped to take on such a unique challenge. P6 is 73 years old and has been caring for his wife for ten years. P6 was formerly an engineer working in heavy industry and his wife was a special needs teacher working at a local college. P6’s wife is approaching the palliative stage of AD. P6: “I can understand people struggling on thinking they are doing a good job, but you need more knowledge than an average person has...”

P4: “I’ve had to adapt...with the illness itself, to the new situation I find myself in...we’ve come to another stage, she’s took a big dip, she wants me there all the time.”

The need to develop a solid knowledge and skills base to feel better equipped for the FCOPWA and the importance of the voluntary sector in providing this for carers. P5 is 60 years old and has been caring for his mother for five years. P5 is an only child whose father passed away twenty years ago.

Any remaining family now live in the South of England. P5 retired from his position as a well paid executive while his wife continues to work for the NHS. P5: "I did all the courses that they (Carers' Association) had."

P8 is 62 years old and has been caring for his mother for one year. P8 lost his wife and father eight years earlier. P8's siblings live in the South of England and Scotland respectively. P8 retired from his professional career in order to take up the carer role. P8: "I went to a Dementia Awareness course that Age UK ran at my church before my mother was diagnosed, became a Dementia Friend. Because I felt the signs were there and I need to develop some knowledge..."

Especially during the Early stage of AD: Peer support that is organised by the voluntary sector as an invaluable source of first-hand advice and knowledge based on lived experiences, rather than the more formal knowledge base utilised by professionals. P12 is 78 years old and has been caring for her husband for nine years. P12 is a former school teacher while her husband worked as a fitter. The local Alzheimer's Society branch has been a God-send to her in terms of providing support and advice.

P12: "We used to share information and it was good, practical-especially for new carers learning the ropes."

P7: "Find out everything there is to know about it. People who have lived with it give you advice. So it's them people who have problems will tell you, it's word of mouth, it's the best information of all I reckon it is."

Carers remaining continually adaptive to adjust to new dementia challenges: P4: "...this is becoming a new thing. Something occurs, this is new and you think: "that's different, let's bring that in, how do we deal with it?"

P8: "So you had to continually adapt- in that respect and you get drawn into it further and further...So it kind of evolves without you realising, you just had to react all the time."

P18: "we just have to learn to live with it...I think you just adapt to it, you adjust to it and find ways of working with it."

Adaptability as a requirement to deal with the variability and unpredictability of AD, but notably the care context does not always permit flexibility and there are important distinctions between 'adaptability' and 'flexibility' with 'adaptability' more often than not denoting the more radical development of new knowledge, skills and abilities: P4: "I want to know where she was at, and I wanted to know time spans and you can't always put that in place, but I thought in two years I'm

going to be doing that and it's going to be more time-spending, to know what to expect, adapt and prepare for it."

Adaptability as a requirement to deal with more radical contextual changes, includes the pace at which daily life revolves. This represents a further step on beyond simply being 'flexible,' requiring wholesale changes to the way carers live and deal with changes wrought changing AD symptomatology: P18: "On a morning when he gets up he's not with us until he has managed to put the cereal in the bowls, put the milk on, bring mam's in as well, he'll make her a cup of tea, take it into the bedroom. It takes him 30 minutes but he gets there eventually... Do it in their own time, they want to be independent..."

P18: I'll say, "come on dad, let's go out for a walk for a bit and he'll say, "no." Half an hour later he'll put his shoes on..."

What worked, for whom, under what circumstances

- Being **adaptive** and maintaining **hope** in the ability to successfully adapt become necessary requirements **from the outset** of the FCOPWA, driven by carers' perception that they are largely left to their own devices by formal service providers.
- Few people come readily equipped to deal with the challenges presented by the FCOPWA and carers view this as a **steep learning curve** in which they must continually adapt by acquiring new knowledge and skills.
- **Peer support and the voluntary sector** can support carers' acquisition of new knowledge and skills that are adaptive in enhancing carers' abilities to carry out the role.
- Hope and remaining adaptive appear to work hand in hand to support carers, promoting a more **positive outlook** that predicts successful adaptation rather than failure.
- Carers gain strength from knowing they are part of a wider, international effort to successfully **adapt** to tackle AD and this provides an important **source of hope** for the future.
- Carers perceive **adaptability and implicit hope in their ability to adapt successfully** as part of **positive outlook** as important inter-connected prerequisites to maintaining the FCOPWA right from the start.
- Carers respond to wholesale changes wrought by changes in AD symptomatology by going much further than remaining 'flexible' to actually '**evolve**' to keep pace with these changes.
- Hope, adaptation and positive outlook **increase in importance as the care journey advances** as new challenges increasingly call upon these assets to maintain **resilience**.

Refined Program Theory

In terms of factors likely to be important to ‘what enables the FCOPWA,’ the RRR identified the CPT: **‘Hope helps mobilise resources to adapt to changes.’** Analysis of the interview data led to the refinement of the original CPT to provide greater specificity regarding how and when causation is generated and in particular, how this supports the overarching MRT ‘resilience.’ The refined PT concludes that, **‘Carer hope forms part of a wider, collective belief in the potential to learn, adapt to and overcome the challenges presented by AD, as carers evolve to remain resilient despite these challenges.’**

Consistent with scientific realist (SR) methodology, the refined PT is expressed in terms of CMO configuration (Figure 25 below).

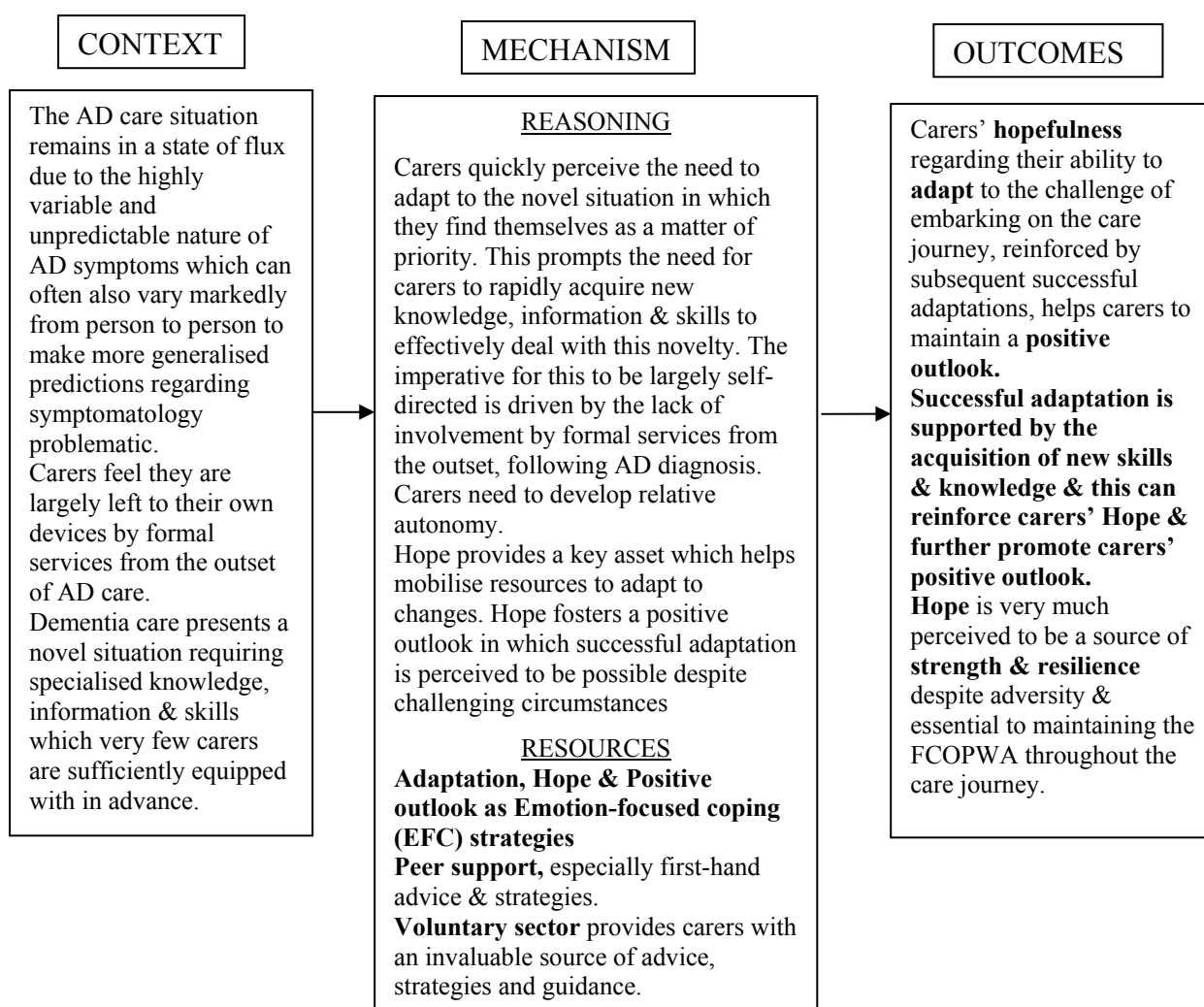


Figure 25. Program Theory 1. Formulated to take account of the interview data analysis.

7.4 PART 2 PT2: Problem-focused Coping (PFC)

What the RRR found: The RRR identified ‘self-efficacy’ (SE) and in particular ILOC as one of the principal psychological resources responsible for equipping FCOPWA with the confidence and belief that they possess the ability to control and manage the care situation.

Candidate Program Theory 2

In terms of factors likely to be important to ‘what enables the FCOPWA,’ the RRR identified the CPT: ‘Raising carer perception of controllability over the care situation to reinforce carers’ internal locus of control, self-reliance, resilience and perceived capacity to master new domains.’

Interview data

The interview evidence goes further to highlight the importance of carers’ ILOC, its close relationship with specific types of coping and their combined ability to augment resilience as an outcome. ILOC represents a construct closely associated with self-efficacy where LOC is defined as ‘carers’ perceived degree of control over decision-making, responsibility and autonomy and overall control over the care situation.’ Importantly, encouraging the PWA’s continued independence for as long as possible can also assist carers’ ILOC by preventing the PWA becoming too dependent on the carer too soon. ILOC also refers here to the degree of control carers exercise over the self-monitoring and safeguarding of their own health and wellbeing while caregiving.

The need for carers to develop a strong ILOC from the outset

The development of a strong ILOC becomes a very necessary requirement right from the outset for carers who, according to the interview evidence, tend to receive minimal support following the diagnosis of a family member’s AD. Carers quickly come to understand that reliance on external support, and with this an external LOC, is not a viable option.

P10 is 62 years old and has been caring for her husband for one year who has an aggressive form of AD with rapidly deteriorating symptoms. P10 believes her husband has had the condition for a lot longer than the diagnosis suggests however. P10 has regular contact with a crisis team, but received minimal support until AD symptomatology became more severe. P10 believes that there needs to be a greater distinction made between conditions which have an impact mentally compared with those which are solely physical. P10: “I remember coming away from seeing the doctor, well that just seemed to be it, they’ve just told you but they didn’t say anything about any further appointments or support or who you could talk to.”

P18: “You are chucked in at the deep end when they are first diagnosed. You think, “where do I go from here? Where do we go now?” So you are finding out for yourself, what to do and how. It’s a learning curve and you are left to your own devices to get on with it.”

P18: “...they did give us some leaflets and said, “there is some research into Alzheimer’s and would You be willing to help out?” But I thought it was too soon and so I said, “no.” I thought, “I’ll get dad home now!”

The data also highlights the predominance of The Medical Model in which diagnosis, pharmacological treatment and the recruitment of PWA as subjects for medical research appear to be given greatest priority.

The stance adopted by formal health care providers sends out the clear message that from this point forward the carer and PWA are largely on their own. This reinforces carers’ need to develop a strong ILOC from the outset. Carers go on to cite the absence of formal support a systemic problem and failure. P17 still works as a local councillor and has a sound knowledge of the systems and infrastructure that surrounds carer support. P17: “I have absolutely no help with the dementia...There seems to be nothing, no support. For the carers-there is nothing...There is just nothing...I’ve looked everywhere for help and there is none, and if I can’t find it knowing the system-I don’t believe anyone can...There may be some in other towns for helping the carers, but it’s not here.”

Where formal dementia support systems do exist there appears to be a fundamental lack of integration and communication between them to allow these to function effectively to meet carers’ needs: P5: “The people are lovely, people are skilled and trained and want to do well, the systems are all rubbish... Everybody works in silos...“But the computers don’t talk to each other!” But that’s really a smoke screen, it’s not about the computers, the people don’t talk to each other.”

Carers developing ILOC via the acquisition of PFC skills

While absolute confidence and control can never be guaranteed or assured within any care situation, it is nonetheless important for family carers to perceive at least some modicum of control and capacity to influence events overall. This becomes particularly the case where carers and PWA are left largely to fend for themselves following the dementia diagnosis. The interview evidence revealed that a main way in which carers achieve ILOC from the outset of caregiving is via their continuing development of often very practical-based but important **PFC skills**. There are many examples extrapolated from the interviews of carers employing PFC to improve their degree of control over the

FCOPWA and the following represent just a small portion of these: P10: “You just do what you think at the time, it might not always be the right thing but you don’t know that-you just do it because you think this is what the right way is to deal with the problem at the time.”

P11 is 53 years old and has been caring for his mother for one year and was caring for his sick father prior to that, but his father passed away a year ago. P11 decided to move in with his mother once she began to wander off at night-time. He works as her full-time carer and has found becoming a FCOPWA challenging, but made easier through the help and support he has so far received from his local Alzheimer’s Society branch. He has an estranged brother who lost contact with the family, as well as a second brother who lives in London. P11: “When she put weight on and I didn’t realise it at the time, but obviously when she has a cuppa she was nibbling biscuits and cake. They said when they have dementia they eat a lot of stuff like that. So I keep some stuff in my bedroom and I might put a couple of packs of biscuits out but she’ll eat them in a day.”

P15 is 70 years old and has been a carer for her husband for four years. P15 has a daughter who lives in Spain but provides good moral support via regular telephone calls and offers to accommodate her parents whenever they wish to visit her. P15’s husband’s memory loss and inability to create new memories can be a source of frustration for both of them. P15: When ‘X’ repeats something for about the 10th time that day it can be frustrating. I try to change the subject or point out something completely different.

P12: You just have to learn the strategies for dealing with everything and you’ve got to try and be one step ahead.

The data reveals that PFC is often based on resolving or preventing mundane issues, but these form the fabric of daily carer life. Exercising PFC to deal with daily issues and challenges can increase carer (and PWA) autonomy and ensure daily routines are conducted as efficiently as possible and with minimal stress. This is important since CVS as the principal manifestation of the health inequalities FCOPWA face is generated not only from occasional crises of some magnitude, but more frequently from the constant accumulation of smaller daily stressors generated by regularly occurring challenges that left unchecked / uncontrolled can escalate from a minor incident to a full blown crisis: P18: “If we do leave him we leave him little messages of where we’ve gone. But not too long: If it’s too long, then it’s a panic situation.”

Exercising PFC often involves pre-empting certain difficulties and putting strategies in place to circumvent them. This in turn lends itself to making the FCOPWA manageable. Here, deliberately

shortening the duration of an activity and providing constant prompts to remind the PWA about the forthcoming activity to avoid this coming as a shock. P1 is 73 years old and has been caring for her husband for three years. They have been married for 57 years. P1's husband had been a ship's captain and had always been excellent at maths. Although he continues to complete sudoku puzzles P1 believes that her husband simply goes through the motions of doing this. Trying to help her husband to memorise upcoming events involves constant reminders in the hope that a memory is retained. P1: "I've got to plan everything because Bill cannot plan himself you know, and everything. So it's the 'Singing for The Brain,' so instead of going for an hour, just the half hour, you're reminding him all the time in many ways. That's all planning ahead, thinking ahead, yes."

PFC provides ways for carers to adapt and reshape the care environment to optimise the FCOPWA. This not only serves to resolve current problems the carer (and PWA) may face, but also they help to maintain some necessary level of independence and autonomy also for the PWA: P17: "I discovered I can't even leave him with a frozen meal because he doesn't understand the instructions. So I have to make chicken and dumplings, chilli what have you, so he just has to put it in the pan to heat it up..."

P18: "He goes into the kitchen and he used to come back in and ask, "where's the plate for such and such?" My son made these sheets of paper with words on like bowls, cutlery, so all the cupboards have the signs on."

P18: "We bought him his clock (a digital speaking clock) on his bedside, his own clock, as he would say "what day is it?" and he'd go to his newspaper. So 'X' mentioned the clock so we bought him that online. He'll wander into the bedroom to find out the date, day and time and it's his clock and not anybody else's."

Evidence also indicates that carers need to judiciously gauge where the dividing line exists between PWA autonomy and the need for carers' PFC intervention. This is necessary in order to avoid creating too much workload for themselves which can over time translate into stress: P11: "Well, I didn't know if I was doing right or wrong. I know there are some things that confuse her, but the fine line is the difference between expecting her to do stuff that she can't do and what stuff you know she can do. So like simple things, like turning the TV on, she doesn't change channel but I know she can switch it on."

Much of carers' attempts to apply PFC to prevent or minimise the occurrence of stressful events involve intervening to control the care environment. Quite often the ways in which carers employ PFC can be relatively sophisticated, although the solutions may seem obvious with hindsight, e.g. ensuring a light-hearted atmosphere is created by manipulating the type of T.V. program being

broadcast: P7: ...he's still got a sense of humour. He watches TV a lot, he likes humorous stuff, and he watches all the comics. Last night he had the 'Two Ronnie's' on and 'Yes Minister.' If I put a stressful program on he gets up and says, "stop doing that!" "Tell them to stop that!" It becomes real for him, yes."

The voluntary sector can be invaluable in assisting FCOPWA to develop PFC skills and strategies and many of the carers who were interviewed recommended that all carers should be encouraged to make contact with the voluntary sector as early as possible: P8: "Bringing in the 'X's (Centre Manager at the local Alzheimer's Society branch) of this world from Alzheimer's UK at that point to sit down with you, I think would be very helpful."

P11: "It does make a massive difference...I mean 'X' (Centre Manager at the local Alzheimer's Society branch) has an answer for everything. Doesn't matter what the problem is, she'll say "have you thought of this, done this?"

Once carers have begun to establish a reasonable knowledge base that supports PFC, they can then exercise their own discretion regarding which further training events they will attend and this in turn demonstrates carers' developing ILOC: P2: "They have regular carer meetings which I don't go to every time but I've been going quite a lot lately. I'd always look on the sheet of who's the speaker and what it's about and if I don't know that one I like to go and hear that one..."

Peer support via the voluntary sector

P15: (At Alzheimer's Society)...information about the disease-what it's about. How it affects people. Most of all you get information from other people, other carers...at carer meetings.

What worked, for whom, under what circumstances

- The development of a strong **ILOC** becomes a very necessary requirement right from the outset for carers who tend to receive minimal support from formal health care providers following a family member's diagnosis of AD. The clear message conveyed is that from this point forward the carer and PWA must largely fend for themselves.
- The predominance of **The Medical Model**, as well as the limitations imposed by it, is made clear to carers from the outset-that formal health care support for the FCOPWA principally revolves around diagnosis, pharmacological treatment and PWA being regarded as subjects for medical research. More practical support and empathy is notably absent.

- Carers achieve ILOC during the Early stage of AD via the development of a **PFC approach** to the care challenges which they face. PFC enables carers to deal directly with the source of stress, i.e. the problem or challenge, and to establish ways in which these can be **pre-empted, mitigated or resolved outright**.
- PFC provides ways for carers to **adapt** and reshape the care environment to optimise the care of a PWA. This not only serves to resolve current problems the carer (and PWA) face, but often also it also helps maintain some necessary level of **independence and autonomy for the PWA and I turn** reduce the workload and potential to experience stress **for carers**.
- PFC may often be employed to resolve mundane issues, but these form the fabric of daily carer life and can become cumulative '**daily hassles**' that lead to overwhelming carer stress where they are left unchecked. PFC can prevent 'daily hassles' developing from a steady trickle into more debilitating 'allostatic load' over time.
- **The voluntary sector and the peer support** associated with it can provide valuable assistance to carers with regard to expanding their knowledge, information and skills **to assist the development of PFC**. Carers who have benefited from this are highly vocal in advocating it to their peers, advising those who are newly setting out on the care journey in particular to contact the voluntary sector as soon as possible.
- Given the frequent and widespread use of **PFC** by carers evidenced in the data, particularly during the Early stage of AD, there appears to be a strong case for concluding that early successes in employing PFC may reinforce its continued use by carers as a primary approach to managing and coping with the care situation during this stage of AD.

Refined Program Theory

In terms of factors likely to be important to 'what enables the FCOPWA,' the RRR identified the CPT: '*Raising carer perception of controllability over the care situation to reinforce carers' internal locus of control, self-reliance, resilience and perceived capacity to master new domains.*' Analysis of the interview data led to the refinement of the original CPT to provide greater specificity regarding how and when causation is generated and in particular, how this supports the MRT 'resilience.' The refined PT concludes that, '**Resilience can be significantly enhanced throughout the Early Stage of AD where carers increase internal Locus of Control (ILOC) via the application of problem-focused coping (PFC) to directly mediate the source of stress by addressing the problem at its source.**'

Consistent with SR methodology the refined PT is expressed in terms of CMO configuration (see Figure 26 below).

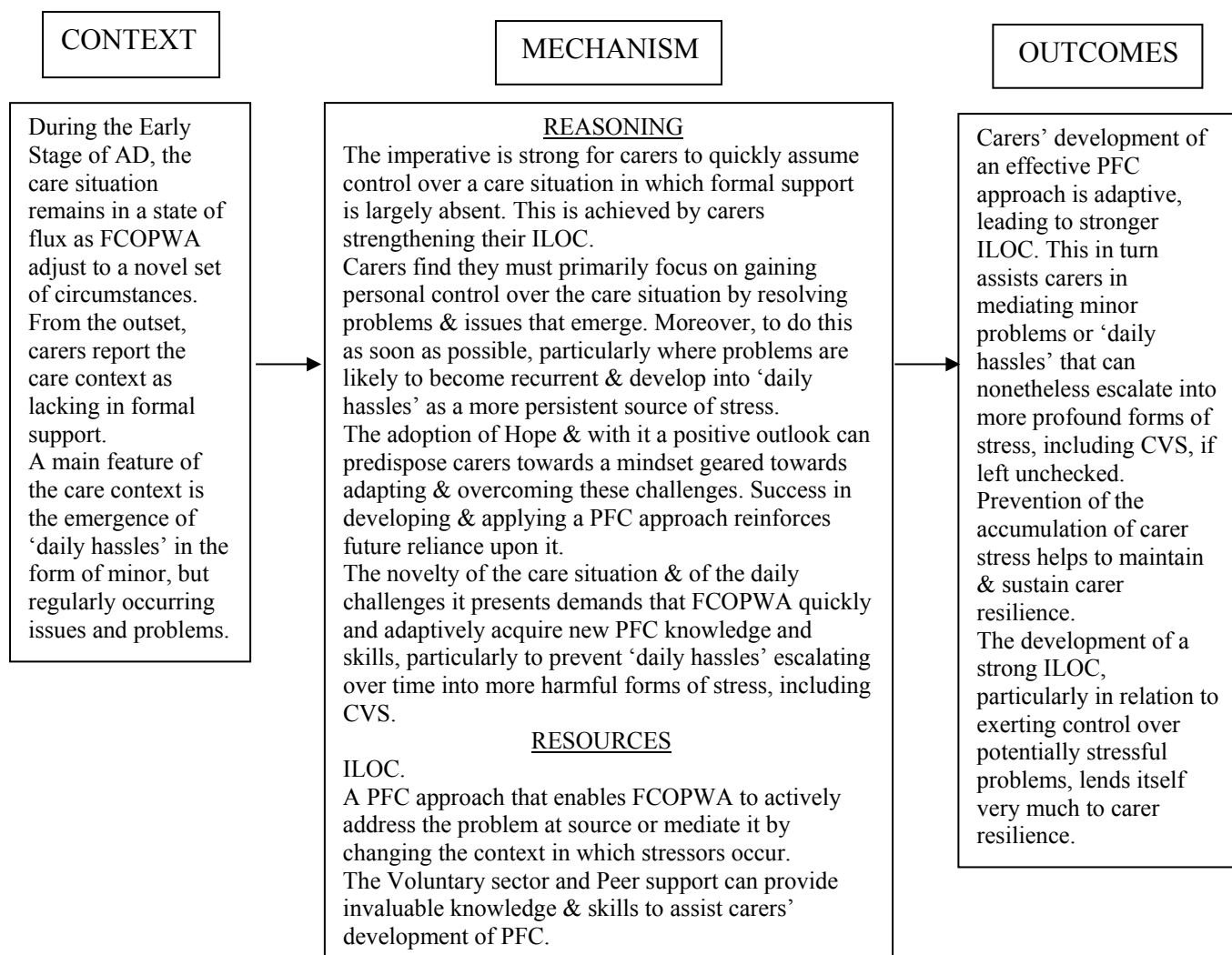


Figure 26. Refined Program Theory 2. Formulated to take account of the interview data analysis.

7.5 PART 3 PT3: Emotion-focused Coping (EFC) applied to deal with care-based challenges

What the RRR found: While Adaptation was identified in PT 1 as a potentially critical process that contributes to 'what enables the FCOPWA,' a main question concerned the means or mechanisms by which this process was brought about. Among the factors uncovered by the RRR was 'Coping ability' which was identified as one of the principal psychological processes responsible for managing stress within the care situation. However, the RRR left many questions unanswered in relation to this concept:

- The need to pinpoint which specific Coping approaches and strategies were most appropriate and effective for FCOPWA among the wide range of available;
- To establish how their effectiveness may be dependent on the context to which they are applied;
- To identify Coping approaches and strategies that may prove maladaptive and which carers should avoid.

Candidate Program Theory 3

In terms of factors likely to be important to ‘what enables the FCOPWA,’ the RRR identified the CPT: *‘The adoption of acceptance-based coping strategies has been shown to be more effective than avoidance-based coping strategies that fail to tackle daily challenges and obstacles that need to be overcome. This has also been demonstrated to alleviate anxiety and stress in the longer term.’*

Interview data

The carer interviews support the counter-factual argument that in fact FCOPWA often employ a form of ‘avoidance coping,’ particularly as they approach the Mid-stage of AD. However, how ‘avoidance coping’ is employed involves far more than simply avoiding or steering clear of potentially stressful events. ‘Avoiding facing challenges’ is how ‘avoidance coping’ strategies are generally depicted in the literature and this form of ‘avoidance’ is often perceived to be a maladaptive coping strategy that is associated with ‘running away from the problem.’ By contrast, the data reveals how ‘avoidance coping’ can represent a key component as part of a more complex and sophisticated coping process that is adaptive. P18: “She has to change the subject or go to do something else...Or she’ll go to the kitchen and put the kettle on and come back in and ask if he wants a piece of cake or a drink, just to change the subject, it doesn’t always work but it can sometimes. She has a television in her bedroom so she’ll go off and let him get out of it, rather than confront him or argue, as it only makes it worse: don’t try and solve the situation.”

P10: “You have to stop instead of arguing...It diffuses the situation, but it’s really difficult for you just to become someone who has to agree to whatever they say, no matter how silly or ridiculous it is.”

P12: “The best piece of information I’ve ever been given from another carer was: ‘get out of the room’.”

Arguably, what is taking place throughout these examples might more accurately be described as inhibitory control-‘rapid and accurate execution of a thought or action, and on occasion, stopping of

this action' (Schachar, Tannock, & Logan, 1993). In particular, carers inhibiting their instinctive and initial 'fight or flight' emotional response to potentially stressful events. A juncture often appears to be reached towards the Mid-stage of AD where AD symptoms advance from being 'mild' to being 'moderate,' and problems or challenges which emerge within the care situation may be increasingly generated by deteriorating AD symptomatology, over which FCOPWA may have limited control. A main point is that these changes to the care context can generate stressors that are less amenable to a PFC approach. Instead, there is a developing need to address the potential emotional impact deteriorating AD symptomatology can provoke in carers. Left unchecked, this emotional impact can quickly develop into stress. Moreover, a particularly debilitating type of stress-CVS-can accumulate via repeated exposure to stressors, including daily stressors that may appear relatively innocuous until they amass over time to exert a more profound impact on carers. CVS is characterised by:

- (a) chronic persistence over time;
- (b) variability and unpredictability from day-to-day;
- (c) accumulation over time via 'daily hassles' as well as by more profound stressful events;
- (d) a high level of variability which makes CVS difficult to adapt to (Herman, 2013).;
- (e) a propensity to compromise resilience to future novel stressors (Herman, 2013).

In view of the mounting challenges brought about by deteriorating dementia symptoms and carers' vulnerability to health inequalities, particularly those which are generated by stress within the care environment, it is contended here based on the interview data that FCOPWA are compelled to look to a separate coping approach to PFC. The data reveals the most likely candidate to be a form of Emotion-focused coping (EFC). Lazarus and Folkman (1984, 1987) originally developed the concept of EFC to describe how emotion regulation becomes useful where (i) the problem cannot be mediated by direct intervention (ii) the carer does not possess the requisite resources to mediate the problem as the source of stress. Instead, ways are found to better regulate distressing emotions. However, the interviews provided emergent evidence for how FCOPWA employ an adapted form of EFC. To my knowledge, this represents the first time the full process and mechanisms by which carers employ this particular form of EFC have been revealed. While some individual mechanisms associated with EFC were known about previously, how specific EFC approaches and strategies are combined to generate a more complex process of emotion control that is revealed here explores new ground and makes an original contribution to knowledge. The EFC process uncovered by the data reveals that it relies initially on the use of inhibitory control to avoid stressful conflagrations and flashpoints, particularly as carers progress towards the Mid-stage of AD where the emotional intensity of the FCOPWA can increase due to mounting challenges brought about by deteriorating symptomatology:

P13: "...because it's no good losing your temper and if things get to you-walk away and come back afterwards."

EFC appears to remain complementary to PFC as carers move towards the Mid-stage of dementia, rather than superseding PFC. While PFC involves actively intervening to change the care environment to prevent the re-emergence of stressors or directly resolving the problem more locally to eliminate potential sources of stress, EFC by contrast involves regulating one's emotional state in response to stressors. Particularly where these stressors are not amenable to a more direct problem-solving approach. Essentially, EFC provides a means for carers to mediate their perception of stressors:

P11: "She runs and hits me when I'm not looking. It doesn't make a blind bit of difference to me. I say, "you hit me as much as you want if it makes you feel better." Then she stops and goes into the kitchen and slams the door. But as you say, 5 minutes later she doesn't even know she's done it...you've not to take it personally."

An important point also is that making the transition during the FCOPWA from primarily using a PFC approach to combining PFC with an EFC approach crucially relies on the carer acknowledging that the anomalous behaviour demonstrated by the PWA represents a manifestation of the disease rather than a wholly deliberate, premeditated act. This may also help to maintain some emotional detachment from potentially stressful events that occur within the care situation, i.e. to avoid taking things personally. The evidence also suggests that learning to dissociate the PWA's behaviour from the anything deliberately premeditated or personal represents an important adaptation in its own right and potentially, a teachable moment: P10: "But I wish somebody at some point had said that-it would have been easier for me and I wouldn't have argued as much with 'X' and made things worse for him...It's different when you're emotionally attached to someone..."

P10: "I think when people are first diagnosed...if I'd been given a bit more information and help about the way a person's personality would change then you'd be more prepared for it...we've had so many arguments about so many things. If I'd realised that it wasn't him...the accusations, how they become very selfish and they seem to lose all emotion. You think that's just directed against you and it's not, it's the disease that's doing it and it took me a long time to understand I should have known...I think even basic things like that would help."

A strong emotional attachment between the carer and PWA may somewhat paradoxically make it more difficult for carers to inhibit their emotions when challenges emerge within the care situation, particularly if this represents the way disagreements were formerly resolved. Exercising inhibitory control appears to involve force of will to regulate instinctive 'fight or flight' emotional responses in

these situations: P17: “I have learnt in my mind to say, “go back!” That’s how I see what is really going on. You cannot be emotional about it, that’s number one. It’s very hard, but life is hard.”

PFC complements EFC where on the one hand such a combination enables carers to focus on the task in hand in a more pragmatic, ‘needs-must’ way while on the other carers’ strong emotions which are derived not only from the inherent challenges of caregiving but often also their strong emotional attachment to the PWA can be better regulated. This may also represent a generational phenomenon in which older members of the U.K. population have a distinct advantage over their younger counterparts in terms of their ability to inhibit emotions and resiliently move forward, despite adversity: The carer discussing how her mother cared for her father with AD: P8: “That generation had got used to loss and just getting on with it and whatever comes at you. You just have to put one foot in front of the other and just get on with things. Because they had more to contend with, they lived through the war, lost family at an early stage sometimes. And I think there is an element of that, whatever life throws at you, you put your coat on and walk towards it.”

Crucially however, the interview evidence indicates that the way in which FCOPWA employ EFC involves more than just inhibitory control, i.e. it also involves devising a means of releasing the pent-up emotions at some proximal future point. Typically, carers achieve this by:

- seeking emotional support;
- engaging in quality of life (QOL) activities that promote positive affect;
- engaging in physical activities and exercise and to offset the accumulation of allostatic load.

Importantly, unlike ‘avoidance-coping’ per se, carers’ exercise of inhibitory control allows for the **temporary suppression** of emotional response to stressors and this is followed by their later diffusion via diversionary activities which often take place away from the immediate care context. Importantly, this helps to preserve a good carer-PWA relationship and reduce the possibility of the relationship deteriorating, a factor which the RRR identified as a potent source of carer stress. Each carer finds their own preferred conduit for emotional release: P5: “I play computer games, they are fabulously therapeutic-she (spouse) goes to bed at 9 pm, so I tend to stay up...9 pm-11pm I play (video games) when I’m too tired to read.”

P6: “I actually go down to the swimming baths. I’ve started to go back to swimming and that is a terrific benefit for me because it relaxes me. I know I am stressed and I enjoy that. So that has a real impact on me mentally.”

P11: “I see you’re going to the gym?” And I said, “yes, because of the diabetes and because it just gets rid of the stress in a nice manner.”

P16 is 63 years old and has been caring for her mother for five years but who has been manifesting AD symptoms for closer to seven years. P16 became her mother's full-time carer once she recovered from a stroke. P16's brother died suddenly a year ago and her son lives in Lancashire leaving the carer on her own for much of the time. P16 finds the role of FCOPWA heavy going. Her mother has limited mobility and requires round-the-clock care. P16: "But I also relish the hour or so I get a day of just being on my own in my house and doing my own thing. Sitting quietly watching the television at a normal sound level because my mam has it turned right up. So that's what keeps me sane."

EFC becomes important in mediating the cumulative CVS that can build up over time and which might begin to exert more tangible effects on carers' health and wellbeing as they approach the Mid-stage of AD, having by this stage carried out the FCOPWA role for several years. A key point also is that the chronic, long-term presence of CVS can make incremental accretions to carers' allostatic load over time and carers may only realise the full impact once cumulative stress reaches an overload point. It is therefore vital that EFC becomes an important part of carers' adaptation, particularly as PWA advance towards the Mid-stage of AD where the types of challenges carers encounter cannot always be mediated by PFC.

While carers employ (i) initial inhibitory control to withhold their immediate 'fight or flight' response to stress and (ii) find a more appropriate outlet for this pent-up stress, the interview evidence lends support to a third and inter-related component in the EFC process which carers employ: (iii) Positive reappraisal: P12: "You've got to look more at the positive than the negative."

P15: "Top of the list! Very important...staying positive is important. For both of us, together. Be positive-stay positive."

Crucially, the inhibitory control carers initially exercise while deploying EFC permits a hiatus during which carers can further regulate their emotional response to stressors via positive reappraisal in which the original stressor is relegated in terms of its importance and carers can try to view stressful events from a more positive perspective. This can help to dissipate cognitive dissonance (negative thoughts that may persist concerning a stressful event, including moral judgement regarding which party was at fault). Positive reappraisal can be achieved relatively straightforwardly, e.g. by carers giving themselves due credit for handling a potentially challenging situation well and utilising this success as a springboard to keep moving forward: P18: "I just have to think positive. We've been there, done that. We're just going to do it again..." In addition, because appropriate outlets for carers' pent-up stress often involves engagement in pleasurable activities which promote positive affect, this is conducive to placing carers in a more positive frame of mind when they eventually stop, reflect and reappraise earlier care-based challenges. Folkman and Lazarus (1985) draw attention to the fact that

when facing new challenges there is an immediate ‘fight or flight’ appraisal during which the challenge is evaluated as either a challenge or something potentially more harmful, i.e. a threat. According to Transaction Theory (ibid) secondary appraisal of the care situation can then helpfully override primary appraisal to provide a more cogent response to stressors.

A key point also is that PT 1 which identified the more global EFC strategy ‘positive outlook’ allied to ‘Hope’ is also likely to facilitate positive reappraisal by generally predisposing carers to viewing events and situations in a more positive light.

A main contention made here based on the interview data is that FCOPWA may employ EFC to deal with such initial threats via a tripartite process that involves:

- (i) Initial inhibitory control that resists primary appraisal that might precipitate an over-reaction to care-based challenges;
- (ii) Inhibitory control provides a hiatus during which carers can find their own preferred constructive outlets for latent stress. These outlets frequently involve engagement in pleasurable activities that are conducive to carers’ more positive reappraisal of earlier care-based challenges;
- (iii) Positive reappraisal helps to moderate the impact of stress by playing down the importance of any negative aspects of the situation and instead accentuating any positives which can be drawn from it.

Moreover, the inter-relatedness between each component within this tripartite process highlights the importance of these working in conjunction in order to maximise the overall effectiveness of this form of EFC in counteracting the impact of stress.

Adaptation that involves carers learning to successfully utilise this EFC approach is likely to be self-reinforcing, i.e. developing competence in applying it ensuring future reliance on it by carers: P17: “But the release of all your emotions, and sometimes your fears, comes when I get a big win!...that keeps me on a high for a long time! The victories keep you going.”

Positive reappraisal is also frequently achieved by introducing humour when reappraising events which occur within the care situation. Importantly, such humour is not directed at the PWA but at the disease itself. Often also, the humour is shared with the PWA so that they can share in the benefits of a more light-hearted reappraisal of potentially stressful events. Humorous reactions stand in stark contrast to carers losing their temper or showing irritation or anxiety when facing care-based challenges. Humour can also assist in playing down the gravity of the situation surrounding AD, bringing the disease down to size and reducing more fearful perceptions of it. That the carer and PWA refuse to cower before the disease and moreover, are prepared to laugh at it can have the

effect of reducing its power and potency over them. Humour can sometimes be perceived as trivialising important issues. However, its importance as a means to achieve positive reappraisal as part of an EFC

approach to the FCOPWA cannot be understated: here the carer used to become stressed when going out to public places because of the PWA's weak bladder. However, positive reappraisal helped to view the situation from a more positive, light-hearted perspective. At a fundamental level, the use of humour can also facilitate wider socialisation despite emerging challenges: P12: "...but it's also hilarious because 'X' takes a water tablet, so everything is, 'where's the nearest toilet?' I mean when he's ready waiting for the mini bus to come he's in and out of there like a Yo-Yo! Oh, boy! (laughs)."

P18: "He used to laugh about it because if anything went missing he would say, "have a look in Alice's room." Everyone's shoes would disappear and they'd be in my Nana's room. Salt and pepper pots would disappear so they'd look in her own room. False teeth would disappear, she would take them out of the glasses and it would cause chaos. It was quite comical and we used to laugh about it. But it's how we cope and it can be funny..."

P12: On the PWA spontaneously singing out loud in public: "And one of the others he sings, 'give me the moonlight, give me the girls and leave the rest to me,' and I said, 'I hope you don't sing that in church!' [laughs]."

Arguably, humour and its contribution to positive reappraisal provides a further asset in terms of enabling carers to regain control of the care situation and also to demonstrate resilience: P4: "The good thing is we both have a sense of humour and if I can make her laugh, she's been near tears often and I end up making her laugh and I come away and think I can do that. And that's good. It's not negative."

That positive reappraisal represents a learned strategy is also highlighted by the data: P12: "I'll say, 'where are you going?' 'Oh, do I live here?'...'Yes,' I say, 'you've lived here for 30 years 'X.' 'you've got to put up with it...And we make a joke of it, you've got to. Otherwise he gets upset, I get upset, and it's not worth it...you just have to learn the strategies for dealing with everything and you've got to try and be one step ahead."

The increasing need for EFC coincides with a gradual transition in which carers must assume greater control over the care situation as PWA approach the Mid-stage of AD and symptoms change from being 'mild' to 'moderate.' This can denote a period during which the FCOPWA may become more intensive, involved and of longer duration. Carers can perceive the PWA to be more vulnerable and in

need of their protection with the additional emotional strain this can introduce: P13: “Well it’s like a baby-you can’t switch off when you have a baby.”

P1: “...like a little baby you can’t let them fend for themselves, they need you.”

Intensity of care can also increase in terms of FCOPWA having to exercise greater vigilance over the PWA to ensure their continued safety and wellbeing and this can be emotionally demanding: P16: “She had staggered through to the kitchen the other night to make a cup of tea and I was horrified...I’ve had to hide the tea pot, it only comes out when I’m there and I’ve had to tell her off, politely.”

Maintaining constant vigilance can be cognitively demanding and contribute to fatigue which in turn can predispose carers towards feeling tired and emotional if left unchecked: P7: “You have to be vigilant all the time. So I hold his hand so I know where he’s at. It’s like having a child actually.”

The emotional attachment of the PWA towards the carer can also become more intensified and this can be stressful for the carer: P18: “My dad shadows my mam, he’ll follow her around if she goes off into the kitchen and quite often she doesn’t realise he’s there and she gets a fright...”

Essentially, changes in AD symptomatology as PWA approach the Mid-stage of the disease generally signals an escalation in the emotional intensity and involvement of FCOPWA. In turn, this generates increasing reliance on EFC approaches and strategies to deal with care-based challenges that are not amenable to PFC. EFC can help FCOPWA to maintain control over the care situation and this in turn reinforces carer resilience in the face of a newly emergent set of challenges.

What worked, for whom, under what circumstances

- Towards the Mid-Stage of AD, the increasing frequency and magnitude of challenges brought about by deteriorating AD symptoms which are not so amenable to PFC approaches and strategies calls for a significant change in coping approach. Primary reliance on rational problem solving efforts implemented via PFC can become counterproductive, even likely to result in chronic distress when they fail. Instead, carers become increasingly reliant on regulating their emotions, particularly in response to challenges within the care situation.
- The longevity of caregiving, spanning several years as FCOPWA approach the Mid-stage of AD, can begin to exert an emotional toll on FCOPWA. Prolonged exposure to CVS can culminate in the accumulation of allostatic load over time. Carers’ regulation of emotion becomes increasingly important therefore.

- The emotional intensity can also increase within the care situation as FCOPWA as AD symptoms deteriorate, PWA face diminishing control over events and carers are compelled to assume greater control to compensate.
- EFC becomes an increasingly important means of regulating the main threat to the FCOPWA at this stage-uncontrolled stress.
- Of necessity, there is continued reliance on PFC by carers to resolve problems and challenges which emerge from the care situation that are amenable to a PFC approach, however it is contended that this becomes a process which runs in parallel with EFC.
- EFC is likely to operate by different means according to different context. In so far as it is applied by FCOPWA, EFC appears to essentially involve a tripartite process of: (i) exercising inhibitory control to prevent carers' initial and instinctive 'fight or flight' response provoking an emotional over-reaction to challenges that emerge during the FCOPWA (ii) engaging in subsequent diversions away from the PWD that facilitate the release of potentially harmful pent-up emotions (iii) positive reappraisal of the event can enable carers to perceive the event in a more positive light as a further means of emotion regulation.
- A distinction needs to be made between 'Avoidance coping' defined by carers becoming increasingly absent or distal in relation to their role as FCOPWA and 'inhibitory control' where it is employed as part of a deliberate EFC strategy to assist carers' maintenance of control over the care situation.
- It is likely that Program Theory 1 which spans the duration of care and includes the more global EFC strategy of maintaining 'Hope', including maintaining a generally positive outlook, facilitates positive reappraisal.
- EFC and PFC combine to deal effectively with both types of care-based challenges, i.e. those which are amenable to a PFC approach, as well as those that aren't and which may therefore rely more on emotion regulation. Crucially, carers' ability to adaptively maintain control over the care situation can reinforce their ILOC which in turn strengthens carer resilience.

Refined Program Theory

In terms of factors likely to be important to 'what enables the FCOPWA,' the RRR identified the CPT: *'The adoption of acceptance-based coping strategies has been shown to be more effective than avoidance-based coping strategies that fail to tackle daily challenges and obstacles that need to be overcome. This has also been demonstrated to alleviate anxiety and stress in the longer term.'*

Analysis of the interview data led to the refinement of the CPT to include further details concerning the coping approaches and strategies adopted by FCOPWA, as well as greater specificity with regard to 'how,' 'when,' and 'for whom,' these approaches and strategies might operate. Moreover, how these coping approaches and strategies become adaptive in supporting carers' maintenance of control over the care situation despite increasing emotional challenges, and how this in turn serves to strengthen carer resilience. The refined PT concludes that: ***'Towards the Mid-Stage of AD, FCOPWA come to rely on a dual approach in which problem-focused coping continues to prove instrumental to coping and dealing with solvable problems, while emotion-focused coping becomes necessary to regulate the potential stressors created by unsolvable problems which are largely driven by dementia symptoms.'***

Consistent with SR methodology, the refined PT is expressed in terms of CMO configuration (Figure 27 below).

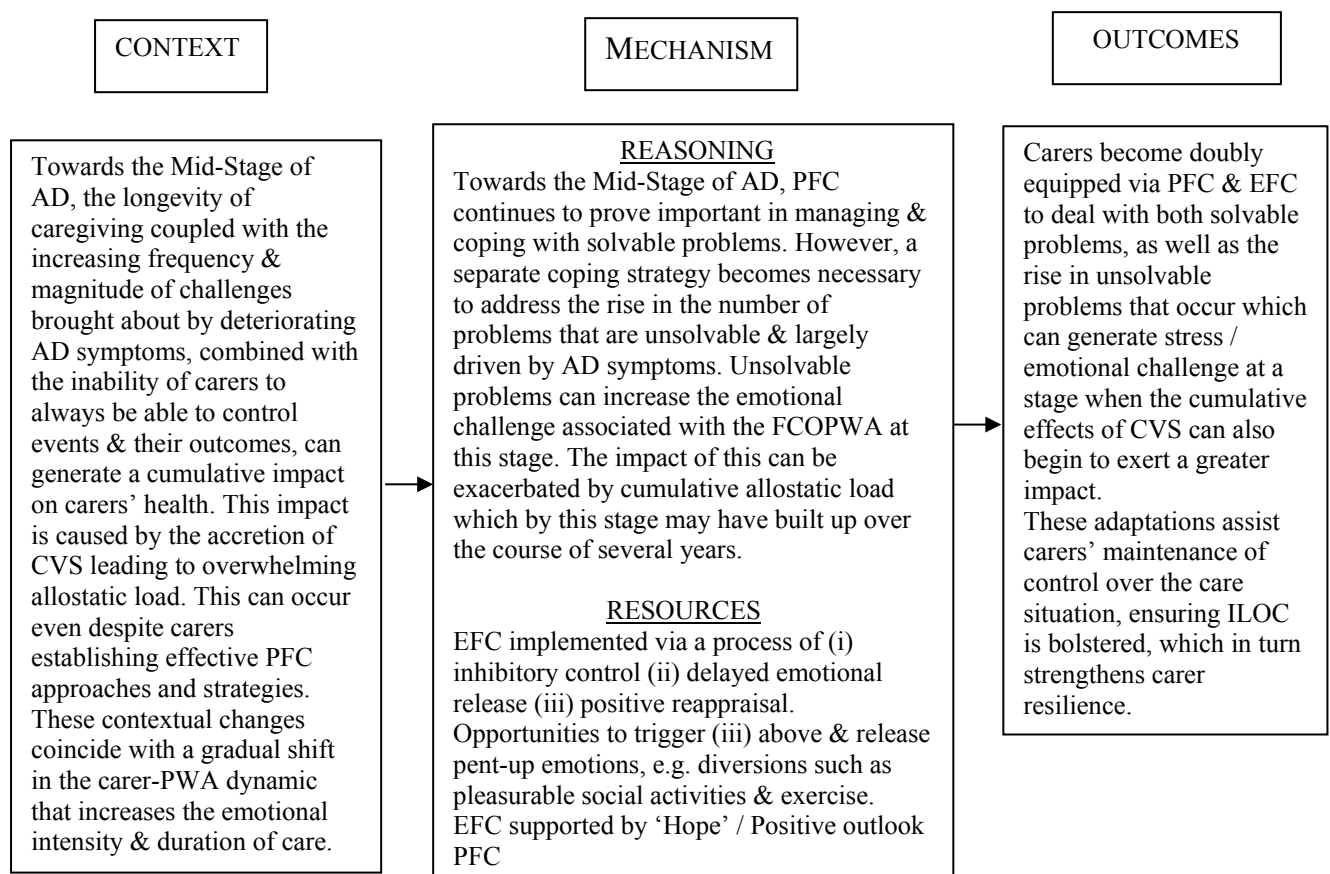


Figure 27. Refined Program Theory 3. Formulated to take account of the interview data analysis.

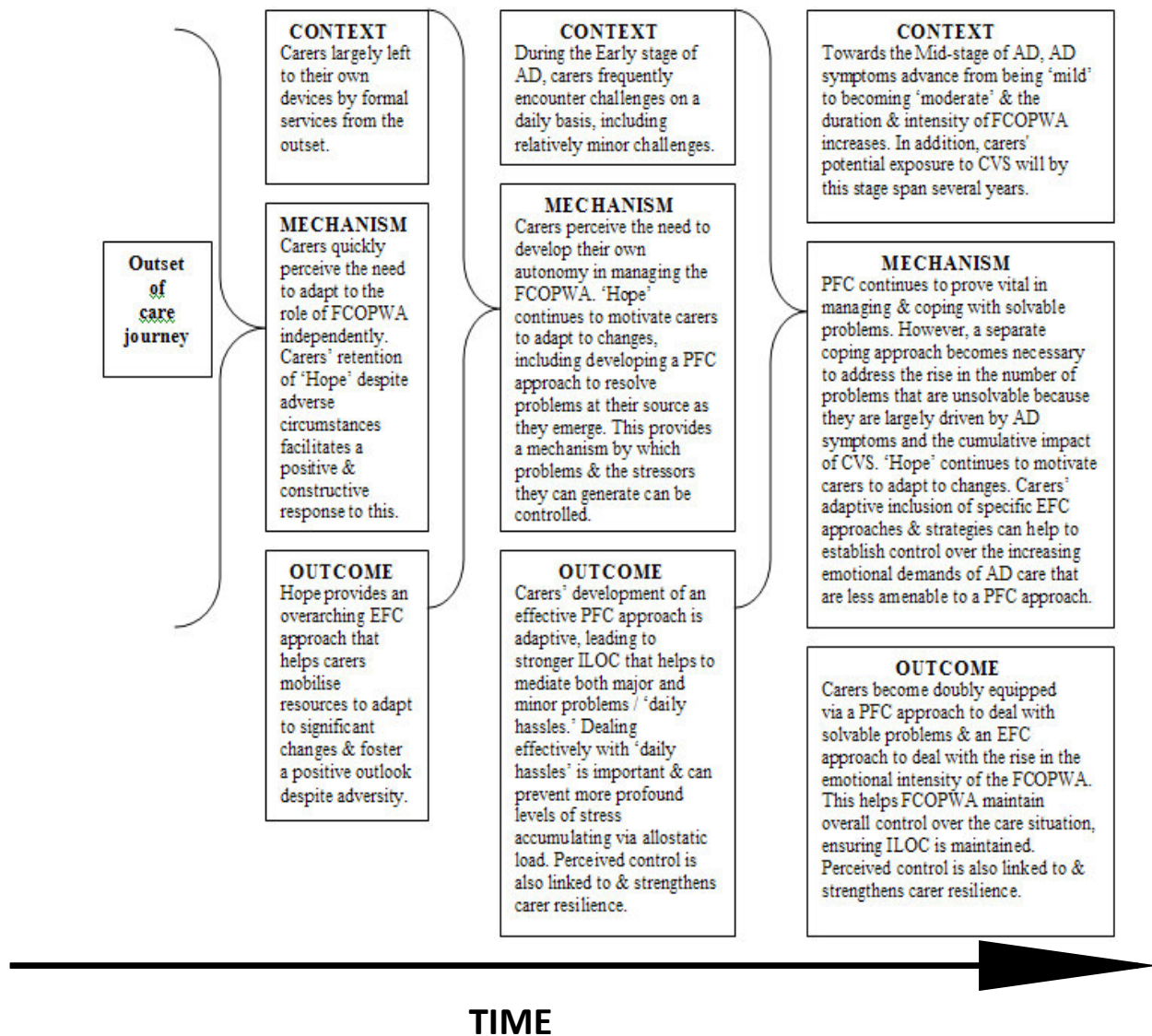


Figure 28. Carers' adaptive employment of EFC and PFC approaches and strategies to ensure resilience is maintained despite an AD care context that is in constant flux.

Figure 28 above illustrates how as PWA approach the Mid-stage of AD the challenges to the FCOPWA which can be exacerbated by deteriorating AD symptoms and prolonged exposure to CVS over the course of several years need to be addressed by adaptively switching from a main reliance on a PFC approach to the additional adoption of an EFC approach. The adoption of a dual PFC / EFC approach can promote carers' perception of maintaining control over the care situation, in turn helping to promote resilience (see Chapter 8 for further discussion).

7.6 PART 4 PT4: Caring style

While the CPTs derived from the RRR highlighted the importance of carers establishing a good carer-PWA relationship as a contributory factor that ‘enables the FCOPWA,’ the interview data shed further light on a related dimension of care, namely caring style. Currently, there is a paucity of information concerning which particular caring style lends itself to successful caregiving within the context of the FCOPWA and this represents an under-researched area. The findings detailed here provide emergent evidence for a specific caring style that appears to work well to enable the FCOPWA and how PFC and EFC approaches can complement this style.

Candidate Program Theory 4

In terms of factors likely to be important to ‘what enables the FCOPWA,’ the RRR identified the CPT: *‘Reduce potential social tensions to alleviate carer anxiety / stress by building a stronger rapport and mutual trust that supports a more harmonious atmosphere around the care situation.’* However, a main question concerned how FCOPWA might strike this balance between maintaining a good carer-PWA relationship while also managing anxiety and stress.

Interview data

The interview evidence revealed a further factor likely to facilitate (or hinder) the development of carer resilience-caring style. Evidence from the literature does not extend to the championing of any particular carer style over another. The findings from the interview data therefore add to the existing knowledge base by identifying three principal caring styles:

- (i) Pragmatic.
- (ii) Over-Responsive.
- (iii) Avoidant.

Each caring style was identified as differentially mediating two key factors:

- (a) ‘Carers’ LOC,’ operationalised here as ‘carers’ perceived level of control over decision-making, responsibility and overall control over the care situation.’ LOC here also refers to the degree of control carers exercise over the self-monitoring and safeguarding of their own health and wellbeing while caregiving;’
- (b) ‘Level of attentiveness,’ operationalised here as ‘carers’ general level of attentiveness to the various needs which may arise within the care situation’ where ‘attentive’ is defined as, ‘being watchful, observant, perceptive and caring,’ (Collins English dictionary, 2014).

As will be revealed, of these three caring styles two appeared to be maladaptive in terms of 'what enables the FCOPWA,' while a third style appeared to be far more effective and adaptive.

7.6.1 Exploring the three Caring Styles revealed by the data

1. Pragmatic caring style:

The interview data revealed how a 'Pragmatic caring style,' defined here as, 'a matter-of-fact approach that is efficient, utilitarian, objective and tough-minded' (Collins English dictionary, 2002) was frequently applied by carers to help deal with adverse, care-based events. This often involved carers employing EFC strategies to regulate their emotional responses to potentially stressful events and combining knowledge and understanding about AD with emotional intelligence to constantly remind themselves not to attribute blame for anomalous and challenging behaviour to the PWA, but to recognise this as a manifestation of the disease. Appraisal of potentially adverse events was therefore moderated by objective rationalisation of events, rather than a more emotional and subjective response that strayed towards being over-responsive or over-reacting: P13: "...because it's no good losing your temper and if things get to you-walk away and come back afterwards. You've got to have the ability to be able to communicate with them, but not in a nasty way. Some people can be abrupt which is something you can't do. Just talk to them as a normal person-sometimes they answer you, sometimes they don't. It's no good losing your rag."

A Pragmatic caring style remains respectful towards the PWA, but involves the carer maintaining overall control over the situation. An important aspect of maintaining this control includes carers pragmatically employing the tools and skills they can bring to the situation. This includes PFC strategies as demonstrated here by the removal of the source of stress as part of the attempt to resolve the problem, while also regulating emotional response to the event by employing EFC strategies: P16: "She had staggered through to the kitchen the other night to make a cup of tea and I was horrified...I've had to hide the tea pot, it only comes out when I'm there and I've had to tell her off, politely. "

A Pragmatic caring style that takes control of the situation via a combination of PFC and EFC is adaptive in enabling carers to assume increasing control over the care situation as AD symptoms deteriorate, but in a diplomatic and understanding way that need not compromise the carer-PWA relationship dynamic. EFC can allow potential flashpoints to be handled sensitively and diplomatically so that a respectful attitude towards the PWA can be maintained, while PFC is employed to resolve situations decisively: P10: "...you act, you don't react to whatever the person is saying to you."

P7: "...he's just irritable, not aggressive, it's a different thing. You can understand him being irritated, always being told what to do. It must be very frustrating for them."

A Pragmatic caring style can also be seen to be demonstrated in carers' ability to adapt to the changes brought about by AD in an accepting, 'needs must' way, even where this means changing the habits developed over a life-time: P12: "If I go upstairs to practise a little bit and he stood on the stairs on the landing and I said, "you don't have to stand there you could go downstairs." But he said, "no, I'll just stand here." It's off putting, let's put it that way. Privacy? You don't have any privacy living with somebody with Dementia."

That maintaining a Pragmatic caring style is adaptive, but also sometimes difficult to achieve due to the variability of AD symptoms is also highlighted: P4: "I always want to respect who she was and what I know she would have liked. And that's hard because if she was further down the track where she was totally oblivious, then you can step in. But now I'm trying to balance the snippets of lucidity with the loss and so it's hard, difficult."

P6: "I suppose for a lot of people they just cannot cope with it (the FCOPWA). The carers (who managed well) were as hard as nails...It was marvellous really-'rough diamonds' though." Such statements further emphasise the earlier point: that achieving a Pragmatic caring style may involve a certain degree of emotional resilience, demonstrated by carers' pragmatic ability to get the job done without letting the emotional challenge interfere with achieving this, i.e. remaining realistic rather than idealistic and accepting the reality that the FCOPWA can be challenging, but nevertheless achievable. The adoption of a Pragmatic caring style is also likely to be facilitated by carers' employment of EFC approaches, especially where this includes exercising inhibitory control to provide an emotional buffer: P7: "The only way I can manage is occasionally switch off altogether-do what I'm doing and then switch off...Not to worry about him at all."

However, there is also a requirement for carers to recognise when they have perhaps reached their limit regarding inhibitory control and need to give vent to latent tension and stress. P9 is 56 years old and has been caring for her mother for three years. P9's mother suffers from severe memory problems and her symptoms indicate her mother is in a more advanced stage of AD than the carer's aunt who has is at an earlier Stage of AD. P9 handles much of the care on her own since relatives live too far away to offer support. P9 nevertheless feels that living over the road from her mother at least allows her to put some physical distance between the caregiving role at the end of each day and this is a source of comfort: P9: "You do (need time to recharge) because I start to get agitated with my mam..." This point also shares links with an important aspect of carers' ILOC: carers' maintenance of their own health and wellbeing despite adverse circumstances. The employment of EFC approaches

and strategies are arguably critical to this. Even brief periods of carer 'time out' can allow stored-up emotions to be released in ways that can regulate stress by restoring carers' emotional balance: P11: "I've still got to be careful because I do a lot of running around...I just go upstairs in the bedroom and stay away for a bit and pull myself together, because I don't want my mam worrying."

Arguably, a Pragmatic caring style recognises the importance of achieving a release of pent-up stress via a brief period of 'time out,' even if this means setting aside any accompanying feelings of guilt. Importantly also, a pragmatic approach can also encourage carers to be proactive in maintaining control over their own health and wellbeing: P11: "I feel guilty sometimes when mam is watching TV downstairs-I'll just go on the computer upstairs. I feel guilty leaving her on her own, but if she's watching the TV it'll be alright. I thought, "you still need your own time." If I was to sit downstairs on the computer she might not sit and rest as much as she would..."

2. Over-Responsive Caring style

An Over-responsive caring style is defined here as: 'excessively careful to fulfil the needs and wants of the PWA.' While on the surface such a caring style might appear to be adaptive in terms of meeting PWA's needs, the interview evidence reveals that carers are guarded about adopting such an approach. Carers' reticence stems from their knowledge and understanding of AD, particularly that symptoms can include ever demanding levels of neediness by PWA that is generated by the disease rather than by the person. Moreover, that this can become almost impossible to satisfy: P5: "The more you do, the more they want."

Furthermore, that if a reasonable and balanced compromise is not reached between meeting PWA's needs and carers attending to their own needs, carers' health and wellbeing is likely to be jeopardised. An Over-responsive caring style risks losing control therefore, an outcome which benefits neither the carer nor the caree: P7: "Self, self, self-they are selfish. And my husband wasn't selfish...you cannot let them rule your life, you really can't!"

Carers' adoption of an Over-responsive caring style can also create a climate of high dependency in which carers needlessly take on a greater share of daily tasks and simultaneously deny PWA the opportunity to retain their own valuable independence and autonomy for as long as possible: P11: I said, "she'll love you (the carer's brother) living up here because you would run around after her. You've got to balance it out a bit so that she's still making an effort, but you're not over-doing it."

A contention also is that carers' adoption of an Over-responsive caring style can, especially in the long-term, become counter-productive by generating resentment of being a carer that is more likely

to precipitate the cessation of FCOPWA: P8: “Because you do get resentful for the person you are caring for because your life all of a sudden is altered and they are the centre and everything rotates around what their needs are.”

Moreover, the adoption of an Over-responsive caring style may undermine carer resilience by leaving no room for a balance between carers’ needs and those of the PWA. In the following example the carer recalls his reaction to spending the entire day attending to the PWA’s needs: P5: “Oh, I’ve just vanished. I’ve just realised I’ve vanished entirely-it tripped me out...I haven’t got the resilience any more, every 100% is used up!”

That such a caring style can lead to the collapse of any carer resilience and signal the end of the FCOPWA is also made clear: P6: “I suppose for some people they have to be protected from themselves, the carer thing-they can do it-but it destroys them.” This underscores the need for carers to make a judicious selection regarding the particular caring style they adopt based on advance knowledge of which are adaptive or maladaptive.

Overall, an Over-responsive caring style appears to be maladaptive. While a compassionate approach such as the Pragmatic approach might be adaptive in establishing realistic goals that permit carers scope to attend to their own health and wellbeing needs, an Over-responsive caring style risks carers becoming too passionate and idealistic. In doing so, it may encourage a level of hyper vigilance that is impossible to maintain and which in the long term is likely to precipitate carer burnout and with this the premature cessation of FCOPWA.

3. Avoidant Caring style

Avoidant caring style is defined here as: ‘being overly reliant on avoidance-coping strategies and inattentive to PWA’s needs.’ Inattentiveness can lead to neglect, indifference and ultimately, the failure to attend to the comfort or wishes of others (O.E.D., 2011). Such a style is likely to be low in terms of overall effective control over the dementia care situation. Of the three caring styles described here, ‘Avoidant caring’ arguably represents the style most likely to precipitate cessation of family care. While Avoidant caring style was not directly adopted by any of the FCOPWA who were interviewed, the interviewees nevertheless shed light on how other, formerly close family members, did adopt this style and how this had negative repercussions. The adoption by some family members of an Avoidant caring style may also help to explain why some family members may react strongly and overturn decades of family loyalty to completely distance themselves from AD: P4: (About the carer’s son): “But the one that works offshore he lives locally, but when he’s home he does very little

by way of input. It's been surprising to me that I've been left with this, I didn't expect that to be honest."

P12: "I was non-existent as far as 'X' (son) was concerned, he wanted no contact, no information whatsoever."

An obvious point is that family members who are more predisposed towards an Avoidant caring style may not make the best candidates for taking on the primary carer role. However, this has relevance where such family members represent the only candidates available, underlining the need for all prospective family carers to be given a greater say regarding the decision to become a FCOPWA: P6:

"Some people cannot cope with it and we just have to realise that: that somebody is loved but they couldn't handle that..." This represents a pertinent issue at a time when a general expectation exists among formal providers in the U.K. that the majority of family members will simply volunteer, irrespective of their personal disposition towards care or how this may impact on their style of care:

P6: In fact it was 'X's sister who said to our son who's 42, "I would look after 'X' for about a week and then he'd be in a home."

P17: "...even in the big families, I know there are only certain ones who do the caring and the others don't want to know."

Moreover, this also further highlights the need to fully respect and support those family members who do step forward to take on the FCOPWA role: P6: "Some people can, some people can't. But also there needs to be greater appreciation and support for those who can and do."

Figure 29 summarises the findings for PT4.

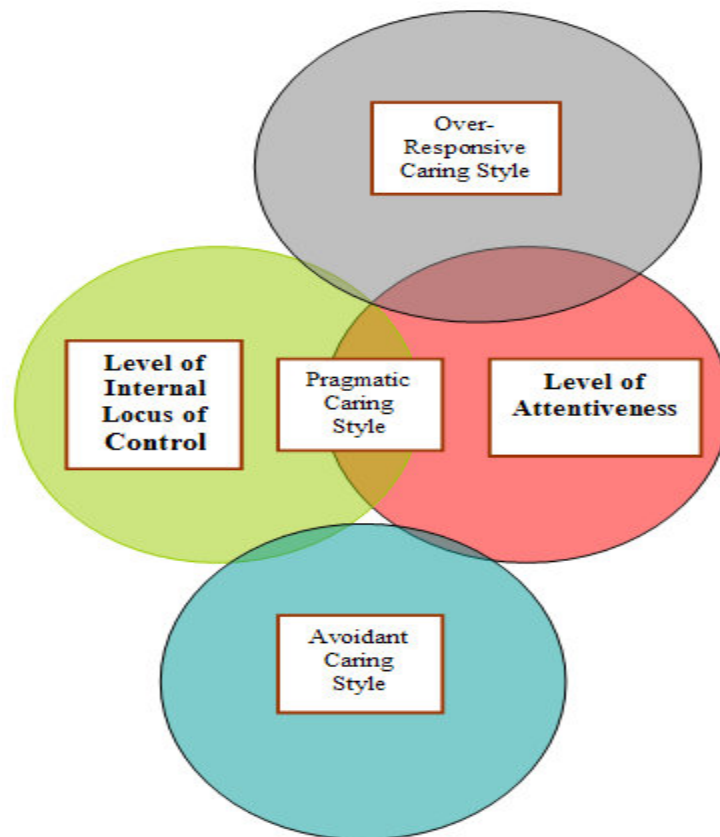


Figure 29. Three principal styles of caring that directly influence ‘what enables the FCOPWA’ (Pragmatic, Over-responsive, Avoidant) mediated by two key factors: (a) carer’s perceived LOC (b) carers’ general level of attentiveness to the various needs that may arise within the care situation.

What worked, for whom, under what circumstances

- Towards the Mid-Stage of AD, AD symptoms may deteriorate from being ‘mild’ to becoming ‘moderate’ with commensurate increases in the intensity and duration of care for FCOPWA. FCOPWA appear to rarely be given advice regarding the adoption of any optimal caring style and this represents an area which is under-researched. A further factor likely to facilitate the development of carer resilience is the adoption of an **effective caring style**.
- **A Pragmatic caring style** represents the optimal and most adaptive caring style in terms of offering the right balance between remaining **attentive to the PWA’s needs** while also maintaining a **strong ILOC** over both the care environment and carers’ health and wellbeing needs. Achieving a balance between these two key factors lends itself well to carer resilience.
- **A Pragmatic caring style** can encourage carers to be realistic rather than idealistic in terms of the goals they set themselves to more likely meet with success. It can also foster a utilitarian approach that is tough-minded and which encourages emotion regulation.

- **A Pragmatic caring style** can assist carers' maintenance of a positive relationship supported by a positive atmosphere in which the PWA continues to be shown respect and compassion and is encouraged to maintain a certain amount of autonomy and independence in terms of carrying out tasks for themselves.
- **A Pragmatic caring style** encourages carers to attribute anomalous behaviour to the disease rather than to the person and this is facilitated by an EFC approach in which negative responses to stressors are inhibited and reappraisal of potentially stressful events includes acceptance and acknowledgement of the reality of the situation, rather than remaining too idealistic and unrealistic regarding certain care outcomes.
- **A Pragmatic caring style** encourages carers to be objective about potential care-based challenges, facilitating the employment of PFC to resolve potential issues.
- **An Over-responsive caring style** may be maladaptive by representing too passionate a caring style that cannot be maintained over the long-term and which can predispose carers to burnout, loss of control and risk the premature cessation of FCOPWA.
- **Avoidant caring style** is characterised by a heavy reliance on avoidance-coping strategies, low control over the dementia care situation and inattentiveness to PWA's needs. It also underlines the need to accept that some prospective family carers may be predisposed towards this style and the need to ensure family members have a greater say in the decision whether to become a carer.

Refined Program Theory

In terms of factors likely to be important to 'what enables the FCOPWA,' the RRR identified the CPT: *'Coping ability represents an overt and learnable skill set that can be flexibly applied to different situations and allow flexible goal adjustment to help deal effectively with the inherently unpredictable nature of dementia and dementia care.'*

However, a main question concerned how FCOPWA might strike this balance between maintaining a good carer-PWA relationship while also managing anxiety and stress to maintain overall control over the FCOPWA. There is currently a paucity of research to indicate any specific caring style that may be adaptive in terms of maximising carers' control over the care situation while also striking a balance between meeting PWA's needs that also permits carers' maintenance of their own health and wellbeing needs. There is also a need for specificity regarding the mechanisms which enable such a style to be facilitated. Analysis of the interview data shed light on these questions, leading to the following refinement of the CPT: ***'Resilience can be significantly enhanced as FCOPWA approach the***

Mid-stage of AD where carers adopt an increasingly Pragmatic caring style that provides a balance between carer control and attentiveness to PWA's needs.'

Consistent with scientific realist methodology the refined PT is expressed in terms of CMO configuration (Figure 30).

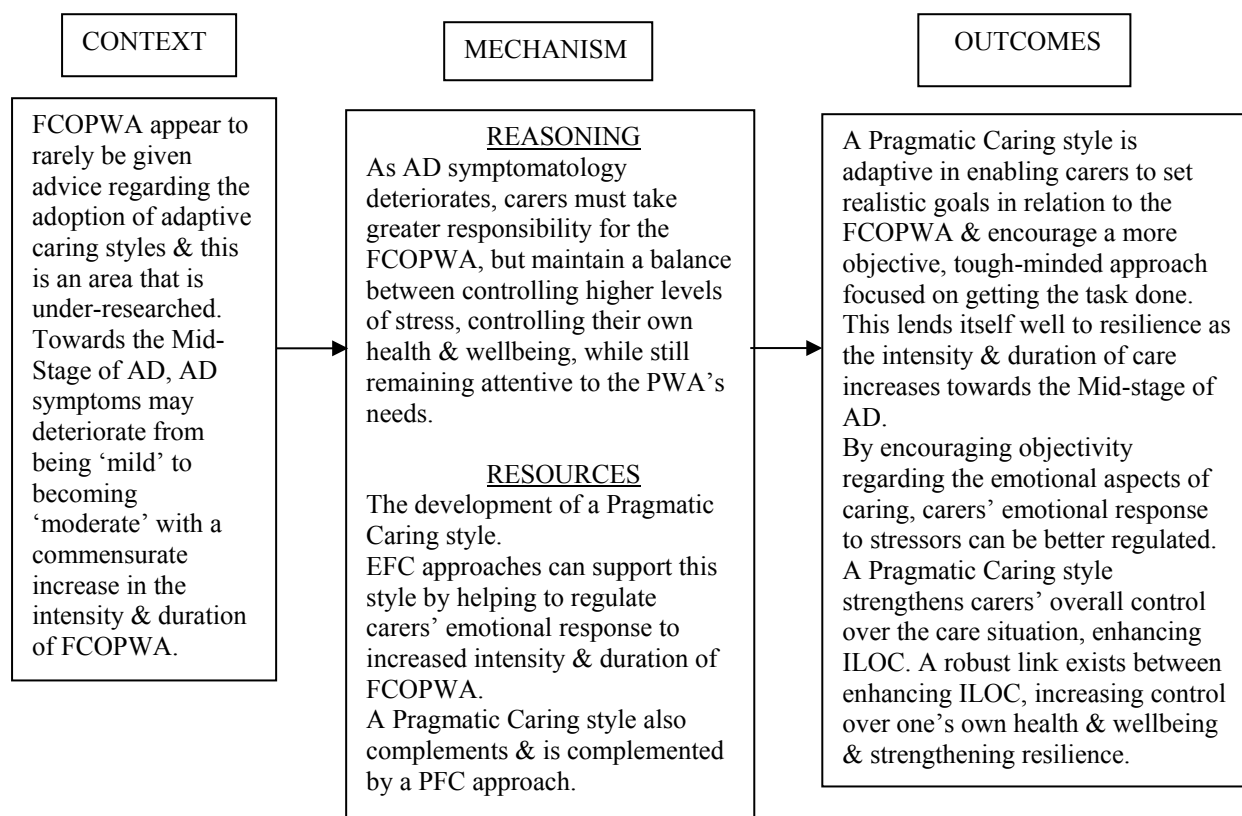


Figure 30. Refined Program Theory 4. Formulated to take account of the interview data analysis.

7.7 PART 5 PT5: Social coping and Acceptance as further adaptive EFC strategies

The RRR highlighted the finding that EFC provides a protective factor against stress via emotional support from others, acceptance and positive reframing. Together, these factors combine to mediate allostatic load.

Candidate Program Theory 5

In terms of factors likely to be important to 'what enables the FCOPWA,' the RRR identified the CPT: ***'Adaptive emotion-focused coping (EFC) (including emotional support from others, acceptance & positive reframing) provide a protective factor against carer stress.'***

Interview data

Emotional support via relational support

The interview evidence reveals that relational support that also provides emotional support can be severely lacking and that family carers of PWA cannot always rely on this: P4: “If I had more support I think it might have been different, I could have looked at doing some work. I never had children, I never had a family, it was my career and I’m missing that now.”

P17: “I know that’s going on, so that’s why dementia and Alzheimer’s are at the bottom of the heap because you depend on families to look after them. Nobody thinks they may not have a family.”

P13: “I don’t rely on them (family)...And it’s the same with my brother and that, he used to come to my house every day until this happened to ‘X’ and he’s never come back.”

Reliance on strengthening ILOC where emotional support via relational support is lacking

If carers cannot rely on relational support to meet their emotional needs, then arguably they must fall back on their own resources and strengthen ILOC instead via a high level of self-sufficiency: P10:

“...up until this point I’ve never really felt the need to do that (invite external support) and I’ve also I suppose been quite independent and wanted to sort things out myself...”

P5: “...it’s a big positive as well because it’s down to me and my wife and we make our choice and that’s it and we don’t have to second guess somebody else.”

However, other carers suggest that maintaining a high level of independence that is facilitated by strong ILOC can also be very challenging: P7: “...there’s no options so you don’t think about it and you don’t realise when it first starts. You think I can cope with this, it’ll be alright. You don’t realise how it’s going to progress and how much more you are going to have to do as the time wears on.”

Also, that carers who try to maintain such a staunchly independent position may be at risk of taking on too much in the longer-term: P18: “She just seems to cope with it, but it worries me that there will come a time that she can’t cope with it.” Indeed, a juncture often appears to be reached where the care context begins to undergo pronounced changes that are likely to threaten carers’ continued independence and maintenance of ILOC:

- The further deterioration of AD symptoms as the PWA moves from the Mid to Later stages of AD;
- Carers’ emotional involvement escalating as day-to-day management of the FCOPWA becomes more intensive and of longer duration;
- By this Stage of AD carers will have been exposed to the cumulative effects of CVS for a considerable number of years.

It is at this critical point in the AD trajectory that carers begin to reappraise the care situation, especially with regard to inviting further external support. However, there may still be considerable inertia towards change, even where such change may prove adaptive in the longer-term. The prospect of admitting the need for additional external support, particularly emotional support, may be anathema to carers who have strived hard over the course of several years to maintain a robustly independent stance towards the FCOPWA. Such a move can be perceived by carers as relinquishing ILOC and an overall admission of defeat: P16: “I think just making people like me who won’t ask for help, making it easier for them to know what’s out there. Because I would have never asked for help. ‘X’ (at Alzheimer’s Society) was shocked. I find it very difficult, it’s what I do, it’s my mam, end of. There is a lot of people out there like that.”

The voluntary sector emerges as strong influence in terms of advocating that carers actively engage in external support-seeking, especially as care-based challenges mount, to ensure the maintenance of FCOPWA in the longer-term. Organisations such as Alzheimer’s Society are well aware of the problem of FCOPWA’s reticence towards support-seeking and how such a stance can be self-defeating, especially as these challenges become more salient as PWA approach the Later stage of AD. A key issue is that carers are largely expected to become independent from the outset of the FCOPWA. Therefore, making way for any wholesale change to this arrangement after a number of years can seem more like a destabilising move than adaptive: P10: “Because sometimes it seems when you get outside bodies coming in like...they just seem to take over. You’ve got no control anymore.”

Carers must first become convinced that allowing such a change can be for the general long-term good of both the PWA and the carer: P11: Even ‘X’ (Alzheimer’s Society) pulled me up and said, “I know you’re one of these that will just get on with it, but you should let people know and get help...because otherwise you will run yourself into an early grave and there is people out there to help...there is people out there to help, you’re entitled to it so you should take it.”

Adaptive change via the adoption of a further EFC strategy: Social Coping

‘Social coping,’ defined here as, ‘seeking emotional support and seeking practical support from others,’ as a specific EFC coping strategy (Folkman & Moskowitz, 2004), represents a further strategy which can be adaptive in encouraging carers towards the uptake of external support. Particularly once PWA approach the Later stage of AD. A key point is that it is more adaptive for carers to adopt this strategy early on, rather than to delay until a crisis point has been reached: P12: “I am no longer independent, I’ve had to learn the hard way and I think a lot of carers-they try to manage on their own...Now that I’ve come to terms with that. I need support, I know that...”

Carers' adoption of Social Coping can be facilitated where formal service providers work collaboratively with carers who are treated as equals in a joint venture to enable the FCOPWA: P11: "...you always need the help of other people, so it's like a joint effort from the different sections. You have to accept the fact that people may knock on the door and get used to having other people in your home, and they're not your family, but you have to be used to it."

Formal external support can prove beneficial

Sitting Services: P6: "I would say it's an essential thing, absolutely, as I say it's allowed me to have breaks, which is good. It's obviously allowed me to keep going and swimming 3 days a week. I would recommend that...that is a terrific benefit for me, because it relaxes me. I know I am stressed and I enjoy that. So that has a real impact on me mentally."

Day Care services: P12: (The carer's G.P. said): "That's the best I've seen her for 9 years!" I said, "that's because I've got 'X' at a Day Centre for a couple of days." And he (the G.P.) says, "Yes! you can tell!" It's surprising how many people have said that to me..."I can see it's done you the power of good." Everybody says that."

Respite Care services: P10: "...it meant I could...have some time on my own and time to think really about things without having any stress or pressure. So that's been really helpful and obviously I've had a lot more sleep. I feel better at the moment."

However, formal external support revolves around three main types of support (sitting services, Day care and respite care) and carer choice seems to be mainly limited to these services. Lack of alternatives adds to carers' existing inertia towards the adoption of Social Coping: P8: "I also tried for continuing health care, my daughter had said someone in her team had recommended that and went through that process, but that was a non-starter and they kicked it out..."

Further issues likely to affect the uptake of external services and which make carers' adoption of Social Coping more problematic than might be assumed include:

Demand outstripping supply: P17: "They are opening the new Dementia Unit at the hospital, but there are only 10-12 beds and people don't realise that. They think it's some huge thing that will cure everything and it's not...How many people in this Borough have dementia in this ward, I bet you there are 5,000 or more because it is an elderly population...and I bet there are more than that."

P5: On the Befriending Services: "But they have a waiting list of hundreds and they can only offer it for 6 months now."

P9: On respite care: "I went into see one recently and she said "I can't promise you, it's if somebody dies you can have the room"...Basically they would have to die today and I'd have to want the room tomorrow."

Lack of information / signposting: P17: Yes, I found out since and I've filled out the form-there is people that could drop in, you have to pay of course...Now I've found out, but I found out after the event.

P9: I don't know enough about it, I don't know...if it's going to be bookable respite...

Lack of consistent quality of services: P5: "...but the reliability of these services? I had a Befriending Service booked for 2 hours through the Carers Support that I get now- "oh, we've changed it to Friday," "oh yes, but you haven't told me."

P13: "I had a day given to me at 'X', but I don't want to go there and all they do is just play bingo, as I had clients that were there and that's all they did."

Affordable services: P12: (On Sitting Services): "It was costing too much."

Accessibility: P9: Arranging alternative Befriending / Sitting: "CAST has said I could ring Age Concern or ring Happy at Home, and I rang one and I got fed up waiting even for them to answer the phone..."

Lack of flexibility: P12: (On Day Care): "If I want to do a morning course it's usually 10am-12pm, whereas I'm not free until 11am. In the afternoon the courses are usually 2pm-4pm, which again means that I've have to leave to come back for him."

P9: "Going into respite is just really difficult to get and I've been to a few, and yes they will take you in for respite, but you can't book ahead."

Trust can be an issue for the PWA: P2: "It's a stranger coming into his house: "what's he here for? What do they want to be here for?"

Fear of formal support representing a prelude to fuller institutionalisation: P12: " 'X' refused point blank to do respite, they had tried him initially when he was first diagnosed. I had the worst of that because he came back and he really ripped into me verbally, his language was deplorable...he refused

point blank to do respite because that was the thin edge of the wedge...he said, ' they're just sitting there waiting to die'."

P11: "(On respite Care): I've always said it's like going into a home...hopefully, it doesn't come."

P17: "(On respite care): but he wouldn't go. He wouldn't go, he would just come home...You would have to lock him up, well I couldn't do that. I don't think anybody would...So to me, it's just not on."

P2: "You know it would be leaving him with strangers, I wouldn't do it."

P18: "My Nana. In those days they called it senile dementia and she went into a care home and as my dad put it, she then went into the lock ward. She was really poorly and I think my dad was thinking he was going to end up like her. And he was panicking because he used to say, ' if I end up like her don't put me away!' "

P1: "The last resort would be getting carers and the very last resort would be getting him respite and I think that would devastate me..."

On the one hand, carers find it expedient to become self-reliant from the outset of the FCOPWA in the absence of formal support. On the other, there are many issues surrounding the choices carers have regarding the types of services that are available, including the fact that the most common services such as Day care and respite care appear to be based on a Medical model that seems to replicate the kind of institutional settings PWA and carers are often striving to avoid. While Social Coping may be adaptive in encouraging carers to seek additional formal support, particularly as the PWA approaches the Later stage of AD, their inertia towards this is perhaps understandable given the data evidence. Furthermore, having by this stage established a strong ILOC that promotes self-sufficiency, carers may be reluctant to relinquish this for what they may *perceive to be* a sudden switch towards an External LOC and reliance on others. Carers may therefore need to be encouraged to instead perceive Social coping as a positive means of 'enabling the FCOPWA' and of extending the duration of family care.

Carers' adoption of a short-term perspective and how this can hinder Social coping that

includes the take up of formal services: Carers often appear to be reticent to fully accept the longer-term prospect presented by AD and a necessary coping strategy which carers tend to develop is the avoidance of prospective thinking that veers towards dwelling on the terminal stage of the disease. This can also mean that FCOPWA become reluctant to plan too far into the future. However, a detrimental consequence of this is that it can lead to carers exercising inertia towards the kind of strategic planning required to take up formal services' support: P4: "What I've had to do is I've had to

stop looking at the picture long term and I've had to live in the moment, which is hard for me...So, I have to take it a day at a time. The old cliché, a day at a time, it's actually an hour at a time, sometimes it's a minute at a time...And respond to everything that comes up... rather than become overwhelmed."

P13: "Well I just take each day as it comes...You just don't know what's going to happen, what's around the corner."

P4: "If I did dwell I would get hopeless because it isn't really out there for us and I can't see it being there as we go forward...So it's important to stay in the moment...I can't dwell, I wouldn't dare!"

P14 is 75 years old and has been caring for her husband with AD for three years. They have been married for 54 years. P14's husband worked at sea for several years before settling down to a career working in the local ship yards, working his way up to becoming a draughtsman for Swan Hunter's. She enjoys the benefits of close support from long-standing neighbours and from nieces and nephews. She copes okay with the FCOPWA but understands there will come a time when symptomatology deteriorates and she will need to consider enlisting more support from the NHS and Social Services.

P14's husband's abrupt losses of ability and function are a constant source of worry, as well as presenting significant challenges for the carer and PWA to adapt to, e.g. although a keen photographer, P14's spouse suddenly forgot how to operate his digital camera. However, a solution was found by substituting it with a more basic 'point and shoot' model. P14 cites this as an example of carers' need to continually adapt and readjust to an ever-changing care context, but often on a much more ad hoc basis rather than more strategically. Such a perspective also avoids focusing too much on the longer-term and catastrophising about the future: P14: "You just take things from day to day. It works better than trying to plan too far ahead."

Carers further adaptation towards the EFC strategy 'Acceptance'

The data reveals how carers' acceptance of AD and the full import of the terminal stage of the disease is necessarily avoided for as long as possible as part of a deliberate EFC strategy. However, that once the Palliative stage of AD draws closer, carers adapt to this significant change to the care context by embracing the further EFC strategy of 'Acceptance coping,' defined here as: 'accepting that a difficult situation is real and must be addressed' (Carver, Scheier & Weintraub, 1989). Importantly, once this state of acceptance has finally been embraced towards the end of the AD trajectory, carers can experience an existential moment in which they more fully come to terms with the disease and

become reconciled with it: P3: “Think positively, just try and accept life, what’s happening to him. Yes, just accepting it. My life has changed so much, yes.”

P12: “I know that ‘X’ isn’t going to get better unless there’s a miracle, and I don’t think it will happen. Because I’m learning an awful lot about my Christianity through this, an awful lot, and I know that if ‘X’ gets to the end of his road, he’s got a superb eternity. So that when that happens, if it happens before me, I’m not sad.”

What worked, for whom, under what circumstances

- A juncture is reached once FCOPWA approach the Later stage of AD (severe symptoms) where the care **context** begins to undergo pronounced **changes** that generate additional challenges and the stressors which are less amenable to resolution via PFC, but can instead be moderated via the **adaptive development of further EFC approaches and strategies**. Important among these is the EFC strategy ‘**Social coping**.’
- ‘**Social coping**’ promotes **support-seeking behaviour** that can include seeking additional formal support. Such a strategy is actively advocated to carers by the voluntary sector, as well as by more experienced peers, particularly for the emotional support and relief from isolation it can provide by facilitating carer (and PWA) socialisation. Social coping can be especially important where carers have strictly limited relational support; a factor which the data reveals may be more common than might be presupposed. Carers who successfully negotiate access to quality formal support report its effectiveness in reducing stress. However, these carers represent the minority and this study found that **a significant hindrance to accepting external support is carers’ perception of formal support as a threat to their hard won independence and ILOC** that was initially driven by the notable absence of formal support at the outset of the FCOPWA.
- **Further hindrances to carers’ adaptation towards Social coping** include: (i) the current bias towards support that more closely resembles the medicalised support normally associated with more formal, institutional settings and which are **mainly based around the Medical model**, e.g. Day care and respite care. Such support can be perceived to represent precursors to full institutionalisation of the PWA, a scenario which PWA and carers are generally keen to avoid (ii) a lack of alternative types of carer support, e.g. 1:1 counselling that provides direct emotional support (iii) lack of service availability, quality, accessibility, flexibility, affordability, suitability, information or signposting. In addition, issues of trust in formal providers. These factors combine to limit the scope and potential of Social coping which could otherwise provide carers with an important means of dealing with stressors, particularly as PWA approach the Later stage of AD.

- An added hindrance to the adoption of Social Coping is **carers' general predisposition towards taking each day at a time**. While such a short-term perspective helps carers to avoid catastrophising about future events, **crucially it can also curtail more strategic, forward-planning that may limit Social Coping and thereby restrict carers' uptake of formal services designed to alleviate carer stress**.
- Arguably, overcoming the many hindrances to carers' adoption of Social Coping calls for formal service providers to take on **a more proactive approach**. One that more directly promotes a more 'enabling environment' in which the uptake of services is regarded as an important component of long-term FCOPWA.
- **Acceptance** represents a further EFC strategy that is more fully embraced once FCOPWA approach the end of the AD trajectory and the Palliative stage of AD. Acceptance is adaptive in bringing with it a sense of **equanimity** that can also be **positive**.
- The differential demands made by a care context that is in flux calls for the adaptive development of a range of approaches and strategies by carers across the AD trajectory with some proving more adaptive than others. Where carers' responses remain adaptive this **can assist carers' maintenance of control over stressors to thereby strengthen carers' ILOC and by association-carer resilience**.

Refined Program Theory

In terms of factors likely to be important to 'what enables the FCOPWA,' the RRR identified the CPT: ***'Adaptive emotion-focused coping (including emotional support from others, acceptance & positive reframing) provide a protective factor against carer stress.'*** Analysis of the interview data led to the refinement of the CPT to provide greater specificity regarding how and when causation is generated and in particular, how this supports the MRT 'carer resilience.' The refined PT concludes that: ***'As FCOPWA approach the Later stage of AD, resilience is maintained by adapting to fresh challenges via the EFC strategy 'Social Coping' which encourages support-seeking behaviour, while 'Acceptance' facilitates coping during the Palliative stage of AD.'***

Consistent with SR methodology, the refined PT is expressed in terms of CMO configuration (See Figure 31 below).

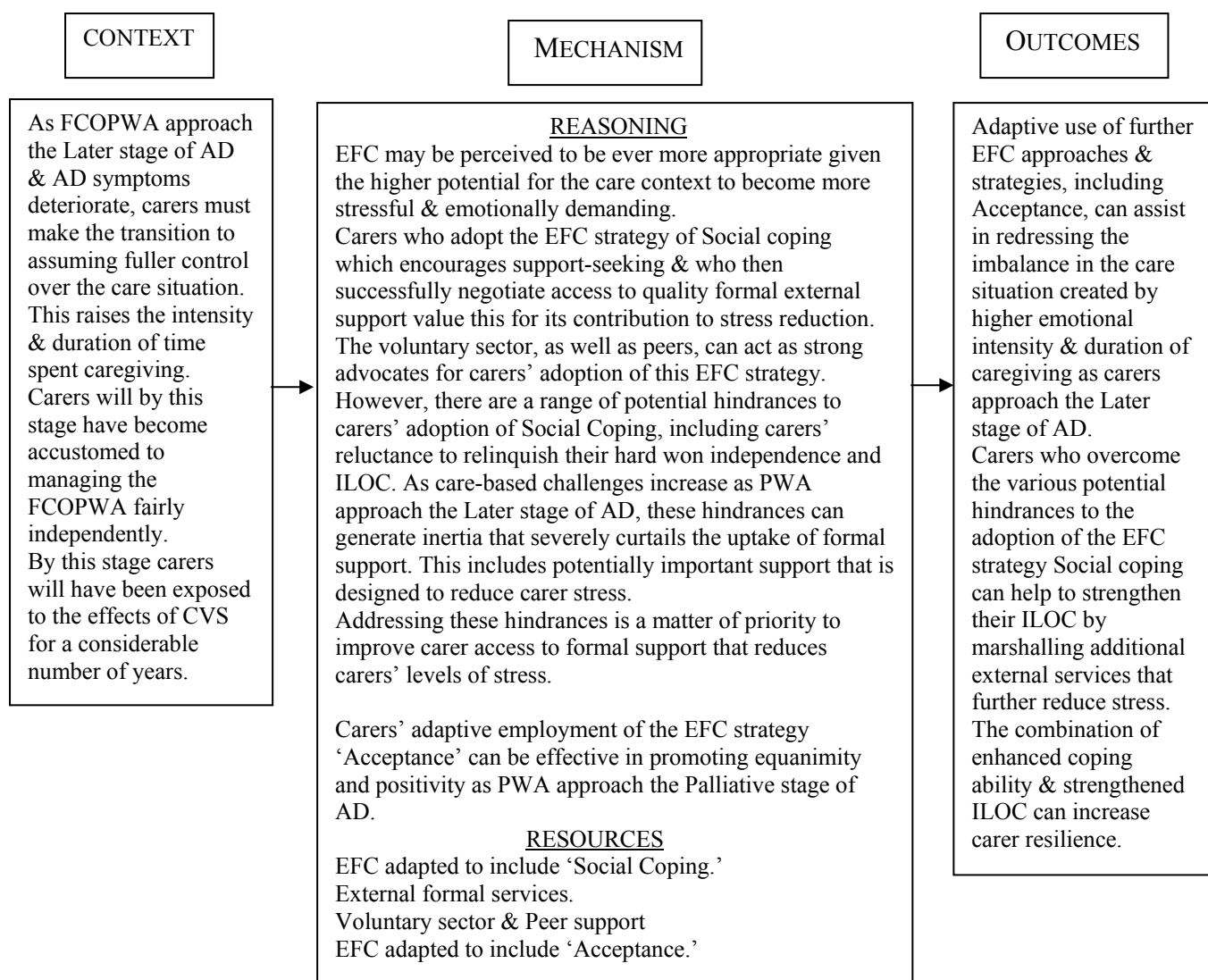


Figure 31. Refined Program Theory 5. Formulated to take account of the interview data analysis.

7.8 Summary

This Chapter presented the key findings from the interviews conducted with FCOPWA, which investigated the CPTs drawn up following the RRR. Analysis of the data revealed five salient PTs underpinned by carer resilience which combine to create an adaptive pathway by which family carers can build and maintain resilience across a dynamic and fluid AD trajectory. The next Chapter will discuss the PTs in further depth, including how current research lends them support and how the PTs can be integrated to provide a holistic approach to carer resilience.

CHAPTER 8: DISCUSSION

8.1 Introduction

This Chapter commences with a discussion of the potential of resilience to strengthen adult health and wellbeing and the need to understand this concept more fully in order to capitalise on its hidden potential, including within the context of the family care of people living with Alzheimer's disease (FCOPWA). The Chapter then moves towards a discussion of the rationale for selecting The Transactional (interaction) Model (Lazarus & Folkman, 1984, 1987) as the basic framework for 'what enables the family care of people living with Alzheimer's disease (FCOPWA).'

The Program Theories (PTs) introduced in the Findings Chapter are then explored in further depth, before being iteratively refined following critical evaluation that includes consideration of how the wider literature informs them. A clearly defined adaptive pathway spanning the full Alzheimer's disease (AD) trajectory will be forwarded based on this study's account of 'what enables the FCOPWA.' This includes guidelines for how specific approaches, strategies, personal assets and external resources can be combined to strengthen carer resilience throughout the duration of family care. Further light is also shed on how the three principal demi-regularities which emerged from this study converge to provide a pivotal causal role in making the pathway work.

The Chapter concludes by discussing the wider translational potential of this study's findings, particularly the opportunity to exploit the wider potential of resilience within the wider sphere of adult public health and wellbeing. Additionally, how the overall findings, particularly the potency of the three principal demi-regularities which emerged-salutogenesis, coping and resilience-might contribute to discussions regarding how the family care of people with similarly long-term, life-limiting conditions might be more optimally placed within a separate health and social care paradigm and system.

8.2 Recognising the potential of resilience in adult health

A contention of this study is that within the context of the FCOPWA, as well as within the context of adult health and wellbeing more globally, there is a need to move beyond perceptions of resilience that limit its scope and potential. In particular, to move away from the reductionist view of resilience which perceives it to be a generic, trait-like quality that is fundamentally dependent on certain heritable characteristics which are largely fixed in adulthood, predetermined and beyond our control. While some researchers continue to maintain the view that resilience exists as a relatively stable and fixed trait in adulthood (Luthar & Brown, 2007; Kirkwood, Bond & May et al; 2010), there is now a

growing body of evidence which counters that resilience is not strictly limited by personality characteristics, but rather it represents a process (Condly, 2006; Fergus & Zimmerman, 2005; Delfabbro & Harvey, 2004; Tusaie & Dyer, 2004; Ungar, 2003; Glantz & Sloboda, 1999). This represents much more than a purely academic debate since the reductionist view of resilience as a trait has presented a significant impediment to its wider translatable potential in terms of bolstering adult health and wellbeing in practice. Until recently, most adult resilience research has focused on individual traits (Bonnano et al; 2007) and this has severely limited the wider application of such research to the context of adult health. Viewed as a process, resilience at once becomes freed from the constraints imposed by an alleged dependency on providence to provide the right combination of heritable traits. Historically, such a reductionist marginalisation of resilience erroneously and misleadingly renders a potentially universal capacity perhaps as rare perhaps as extroversion. This undermines its more widespread potential to promote adult health and wellbeing. However, this reductionist view of resilience is gradually giving way to an alternative view in which resilience is recognised as a multi-faceted construct. Moreover, one which can be mediated in adulthood not only by personal assets, but importantly also the availability of key external resources (Schoon, 2006). A critical point here concerns the myriad possibilities which are opened up once it is realised that adult resilience and its operation is contingent on personal and external factors and that these can be enhanced and augmented respectively to strengthen an individual's resilience.

With specific reference to family carers, this can include formal support that may prove instrumental in providing contexts which are conducive to tipping the balance in favour of enabling carer resilience. This denotes a radical departure from the reductionist view of resilience as being based on personality traits, and largely the responsibility of the individual, who is deemed to be blameworthy for demonstrating any lack of resilience. As opposed to individuals being at least partially dependent on the contexts and resources generated by those in government and authority to ensure the conditions are right to support carer resilience in the first place.

A related point which was also raised in Chapter 5 concerns the need for a more tempered interpretation of carer resilience in which it is emphasised that 'carers do not flourish or become super functioning' (Donnellan et al; 2015, p.5) that restricts resilience to being the exclusive preserve of an elite few. Rather, resilience is becoming increasingly recognised as a pluralistic ability that is potentially available to all adults. Moreover, that resilience exists as a developmental process that is not fixed or immutable (Gartland, Bond & Olsson et al; 2011; Mullin & Arce, 2008), but can be adapted and modified to deal specifically with certain life challenges across the life span. Increasing appreciation of this emergent reinterpretation of resilience denotes a critical breakthrough in adult resilience research. The debunking of the myth that achieving resilience somehow requires superhuman effort

on a Herculean scale (Masten, 2001; Dowrick, Kokanowic & Hegarty et al; 2008) or represents the fixed product of childhood development is gradually being replaced by the radically different view that resilience should reflect the maintenance of normal development or functioning (e.g. mental or physical health),’ (Windle & Bennett (In Ungar (ed), 2012, p.219). Such a view has also helped to move adult resilience research and its application beyond its previously narrow and reductionist entrenchment in clinical settings and centred on loss and traumatic events (Bannono, 2008). This is not to deny the importance of such research, but rather to recognise the need to appreciate the wider potential of resilience research beyond strictly pathological contexts. To this end, this study contends that resilience has an important role and function to play in adult health that extends its utility far beyond the narrower boundaries set by research that focuses only on how adults can ensure their survival in hostile conditions or promote their longevity in life-threatening situations. Crucially, this expands the potential reach of resilience research to include non-patients, including carers. This acknowledges the capacity for all adults to adapt and move forward despite adversity, harnessing a relatively unique human capability (Lecomte, 2004), but one that is universally available to all humans. Moreover, a capability which can be applied not only in extraordinary circumstances, but also more mundane contexts: a message we all need to be reminded of frequently.

Importantly, the view of resilience as process lends itself to intervention since its modifiability at once becomes recognised. To this end, Donnellan et al. (2015) focused not only on what facilitates resilience but also on what hinders it. This recognises that resilience and its effectiveness can be enhanced by the removal of hindrances that may inhibit it and the promotion of facilitating factors, including those which are external, to provide more conducive contexts for resilience to operate. This study likewise endorses the view that resilience is very much context-specific and moreover, that contexts can be manipulated to foster more conducive environments in which carers’ resilience can be facilitated and strengthened. Scientific realism (SR) similarly stresses the pivotal role of context and how this is shaped in determining outcomes: ‘the operation of mechanisms is always contingent on...conductive settings,’ (Pawson & Tilley, 1997, p.216).

This introduces a further key point: that carers should not simply be expected to develop resilience independently of structure. Rather, there remains a need, especially in contexts where salient health inequalities exist among certain population groups, to ensure environments are more deliberately shaped to facilitate carer resilience. SR similarly provides a constant reminder that ‘outcomes’, such as those associated with caregiving, are contingent not only on individual agency, but also on the wider context in which this is set, including the individual assets available at a given time, the availability of key external resources and the current status of the care context, e.g. the stage of AD the caregiving takes place in. This interpretation of resilience is also reflected in the operational definition of

resilience employed by this study: 'Resilience bolstered by assets and resources (Fergus & Zimmerman, 2005) that combine to provide a cumulative buffer against adversity (Schoon, 2006), as well as by supportive behavioural choices and actions.'

A further limitation of the outmoded reductionist view of resilience (Windle & Bennett, 2011) is the maintenance of the view that resilience represents a 'trait' or 'characteristic' that is only observable externally and only capable of being assessed by quantitative measures and numerical scales. Arguably, this ignores the complexity of resilience and how multiple factors can influence how it is manifest in individuals (Aburn et al; 2016). Furthermore, research which focuses mainly on outcome measures, as is evident in many quantitative studies, arguably remain mainly descriptive rather than explanatory, i.e. they focus on net 'outcomes' in which the causal account of how such outcomes were generated becomes opaque. SR, by contrast, seeks to explicate the processes by which certain outcomes emerge and this remains consistent with the view of resilience as 'process.' An additional issue for quantitative measures of 'resilience' is that these have traditionally been based on scales that assess the absence or presence of mental illness or symptoms of a depressive illness (Gwadz et al. 2006; Murphy & Marelich, 2008, Bennett, 2010). Arguably, this has led to the framing of resilience within a pathological paradigm that overemphasises the negative connotations that might be associated with the construct, rather than its constructive potential in adult health. Aburn et al. (2016) contended that this is a flawed perspective which also falls well short of capturing the complexity of this construct. Moreover, that such a biomedical perspective set within positivist frameworks has severely limited much of the resilience research carried out to date (ibid), narrowing its scope and reach to adults in highly medicalised contexts such as those facing trauma or limiting its potential to the field of developmental psychology (Windle, 2010). Such a reductionist view has arguably created an unnatural barrier which has previously limited the investigation of how resilience can be harnessed and utilised to promote adult health and wellbeing in everyday contexts.

All this is not to deny the potential contribution to resilience certain personality factors can make, e.g. personal attributes such as 'hardiness' have frequently been associated with resilience (Bartone & Hystad, 2010; Bonanno, 2004). Rather, the key argument here concerns the serious deficiencies of adopting the more sweeping reductionist stance which seeks to narrow the definition of resilience to a personality trait and nothing more.

Meanwhile, Windle (2010) warns against confusing resilience with 'ego-resilience' (Block & Kremen, 1996) which represents a separate concept that is more closely aligned with personality theory, is relatively fixed in adulthood and which it is deemed to operate in any given contexts or circumstances. By contrast, a defining feature of resilience as a process is that its true function and utility is demonstrated by its ability to deal with a specific context, i.e. one in which stressors are

derived from adverse circumstances. By definition, resilience is not deemed essential to any given contexts or circumstances, but rather it comes into its own and can only be truly gauged by its performance in the presence of adversity. Furthermore, while 'ego-resilience' may be fixed in adulthood, as a process resilience continues to develop throughout adulthood (Windle, 2010) and moreover, can be supported by appropriate external support measures that facilitate its operation, as well as enhanced via the acquisition of skills, strategies, knowledge and experience.

Some accounts of adult resilience have associated it with the concept of 'successful ageing' which emerged from the field of positive psychology (Seligman, 1999). This champions the ability of older adults to exploit their capacity for resilience. However, 'successful ageing' has gained controversy for its bias towards expecting individuals to generate resilience without external support (Stirling, 2016). This study remains sceptical of positive psychology's imputation that no health inequalities exist between the different and varying contexts and circumstances in older adults (who also constitute the majority of FCOPWA) find themselves in and likewise contest the view that external structures are not critical to building and maintaining adult resilience. This study therefore heeds Stirling's (2016, p.22) warning against the utilisation of positive psychology and models associated with it, e.g. PERMA (Seligman, 2011), to investigate resilience.

Research that is based around resilience in older adults also includes the 'strength-based approach' to later life (Zaider & Kissane, 2007). This emphasises the capacity for resilience in older age, acknowledging the positive relationship between resilience and good mental health. Importantly, the 'strength-based approach' shares common ground with how resilience is operationalised in the present study: both perceive resilience-building as contingent on both personal strengths and key external resources (Vehora, 2011). While the 'strength-based approach' remains of importance, its focus nevertheless rests on how 'family resilience' can be achieved. However, as discussed in the previous Chapter, many of the carers who were interviewed revealed how family support was often absent or limited. This underlines the need to develop alternative models and approaches based on harnessing adult resilience which are not crucially dependent on relational support.

Similar arguments can be raised regarding the concept of 'social resilience' or 'ecological resilience' -the collective ability of groups or communities to unite to counteract adverse circumstances (Adger, 2000). That while models and approaches to building adult resilience have recently come to the fore as a means to promote community capital and associations might be drawn between such models and the creation of 'dementia-friendly' communities, there is an assumption all adults have equal access to and ability to gain from social capital. However, the saliency of the health inequalities FCOPWA face and the uniqueness of AD care mean there is a higher likelihood that such carers may lack the necessary social capital needed to carry out such a role. 'Social resilience' therefore detracts from this

study's primary focus on how *all* family carers, including those whose own context and situation may not be so supportive, can build resilience.

Furthermore, there is arguably a need which is foremost to gain a deeper understanding of how resilience operates at the level of the individual before it can be fully understood as a multi-level construct as the 'strength-based approach' and 'social resilience' or 'ecological resilience' models and approaches seek to do.

In addition, there is a need to move beyond models and approaches which are primarily focused on how adult resilience can be strengthened within medical-based contexts. While this study wholeheartedly supports initiatives which seek to extend resilience research beyond its previously narrow basis in paediatric research, there is a need to go further still to ensure resilience research includes the investigation of how it can be reinforced in adults based in non-clinical contexts. A key breakthrough has been the recent incorporation of resilience research in emerging theoretical and practice models of adult care (Michelson, Davenport & Dretzke et al; 2013). However, there is also a need to move research beyond such medical-based paradigms to investigate its wider potential in non-clinical settings and contexts, including those that might include family carers. Again, these arguments return to the need to avoid limiting the scope of adult resilience by over-pathologising it or perceiving it from a largely reductionist perspective. The global views we attach to concepts such as 'burden' and 'resilience' are likely to impact on how FCOPWD perceive them (Aburn, Gott & Hoare, 2016). Therefore how resilience is framed is likely to influence whether 'burden' or its opposite-'resilience'-is embraced and which will most determine the outcome of the FCOPWA. Arguably, there is a need to move beyond the Medical model and the portrayal of 'care as burden' to investigate the wider potential of resilience as a preventative measure that safeguards the health and wellbeing of a broader range of the population, including carers, assisting them to maintain a healthier, pre-clinical state.

A further limitation that needs to be overcome concerns how research can move beyond the traditional narrowing of resilience research to a singular perspective that risks reducing this multi-faceted construct to a single dimension. For example, the tendency to compartmentalise resilience into narrow categories which contain their own inherent biases: 'social resilience,' 'cognitive resilience,' 'psychological resilience,' 'biological resilience,' etc. Responding to this need, researchers such as Schoon (2006) have made a strong case for stating these perspectives could be combined to offer a more holistic and inclusive perspective that takes into account a more complete range of influential factors. A significant challenge however and one which this study had to somehow overcome was how to identify the multiple factors of key importance to resilience, while simultaneously avoiding producing nebulous and unwieldy accounts. Assertions such as Allen et al.'s (2011), that resilience encompasses psychological, physiological, emotional, spiritual, social and

environmental dimensions, while no doubt correct, may ultimately only succeed in adding further confusing layers of complexity that present a barrier to its wider exploitation as a potential asset to adult health and wellbeing. The challenge was how to address the complexity of resilience, but still achieve a level of specificity regarding what, how, when and for whom it works that also facilitates its translation from theory into actual practice and at the same time, increases its translational potential. Arguably, what has previously been lacking is the application of a methodology that is simultaneously capable of addressing and also unravelling resilience's complexity.

The solution was duly found in the selection of SR as the methodological approach adopted by this study. Nonetheless, this still left some formidable challenges to be overcome. Firstly, the sheer variety of contexts and range of experiences in which humans encounter adversity and strive to overcome it makes the study of resilience implicitly challenging. Secondly, addressing the complexity of resilience as a construct by adopting the robust approach to its investigation afforded by SR presented its own challenges. Not least how to rigorously investigate a broad range of factors operating in a variety of different contexts (Windle, 2010), while also establishing their ecological validity via comprehensive empirical testing of hypotheses, all within a strict time frame. In response to these challenges the RRR went beyond the existing research based on Windle and Bennett's (2011) framework (e.g. Donnellan et al; 2015) to uncover a more comprehensive range of factors hypothesised to be critical to carer resilience, both facilitative and potentially a hindrance to 'what enables the FCOPWD.' As outlined in Chapter 5, this led to the identification of specific Themes and their sub-Themes which were hypothesised to enable carer resilience and the subsequent formulation of CPTs which were equally well specified. It also culminated in the development of a new conceptual framework to capture all the core elements uncovered by the RRR, particularly the many factors not explicitly included in Windle and Bennett's (2011) original conceptual framework or the subsequent revisions to it (e.g. Donnellan et al; 2015). This study therefore asserts that there are multiple extant factors which can also mediate resilience.

However, models exist as frameworks that simplify how resilience operates in real life and as a more useful and practicable basis for testing hypotheses. They do not provide an exact mirror image of reality. It was therefore essential that the RRR's findings be subjected to rigorous empirical testing in real world circumstances to more clearly establish and specify 'what enables the FCOPWA, 'how' 'for whom,' 'when' and 'in what circumstances.' Essentially, rendering resilience utilisable by identifying which specific assets and resources may be most critical at specific junctures during the FCOPWA. In the process, uncovering resilience as a very real phenomenon as opposed to an artefact of studies or a hypothetical construct with little basis in reality. Moreover, one which is capable of transcending the limitations imposed by narrow and strictly limited reductionist conceptualisations of resilience at one

extreme and the nebulous and unwieldy interpretations of it at the other which jointly threaten to limit its real world application to support adult health and wellbeing. Resilience is manifest in all individuals (Windle, 2010). However, as Watson appositely stated: 'The belief that it is impossible to promote resilience is as much a myth as to believe that all resilience is just a matter of pulling ourselves together,' (Watson, 2007, p.36). While this statement acknowledges the wider translational potential of resilience research, it also alludes to the need to pinpoint the precise mechanisms and their contexts that facilitate resilience which this study set out to achieve and to crucially pave the way for a more interventionist approach that takes full advantage of the ability to manipulate and mediate how it is manifest in adults across the full course of the life span. This study represents an attempt to achieve this, the outcomes of which are discussed in Section 8, following the presentation and discussion of the revised PTs further on in this Chapter.

8.2.1 Resilience strengthened via external support

Resilience is becoming increasingly recognised as a process in which environmental and individual factors interact (Fontes & Neri, 2015; Hildon et al; 2010, 2008; Dorfman et al; 2009). However, the previous Chapter revealed how carers are largely left to fend for themselves for the majority of the care journey. This led to an emphasis in this study on how individual carers develop and employ their own particular approaches and strategies to adaptively meet the variable demands of a changing AD care context. However, it is important that 'resilience' is not defined and presented as an attempt to recommend some form of 'people fixing' (Barnes, 2013). While the importance of carers adaptively developing new knowledge, skills and abilities cannot be underestimated, this should not detract from the fact that FCOPWA face significant health inequalities compared to non-carers (Hirst, 2005), and indeed in comparison to other carers (Murray, Kendall & Boyd et al; 2005) that makes it unacceptable to continue to expect FCOPWA to negotiate the care journey without external support.

A contention made here based on the data from this study is that carers and PWA generally experience a minimum two year interregnum prior to an official diagnosis of AD being given. Crucially, it may be during this hiatus in which formal support is generally absent that the scene already becomes set for prospective carers to become habituated to 'going it alone.' A pattern which is further cemented by the distal, 'hands off' approach adopted by formal providers towards FCOPWA subsequent to diagnosis. Previous authors have similarly voiced concern that research which is focused on resilience should not be based upon an expectation that individuals can achieve resilience alone, i.e. as some form of independent and autonomous self-care (Fergus & Zimmerman 2005; Lindstrom 2001; Doll & Lyon 1998). A main criticism of alternative concepts such as 'Successful ageing' concerns their inherent bias towards individual responsibility and inattention to the important mediating

influence of structural factors, including the specific contexts different people may find themselves in. This study therefore responds to the need not only to investigate how such carers can self-manage AD care, but also the additional need which cannot be overlooked to explore ways in which external support might be improved to further promote carer resilience in future. This pertinent issue is addressed more fully during the later discussion of PT5. There remains a need which is pressing, both in the U.K. and more globally, for radical structural change at a wider political, economic and cultural level designed to create a more 'enabling environment' in which the FCOPWA is more fully supported. Structural factors, including formal support systems, have the potential to make a vital contribution to the formation of contexts which are conducive to resilience. Ultimately, carer resilience needs to be supported via an infrastructure that includes ongoing health and social care support within local environments, i.e. individual resilience is also crucially reliant on the presence of 'enabling environments' that facilitate it. As Vanistendael (2000) highlighted: it is too much to assume that even the most competent individuals can remain self-reliant without any recourse to external support some of the time.

8.2.2 Rationale for selecting The Transactional Model as the basic framework

To be candid, the foundations of The Transactional Model (Lazarus & Folkman, 1984, 1987) were laid down over thirty years ago. Therefore, an a priori but misplaced assumption was made during the initial RRR that any light that might be shed upon the question of 'what enables the FCOPWA' by The Transactional Model had already been achieved. This view proved to be mistaken however, a discovery which became apparent once the interview data had been analysed. What became salient among the emerging evidence was the extent to which carers appeared to devote time and energy to:

- (a) resolving problems that emerged in the context of AD care in order to mitigate or attenuate the stressors these problems generated;
- (b) dealing with their emotional response to these problems, particularly where problems could not be immediately or directly resolved;
- (c) how carers' effectiveness in achieving these aims might mediate their perception of being in control of the care situation;
- (d) by corollary, the propensity of these efforts to contribute towards carers' perceptions of maintaining resilience despite adverse circumstances.

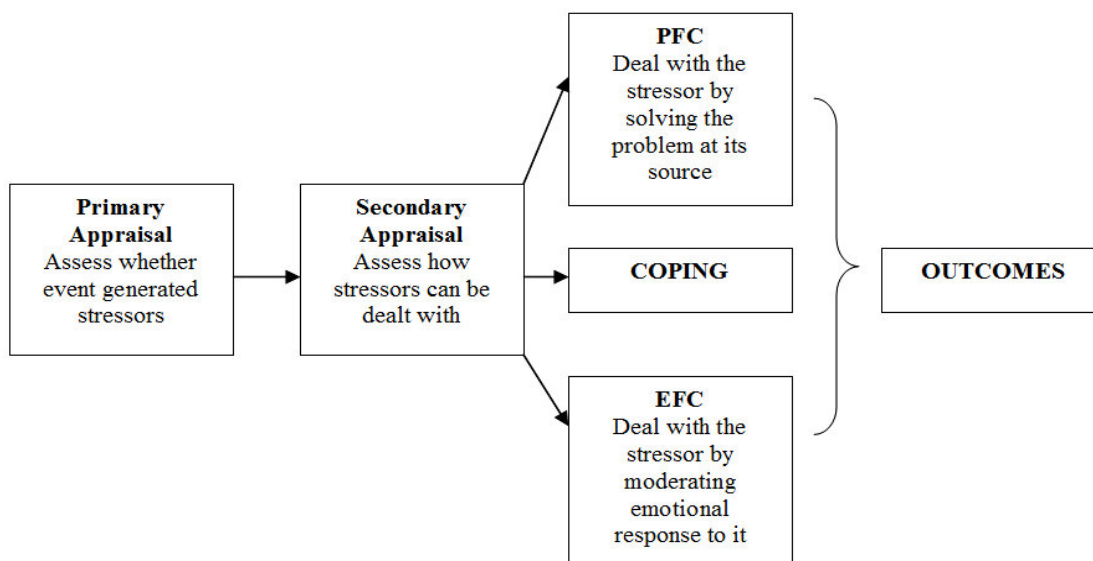


Figure 32. The Transactional (interactive) Model of stress and coping (Adapted from Lazarus & Folkman, 1984, 1987).

While the Transactional Model (see Figure 32) specifically explores points (a) and (b) outlined above, point (c) was noted following the analysis of the data in this study. Meanwhile, point (d) is supported by various authors who have found that the successful deployment of problem-focused coping (PFC) and emotion-focused coping (EFC) strategies to overcome adversity are linked with resilience (e.g. Caltabiano & Caltabiano, 2006; Masten & Reed, 2005; Rutter, 1987). In addition, resilience has been described as a measure of stress-coping ability (Connor & Davidson, 2003). Factors which are closely associated with the Transactional Model were also found to be contained within the CPTs drawn up following the RRR. In particular: hope, adaptation, positive outlook, controllability, internal Locus of control (ILO), resilience, acceptance, coping ability, EFC, positive reframing and strong carer-PWA rapport. This led to the conclusion that the Transactional Model and factors associated with it provided a 'good fit' with a range of key factors also identified by the RRR. Essentially, the Transactional Model provided a useful means of articulating and explaining not only why FCOPWA invested so much time to the above-mentioned activities (a), (b) and (c), but also explicating 'how' these actions 'enabled the FCOPWA' by elucidating the processes involved and how at a fundamental level, they served to mediate the effects of stressors and to in turn strengthen resilience. This was a realisation which only became clearer retrospectively, following analysis of the data, once carers' ability to control stressors was recognised as fundamental to 'what enables the FCOPWA.' Realisation of the Transactional Model's potential to unravel some of the complexity associated with the research question was therefore very much a key part of the emergent evidence rather than predicted or premeditated following the RRR.

A further strength of the Transactional Model lay in its compatibility with SR inquiry-in particular, the model's focus on adaptive, mechanistic processes which can mediate carer stress as the primary threat to the maintenance of family care. Furthermore, the model's focus on how adaptive processes are crucially contingent on context (Folkman & Lazarus, 1988; p.473). Moreover, the model's emphasis on the inter-connectedness of 'context,' 'resources' and 'outcomes' which shares close parallels with how SR depicts how causation is generated by a combination of 'context (C) + mechanism (M) = to generate the 'outcome' (O) (Pawson & Tilley, 1997, p.77).

The utilisation of the Transactional Model also remains consistent with SR's recommendation to adopt suitable, existing explanatory frameworks where possible in research, rather than attempt to 'reinvent the wheel' (Pawson, 2013, p.92). Nevertheless, in keeping with the principles of SR this study builds on Folkman and Lazarus' earlier findings by demonstrating how their Model might be usefully modified and adapted to specifically meet the needs of FCOPWA. This adds to the existing knowledge base and also addresses Folkman and Moscovitz's caveat raised in 2000, that the Model contained some ambiguities, e.g. concerning the effectiveness of a PFC approach at different stages of chronic illness (Folkman & Moscovitz, 2000, p.116), and was not intended to provide a definitive answer to the question of 'what enables the FCOPWA.' Hence, this study goes further to state which processes work, 'how' 'when' and 'for whom,' by revealing how carers' adoption of specific PFC and EFC approaches at key junctures and the specific ways in which these are applied enables carers to regulate care-based stressors, increase control and with it-perceived ILOC-to in turn strengthen resilience. Much is already known concerning how internality of LOC can reinforce resilience and this important relationship has been substantiated by many previous studies (e.g. Ryan & Caltabiano; 2009; Luthans et al., 2006; Masten & Reed, 2005; Tedeschi & Kilmer, 2005; Hardy et al., 2004; Kumpfer, 1999). Crucially, individuals who believe they can influence their own circumstances and personal outcomes are more likely to face adverse conditions with resilient approaches (Friborg et al., 2006; Kumpfer, 1999; Werner & Smith, 1992). While previous studies have found a close link between resilience and the employment of EFC and PFC approaches as mechanisms that facilitate coping despite adversity (Caltabiano & Caltabiano, 2006; Masten & Reed, 2005; Rutter, 1987), this study goes further to explain 'how they work,' 'when,' 'in which circumstances,' and 'for whom.' It is crucially this additional level of detail and specificity that is required to bridge a significant gap in current knowledge and in order to tap the fuller translational potential of resilience in adult public health. The emergent view of resilience as a life-long process that continues to develop throughout adulthood (Rutter, 2008; Condy, 2006; Fergus & Zimmerman, 2005; Delfabbro & Harvey, 2004; Tusaie & Dyer, 2004; Ungar, 2003) denotes a watershed for resilience research. However, resilience remains a somewhat illusory quality that is difficult to define or categorise and this makes its use as an asset or resource in adult public

health somewhat limited. Resilience is also a dynamic process across contexts (Gartland et al; 2011) and highly dependent on the context to which it is applied. This means that to be effective, how, when and to whom it is applied also needs to be variable, dynamic and context-specific. This requires that the context in which mechanisms operate to facilitate resilience also be taken fully into account. Therefore, the next step is to clearly define what works, how, when and for whom, which the SR approach specialises in.

A main concern is that at present ‘no single [resilience] trajectory exists...that practitioners can recommend’ (McCubbin et al; 2002). While it is acknowledged that ‘one-size-fits-all’ solutions to how resilience might best be applied to promote adult health and wellbeing are unlikely to provide a panacea that meets the needs of everyone, there is at least a minimum requirement for some general guidance that can assist in directing people towards more adaptive pathways that increase the possibility of achieving resilience. To this end, the Transactional Model provided an important basis for the development of the Program Theories (PTs) presented below and explication of the mechanisms and their contexts which facilitate successful carer adaptation that strengthens resilience. The PTs provide insights into the specific approaches and strategies that crucially enable resilience as an overarching philosophy to be translated into practice. The PTs may also have broader applicability to other, perhaps similar population groups.

8.3 Program Theories

The initial PTs and the CMO configurations outlined in the Findings Chapter were formulated on the basis of the data concerning the candidate PTs (CPTs). However, consistent with the iterative nature of SR inquiry, these are further refined here in the light of subsequent critical reflection, including a further review of how the literature supports and informs the findings.

An important point to note is that all the PTs remain integral and complementary to one another, with each PT supportive of the others. Thus, although they are outlined here separately for the sake of clarity, they should be regarded as five key components that build to create an adaptive pathway by which carer resilience can be achieved that is also central to ‘what enables the FCOPWA.’

8.3.1 Program Theory 1

Program Theory 1: *‘Carer hope forms part of a wider, collective belief in the potential to learn, adapt to and overcome the challenges presented by AD, as carers evolve to remain resilient despite these challenges.’*

8.3.2 Adaptation and the maintenance of carer resilience

Adaptation was identified as critical to 'what enables the FCOPWA,' as outlined by PT 1. Successful adaptation despite adverse circumstances represents a hallmark of resilience and most studies converge on the definition of resilience as the capacity to adapt successfully when faced with the stress of adversity (Dias, Santos & de Sousa et al; 2014). While chronic variable stress (CVS) (Herman, 2013; Katz, 1981) represents a primary manifestation of the health inequalities faced by FCOPWA, as well as a main factor which can disrupt AD care, successful carer adaptation that leads to resilience can provide an important protective factor that buffers against CVS to protect carers against the impact of the health inequalities they face.

Adaptation relies on a dynamic process, both cognitively, behaviourally and emotionally, and an openness to making changes to oneself and /or the environment in order to deal more effectively with the challenges that emerge during the FCOPWA (Suls et al; 1985). Crucially, adaptability confers a willingness to change rather than remain rigid (Grootinhuis et al; 1997), highlighting the fact that resilience is not always about rigidity in the face of challenge.

Although challenges can demand rapid decision-making, carer adaptability arguably works best when it is carefully reasoned, evaluated and well co-ordinated, rather than impulsive. To assist in this endeavour, the identification of a clearer pathway by which family carers can navigate the care journey could alleviate the need for a more spontaneous and haphazard approach to the FCOPWA. To this end, the adaptive pathway outlined by this study and which is revealed through the progression from PT1 through to PT5 in the following sections, sheds light on how the care journey can be more deliberately and adaptively managed despite the challenging health inequalities FCOPWA face.

Various authors have described long-term caregiving as a journey through several stages, requiring adaptation at each stage (Aneshensel et al., 1995). A contention is that carer resilience relies on adaptive change by FCOPWA throughout this journey. Windle (2011) describes resilience as a capacity to 'bounce back.' Indeed, 'resilience's philological origins stem from the Latin 'resilare,' meaning 'to leap back.' Traditional metaphors derived from other disciplines such as physics and engineering similarly employ the term 'resilience' to denote 'flexibility' within materials that allows them to withstand a certain level of pressure or stress and return to a previous state. However, such analogies tend to emphasise the maintenance of the status quo (Vanistendael, 2007). The notion of 'resilience' as synonymous with 'bouncing back' to a previous baseline state is also emphasised in the American Psychological Association's (APA, 2009) definition of this construct.

Arguably though, the FCOPWA creates a unique context in terms of its inherent variability from day-to-day due to changeable, as well as progressive AD symptomatology, to create a context that is in constant flux. This means there is no true rebound or default position available to FCOPWA. Rather, a

volatile and shifting care context, largely dictated by the AD trajectory, requires a commensurately progressive and adaptive type of resilience that always needs to remain modifiable to meet new and highly variable challenges. This raises significant challenges regarding how carer resilience can be successfully modified to remain adaptive in such a uniquely dynamic and fluid context which:

- (i) remains in a state of flux due to the highly variable and unpredictable nature of AD symptoms;
- (ii) creates a great deal of uncertainty for carers since how AD is manifest can vary markedly from person to person to make more generalised predictions regarding symptomatology problematic;
- (iii) can be highly variable in terms of longevity due to the different rates of AD progression from person to person that can range from an average of 7 years rising to a maximum of around 18 years (Clark, 2000);
- (iv) often leaves carers to their own devices by formal services;
- (v) requires relatively specialised knowledge, information and skills which very few carers are sufficiently equipped with in advance: 'Good caregiving requires a level of insight that goes far beyond common sense,' (Kitwood, 1993, p.52) and for which there is '...no cultural preparation;'
- (vi) exposes FCOPWA to salient health inequalities that may be primarily manifest in a potentially seriously debilitating form of stress-CVS-that predispose them towards physical and mental health problems (Hirst, 2005).

Therefore, a key issue concerns how carers can continually remain adaptive in the face of the significant challenges enumerated above and keep pace with an AD context that is in constant flux, including developing fresh ways to regulate the factors which generate CVS. Alternatively, where these factors are not amenable to direct intervention, how carers can learn to less directly, but nonetheless adaptively, moderate their emotional response to stressors. Zaidler and Kissane (2007) similarly noted that successfully navigating adverse circumstances often requires adaptation in which we move forward as opposed to maintaining a status quo. Importantly, this means carers remaining flexible in how resilience can be adapted and applied in order to deal with the dynamic nature of AD and AD care. 'Adaptation' is operationalised here according to the interview findings as: 'the process by which carers positively adapt to CVS to achieve resilience.' This study therefore identifies carer adaptation as intrinsic to achieving and maintaining carer resilience and an important means by which to address carers' inherent health inequalities, particularly CVS: '...unless we focus on change we cannot learn how people come to manage stressful events and conditions,' (Folkman & Lazarus, 1985; p.150).

The interview evidence lends support to the concept of carer adaptation throughout the course of the dementia trajectory, as will be discussed later in this Chapter. Carer adaptation may also help to account for the somewhat counter-intuitive finding that some carers appear to grow more resilient as they progress along the dementia journey (Gaugler et al; 2007). This concurs with the findings of

O'Shaughnessey et al. (2010), Riedijk et al. (2006), Argimon et al. (2005) and Markowitz et al. (2003) who likewise found that carers who have been caring for longer demonstrate greater adaptability, including adaptation that is manifest in higher levels of resilience than carers who have been in the role for a relatively short time and who have yet to adapt. A related finding is that carers who begin to build a relevant knowledge base and expertise early tend to be better equipped to deal with future challenges. This suggests that in terms of 'what enables the FCOPWA' a predisposition by carers from the outset of the care journey towards adaptation that includes the acquisition and development of further skills, strategies and knowledge very much supports carer resilience. This key point is also echoed in the findings of Hellstrom et al. (2007) who stressed the importance of carer adaptation commencing as early as possible. The PTs and CMOs revealed by this study and the progressive, adaptive pathway they collectively depict highlight a further key point: that FCOPWA face an uncompromising choice to either change and adapt to keep pace with AD, or face being left behind. There is no going back. This strongly suggests carer plasticity rather than elasticity to ensure resilience, as well as the need for carers to become receptive to this as early as possible, i.e. during the Early stage of AD (see Figure 33).

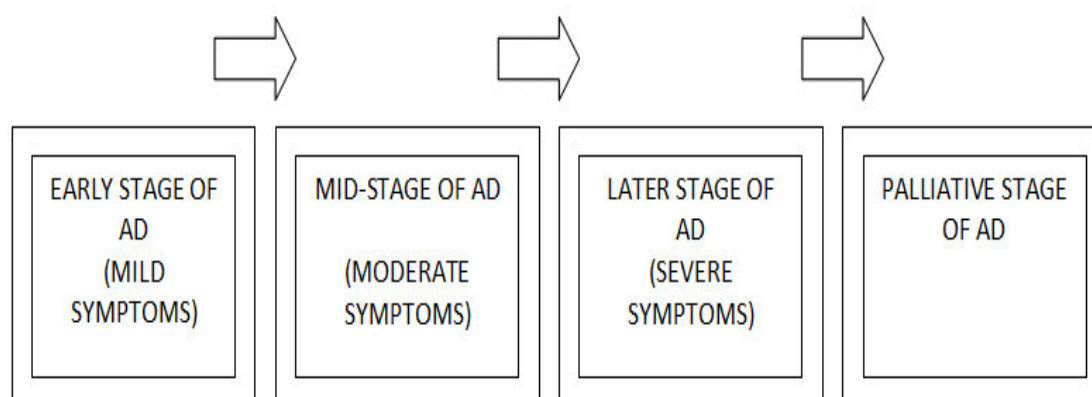


Figure 33. The three broad Stages of the Alzheimer's disease trajectory which can span up to 18 years (Clark, 2000), before palliative care becomes necessary.

The dementia trajectory has been variously depicted as ranging from three distinctive stages to seven. For the purposes of this study it is broadly referred to according to its three main stages, Early (mild symptoms)-Mid Stage (moderate symptoms)-Later Stage (more severe symptoms). This remains consistent with how the trajectory is referred in non-clinical settings and more importantly, how carers themselves perceive it.

The interview data reveals how the imperative for an adaptive response to becoming a FCOPWA is largely self-directed and driven by the lack of involvement by formal services from the outset. Furthermore, that the uniqueness of the FCOPWA, including the uniqueness of the type of stressors

involved which are also non-normative, means that carers will seldom possess the requisite skills and resources needed to deal with such a context in advance. AD care represents a unique and sizeable challenge for the majority of family carers and there is very little in life that adequately prepares people for this challenge. Typically, FCOPWA may find they are embarking on a journey of learning and discovery at a time in their lives where the prospect of such a challenge may come as a surprise, as well as presenting a somewhat daunting task that may appear to be overwhelming. The interview data also reveals how this journey forms part of an ongoing adaptive process that often begins in the 'pre-dementia diagnosis' stage, when dementia-like symptoms are first observed and prospective carers have already begun the process of adaptation in order to accommodate them. With regard to this challenge, the data reveals how both peer and voluntary sector support, especially where this includes first-hand advice, tried and tested strategies and insightful guidance based on personal experiences, can crucially support carers' successful adaptation.

Nevertheless, as will be argued in greater depth later in this discussion, there is also an important role to play for formal health and social care services to facilitate carer adaptation that lends itself to carer resilience. Not least to ensure that all carers, including those who for whatever reason do not contact the voluntary sector, receive good advice regarding how to adapt successfully to the FCOPWA. That carer adaptation is critical to 'what enables the FCOPWA' is highlighted by the finding that dementia carers who remain adaptive demonstrate fewer depressive symptoms and are, in turn, less likely to cease the family care (O'Rourke et al; 2010). By contrast, poor adaptation by carers is manifest in depressive symptoms and compromised health (Monin & Schultz, 2009) which are known determinants of the premature cessation of FCOPWA.

8.3.3 Adaptation to gain a sense of control

Carers' ability to adapt to the initial challenge of embarking on the care journey and later adaptations to deal effectively with subsequent challenges can become a source of strength. While stress, particularly in the form of CVS, can be debilitating and destabilising, the ability to adapt to the FCOPWA can provide an important means of perceiving some control over a potentially volatile care context. Perceived control over stressors is mediated by internal Locus of control (ILOC) which can importantly reduce physiological reactions to stress, including lower cortisol production (Bollini, Walker & Hammen et al; 2004). As discussed earlier in this Chapter, ILOC represents a mechanism which is closely associated with resilience (e.g. Ryan & Caltabiano, 2009). It is contended here that adaptation that leads to more effective control over CVS can increase carers' perceived ILOC to in turn augment carer resilience. Crucially also, the relationship between adaptation, ILOC and resilience is

likely to be reciprocal, with resilience further enhancing carers' perceived ability to make successful adaptations in future that enable some degree of control over potential stressors. This also reflects the cyclic and cumulative nature of resilience which, as Mullin et al. (2008) previously noted, represents an ever changing and moving phenomenon in terms of how it develops and operates as a process.

8.3.4 Where there's Adaptation there's 'Hope'

Previously, this discussion considered the importance of FCOPWA being receptive to adaptation early on in the care journey. However, a fundamental question that is also central to the SR nature of this study concerns 'how' such a predisposition towards adaptation can be facilitated. Responding to this question, the interview data reveals how 'Hope' provides an important catalyst which can instil in carers the belief and motivation that they can successfully adapt to the ever-changing AD care context. Hope can encourage carers to remain open and amenable to change and new experiences and in orienting carers' outlook towards the future in a positive way, rather than dwelling too much on the past, becoming regretful that so much has changed and perceiving the outlook with regard to the future as bleak. FCOPWA perceive the maintenance of hope as essential to 'what enables the FCOPWA' and that without it there may not be the will to carry on. The interview data illustrates how hope provides carers with a *raison d'être* to adapt, to keep moving forward and to remain as strong as possible to achieve all this, even despite adversity. Examples from the data of how carers employ hope include:

- (a) hope that the FCOPWA can be maintained and sustained for as long as possible;
- (b) hope that the AD symptomatology will be mild and gradual rather than severe and rapid;
- (c) hope that carers themselves can maintain their own health and wellbeing and that of the PWA as well as possible throughout the care journey.

Importantly, 'hope' represents a critical factor in emotion regulation, referred to here as emotion-focused coping (EFC). The data reveals how hope is instrumental in furnishing carers with a positive, overarching mindset with which to oversee the care situation at a meta level. Additionally, identification of 'Hope' and its previously established role in EFC remains consistent with and further validates the utilisation of the Transactional Model as the basic framework to explain this study's findings.

The role of hope in instilling carer resilience is also vitally important and in particular, the role of hope in mediating carers' positive outlook to create a mindset that is biased towards adaptation and its successful achievement. Hope lends itself to carer resilience by offering a potentially powerful alternative to the instinctive human 'fight or flight' response to the novel situations which FCOPWA

may frequently find themselves faced with and which they may feel ill-equipped to deal with. Not least, by assisting carers in overcoming the catastrophic thinking which can often accompany innate biological responses to major life challenges. By doing so, hope can provide a more reasoned and grounded response that more constructively biases carers towards positivity despite adverse circumstances.

It is important however that 'hope' and its pivotal role in the FCOPWA be dissociated from how this construct is popularly depicted within positive psychology. While positive psychology often infers that 'positive outlook' includes the capacity to 'flourish' despite adversity, analysis of this study's interview data reveals how carers adopt and apply 'hope' in a more grounded, pragmatic and realistic way. This interpretation takes fuller account of the saliency of the challenges, including health inequalities, which FCOPWA face. It also veers away from the less realistic notion of 'flourishing' and its implicit assumption that unless carers are somehow 'flourishing' they have failed to maintain positivity to some required standard.

8.3.5 Hope and positive outlook

Folkman (1997) emphasised the crucial role of positive emotions in resolving stress and sustaining coping resources over the duration of the stressor or stressors. This recognised that in adverse situations there is often an elevated need to accentuate the positives that can be derived from a situation, rather than to dwell on the negatives. Park and Folkman (1997) reported that deliberately focusing on the positives within the care situation can enhance coping and alleviate stress, while Wallander and Varni (1998) emphasised the importance of cognitive appraisal and coping strategies to actively promote a positive outlook. The interview data further reveals how carers' investment in and prioritisation of the 'maintenance of hope' remains pivotal to enabling the FCOPWA, particularly in the long-term. This study therefore contends that 'hope' provides a principal mechanism that 'enables the FCOPWA,' crucially providing a catalyst for: (a) the motivation to remain adaptive throughout the care journey (b) the maintenance of a generally positive global outlook throughout the care journey that helps to keep negative emotions and perceptions in check and to foster positivity.

Furthermore, positive outlook and taking away the positives from potentially adverse situations has been linked with emotion regulation (Ong, Bergeman & Boker, 2009; Fontes & Neri, 2015). It is further contended therefore that 'hope' represents a critical factor in emotion regulation. Moreover, that 'hope' provides an important overarching EFC approach in the FCOPWA and a catalyst for carers' motivation, adaptation and positive outlook. 'Hope' is therefore instrumental to the maintenance of resilience throughout the care journey, providing carers with the right mindset to move forward

despite adversity and of central importance in enabling all the other PTs operate effectively. This reinforces the need to regard the PTs as integral and complementary to one another.

8.3.6 Hope and positive outlook offering an alternative perspective to the traditional 'burden of care' paradigm

Previous research has identified the role of positive outlook in conferring inner strength and resilience (Nygren, Norberg & Lundman, 2007) and in providing an accurate predictor of resilience (Lamond, Deep & Allinson et al; 2008). By contrast, Tebb (1995) aptly described 'carer burden' as 'the inability to be resilient,' indicating that the perception of AD care as 'burden,' as frequently promulgated by the Medical model of care, represents the polar opposite of carer resilience. A contention made here is that 'Hope' and its corollaries: 'motivation towards adaptation' and 'positive outlook,' together with their ability to promote carer resilience, offers a more viable and alternative paradigm in which to situate the FCOPWA. One in which 'carer resilience' more constructively replaces 'care as burden' as the main driving mechanism underpinning the maintenance and sustenance of the FCOPWA.

While the traditional 'burden of care' paradigm presents a view of AD care in which carer health deficits and decline are seen as inevitable, alternative paradigms that focus on carer resilience and which are driven by a more positive outlook are more likely to be associated with positive health and wellbeing (Ma´rquez-Gonza´lez, Losada & Pen˜acoba et al; 2009; Gottlieb & Rooney, 2004; Hooker, Monahan & Shifren et al; 1992). Conceivably, how carer health and wellbeing is viewed, including the paradigm in which it is set, can have a significant influence on carers' perceived wellbeing and future outlook in regard to this. The contention made here is that carers' maintenance of hope crucially provides the overriding mindset that predisposes them towards being resilient. In doing so, hope offers a more viable and salutogenic paradigm to replace the traditional 'burden of care' paradigm.

As PTs 2, 3, 4 and 5 will shortly demonstrate, ways can be found to enable the FCOPWA, but first and foremost there must be *a will to succeed* and this ultimately relies on the particular mindset that is adopted by carers. This argument also extends to how the FCOPWA is perceived within the health and social care system, but also within academia, as well as at a wider societal level: that the paradigm in which the FCOPWA is situated needs to be radically altered to reflect a more positive and constructive perspective which emphasises the enablement and sustainability of family care. Arguably, the current positioning of AD and AD care within the 'burden of care' paradigm provides a significant hindrance to this by anticipating inevitable failure, rather than predicting any kind of success.

Fitzpatrick and Vacha-Haase (2010) likewise argued the case in favour of challenging the stereotypical notion of carers facing an inevitable decline as they struggle with ageing and caregiving.

Historically, the predominant view that politically, economically, medically and socially, AD represents a 'lost cause' has led to dementia being under-represented, under-funded and destined to be marginalised as a low priority in public health terms while the majority of health-based research is focused on illness and sickness (Mitchell, Kiely & Jones et al; 2006). While it is important to recognise how health inequalities can be dealt with at an individual level, there is also a need to address how such inequalities can be alleviated at a broader macro level. Again, this calls for a paradigmatic shift regarding how AD is perceived at all levels of society in order to radically alter the mindset which drives current government policy, funding and practice, including how formal health and social care systems deal with AD and how these institutions present prevailing views and attitudes towards AD which filter down to permeate our social norms. This represents a key issue and one which has also recently been taken up by, inter alia, Clarke and Wolverson (2016) and Aburn et al. (2016). That unless AD, as well as other similarly chronic, life limiting diseases, are placed on a more equal footing with chronic, life-threatening diseases such as cancer then disproportionate carer health inequalities will persist.

Moreover, the incompatibility of a 'burden of care' paradigm that is based around illness, loss and decline remains completely at odds with the notion of 'enabling the FCOPWA' over the long-term which lies at the heart of this study. As Swain and French (2000) previously noted, the predominant perception of illness as automatically denoting 'personal tragedy' needs to be fundamentally challenged and instead be regarded as a 'normal,' as opposed to an 'extraordinary,' part of human experience. This assertion carries even greater resonance today when viewed against the statistic that currently 1:3 people born in 2015 in the U.K. will die with dementia (Alzheimer's Research UK, 2015). From a life-span perspective, dementia and especially AD are becoming increasingly the norm in the U.K. and part of our everyday life and living. This forces us to reconsider how we can improve how PWA and carers live with the disease, including how we can progress towards more constructive prevailing attitudes and paradigms that embrace the challenge of dementia rather than fearfully keeping it distal and locked behind household doors. Towards a wider recognition that carers and PWA still have very much a life left to live together that can extend for upwards of eighteen more years beyond the AD diagnosis (Clark, 2000) and of the need therefore for a primary focus on how carers' and PWA's quality of life can be enriched throughout this significant span of time.

From a translational standpoint, this argument is also relevant at a broader level and there is a burgeoning need to review how the health and wellbeing of older people in general within the U.K. population, and not only FCOPWA, is more generally viewed and perceived. In particular, to move beyond paradigms which are based around predominant but anachronistic cultural depictions of ageing as synonymous with 'impairment,' 'disability' and 'loss' (Edwards, 2005) which reflect the

Medical model of care and its pathological focus on illness, health deficits and decline. Instead, to address the need to adopt more positive attitudes, policies and practices which better support older people's increased longevity and their potential to enjoy an extended quality of life. While it is acknowledged that the Medical model is likely to continue to predominate in the future, including here in the U.K., as the principal health care approach and that health care professionals' training and practice will continue to follow a mainly pathogenic model of treatment and care, there nevertheless needs to be at least scope for the development of a parallel paradigm. One in which illnesses such as AD that would be better served by the adoption of a more life-enhancing, salutogenic approach can also be accommodated. This would enable those forms of illness which are best served by the existing Medical model, i.e. reliant on treatment and preservation of life to perhaps co-exist alongside a separate, parallel system, i.e. one which specialises in prevention of ill health, preservation of health and wellbeing, capitalising on people's strengths and culminating in continued enhancement of life. Arguably, the resilience-based paradigm presented by this study offers such an alternative. Arguably also, 'Hope' remains pivotal to providing a will and a mindset that is predisposed towards building and maintaining resilience and therefore represents a key component within such a paradigm.

8.3.7 Hope, positive outlook and links with Program Theory 4

The interview evidence revealed how the need to seek some profound philosophical meaning from the care experience was generally replaced by a more utilitarian need to apply hope and positive outlook in a more pragmatic and 'down to Earth' way. For the majority of the carers involved in this study there was no hidden purpose or divine grand plan at stake. Rather, carers' consensus view was that the dementia 'just is' and that the key goal to keep in mind was to more pragmatically seek meaning, as well as purpose, in the everyday tasks they were performing. An important point therefore is that how 'hope' and 'positive outlook' which form the basis of PT1 are perceived by carers, as well as how they are interpreted and portrayed within this study, should be regarded as distinct and separate from how such concepts are generally depicted by the 'positive psychology' movement. Carers' adoption of hope and positive outlook form part of a more pragmatic approach to mundane, quotidian tasks and challenges that nevertheless biases them towards achieving success.

Carer pragmatism represents a recurrent demi-regularity (semi-predictable pattern or pathway of Program functioning) (Wong, Greenhalgh & Pawson, 2010, p.2) within the data and is returned to during the later discussion of PT4 where it also represents a key component of carers' adaptive style. The importance of carer pragmatism lies in its ability to keep carers' general outlook grounded in everyday caregiving and regularly applied to more mundane sets of goals and objectives that are

nevertheless critical to the smooth running of the FCOPWA. Hope, positive outlook and pragmatism complement each other well where they are regularly instrumental in setting achievable carer goals and objectives that are realistic and therefore more likely to succeed.

Previous research also highlights the importance of finding meaning and purpose in everyday tasks and moreover, how this may also be key to resilience (Brody & Simmons, 2007). As well as there being *a way* to achieve resilience, there must also be *a will*. Of significance is how PT1 provides an account of how this will is instilled in carers, as well as how it is maintained throughout the care journey to ensure that resilience continues to be strengthened despite adverse circumstances.

In summary, PT1 provides an account of how 'Hope' is intrinsic to 'what enables the FCOPWA,' instilling in carers a positive outlook and a mindset that is predicated towards the motivation and belief in carers' potential to develop ways to adapt and overcome the challenges presented by AD care. The uniqueness of the FCOPWA, including the relative uniqueness of the type of stressors involved which are also non-normative, means that carers will seldom possess the requisite skills and resources needed to deal with such a context in advance. This calls for FCOPWA to be receptive to adaptation from the outset of care and to maintain this adaptive mindset throughout the care journey. Such a mindset offers a more constructive and salutogenic-based (health creating) paradigm to replace the traditional 'burden of care' paradigm and one that is much more closely aligned to 'what enables the FCOPWA.'

As well as there being a way to achieve resilience, there must also crucially be a will. PT1 provides an account of how this will is instilled and maintained to ensure that resilience continues to be strengthened despite the continual emergence of fresh challenges generated by a volatile care context. Hope also represents a key factor in carers' emotion regulation, sometimes also referred to as EFC. As an EFC approach 'hope' provides a critical mechanism which supports carer resilience by assisting in the regulation of CVS.

8.3.8 PT1: Further refinement of what worked, for whom, under which circumstances

The literature provides support for PT1 and the CMO configuration which is associated with it. Further critical analysis that also takes account of the literature serves to highlight the importance of 'Hope' to emotion regulation as an EFC approach. Moreover, how this can be instrumental in controlling negative emotions and perceptions to strengthen carer resilience. Additionally, how this can make an overall contribution to the promotion of an alternative paradigm to replace the 'burden of care' paradigm in which AD and AD care are normally situated. These key points are added to the CMO configuration and highlighted in italics in Figure 34 below as a further iterative refinement to their depiction in the preceding Findings Chapter.

Consistent with SR methodology, the refined PT 1 is expressed in terms of CMO configuration (Figure 34).

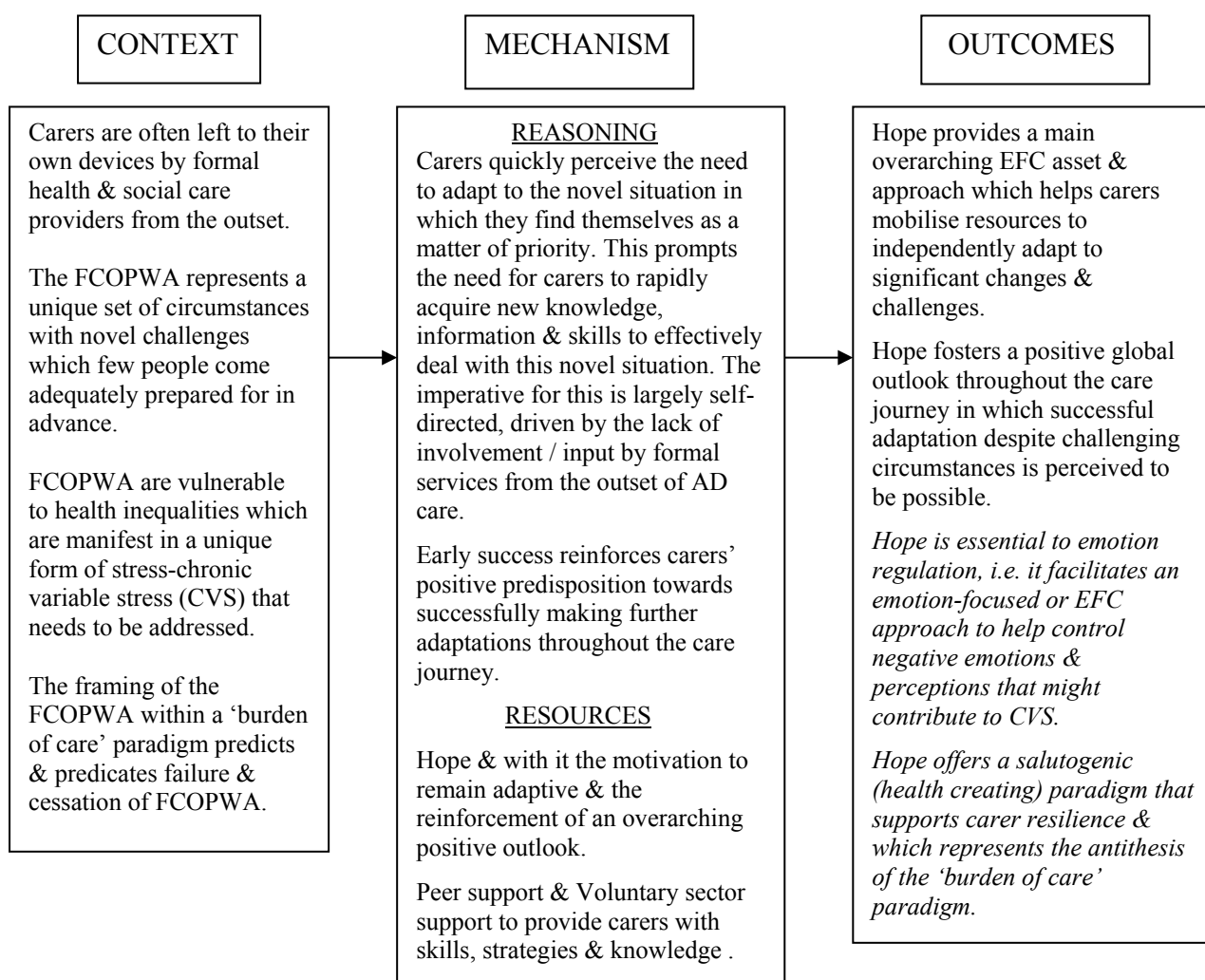


Figure 34. Further refined CMOc associated with Program Theory 1.

8.4 Program Theory 2

'Resilience can be significantly enhanced throughout the Early Stage of AD where carers increase internal Locus of Control via the application of problem-focused coping (PFC) to directly mediate the source of stress by addressing the problem at its source.'

While Hope (PT1) provides carers with a positive mindset that is predisposed towards adaptation that can lead to resilience, specific coping approaches and strategies are additionally required to provide the actual means and the mechanisms to permit this mindset to be translated into practice. The interview evidence revealed that a main focus of carer adaptation, particularly early on in the care journey, is on taking control of the care situation. Moreover, that this is achieved during the Early

stage of AD via the development of problem-focused coping skills (PFC) (Folkman & Lazarus, 1980), which comprises PT2. Although the PTs are listed separately throughout this discussion, they should be viewed holistically as part of carers' ongoing development of an adaptive pathway that involves the acquisition and accumulation of an increasingly sophisticated range of knowledge, skills and strategies. This pathway is represented in the schematic (see Figure 46) towards the end of this Chapter, but for now the discussion will focus on its key constituent components denoted by PTs 1 to 5 inclusive.

Coping represents a mediator variable which promotes adaptation (Korte, Bohlmeijer & Westerhof et al; 2011) and has been generally defined as: 'the cognitive and/or behavioural actions people deploy in response to perceived stressors / challenges' (Lazarus & Folkman, 1984). More specifically, PFC has been defined as, 'actions taken to address the source of a stressor to reduce or remove it' (ibid) and this is the definition which is utilised in this study. The importance of PFC to 'what enables the FCOPWA' stems from its capacity to mediate the most salient manifestation of the health inequalities faced by FCOPWA-namely, CVS. As discussed earlier, CVS represents a critical factor which can determine the outcome of whether or not the FCOPWA can be maintained and sustained in the long-term, amassing over time to exert a cumulative impact on health and wellbeing (Snyder, Fauth & Wanzek et al; 2015). Therefore how FCOPWA adapt to successfully deal with CVS becomes critical. While Vitaliano et al. (2003) cited the important mechanistic role stress plays in mediating carers' health, this study highlights the mechanistic role PFC can play in mediating stress.

The interview data revealed how PFC is often employed by carers to resolve or prevent relatively mundane problems. However, the cumulative impact of this approach where it is applied over a substantial portion of the care journey cannot be underestimated. By going directly to the source of problems and finding sometimes innovative ways of solving or attenuating them, potential future sources of stress can be effectively mediated. Furthermore, since mundane, quotidian problems, also sometimes referred to as 'daily hassles,' form the fabric of daily carer life, their resolution is important to carers and to the smooth-running of family care. 'Daily hassles' is defined here as: 'events, thoughts or situations which, when they occur produce negative feelings such as annoyance, irritation, worry or frustration, and/or make you aware that your goals and plans will be more difficult or impossible to achieve' (Conner, Fitter & Fletcher, 1999). It is important to recognise that while there may be a tendency for people outside the care situation to focus exclusively on the more dramatic events which may occur, it is the frequency and regularity of 'daily stressors' which can ultimately generate a more profound impact (Lazarus & Folkman, 1987). While minor problems which generate low level stress may appear to be fairly innocuous, it is important not to underestimate the overall impact on FCOPWA of frequent and cumulative stressors which can build from being a steady trickle to become a more substantial 'allostatic load' over time. 'Allostatic load' refers to biological responses to stressors which

can become maladaptive over time, leading to exhaustion, burnout and depression (McEwan, 2005). Left unchecked, its effects can threaten to derail the FCOPWA. Furthermore, FCOPWA may be especially vulnerable to 'allostatic load' due to the saliency of the health inequalities they face. This is borne out by several studies in which the impact of chronic stress on FCOPWA has been shown to lead to higher rates of carer depression, anxiety, and emotional overload relative to non-carer controls (e.g. Schulz, Boerner & Shear et al; 2006).

The interview data reveals how carers take a certain pride in their ability to resolve problems that emerge during the FCOPWA, particularly where this sometimes involves resourceful and insightful thinking that succeeds in directly removing a potential future source of stress. Moreover, that success in this appears to increase carer's perceived capability, as well as their autonomy. This corresponds with the earlier finding from the data that FCOPWA may be compelled from the outset to rapidly develop autonomy in the absence of more tangible support from formal health and social care systems. Arguably, carers' development of PFC approaches and strategies assists carers in developing autonomy by reinforcing their ability to manage problems and issues independently. The imperative for carers to quickly develop 'self-agency' and 'personal control' further motivates carers towards the establishment of a strong ILOC (Bluglass, 2007). Moreover, carers' development of personal autonomy, perceived control and resilience all share close links (O'Rourke et al; 2010). It therefore seems likely that carers' development of a repertoire of effective PFC strategies lends itself well to building carer resilience. Strategies which result in a sense of personal autonomy and a belief in being able to directly affect the course of life events can generally enhance perceived control and by doing so, strengthen psychological resilience. This led Windle et al. (2008) to identify the concepts of 'resilience' and 'control' as related elements. Arguably, it is especially the case that resilience is being generated and strengthened in circumstances where a sense of control has been gained over stress and where the strategies which are employed provide an important protective factor against stress. It is contended here that carers' development of effective PFC strategies is instrumental in achieving resilience, providing a crucial mechanism that facilitates this process. While Grootinhuys et al. (1997) previously noted that the development of problem-solving skills is adaptive and serves to eliminate the catalyst for stress by the removing the problem at its source, this study goes further to state the relationship between carer autonomy being developed via the acquisition of PFC strategies to exert control over CVS in turn generates carer resilience. This causative chain (see Figure 35 below) is outlined here for the first time and consistent with the principles of SR (Pawson & Tilley, 1997, p.215) sheds light on how specific contexts and circumstances, coupled with the availability of personal assets, can combine with carer reasoning to generate resilience.

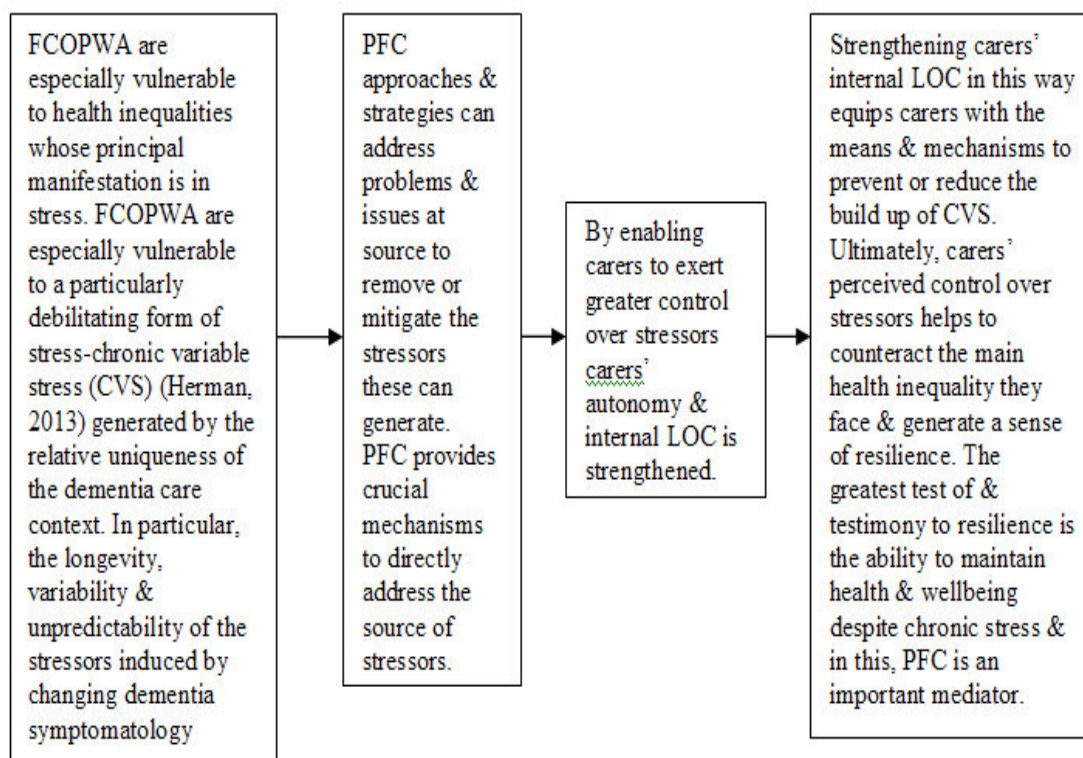


Figure 35. PFC as a critical mechanism within the causative chain that leads to carer resilience.

The interview evidence demonstrates how FCOPWA develop PFC strategies independently, but can also benefit greatly from acquiring PFC strategies via peer support meetings and via voluntary sector support, advice and information sharing.

Additionally, there is evidence to indicate that PFC not only provides a protective buffer against carer stress, but can go further to actually improve carers' health and wellbeing (Kneebone & Martin, 2003; Kramer, 1993). There is often a tendency to view 'coping' as implying 'getting by' and by association to connote '*just say getting by.*' However, a main contention made here is that the right coping approaches and strategies at the right time can achieve far more than this to make a crucial contribution both to 'what enables the FCOPWA.'

Importantly, the type of coping approach that is developed, the strategies used to apply it and the context to which such strategies are applied, including the temporal context, are likely to be critical to their overall effectiveness. Not surprisingly, far from enabling the FCOPWA, applying the wrong coping approach and strategy to the wrong context at the wrong time may prove to be entirely maladaptive, generating negative repercussions for FCOPWA. However, this does not prevent the employment of maladaptive approaches by carers and selecting more adaptive approaches may be less straightforward than people might assume. The interview data reveals that PFC approaches appear to mainly prove useful during the Early and Mid stages of AD where problems and issues are more

directly amenable to a problem-solving approach. However, as carers approach the Later stage of AD where symptoms can become more severe, the adoption of a PFC approach may become less frequent and this change is likely to reflect the changing care context, especially the fact that as problems become increasingly generated by AD symptomatology they may become less solvable and less amenable to direct PFC intervention. The data reveals how PFC tends to be applied to contexts and environments which lend themselves to manipulation and change and where carers feel they can exert some direct control to address problems and challenges at their source by finding solutions to them. However, as will become clear during the later discussion of PT 3, as the care context changes across the AD trajectory so too must the particular coping approaches adopted by carers, as part of a continual process of adaptation. What is crucial is in knowing which coping approach to apply to each set of circumstances (Tavris, 1984). Arguably, this represents a potential intervention point that lends itself well to the provision of advice as carers approach this juncture of the AD trajectory. It also has important implications for the type and level of external support, including formal support, which is made available to carers at this stage of the care journey, a key point which will be returned to during the later discussion of PT3.

As stated earlier, the PTs should be regarded holistically and as mutually supportive. Hope and with hope-the adoption of a positive outlook (PT1) is likely to prove crucial in motivating carers to seek out adaptive responses to care-based challenges, including the development of the approach outlined in PT2.

Research reveals that chronically stressful situations can induce a vulnerability to the adoption of a negative outlook and moreover, that this can have the effect of narrowing carers' focus to the extent that they become prone to overlooking practical strategies for managing their situation (Zarit & Zarit, 2012). This further emphasises the need to view the PTs presented by this study as inter-connected, combining to create an adaptive pathway within a longer implementation chain.

8.4.1 Summary

In summary, PT1 helps to provide a mindset which encourages carers to remain adaptive to the changing and volatile care context. An important part of carers' adaptation during the Early stage of AD and one which lends itself to carer autonomy is the development of a PFC approach and associated strategies (PT2). These are often focused on either removing a problem or attenuating its effects, particularly in relation of stressors. While attention tends to be largely given over to the more significant challenges carers face at particular milestones along the AD trajectory, this study emphasises the importance of recognising the potential attrition generated by smaller 'daily hassles'

which to those who are outside the immediate care situation may appear to be relatively innocuous. However, left unchecked, their continual accumulation over time can culminate in ‘allostatic load’ and indeed ‘overload.’ It is contended that carers’ adaptive development of a PFC approach can provide an important buffer against these effects, particularly against the principal manifestation of the health inequalities carers face, i.e. CVS. PFC also appears to be especially useful during the Early and Mid stages of AD where problems and issues are more directly amenable to a problem-solving approach.

Moreover, PFC may potentially go further to actually improve carers’ health and wellbeing by enabling carers to marshal control over stressors, in the process increasing carers’ perceived control, ILOC and ultimately, carer resilience.

While carers frequently develop their own PFC approaches and strategies to deal with specific problems, they also report the benefits of acquiring further PFC skills and strategies via peer support meetings and voluntary sector advice. This represents a potential intervention point therefore which could be made more widely available, perhaps presenting an opportunity for formal support provider involvement to help disseminate useful advice and guidance.

8.4.2 PT 2: Further refinement of what worked, for whom, under which circumstances

The literature provides support for PT2 and the CMO configuration associated with it. Further critical analysis that also takes account of the literature serves to highlight the importance of PFC’s potential to extend beyond mediating stress to actually enhance carers’ health and wellbeing. This further underlines the importance of carer resilience in enabling the FCOPWA and the key role played by those mechanisms which help to promote it. These points are added to the CMO configuration and highlighted in italics in Figure 36 below as a further iterative refinement.

Consistent with SR methodology, the refined PT 2 is expressed in terms of CMO configuration (Figure 36).

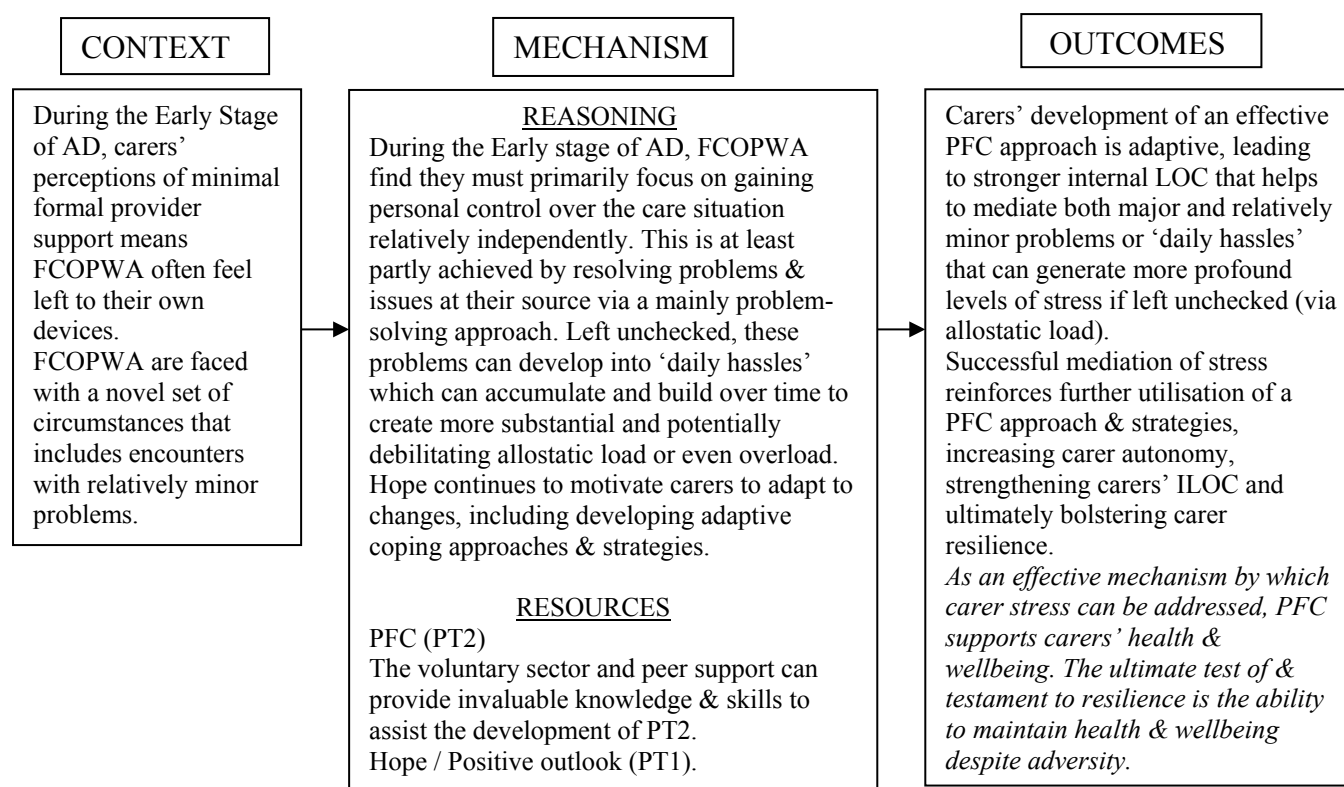


Figure 36. Further refined CMOc associated with Program Theory 2.

8.5 Program Theory 3

'Towards the Mid-Stage of AD, FCOPWA come to rely on a dual approach in which problem-focused coping continues to prove instrumental to coping and dealing with solvable problems, while emotion-focused coping becomes necessary to regulate the potential stressors created by unsolvable problems which are largely driven by dementia symptoms.'

The interview evidence revealed that while reliance on PFC represents an adaptation which assists carers in dealing with potentially solvable problems during the Early stage of dementia, contextual changes in the care situation that occur towards the Mid-stage of AD as symptoms advance from being 'mild' to 'moderate' demand a different approach. This need is also driven by further changes, particularly carers' potential for higher exposure to CVS due to increased duration (typically extending to several years), increasing intensity of FCOPWA in response to deteriorating AD symptoms and the commensurate accumulation of allostatic load these changes can precipitate over time. These factors can begin to exert greater effects on carers' health and wellbeing and moreover, may also represent issues which are dictated more by context and circumstances and less resolvable by direct problem-solving means. In general, problems which are generated by AD symptoms or previously accumulated allostatic load are less amenable to a PFC approach.

Furthermore, the maladaptive employment of a PFC approach to deal with problems which are in themselves unsolvable may result in failure that in turn generates frustration. This can exacerbate rather than alleviate stress: 'There is ample evidence that under certain conditions-particularly those in which nothing useful can be done to change the situation-rational problem-solving efforts can be counterproductive, even likely to result in chronic distress when they fail' (Lazarus, 1993, p. 238). The interview evidence indicates that once these contextual changes begin to impact on FCOPWA towards the Mid-stage of AD, this gives rise to the elevated need for carers to find further ways to exert control over potential stressors. Carers may continue to employ PFC approaches where such approaches remain appropriate, but also increasingly come to rely on a separate, parallel coping approach to address problems which are less solvable. This second approach revolves around Emotion-focused coping (EFC), defined here as: 'an approach to regulating the heightened emotions which can be generated by stress that cannot be easily mediated by a PFC approach.'

Essentially, EFC is important in dealing with problems that cannot be mediated by direct problem-solving intervention, i.e. problems which are generated by AD symptoms or previously accumulated allostatic load. The question then turns to how carers can regulate their response to these stressors as the next best form of control. The solution is at least partly derived from carers' employment of a dual process approach in which PFC and EFC can be applied strategically to either deal with potential stressors by resolving the issue at its source or regulating carers' emotional response to potential stressors for issues that are not resolvable. Similar to PFC, a strength of EFC is its ability to enable FCOPWA to marshal some control over potential stressors and there are therefore close links between PT2 and PT3 in this important regard. While PFC and EFC function differently regarding how each approach achieves this, both are essentially involved in stress regulation and control.

Importantly, how and when different EFC approaches and strategies are applied can be critical to the success of EFC in dealing with stressors. As will be explored in greater detail later in this discussion, EFC can also be employed maladaptively, therefore greater specificity regarding 'what' 'how' 'when' and 'for whom' specific forms of EFC works is essential. The interview data revealed that an important way in which FCOPWA utilise EFC involves a sophisticated tripartite emotion regulation process that includes:

(i) Exercising inhibitory control that prevents family carers from over-reacting to potentially adverse events, typically generated by AD symptomatology. This involves at least temporarily suppressing the initial 'fight or flight' response which is normally generated on first experiencing stress. 'Inhibitory control' is defined here as: 'rapid and accurate execution of a thought or action, and on occasion, stopping of this action' (Schachar, Tannock, & Logan, 1993). A key point is that exercising inhibitory control does not equate to 'avoidance coping.' 'Avoidance coping' represents the attempt to try to

ignore the problem. By contrast, inhibitory control suppresses a more extreme over-reaction to the stressor and postpones any fuller reaction until later, when it can be dealt with more rationally;

(ii) Once the challenge has been dealt with, carers deliberately engage in subsequent activities, often of a pleasurable or diversionary nature, that promote positive affect and facilitate the release of potentially harmful pent-up emotions. A key point here is that carers employ this as part of a deliberate strategy with the diversionary activity acting as a mechanism for achieving a form of cathartic release of the latent tension derived from an earlier adverse event;

(iii) A further stage in how FCOPWA employ this EFC strategy involves their engagement in positive reappraisal of the challenge that enables carers to perceive the event retrospectively in a more positive light. This also helps to counteract any negative emotions that might resurface following recall of the event. Carers' overarching positive outlook (PT1) is also likely to provide a mindset which is conducive to reappraising potentially negative events more positively. In addition, the interview evidence highlights the importance of FCOPWA employing humour as a form of positive reappraisal in which potentially negative events are reassessed in a positive light. Gallagher et al. (2011) similarly found that humour represented a main EFC strategy, as well as an independent predictor of reduced caregiver depression. Moreover, Wagnild and Young (1993) identified 'sense of humour' as an independent factor that predicts resilience. Such findings further emphasise the potential health and wellbeing benefits to be gained from successfully employing EFC approaches adaptively, as well as their important relationship with resilience. They also underline the importance of humour as a mechanism which lends itself to positive reappraisal and also to resilience, justifying its inclusion in the iteratively refined CMOc (see Figure 37 below). The importance of reappraising stressors as less harmful than first assumed and finding ways to divert emotions to avoid conflagrations is also supported by previous studies (e.g. Baker & Berenbaum, 2007). Frijda (1986) also noted that healthy adaptation involves regulation of negative emotions. More specifically, positive reappraisal as part of EFC has been shown to be an effective coping strategy despite adverse circumstances in a number of studies (e.g. Fredrickson, Tugade & Waugh et al; 2003; Folkman & Moscovitz, 2000).

Thus, while the key mechanisms or components of this process are supported by previous individual studies, this is the first time the full tripartite process of emotion regulation in the context of the FCOPWA has been expounded. Importantly, it adds much needed specificity regarding how EFC can be effectively employed by FCOPWA to adaptively respond to care-based stressors (Figure 37).

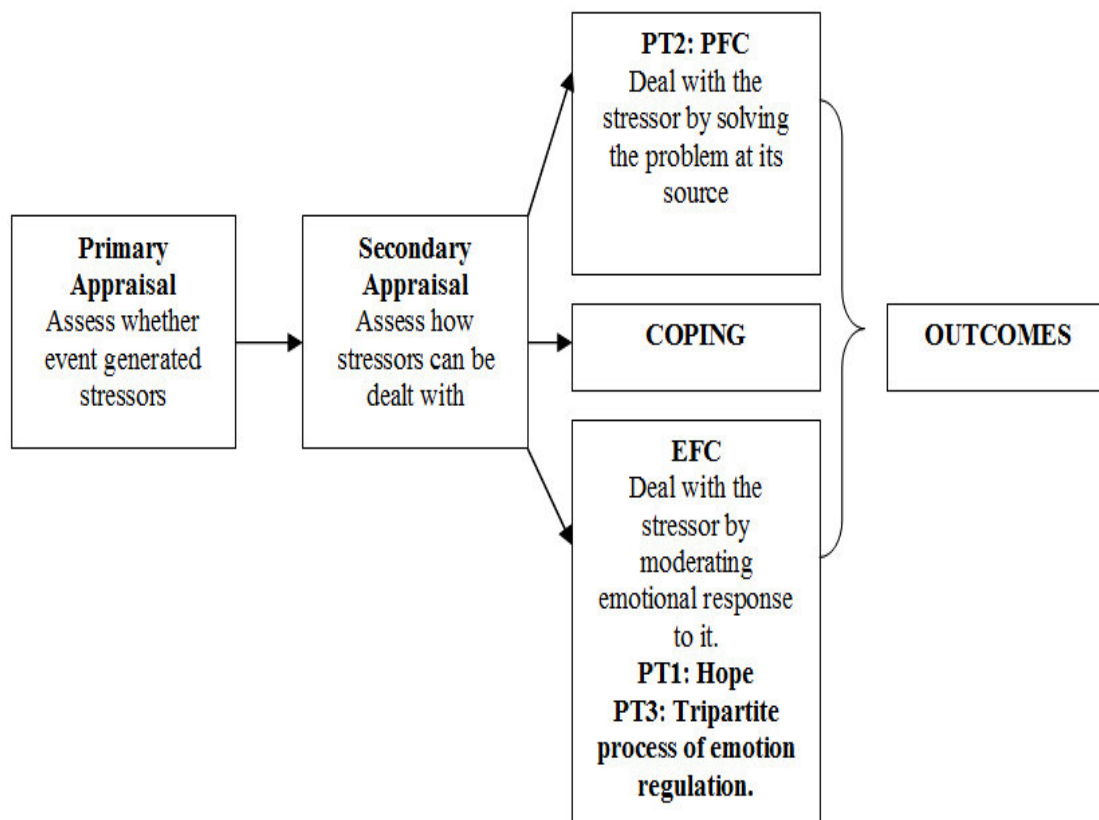


Figure 37. Further specificity regarding how EFC can be effectively employed by FCOPWA to regulate their emotional response to care-based stressors (adapted from *The Transactional Model of stress and coping* (Lazarus & Folkman, 1984, 1987).

8.5.1 The relationship between ability to regulate stress, ILOC and resilience

ILOC represents an important mediator of stress and illness (Roddenberry & Renk, 2010), with increased perceived control over stressors improving health and wellbeing outcomes by reducing physiological reaction to stress, including lowering cortisol production (Bollini et al; 2004). This is especially important in the context of the FCOPWA where CVS represents a salient health inequality which often threatens to hinder the continued FCOPWA.

Improving carers' ability to regulate stressors via EFC can increase carers' perceived ability to exert influence and control over the care context, i.e. it can enhance perceived control (Lefcourt, 1976), thus strengthening ILOC. Importantly, ILOC represents a psychological construct that is capable of being manipulated by our own perceptions. This opens up the possibility of ILOC being adaptively augmented, e.g. by the acquisition of a fresh means to deal with care-based stressors, to meet the needs of changing contexts. Gurin and Brim (1984, p. 286) also noted how, 'the outcome expectancy...is the person's estimate of the extent to which a particular behavior will lead to a desired outcome in [a] particular environment.' This recognises that a sense of control is essentially a function

of causal reasoning and based on the perception that we can act to determine the outcome of a situation (ibid). SR inquiry is similarly interested in the mechanisms which influence causation to generate certain outcomes and the role of individual reasoning in this process (Pawson, 2013, p.26). A contention made here is that EFC as a tripartite process provides an important mechanism in the regulation of emotions in the context of the FCOPWA, enhancing carers' perceived control over the care situation and their ability to determine its outcomes. Thus, EFC strengthens carers' ILOC.

Meanwhile, the switch from a primarily PFC approach during the Early stage of AD care to a dual approach that also relies on EFC as carers approach the Mid-stage of the AD trajectory underlines the importance of recognising the fluidity of ILOC (Rotter, 1966; Kormanik & Rocco, 2008) and the need therefore to remain adaptive regarding how it is manipulated. The ability to adapt ILOC, e.g. by strengthening it, has been demonstrated in older adults (Wolinsky, Vander Weg & Martin et al; 2010), indicating that age presents no barrier to achieving this, including for FCOPWA whose average age in the U.K. is 65 years. However, Cain (1994) also warned that perceptions of ILOC can change as a result of critical events, while Kormanik and Rocco (2009) noted that ILOC and its orientation can change with life experiences. This suggests carers' adaptive development and employment of an effective means of manipulating ILOC during the challenging care journey may also be pivotal to 'what enables the FCOPWA.' Moreover, this presents a potentially critical intervention point to ensure carers have timely access to relevant information and advice regarding which factors may support their ILOC at different stages of AD.

PT3 emphasises the importance of EFC as a mechanism which can enhance carers' perceived control and provide a buffer against stress. Moreover, augmenting carers' stress-coping ability very much lends itself to strengthening resilience (Connor & Davidson, 2003). More recently, Watson and Neria (2013) found evidence for the biological correlates of this relationship in improved maintenance of a homeostatic balance and a more adaptive level of functioning. Importantly also, a key component of the tripartite EFC process employed by FCOPWA reported by this study-positive reappraisal-has also been found to share close links with carer resilience (McCubbin et al; 2002). A contention made here is that towards the Mid-stage of AD, FCOPWA who adapt by employing specific EFC approaches and strategies alongside existing PFC approaches are better equipped to control and moderate stressors. Furthermore, that this enhances carers' ILOC to, in turn, strengthen carer resilience. Strong ILOC has also been identified as a key component of resilience (Monroe & Oliviere, 2007), while enhancing personal control has been shown to directly contribute to resilience-building (Fitzpatrick & Vacha-Haase, 2010; Seligman & Peterson, 2003). Furthermore, there are also important links between maintaining control over the care situation for as long as possible and avoiding institutionalisation of

the PWA (van Exel, de Ruiter & Brouwer, 2008). Via its enhancement of ILOC, and in turn resilience, EFC arguably represents a critical mechanism in enabling the FCOPWA.

8.5.2 Specificity regarding how resilience operates and wider translational potential

Specificity regarding the mechanisms that facilitate resilience is much needed, not only within the context of FCOPWA but also other contexts, in order to exploit its wider translational potential in adult health. As this study demonstrates, specificity is also needed regarding 'how' 'when' and 'to whom' such mechanisms work. This recognises that resilience and how it operates is context-specific (Ungar, 2008). Therefore, different contexts and circumstances may require different approaches, as well as different assets and resources, which support them. While increasing recognition of adult resilience as process driven, developmental and capable of being adapted and augmented across the life span remains crucial, so too does increasing our ability to more precisely pinpoint: 'how,' 'when,' 'for whom' and 'in which circumstances' adult resilience can be strengthened. Ultimately, the success or failure of resilience in the context of the FCOPWA, or indeed any other context, rests on increasing our level of specificity in these key domains. While this may eventually require the formulation of policies, practices and advice tailored according to different age groups, health settings and types of adversity, for the present there is at least a basic requirement to learn what works for specific population groups first and then to perhaps apply and test whether this also works elsewhere, i.e. has wider translational potential. This level of specificity has been largely absent from adult resilience research and arguably this has presented a main hindrance to its wider translation.

Many examples can be found to illustrate this need for greater specificity regarding 'what' 'how' 'when' and 'for whom' resilience works. For example, Lilly and Graham-Bermann (2010) found that EFC approaches proved most appropriate and effective in situations that involved high amounts of stress. Furthermore, that those who are exposed to only moderate amounts of stress do not appear to derive the same benefits of adopting EFC approaches. Similarly, Cooper et al. (2008) noted how EFC may be especially useful where the care environment becomes less controllable. A contention made here is that during the Later stage of AD where the care context may be more frequently influenced by unpredictable and highly variable AD symptomatology that may also be difficult to regulate, EFC approaches and strategies become increasingly important in dealing with the higher frequency of events that may be emotionally intense. This also underscores the need to differentiate the coping approaches that are applied according to the demands of the context or circumstances. In general, those who flexibly deploy different coping strategies to match the demands of the environment are better adjusted and more adept at dealing with stress (Cheng, 2001).

Directly related to what determines the translational potential of adult resilience is how richer and more detailed knowledge of how, when and to whom it should be applied that is derived from research is actually disseminated to potential beneficiaries. Knowing precisely when and how to employ specific EFC approaches and strategies may not be at all obvious. Indeed, the finding by this study that carers invest much time and energy towards establishing a repertoire of skills based around PFC during the Early stage of AD that often prove to be effective is likely to generate some inertia towards switching toward an alternative EFC approach later on in the care journey. As Thayer and Lane (2000) emphasised: EFC involves changing oneself and includes regulation of emotional reactions to events that is likely to require deliberate and careful self-control. 'Careful' remains the watchword here and a salient example of the need for care regarding how and when EFC approaches and strategies are utilised can be found in the consistent finding that many carers are prone to repressing their emotions, rather than temporarily inhibiting them for later release and positive reappraisal, as outlined here. Gross (1998) noted the important distinction which exists between carers who inhibit their emotions and carers who regulate their emotions, while Lakkis et al. (2016) concluded that carers' strategy of repressing their emotions is often maladaptive in the longer term, serving to mask 'hidden sufferers' and 'hidden suffering.'

Further examples of how EFC can be employed maladaptively include 'avoidance coping' and 'wishful thinking' which represent variants of EFC. These have been demonstrated to increase carers' perception of care as 'burden' over the longer term (Zucchella et al; 2011; Papastavrou et al., 2011; Di Mattei et al., 2008). 'Wishful Thinking' has also been found to be associated with higher symptoms of depression among caregivers (Snyder et al; 2015; Piercy et al., 2012). That EFC can become maladaptive rather than adaptive underscores the need for specificity regarding how it is employed to strengthen resilience. Moreover, the level of sophistication needed to ensure EFC functions adaptively suggests such specifics may need to be more overtly and explicitly learned, e.g. via some form of intervention, rather than simply rely on their acquisition being instinctive or implicit. This could also include advice regarding which EFC approaches and strategies may be optimal at different stages of the AD trajectory. As Nolan (2002) also highlighted: it is crucial that carers adopt the 'right' coping strategies at the 'right time.'

Understanding how specific coping approaches and strategies can be adapted to strengthen carers' ILOC is important, but remains at a nascent stage, a situation which led Contador et al. (2012) to strongly advocate the need for future research to further explore the relationship between control and coping style in order to optimize the care and management of PWD. In response, the interview findings shed further light on this important issue, as summarised by Figure 38.

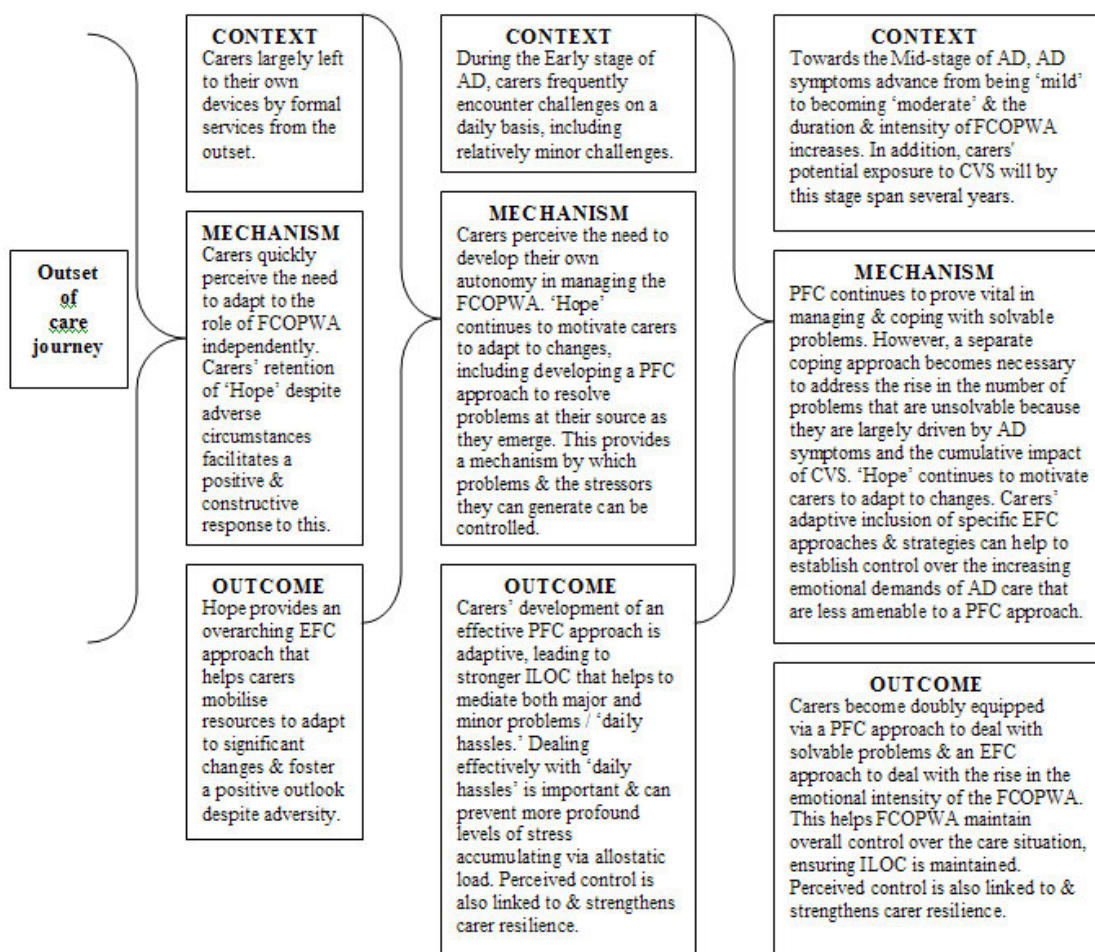


Figure 38. Recap of carers' adaptive employment of EFC and PFC approaches and strategies to ensure resilience is maintained despite the changing care context

Figure 38 depicts a fairly well prescribed pathway and individual carers' experiences are likely to differ. Nevertheless, a principal argument made here is that there is at least a minimum requirement first and foremost to develop more specific guidelines than is currently available regarding how resilience can be maintained across a variable trajectory of stress to ensure better informed choices can be made. Moreover, to perhaps investigate the wider translational potential of such guidelines to other, perhaps similar population groups. Arguably, the alternative is to continue to leave care outcomes to chance and as Rotter (1966) noted: this remains more consistent with the establishment of an External LOC and a loss of perceived control that is likely to have negative repercussions for resilience.

8.5.3 Summary

In summary, towards the Mid-stage of AD, the increasing frequency and magnitude of challenges brought about by deteriorating AD symptoms as these advance from 'mild' to 'moderate,' coupled

with their lack of amenability to PFC approaches, calls for an additional coping approach to improve control and regulation of carers' emotions. Carers may continue to rely on PFC to resolve problems and challenges which are amenable to a problem-solving approach, but this approach begins to run parallel with the employment of EFC as an adaptive means to deal with the higher potential for increasing accumulation of chronic stress and to address issues which are not directly amenable to a PFC approach. How carers effectively deal with higher emotional intensity remains of critical importance since it can exact a significant mental toll, with a recent report finding that as many as 68.8% of carers experience an adverse impact on their psychological wellbeing as a direct consequence of caregiving (Age UK, 2017).

EFC approaches and strategies can be sophisticated, as well as only adaptive for certain contexts. Therefore, an important prerequisite to increasing the wider translational potential of resilience, not only to FCOPWA, but also to other, perhaps similar population groups, is the need to establish greater specificity regarding 'what works' 'how,' 'when' and 'for whom.' Arguably, this need has never been greater at a time when a seismic demographic shift is occurring within many populations, including here in the U.K., towards increasingly ageing populations: a situation which formal health and social care services are currently ill-equipped to deal with by themselves.

8.5.4 PT 3: Further refinement of what worked, for whom, under which circumstances

The literature provides support for PT3 and the CMO configuration associated with it. Further critical analysis that also takes account of the literature reiterates the importance of differentiating how both PFC and EFC are employed to ensure they remain adaptive and the need to tailor how adult resilience is supported and strengthened according to different contexts and situations. The importance of humour in reappraising potentially negative events in a more positive light is added to the CMO configuration as a further iterative refinement and placed in italics in Figure 39 below.

Consistent with SR methodology, the iteratively refined PT is expressed in terms of CMO configuration (Figure 39).

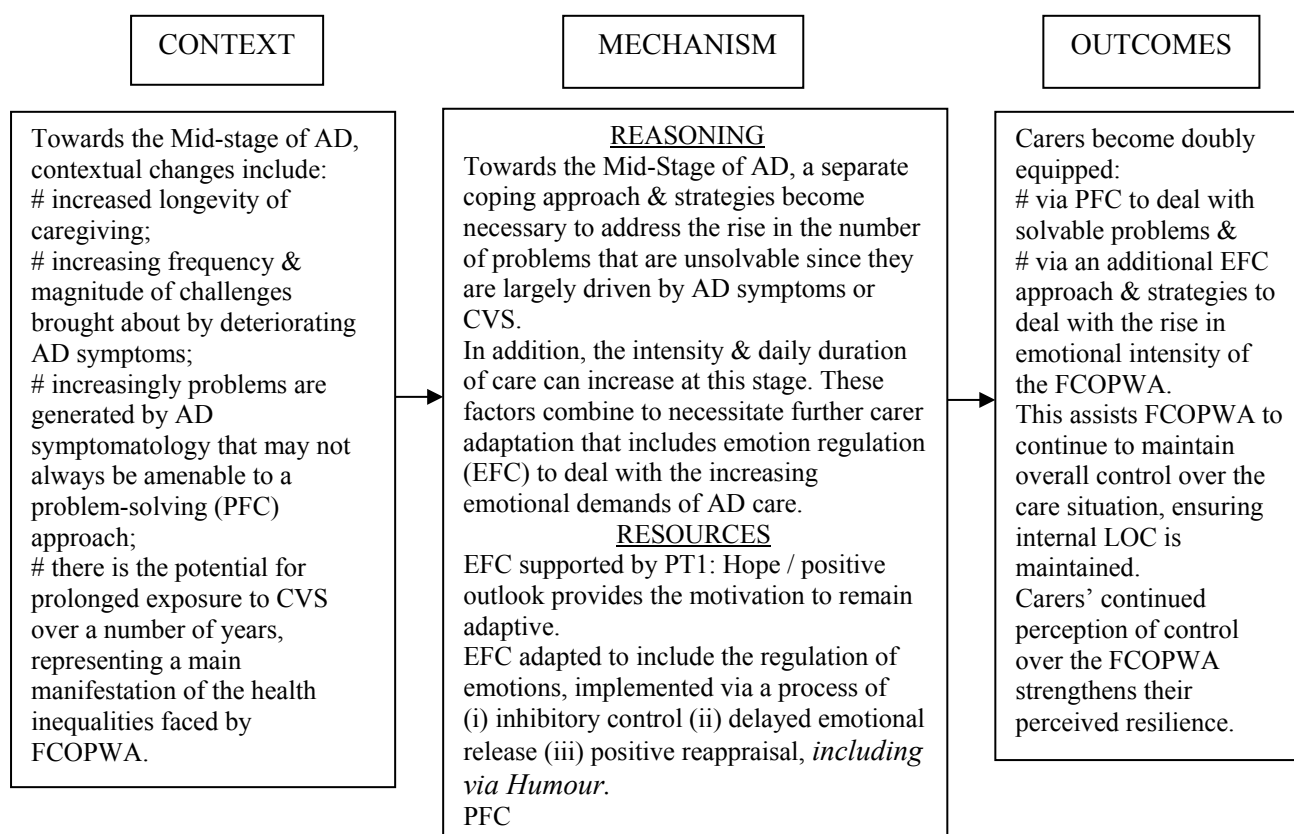


Figure 39. Further refined CMOc associated with Program Theory 3.

8.6 Program Theory 4

'Resilience can be significantly enhanced as FCOPWA approach the Mid-stage of AD where carers adopt an increasingly Pragmatic caring style that provides a balance between carer control and attentiveness to PWA's needs.'

The interview data reveals how towards the Mid-Stage of AD there is a gradual shift in the carer-PWA dynamic as FCOPWA assume greater control and responsibility for AD care and the management of day-to-day living as AD symptoms deteriorate. This can be accompanied by increases in carers' perceived responsibility for the welfare and safety of PWA. Additionally, the intensity and duration of FCOPWA can increase at this juncture. These contextual changes can contribute to higher levels of carer stress. While EFC approaches and strategies (e.g. PT1 and PT3) may continue to be of great benefit to carers in terms of regulating potentially elevated levels of stress, the data reveals how carers can develop a further important buffer against stress by modifying their caring style. In particular, carers' development of a more 'Pragmatic' caring style, defined here as: 'a matter-of-fact caring style with a main focus on remaining efficient, utilitarian, objective and tough-minded' can

assist carers in striking a better balance between carrying out the role in a way that remains *compassionate* but crucially avoids becoming too *passionately* immersed in the carer role. Ultimately, achieving better equilibrium between remaining attentive to the PWA's essential needs on the one hand, while maintaining a strong ILOC with regard to controlling and managing the care situation on the other. Importantly, this also extends to carers' maintaining a strong ILOC over the maintenance of their own health and wellbeing.

Furthermore, the interview data reveals how carers' adoption of such a caring style can also benefit PWA by encouraging them to continue to perform tasks they are still capable of carrying out for themselves to feel valued and included, as well as helping to maintain their independence and autonomy for as long as possible.

A pragmatic caring style can also encourage emotional self-restraint that helps to control and moderate carers' overall immersion in and reaction to events. In particular, the data reveals how the adoption this style is facilitated by carers learning to attribute anomalous behaviour exhibited by the PWA to the disease rather than to the person. In turn, this can assist carers' maintenance of a positive carer-PWA relationship that remains person-centred, allowing space for negotiation and compromise while also preventing heightened emotions generated by events whose origins stem from AD symptomatology from damaging this relationship. These findings are also supported by the RRR which similarly found that the maintenance of a harmonious carer-PWA relationship can greatly contribute to 'what enables the FCOPWA.'

By contrast, less adaptive caring styles can result in the dysregulation of carers' emotions and left unchecked this can over time have major repercussions for carers' overall perceived level of control over the care situation (see Figure 40 below):

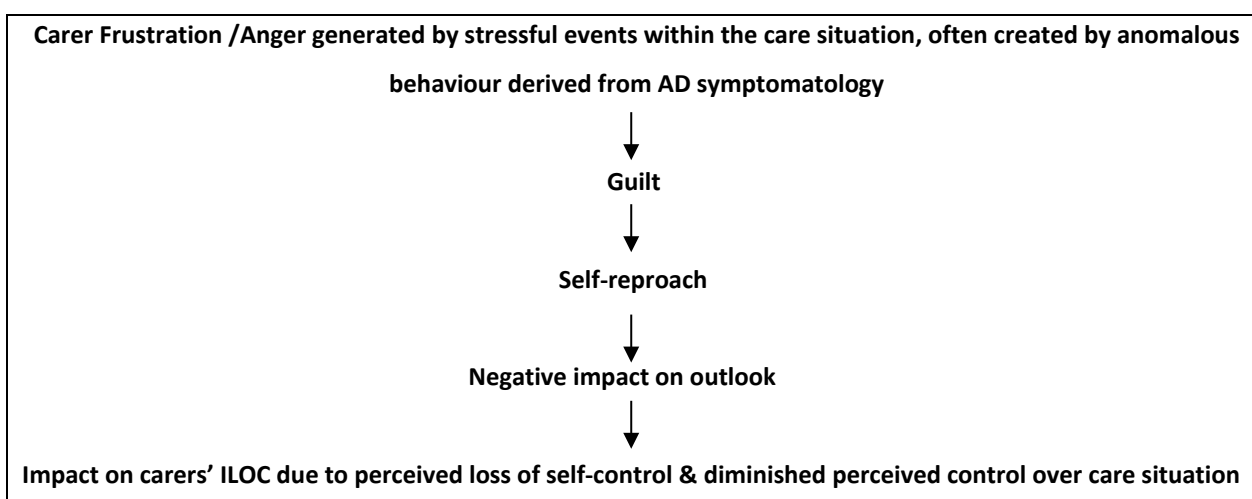


Figure 40. Increasing challenges which can emerge within the FCOPWA towards the Mid-Stage of AD, including aberrant behaviour by the PWA that is driven by AD symptoms, can necessitate the adoption of a more adaptive caring style in order to avoid negative repercussions for carers' overall perceived level of control over the care situation.

The adoption of a pragmatic caring style can also assist carers in avoiding becoming constantly over-attentive of the PWA. The data reveals how the adoption of such a style is actively encouraged and promoted by the voluntary sector, as well as by more experienced carers during peer group meetings, to instil in carers, especially those who are new to the role, the importance of standing back from the care situation. To avoid the instinctive response of becoming over-attentive and over-protective which can over time become all-consuming and overwhelming. While it is acknowledged this is by no means any easy feat to achieve, involving carers' suppression of strong, intuitive reaction to events, it nevertheless emerged from the findings as an important means by which carers could learn to improve their management and control over the care situation, including the regulation of stressors.

How FCOPWA handle the state of flux that is inherent to the care situation remains critical (O'Shaughnessey et al; 2010). In terms of 'what enables the FCOPWA,' avoiding the emotional exhaustion which can arise as a consequence of being constantly over-attentive of the PWA remains paramount. Not least because such exhaustion has been found to be strongly associated with burnout (Maslach et al; 2001). Research not only indicates that FCOPWA may be highly susceptible to burnout (Takai et al; 2010; Truzzi et al; 2008), but importantly also, carer burnout represents a main predictor of premature cessation of FCOPWA. A contention made here is carers' perceptions of uncontrollability over the care situation increases levels of stress. Almost invariably, this leads to worse outcomes (Vellone, Sansoni, & Cohen, 2002). By contrast, carers' ability to increase control and in the process strengthen their ILOC can provide a protective factor against carer stress (McNaughton, Patterson & Smith et al; 1995). Indeed, beliefs about one's own abilities and ILOC have previously been highlighted as two of the main factors that support the construct of resilience (Connor & Davidson, 2003). Moreover, the adoption of a more pragmatic disposition towards adverse events within the dementia care situation has been shown to be associated with carer resilience (Fitzpatrick & Vacha-Haase, 2010). A further contention made here is that carers' developing ability to regulate CVS via the adoption of a pragmatic caring style represents a further adaptive response to the changing nature of AD and critical to 'what enables the FCOPWA.'

Support for PT4 also includes evidence that pragmatic interpretations of otherwise adverse events can provide an important means of reappraising situations in less negative terms (Gross, 1998). Gross also found that the employment of positive reappraisal can reduce emotional response to stressors with positive repercussions at a physiological level, indicating physical as well as psychological health benefits.

There are also important links here with PT3 which similarly illustrates how carers' employment of inhibitory control can prevent an immediate overreaction to potentially stressful events while the subsequent release of latent emotions via diversions, coupled with positive reappraisal, can enable

carers to perceive events in a more positive light. This further highlights the connectedness between the PTs outlined by this study and how they are mutually supportive. Overall, emotional regulation, which a pragmatic caring style arguably contributes towards, has been shown to be adaptive and moreover to improve carers' long-term health and wellbeing outcomes (Zarit & Zarit, 2012).

The adoption of a pragmatic caring style can foster a matter-of-fact approach that is utilitarian and tough-minded and this is revealed in the finding from the data that it can assist in prioritising engagement in and completion of tasks in a 'needs must' fashion, rather than dwell on how challenging this may sometimes be. A related finding is that such a style can encourage carers to be *realistic* rather than *idealistic* in terms of the goals they set themselves and therefore more likely meet with success that lends itself to subsequent positive reappraisal. Carers' adoption of a PFC approach (PT2) that is geared towards tackling and resolving problems arguably also complements the objective and tough-minded approach fostered by a pragmatic caring style.

Carers' adaptation towards a pragmatic caring style directly complements the dual development and employment of EFC and PFC approaches and strategies as carers approach the Mid-stage of AD. Both would appear to be mutually supportive in reinforcing carers' ILOC to in turn, strengthen carer resilience.

The data also elucidated a related point, that the caring style that is adopted may affect how well carers are able to strike the crucial balance between (a) remaining attentive (but not over-attentive or inattentive) to PWA's needs, while (b) also maintaining a strong ILOC in which carers' perceptions of being to control and manage the care situation remain relatively high despite challenge and adversity. It is contended that some tension exists between these two variables and moreover, that carers' adoption of a pragmatic caring style can permit a better balance to be achieved between them that lends itself to 'what enables the FCOPWA.' However, the data also reveals how some caring styles can prove less adaptive by creating a distinct imbalance between these two key variables. In particular, the two alternative caring styles 'Over-responsive' and 'Avoidant' were identified as falling into this category (Figure 41).

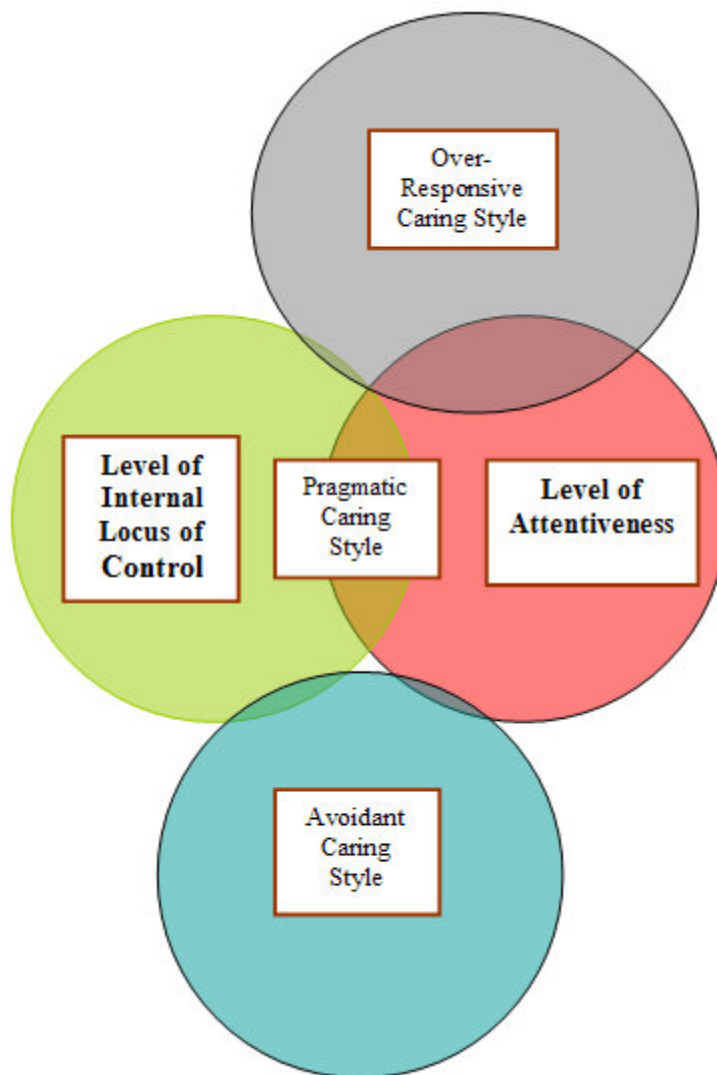


Figure 41. Recap of Three principal styles of caring (Pragmatic, Over-responsive, Avoidant) hypothesised to mediate two main factors: (a) carer's perceived level of LOC (b) carers' general level of attentiveness to every possible task that could be performed within the care situation.

It was stated earlier how Contador et al. (2012) had already highlighted the current paucity of knowledge concerning how perceived control and coping style can be made more adaptive in order to optimise the care and management of the FCOPWA. Furthermore, how this called for future research to address this deficiency (ibid). The findings presented here which form the basis for PT 4 add to the existing knowledge base by providing further insights regarding how a specific caring style can provide a means / mechanism to achieve equilibrium within the fluid context of AD care. Namely, by providing a better balance between two competing variables that enhances carers' control over the care situation and in the process strengthens carer resilience (Figure 42).

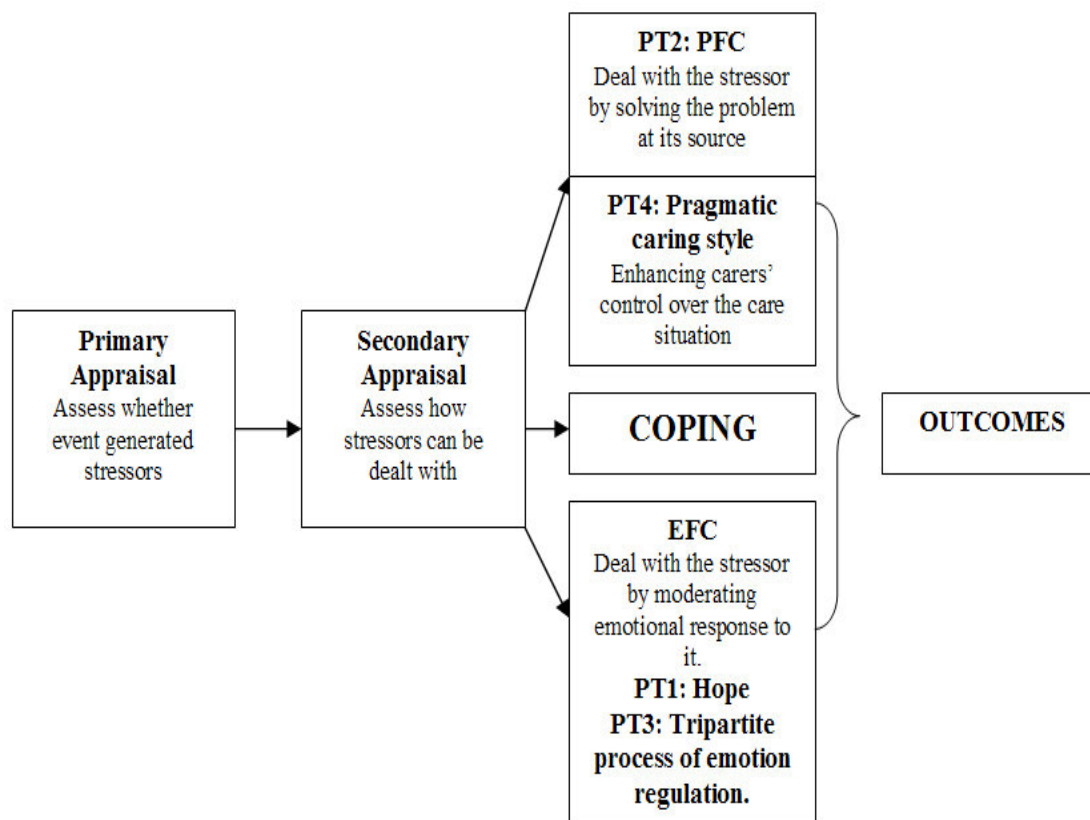


Figure 42. EFC and PFC approaches and strategies mutually supporting a Pragmatic caring style to strike a balance between two key variables: (a) remaining attentive (but not over-attentive or inattentive) to PWA's needs while (b) maintaining a strong ILOC in which carers perceptions of being able to control and manage the care situation remain relatively high despite the challenges of AD care. Enhancing carers' control over the care situation in turn strengthens carer resilience (adapted from *The Transactional Model of stress and coping* [Lazarus & Folkman, 1984, 1987]).

However, there is currently a paucity of research which focuses on adaptive caring styles in the context of the FCOPWA and the hypotheses which are presented here represent novel findings. Moreover, it cannot be automatically assumed that carers are cognisant of the importance of making adaptive changes to their caring style as they progress along the care journey nor can it be assumed they implicitly possess the knowledge that is contained in PT4 in order to make better informed and adaptive choices. Since such decisions and their enactment can potentially make a critical contribution to 'what enables the FCOPWA,' PT4 lends itself to some form of intervention, i.e. information, advice or guidance which is specifically given to carers prior to reaching the Mid-stage of AD, if not sooner.

8.6.1 Summary

A pragmatic caring style can prove optimal as carers approach the Mid-stage of AD, as AD symptomatology deteriorates from being 'mild' to becoming 'moderate' and the intensity and

duration of care increase, enabling carers to strike a crucial balance between (a) remaining attentive (but not over-attentive or inattentive) to PWA's needs while (b) also maintaining a strong ILOC in which carers' perceptions of being able to control and manage the care situation remain relatively high despite challenge and adversity. Effectively, the enhancement of carers' control over the care situation at a juncture when there is an increased risk of carer burnout as the FCOPWA becomes more challenging, can strengthen carer resilience. Furthermore, carers' adaptive development of PFC and EFC approaches and strategies complements a pragmatic caring style. By contrast, some alternative caring styles can prove less adaptive by creating an imbalance between these two key variables. In particular, the two alternative caring styles 'Over-responsive' and 'Avoidant.'

A pragmatic caring style can also benefit PWA by encouraging them to continue to carry out some tasks independently, rather than carers automatically assuming responsibility for every task. Such a style is critically reliant on carers' understanding that the anomalous behaviour exhibited by PWA is derived from AD symptomatology rather than deliberate. This also lends itself to maintaining a more harmonious carer-PWA relationship.

FCOPWA appear to be rarely given advice regarding those caring styles which may be most adaptive, particularly those which might lend themselves to strengthening carer resilience. This represents an area that is under-researched and there is a strong argument for suggesting carers may benefit from knowing more about adaptive caring styles and the factors which facilitate them in order to make better informed choices. Such knowledge may also possess wider translational potential to other, perhaps similar populations.

8.6.2 PT 4: Further refinement of what worked, for whom, under which circumstances

In the context of AD care adaptive caring styles represents an under-researched area. The general literature provides support for PT4 and the CMO configuration associated with it. Further critical analysis that also takes account of the literature serves to highlight the importance of the relationship between carers' perceived control over the FCOPWA and resilience and how *a pragmatic caring style* can provide a further mechanism which facilitates this. *Crucially also, an adaptive caring style may help to circumvent carer exhaustion that leads to burnout and premature cessation of family care.* Carers can benefit by knowing more regarding which caring styles are most adaptive. Such knowledge also possesses wider translational potential. These refinements are placed in italics in Figure 43 below to highlight them.

Consistent with SR methodology, the refined PT is expressed in terms of CMO configuration (Figure 43).

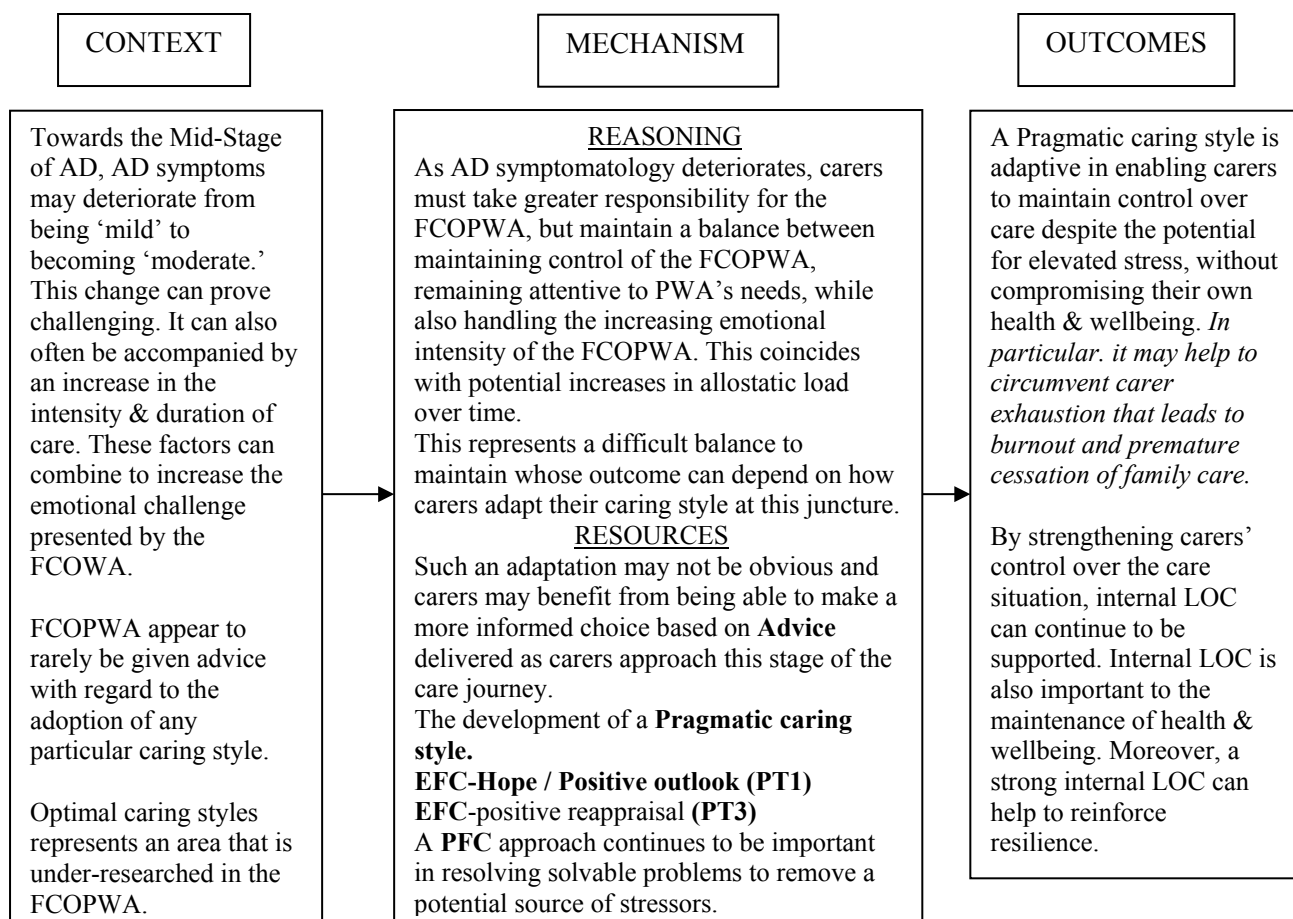


Figure 43. Further refined CMOc associated with Program Theory 4.

8.7 Program Theory 5

‘As FCOPWA approach the Later stage of AD, resilience is maintained by adapting to fresh challenges via the EFC strategy ‘Social Coping’ which encourages support-seeking behaviour, while ‘Acceptance’ facilitates coping during the Palliative stage of AD.’

8.7.1 The changing context of AD care requires further carer adaptation

As discussed earlier, a key finding of this study is that following the AD diagnosis, carers frequently reported how they felt largely left to their own devices to manage the FCOPWA. Furthermore, how this triggers the need for carers to establish a strong sense of autonomy early on in the care journey. While this can be enhanced by the development of certain approaches, strategies and caring styles (PTs 1 to 4) that strengthen carers’ ILOC, independent resourcefulness and ultimately resilience, the interview evidence also indicates these adaptations may not be effective by themselves indefinitely. In

particular, as carers approach the Later stage of the AD trajectory several factors can begin to exert a greater cumulative effect, including: AD deteriorating from being 'moderate' to becoming more 'severe' leading to carers' greater intensity and duration of involvement in day-to-day care. Carers' emotional involvement can also become intensified as AD symptoms become more pronounced in response to increasing frequency, unpredictability, variability and duration of daily challenges. Carers can also become increasingly anxious regarding the welfare of the caree. Moreover, carers may by this Stage of AD have been exposed to CVS as a principal manifestation of the health inequalities FCOPWA face for a considerable number of years. The cumulative effects of all these factors can begin to take their toll on carers' health and wellbeing via significant accretions to allostatic load over time. The impact of this can also be exacerbated by increasing isolation, for both the carer and PWA, as opportunities to socialise become limited due to deteriorating AD symptomatology. The data revealed this was more common than might be presupposed, affecting at least half of the interviewees. Ironically, these changes can occur at a time when carers require increasing rather than diminishing emotional support, such as that which opportunities to socialise can provide.

The interview data reveals how these changes to the context of AD care raise the need for FCOPWA to reconsider their previously independent stance and to contemplate what carers may perceive to be a radical alternative: the adoption of support-seeking strategies that invite closer external support, including from formal health and social care services. An important finding also is that FCOPWA crucially require emotional support at this juncture in addition to practical support, especially where carers receive strictly limited relational support from family and friends. Various studies highlight the importance of being properly supported emotionally in order to tackle adversity, e.g. emotional functioning has been found to be important to resilience (Fontes & Neri, 2015). Furthermore, strong links have been found between older people who are vulnerable to the symptoms of depression (e.g. FCOPWA), a disposition towards seeking external support and the strengthening of resilience (Smith, 2009).

8.7.2 Social coping

Folkman and Moskowitz (2004) identified 'social coping,' defined as: 'seeking emotional support and seeking practical support from others,' as a further adaptive EFC strategy. The interview evidence reveals how carers cite the benefits which can be gained by adapting towards social coping. Specifically, how social coping invites further social support and moreover, how this proves be particularly adaptive as carers encounter the additional challenges outlined above, as they approach the Later stage of AD. Social coping denotes a demi-regularity ('semi-predictable patterns or pathways

of Program functioning') (Wong et al; 2010, p.2) regarding how FCOPWA adapt throughout the various Stages of AD. Increasing reliance on EFC approaches and strategies as carers progress from the Mid to Later stage of AD also reflects carers' increasing emotional needs. Its adoption at this juncture is arguably critical to 'what enables the FCOPWA.' This also accounts for the finding that such a strategy is strongly advocated to carers by the voluntary sector and by peers and vital to 'what enables the FCOPWA.' Furthermore, that it can be achieved via carers' adoption of support-seeking behaviour that increases opportunities to derive emotional benefits from the creation of opportunities to socialise, accessing supportive environments in which they can share their feelings and engage in activities that promote stress relief. Carers who negotiate good quality formal support report its effectiveness in reducing stress (Gaugler, Kane & Kane et al; 2005). By contrast, Morgan et al. (2002) found that carers' inertia towards the uptake of formal services precipitated crises that could jeopardise the FCOPWA. This indicates that carer coping over time may crucially rely on support systems, a key point also noted by Kupst et al. (1995).

Moreover, close links have been found between Social coping that encourages support-seeking and carer resilience (Donnellan et al; 2015). Timing of uptake also appears to be critical (Gaugler et al; 2007), with early rather than delayed uptake of external support helping to prolong the FCOPWA (Gaugler et al; 2005). Despite this, the interview data reveals how carers can be slow and even reluctant to acknowledge when they've reached the limits of what they can achieve independently. This further underscores the need for a more proactive approach by formal service providers in which they, rather than carers, take the initiative in the creation of a more 'enabling environment' that encourages social coping via carers' uptake of services.

8.7.3 Overcoming potential hindrances to Social coping

While from a neutral's perspective, those who are not involved in AD care might point out that there are potentially 'ready-made' solutions to alleviate FCOPWA's experiences of stress, especially as carers approach the Later stage of AD, e.g. respite care, the interview evidence reveals the situation to be more complex. Up until this stage of AD carers will have often worked hard to establish a strong ILOC that focuses on managing the care situation as independently as possible. Self-reliance is further reinforced where there is a singular lack of service options available and these appear to be narrowly constrained to a predominantly Medical model-based approach based around institution-like settings, e.g. Day care, respite care, hospice care etc. The data reveals how such services are often perceived by carers and PWA alike to represent precursors to full institutionalisation of the PWA, a scenario which both are generally keen to avoid. As such, such services discourage carers from adopting Social coping that is largely focused around this type of support. Unfortunately, this type of support currently

represents the mainstay of carer support and this study reveals how a lack of alternative support represents a key issue for the FCOPWA. A prime example being the lack of opportunities for carers to receive 1:1 counselling to provide much needed individualised emotional support. This further underlines the need for formal support to extend beyond practical support to include emotional support, acknowledging the importance of maintaining carers' health and wellbeing. As Li et al. (2012) noted: carers who receive external emotional support report lower carer anxiety and reduced rates of depression.

Further hindrances to Social coping which were highlighted by the data in this study included, *inter alia*: variable quality of formal services, limited accessibility / flexibility, lack of information / signposting, issues of affordability and issues of trust in such services. Combined, the hindrances outlined here can provide a potent deterrent against carers' adoption of Social coping as an adaptive EFC strategy by undermining the perceived benefits to be gained from the uptake of external support.

Moreover, where a climate is created that leaves carers with little option other than to develop a strong level of autonomy from the outset of the FCOPWA, carers may already have become so accustomed to being the principal facilitator of AD care and regarding formal providers as 'outsiders' who are estranged from the day-to-day running of the FCOPWA, that accepting such a wholesale change to this strategy is likely to prove anathema.

Nevertheless, failure to embrace Social coping may prove maladaptive in the long-term where it leads to carers becoming ever more insular and resolutely focused on providing the bulk of the care despite increasing challenge. Carers do not possess infinite resources and energy to be drawn upon. Once the cumulative effects enumerated in Section 8.7.1 above begin to take hold, it can become wholly maladaptive to postpone Social coping any longer.

In terms of what could be done to remedy this situation, addressing the issue of trust or lack of trust between carers, PWA and professionals appears to be salient here. Where carers have largely been left to their own devices up until this Later stage of AD trust can become seriously eroded. Arguably, inter-dependency between AD carers and professionals should be regarded as the norm (Cameron, in Hunt, Swain & French et al; 2013). However, as also highlighted by Cameron, as well as demonstrated by the interview data, such inter-dependency is rare as opposed to the norm. Payne (2007) goes further to assert that social and health care professionals need to become far more proactive in creating an 'enabling environment' that fosters carer resilience via the establishment of a long-term and meaningful collaboration with FCOPWA. Such a notion represents more than wishful thinking and the data provides ample evidence to indicate that it is more than possible to achieve. Most notably it is demonstrated in the rich and 'enabling environment' capable of being fostered by voluntary sector staff, carers and their peers in which advice, information and coping strategies are

freely shared to generate a co-operative, unified strength. Importantly, the bond of trust that is created in such an environment can openly encourage and facilitate carers' adoption of Social coping as an important adaptive strategy. The data reveals that where Social coping comes highly recommended by peers and experienced voluntary sector staff alike who can vouchsafe for the benefits and whose advice can be trusted it is far more likely to be adopted. Formal health and social care services would do well to imitate these efforts towards the creation of such an 'enabling environment' that is built on trust and which promotes Social coping as a key enabler of the FCOPWA, rather than creating a context in which Social coping may frequently be undermined. This may also require formal providers to move away from their current adherence to the Medical model of care and associated with this, the 'burden of care' paradigm. Particularly, its depiction of the FCOPWA as 'burdensome' and how such a view arguably reinforces the notion of formal support being principally focused on 'damage limitation' rather than on how the FCOPWA can be enabled. Even the terminology that is used by formal providers to describe some forms of formal support, most notably 'respite care,' suggests far from creating an 'enabling environment' their role is principally one of occasionally providing carers with temporary relief from their 'terrible burden.'

Moreover, where such an environment is based on mutual respect and close collaboration it is far less likely to be perceived by carers as usurping their role as the primary carer and more likely to be viewed as strengthening it. A related point that is raised here concerns the fact that Social coping may initially appear somewhat counter-intuitive in terms of enabling the FCOPWA. A fundamental issue is in carers overcoming the apparent paradox that Social coping that promotes support-seeking behaviour can strengthen rather than diminish their hard won ILOC in the long-term. Ultimately, bolstering the practical and emotional support that is made available to carers can instil further belief and confidence in carers' ability to maintain and sustain the FCOPWA for longer. Singh et al. (2014) also noted that carers who actively seek external support when the context demands it are being proactive, rather than passive. This reinforces the message that may initially appear counter-intuitive, that carers whose actions include the recruitment of additional, external support are nevertheless instrumental and agental in determining care outcomes and in consolidating their position as carers. Cameron (2013) cites a key point related to all this-the need for FCOPWA to strike a better balance between gaining independence, autonomy and control and seeking the support of others. Essentially, there is a need to balance contradictory imperatives based around achieving individual autonomy at one extreme and at the other, all parties involved in the FCOPWA taking on a more collective and collaborative responsibility. Differences between carers in terms of their experience of the FCOPWA rests not only on the idiosyncrasies associated with how AD symptomatology manifests itself from individual to individual or indeed the demographic factors which impinge on carers, but crucially also

the balance they achieve between individual autonomy and collective responsibility, including the involvement of formal services.

A further argument for asserting that formal health and social care services should become more proactive in collaborating with FCOPWA is the finding from the interview data that carers frequently adopt a strategy whereby they focus mainly on setting and achieving short-term goals and adopt a short-term perspective, particularly as they approach the Later stage of AD when the intensity and duration of care can be set to increase. By deliberately focusing on each day as it comes, carers can make the FCOPWA appear to be a less of a sizeable challenge and therefore more manageable. Such a strategy can also help carers to avoid projecting their thoughts too far into the future to minimise catastrophic thinking with regard to the terminal nature of AD. However, a significant setback can be that such a strategy also becomes myopic and a serious hindrance to longer-term, strategic planning. A related issue is that formal services generally require that uptake of services by carers be arranged in advance and such services may require a significant amount of time to be processed. This further adds to the argument for the establishment of a more enabling environment in which formal service providers are far more proactive and also more flexible in terms of being able to offer services at short notice. Structural factors, including formal support systems, have the potential to make a vital contribution to the formation of contexts which are conducive to carer resilience. As argued earlier in this discussion, carer resilience needs to be supported via an infrastructure that includes ongoing health and social care support within local environments, i.e. individual resilience is also crucially reliant on the presence of 'enabling environments' that provide suitable contexts that facilitate it.

As stated earlier, this also represents a situation which can only be effectively changed by establishing closer links and support from the outset of the FCOPWA in carers (and PWA) become an integral part a more equal partnership from the outset. How the care context is shaped and formed is vital to 'what enables the FCOPWA.' The bulk of AD care will be conducted within a domestic environment. Left unchecked, this can create a substantial division between carers, PWA and professionals in which the boundaries of responsibility and involvement are left unclear and ambiguous. Tension and dissonance can emerge when the framing of carer support is unbalanced or opaquely defined. This is arguably symptomatic of the Medical model approach (Carr, 2004, p.856) and its automatic assumption of the majority control and influence over how support should be delivered. Such an approach offers insufficient compromise or merger between the domestic environment and its medicalised counterpart or any encouragement towards greater participation between carers and professionals that is on a more equal footing. The interview data serves to reinforce a key message: that carers anticipated and would greatly appreciate a radical change to the present system that included formal support from the outset of care, as well as allowing carers a much larger say in the

types of support made available to them, including ways to support theirs' and PWA's health, wellbeing and quality of life throughout. The move towards a more equal partnership between carers and professionals is likely to lend itself to enhancing carers' perceived control (Carr, 2004, p.854), here more generally referred to as ILOC. This underscores the earlier key point: that greater 'carer-professional' collaboration further enhances rather than diminishes carers' ILOC, in the process strengthening as opposed to weakening carer resilience.

8.7.4 From Hope to Acceptance

The interview data reveals that during the final part of the care journey, as PWA move towards the need for palliative care, carers further adapt by adopting a further EFC strategy-'Acceptance' (PT5) (Figure 44 below). 'Acceptance' as a means of 'coping' is defined here as: 'accepting that a difficult situation is real and must be addressed' (Carver, Scheier & Weintraub, 1989). The data sheds light on how acceptance involves carers positively reflecting on the historical relationship between the carer and the PWA and taking stock of the good experiences and memories they have shared together. As MacArtney et al. (2015) also recently noted: it therefore represents a further adaptive change, as well as a further means of maintaining resilience at this difficult juncture of the care journey. This study elucidates how acceptance can be both positive and adaptive and how carers seem to approach acceptance with an almost preternatural calm and equanimity. Acceptance therefore denotes a subtle, yet important shift in carers' mindset from a primary reliance on Hope to provide a generally positive outlook regarding the FCOPWA and the motivation to remain adaptive (PT1) to an eventual, overarching acceptance that the care journey has almost run its course and the repercussions of this (PT5), as the final significant adaptation along this journey.

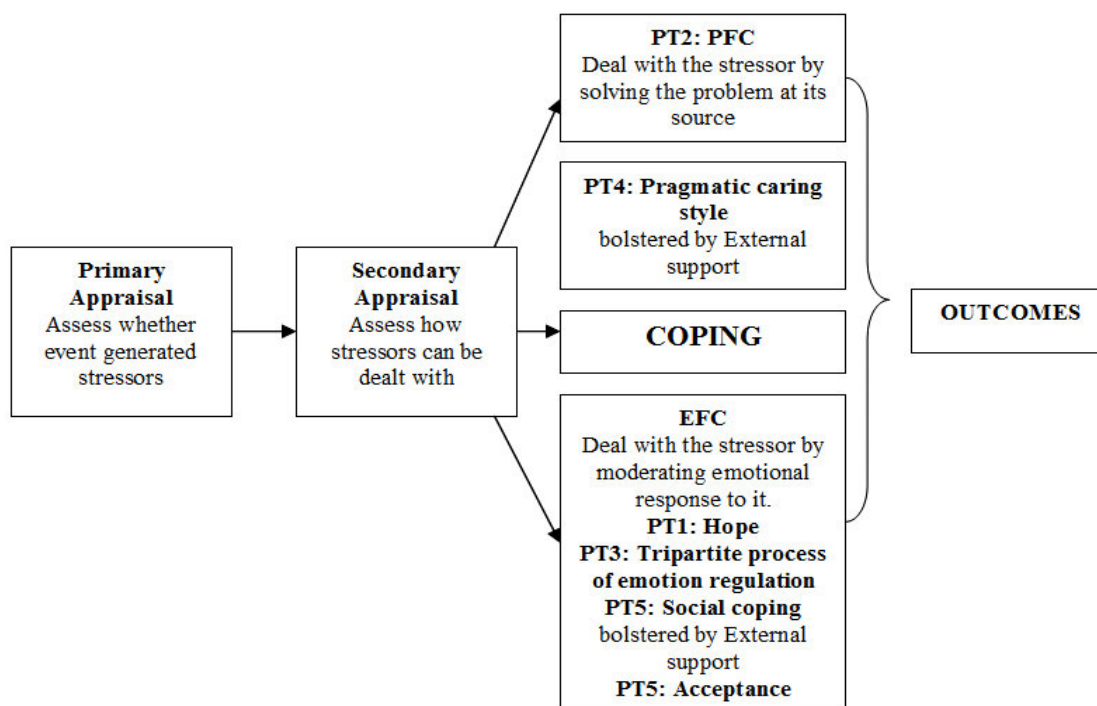


Figure 44. Carers' further adaptation to include the EFC strategies Social coping and Acceptance assists carer resilience as they approach the Later stage of AD (adapted from *The Transactional Model of stress and coping*, (Lazarus & Folkman, 1984, 1987).

Furthermore, the data reveals how in many ways the journey has been akin to a rite of passage and carers have achieved what they set out to do despite myriad challenges-to maintain and sustain the FCOPWA for as long as they could. In this endeavour they have largely remained resilient and stayed the course by this stage. This adaptive change by carers towards acceptance provides a further example of how resilience represents a dynamic rather than a static process (Gartland, Bond & Olsson et al; 2011, Mullin & Arce, 2008) and moreover, a process which undergoes a series of adaptations as a necessary response to a care context that is in constant flux.

8.7.5 Summary

Important changes to the care context as carers approach the Later stage of the AD trajectory calls for further adaptive changes. These include carers' adoption of Social coping (PT5) as an important EFC strategy which encourages carers to actively seek practical and emotional support. A contention made here is that this adaptation can prove critical to carers' maintenance of ILOC and in turn, carer resilience by marshalling additional external resources in support of carers which enable them to overcome potentially greater challenges as they negotiate this stage of AD.

However, this study also reveals how there are many potential hindrances that could prevent carers' adoption of Social coping, many of which could be addressed by a policy shift towards a closer

collaboration between FCOPWA and formal health and social care providers. Especially where this was geared towards the creation of an enabling environment in which it became normative for carers to receive the right kind of formal support from the outset of the FCOPWA and for the full duration of AD. This study argues for a sea change regarding how resilience-building is achieved by carers that relies not only on the adaptive development of individual assets / capabilities, but crucially also the provision of external resources to facilitate this process via the establishment of key external structures, systems and resources at a local level. Ultimately, a more even balance needs to be achieved between carers maintaining individual autonomy versus the creation of contexts which encourage collective responsibility, including the involvement of formal services.

During the final part of the care journey, as PWA move towards the need for palliative care, carers further adapt by adopting an attitude personified by the EFC strategy of Acceptance (PT5). Acceptance may denote a subtle shift in orientation by carers from the Hope (PT1) which sustained them well up until this juncture. Acceptance is adaptive in encouraging carers to accept that the care journey has almost run its course, to come to terms with this in a positive way and to derive a sense from calm and equanimity from so doing.

Overall, there is a gradual shift in the balance between PFC and EFC approaches and strategies as AD advances, with EFC approaches and strategies becoming increasingly important to 'what enables the FCOPWA,' as well as essential to carers' maintenance of ILOC and strengthening of carer resilience.

8.7.6 PT 5: Further refinement of what worked, for whom, under which circumstances

Further critical analysis that also takes account of the literature serves to highlight how carers establish a strong ILOC to bolster carer resilience and how this is largely developed in the absence of formal support from the outset of the FCOPWA. Furthermore, how the prolonged absence of external support can become a hindrance to the uptake of external support later in the care journey, at a time when it may become even more critical due to the cumulative impact of health inequalities. This represents one among several hindrances to uptake which need to be overcome via the creation of a more 'enabling environment' in which carer resilience is better supported and enhanced by closer, collaborative formal services' involvement from the outset of the FCOPWA and thereafter. This places the emphasis on resilience as an adaptive process being developed from within via the acquisition of a repertoire of capabilities, strategies and adaptive approaches, but crucially also, from without. These iterative refinements are placed in italics in Figure 45 below to highlight them.

Consistent with SR methodology, the refined PT is expressed in terms of CMO configuration (see Figure 45 below).

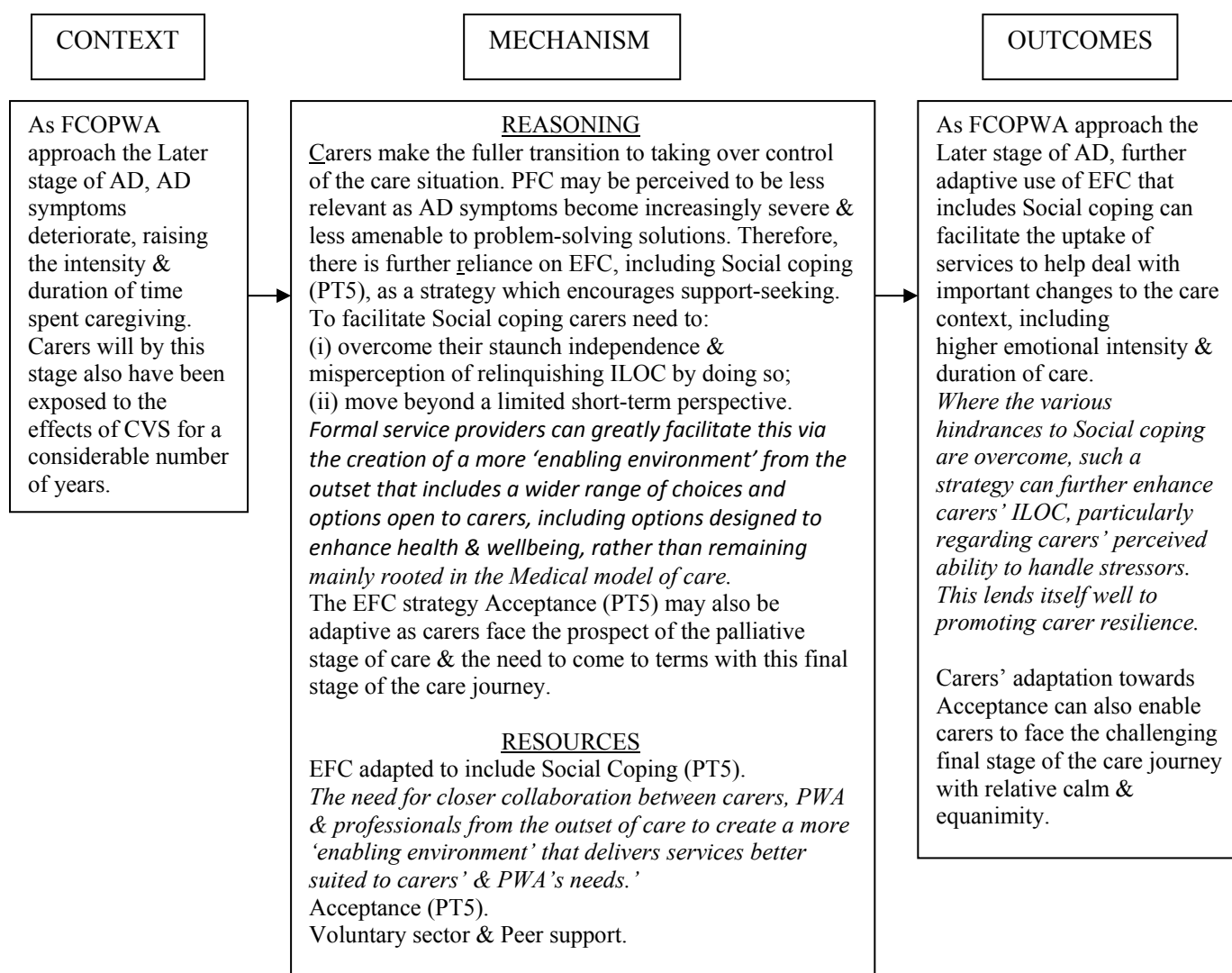


Figure 45. Further refined CMOc associated with Program Theory 5.

8.8 Increasing the translational potential of resilience in adult public health

As recently as 2015 the problem of resilience as an under-represented and under-utilised asset to adult public health and wellbeing was writ large in a review by Jensen et al. (2015). Of particular relevance to this study, Harris (2016) noted the tendency and fallacy which persists for research which ignores or underestimates the importance of resilience's contribution to ordinary older adults' health and wellbeing. As stated towards the end of Section 8.2, in order to correct this oversight and also to exploit the fuller potential of resilience greater specificity is required regarding 'how resilience might work, for whom, when and in which contexts and circumstances.' Essentially, this presented the twin need to demystify and 'unpack' what we mean by resilience: in particular what constitutes and contributes to resilience. This calls for more specific guidelines concerning how resilience might be

harnessed and utilised, when and by whom. To this end, the next section explores how the SR approach adopted by this study enabled the findings to incorporate more specific guidance detailing both the nature of resilience and how it operates in the context of the FCOPWA, and importantly also, how carers can develop and support their own resilience as part of a more adaptive pathway. Such knowledge is important in helping to shape future policy and practice that is designed to tackle the health inequalities faced by FCOPWA. Arguably, it also opens up the possibility for exploiting the wider translational potential of resilience not only for FCOPWA, but also for other, perhaps similar population groups.

8.8.1 Defining a carer pathway that 'enables the FCOPWA'

Charting a pathway by which carers might best negotiate the many unpredictable and profound changes associated with AD presents a significant challenge. This study rose to that challenge to produce an explanatory account of how specific coping approaches and strategies complemented by a certain caring style can be adaptively employed to take account of the changing context and circumstances inherent to the FCOPWA. Importantly, the pathway produced provides carers with guidance regarding how they can negotiate some of the key challenges they face during the course of the care journey. This addresses a notable gap in current knowledge, uncovering key answers to the important question of 'what enables the FCOPWA,' particularly over the long time course that is associated with AD. The pathway presented represents a tailored and differentiated approach, responding to the need which was paramount from the outset: to unravel the complexity of the research question and to produce answers which are specific, including critical details regarding the precise contexts and mechanisms required to enable carers to carry out their role, despite the high probability of them facing significant additional challenges at specific key junctures. Achieving this owes much to the SR approach adopted by this study (see Figure 46 below).

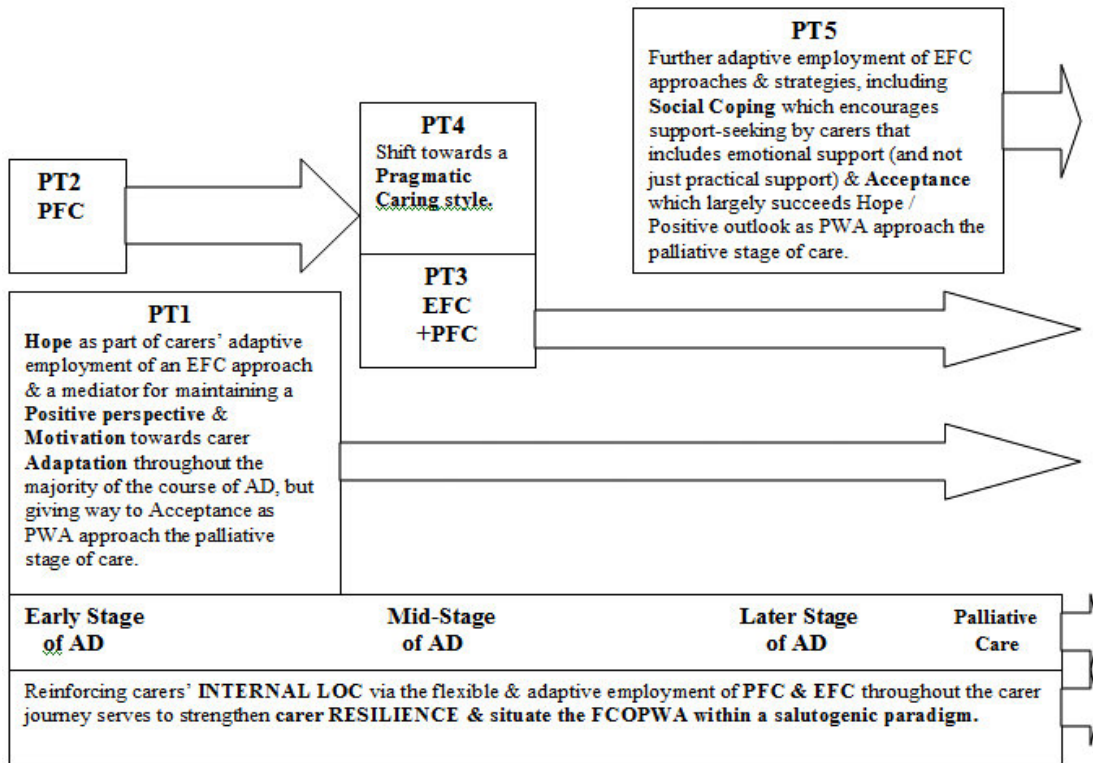


Figure 46. Summary of the adaptive carer pathway revealed by the present study, including how the Program Theories combine to enable the FCOPWA across the AD trajectory.

The SR approach adopted in this study and its ability to tackle complex research questions is further reflected in how it facilitated the development of 'meta theory' to crucially elucidate the principal demi-regularities that combine to enable the carer pathway to work in the first place. This included 'meta theory' concerning how underpinning, overarching and facilitative mechanisms can be created and combined to effectively enable the FCOPWA (see Figure 47 below).

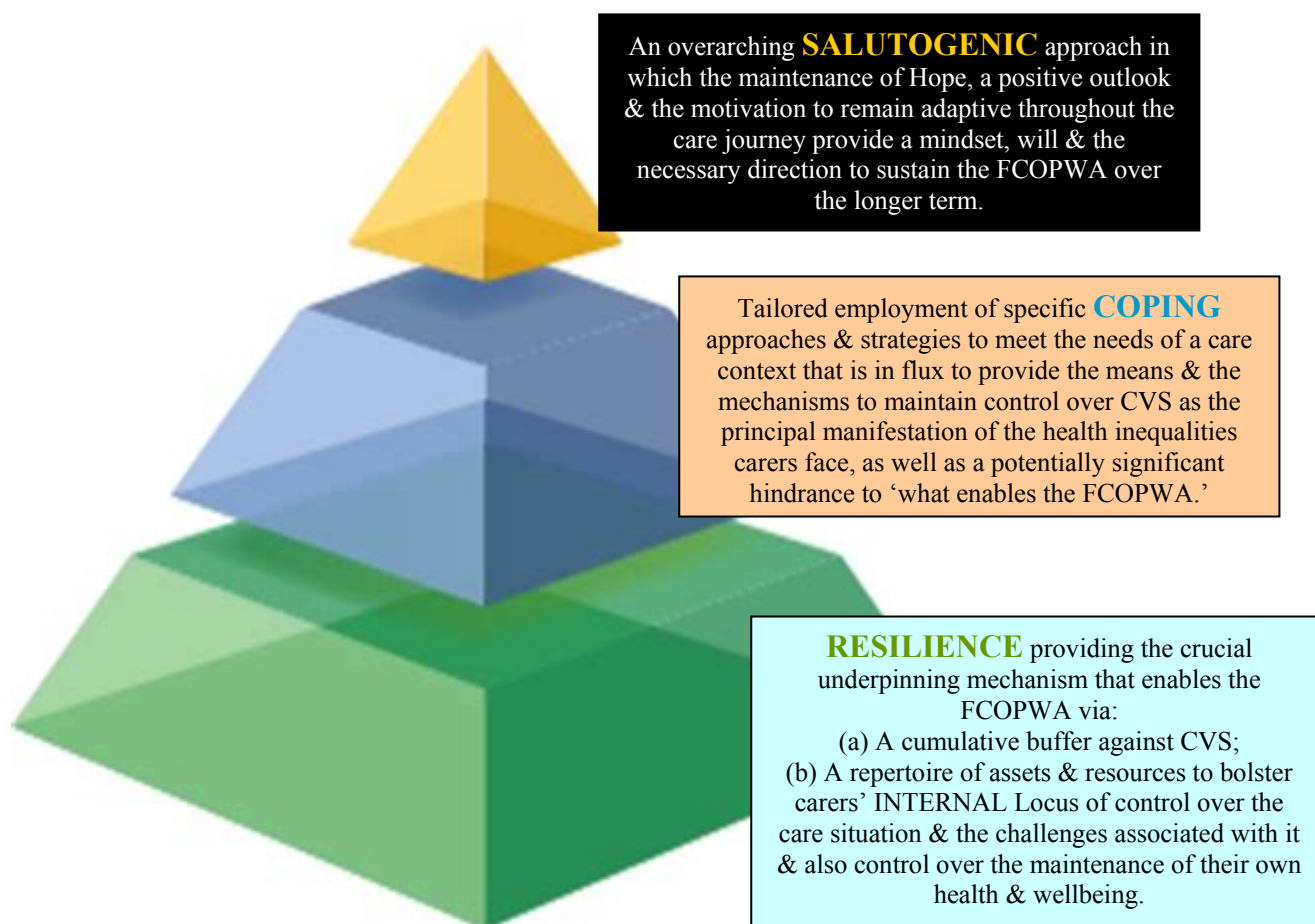


Figure 47. The three principal emergent demi-regularities derived from this study (i) Salutogenesis (ii) Coping & (iii) Resilience and how they combine to provide the will, the way & the means / mechanisms to maintain & sustain the FCOPWA over the longer term.

While each carer's journey may be experienced differently, the same three principal demi-regularities which emerged from this study: (i) Salutogenesis (ii) Coping and (iii) Resilience and how they uniquely combine are nevertheless likely to be critical to the majority of FCOPWA and crucial in enabling them to maintain and sustain such care in the long term. Essentially, these three components collectively provide: the will, the ways, the means and the mechanisms, including resilience as the crucial underpinning mechanism, to facilitate the role.

Previous research has indicated the potential for strong links to exist between these three key constructs. Coping approaches, and in particular PFC and EFC, feature prominently in this study as adaptive mechanisms which allow FCOPWA to exert stronger regulation and control over the principal manifestation of the health inequalities they face-CVS-which left unchecked might otherwise threaten to derail family care. Meanwhile, increased perception of carer control is closely associated with ILOC (Bollini, Walker & Hamman et al; 2003), which in turn shares strong links with resilience (Ryan &

Caltabiano; 2009; Luthans et al; 2006; Masten & Reed, 2005). Coping and control also go hand-in-hand and LOC should not be viewed in isolation from coping skills and strategies (Schaefer & Moos, 1992).

Additionally, coping complements resilience and resilience-building well since it provides the capability to be adapted to meet changing circumstances (Moos & Holahan 2003). Furthermore, resilience provides a bridge between coping and adaptation within the context of older adults' health (Leopold & Grieve, 2009), which is relevant given that the average age of FCOPWA in the U.K. is 65 years. Moreover, salutogenic approaches to health and wellbeing typically emphasise the importance of individuals developing higher levels of perceived control (Wennerberg, Lundgren & Danielson, 2012) and as outlined above, perceived level of control is strongly associated with resilience.

Salutogenic approaches have also been found to be particularly apposite in situations where health problems occur outside the traditional boundaries of health care provision (Lamprecht & Sack 2003), i.e. family carers. Moreover, salutogenic approaches serve an important purpose in attempting to bridge the gap created by health inequalities by highlighting vulnerable groups within populations who may otherwise be under-represented (Eriksson & Lindstrom 2005), i.e. family carers.

Essentially, salutogenesis, coping and resilience all complement each other in terms of their shared aim of providing preventative approaches to help maintain health and wellbeing. Indeed, a notable feature to emerge from these three demi-regularities as this study progressed was how well they appeared to complement each other and combine to strengthen each other. Wennerberg et al. (2012) also noted that research that explores individual, non-iatrogenic protective factors associated with health and wellbeing that move away from the Medical model are typically based around one of three main frameworks: (i) Salutogenic (health creating) (ii) Coping or (iii) Resilience frameworks. However, the authors also highlight a salient point: that traditionally these three frameworks have been focused on separately. This may no doubt be attributable to the fact that by compartmentalising each construct separately they might more easily be researched and examined, avoiding the additional complexity that might be introduced by investigating how they more dynamically interact. While this may well be the case, the findings of this study nevertheless emphasise how salutogenesis, coping and resilience appear to work more in combination than they do individually. Moreover, how their effectiveness in enabling the FCOPWA appears to increase exponentially as a consequence of their working in tandem. Ultimately, what they all share in common is a focus on maintaining health and wellbeing despite adversity within a non-iatrogenic paradigm.

Together, Figures 46 and 47 above provide a reasonably succinct overview of this study's key findings, presenting a specifically defined and clearly delineated pathway that is closely aligned with 'what enables the FCOPWA.'

The findings outlined here also offer a way to move beyond the current situation FCOPWA often find themselves in, which is largely based around the adoption of a 'trial and error' approach to carrying out the role (Gaugler, Kane & Kane et al; 2005) and which creates unpredictable and uncertain outcomes for FCOPWA in what is already a potentially volatile and highly variable care context.

The findings are very much oriented towards how carers can help themselves, but as argued earlier, this becomes an expediency that is mainly brought about by an absence of formal support from the outset of care, rather than necessarily representing the ideal. The current politico-economic climate in the U.K. and the fact that AD care is given a low priority in terms of health and social care spending with a 25% decline since 2009 (Community Care Statistics, 2013), with rates for the next few years expected to be constrained as demand for services actually increases (Alzheimer's Society, 2014), makes the need for studies which emphasise how carers can help themselves more necessary than ever. Hence, while this study acknowledges the need for formal support to be made available to FCOPWA at any point along the AD trajectory and moreover, as a major step towards creating a more 'enabling environment' that better facilitates the FCOPWA, PT5 (Social coping) is positioned towards the Later stage of the AD trajectory. This denotes the juncture at which Social coping is most frequently employed by carers according to this study's findings, as well as the juncture at which it arguably becomes most critical to 'what enables the FCOPWA.'

However, it is emphasised here that a more ideal scenario would be for Social coping (PT5) to be actively encouraged by formal service providers from the very outset of the care journey. As Carr (2004, p.856) highlighted: there is a need 'to develop an understanding of the continuum of care as opposed to the snap-shot experienced during time limited engagements with service users.' At present, there is arguably too much emphasis in the U.K. on services provision during the Later stages of AD, and in particular the palliative stage of care, which denotes a relatively small fraction of the AD trajectory.

8.8.2 Further increasing the translational potential of resilience in adult public health

A further argument for linking salutogenesis, resilience and coping is that all three are primarily aimed at being preventative and in preserving health and wellbeing. Moreover, as illustrated by Figure 47 above, they can crucially be combined to provide a more holistic and workable solution to what supports adult health and wellbeing that includes not only the mindset to achieve this, which positive psychology often also seeks to do, but of vital importance also, the mechanisms, including underpinning mechanisms that crucially provide the means to transform positive will into positive

action. Meanwhile, the adaptive pathway depicted in Figure 46 above provides a blueprint for how salutogenesis, resilience and coping can be achieved at the level of the individual.

Arguably, such an integrated framework (Figure 47) and the adaptive pathway associated with this (Figure 46) may also have wider translational potential to other carer groups, as well as adult populations more generally in terms of offering a holistic approach to adult health and wellbeing, including outside iatrogenic contexts, where they can provide an important means of securing health and wellbeing and preventing health problems from arising. Particularly so given that resilience, coping and salutogenesis are by no means exclusive to carers or solely the preserve of adults within iatrogenic contexts, or limited to paediatric contexts.

However, as this study demonstrates, the complexity of these three constructs and how they may sometimes uniquely operate and interact in specific contexts and circumstances first needs to be clarified in order for them to be applied in ways which maximise their effectiveness. This calls for further research to investigate how resilience, coping and salutogenesis can be combined to benefit other population groups in different contexts. Nevertheless, the findings may still possess wider translational potential at a more general level to other, perhaps similar population groups. In particular, among adults who share similar criteria and contexts to FCOPWA, i.e. adult carers of people with chronic life-limiting diseases (but not life-threatening) diseases and where there may be a relatively common ground in terms of shared experiences, equivalent challenges and comparable health inequalities. In particular, carers of adults with chronic and life-limiting neurodegenerative diseases or cardiovascular disease.

Furthermore, the collective grouping of similarly chronic, life-limiting, but non-life threatening diseases, together within a salutogenic-based paradigm as an alternative to the traditional Medical model may present a more viable solution with regard to how dementia might be dealt with separately from how health and social care systems deal with life-threatening diseases. Arguably, such a move could enable the carers and carees directly involved in such long-term diseases to be maximally supported via an approach which is geared towards health promotion, life-enhancement and quality of life. As opposed to perpetuating their positioning within a Medical model whose emphasis remains on a treatment-based approach and a primary fixation on the inevitability of health declines, deficits and loss, including for carers, that stands in total opposition to a resilience-based approach.

Moreover, the placing of carers and carees associated with similarly chronic, life-limiting, but non-life threatening diseases under a collective umbrella system that would perhaps exist outside acute care and the care of people with chronic, life-threatening diseases would also help to justify the practical, logistical, legal and financial investment and effort that would be required to establish such a separate, parallel care system. Increasing longevity in many societies, including here in the U.K., has

fuelled the need for the development of new and innovative ways to deal with the exponential increases in the numbers of those who will likely succumb to chronic, life-limiting diseases. Importantly, this also needs to include finding new ways to support and strengthen the position of family carers who provide the bulk of care to better enable them to carry out the carer role over the long term. In the process, to more effectively address the heightened vulnerability to health inequalities which they face as a consequence of taking on the carer role and which threaten to hinder long-term family care by jeopardising carers' own health and wellbeing.

Responding to these burgeoning issues, this study adds to the existing knowledge base by providing a comprehensive and explanatory account of how the family care journey in relation to the care of AD might be supported to ensure its maintenance. This despite the presence of health inequalities such carers face which may be more salient and potentially debilitating than previously reported and manifest in a more severe form of stress-CVS. Specifically, how the care journey can be negotiated by following an adaptive pathway that crucially enables carers to maintain control over CVS as the principal manifestation of the health inequalities they face. Additionally, how the three demi-regularities identified by this study-salutogenesis, coping and resilience-and their dynamic interplay can play a pivotal role in ensuring the effectiveness of this pathway by making it work. Essentially, the findings present specific ways, including contexts and mechanisms, in which adult resilience can be harnessed to strengthen health and wellbeing. Moreover, the findings may also have wider translational potential to other, perhaps similar population groups. Research into the resilience of family carers of elderly people represents a new line of research (Fontes & Neri, 2015), but one which looks set to become of inordinately greater importance in the future.

8.9 Chapter summary

This Chapter explored the potential of resilience to strengthen adult health and wellbeing and the need to understand how resilience operates as a process more fully in order to capitalise on its hidden potential. The rationale for selecting The Transactional Model as the basic framework for interpreting and explaining 'what works to support FCOPWA' was then explicated and the need to investigate the specific pathways that can lead to carer resilience was also discussed.

The Chapter then focused on the PTs outlined in the Findings Chapter, exploring these in further depth and subjecting them to further iterative refinement. This led to a summary detailing how the PTs could be integrated to provide a specific, adaptive carer pathway based on 'what works, how it works, for whom and in what circumstances.' Further light was also shed on how the three principal

demi-regularities which emerged from this study converged to exert a pivotal role in making the pathway work.

The Chapter concluded by discussing the wider translational potential of this study's findings, particularly the potential to harness resilience to promote adult health and wellbeing, to other, perhaps similar population groups. Additionally, how the overall findings might contribute to discussions regarding how the family care of people with similarly long-term, life-limiting conditions might be more optimally placed within a separate health and social care paradigm and system. The next Chapter will provide a brief overview of the main conclusions drawn by this study.

CHAPTER 9: CONCLUSION

9.1 Chapter introduction

This Chapter will provide an account of how the research aims were achieved and the research question addressed. The strengths and the weaknesses of how realist evaluation was applied in this study and the strengths and the weaknesses of the scientific realist (SR) approach more generally will then be examined. This study's findings will then be summarised, including its overall contribution to the existing knowledge base and the overall translational potential and potential research impact of this study. The Chapter concludes by presenting recommendations for future research.

9.2 Achieving research aims

To recap, phases 1 and 2 of this 4-phase study focused on the Rapid Realist Review (RRR) (see Boxes 1 and 2 of Figure 48).

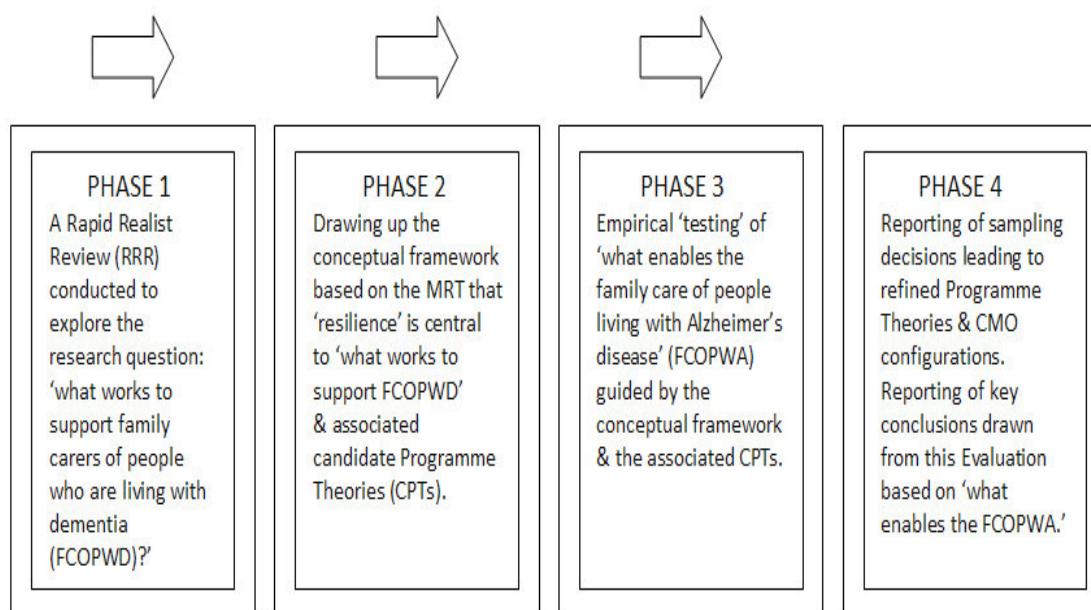


Figure 48. Four Phases of this study to investigate 'what enables the FCOPWA.'

The RRR initially addressed the question: 'what works to support family carers of people who are living with dementia (FCOPWD)?' This question was further narrowed (see Boxes 3 and 4 of Figure 48 above) to more specifically investigate: 'what enables the family care of people living with Alzheimer's disease (FCOPWA).' An important and timely research question in view of the exponential rise in Alzheimer's disease (AD), representing the most prevalent form of dementia in the U.K., as well as more globally, and the increasing reliance on family carers to provide the backbone of care, even in spite of the salient health inequalities such carers face.

9.3 Refinement of research aims

Phases 3 and 4 of this study which focused on empirical ‘testing’ of the CPTs against primary evidence (see Boxes 3 and 4 of Figure 48 above) included the rigorous critical analysis of each of the sub-Themes contained within the conceptual framework produced by the RRR and the CPTs associated with these. This culminated in the further refinement of this study’s research aims (Table 15).

Table 15. Further refinement of this study’s research aims following rigorous critical analysis of each of the sub-Themes contained within the conceptual framework produced by the RRR and the CPTs associated with these.

Research Aim 1

To determine which of the factors contained in the CPTs remained most critical the long-term maintenance and sustenance of the FCOPWA.

Research Aim 2

To determine the validity of the MRT ‘resilience’ and its contingency ‘resilience-building.’

Research Aim 3

To establish PTs that account for ‘what works’ ‘how’ ‘for whom’ and ‘in what circumstances’ with respect to ‘what enables the FCOPWA.’

Research Aim 4

To determine ‘when’ the PTs work.

Research Aim 5

To determine whether an additional MRT or MRTs might supersede or be conjoined with the existing MRT ‘resilience.’

Research Aim 6

To determine the validity of the conceptual framework derived from the RRR.

These aims were also informed by the need to consider how those factors which mediate resilience might change over time, particularly in response to different contexts and circumstances. This area of adult resilience research is sorely in need of expansion in order to gain a fuller understanding of how resilience operates as a process, including how it can be adaptively modified over time in response to changing contexts and circumstances that generate different challenges. Investigation of how adult resilience can be differentially supported over time currently represents a significant gap in knowledge (O’Dwyer, Moyle & Taylor et al; 2017) which this study sought to address.

9.3.1 Addressing refined research aims

Each of the six research aims outlined in Table 15 above will now be addressed in turn.

9.3.2 Achieving research aim 1

Research Aim 1

To determine which of the factors contained in the CPTs remained most critical the long-term maintenance and sustenance of the FCOPWA.

Following the analysis of the data collected during phase 3 of this study (see Figure 46, Box 3 at head of Chapter), what became salient among the emerging evidence was the extent to which FCOPWA appeared to devote time and energy to:

- (a) resolving problems that emerged in the context of dementia care in order to mitigate or attenuate the stressors these problems generated;
- (b) dealing with their emotional response to these problems, particularly where problems could not be immediately or directly resolved;
- (c) how carers' effectiveness in achieving these aims might mediate their perception of being in control of the care situation;
- (d) by corollary, the propensity for these efforts to contribute towards carers' perceptions of maintaining resilience despite adverse circumstances.

These factors shared some common elements with some of the CPTs, particularly those which related to: hope, adaptation, positive outlook, controllability, internal LOC (ILOC), resilience, acceptance, coping ability and strong carer-PWA relationship. These findings helped to determine which of the factors contained in the CPTs might be most critical the long-term maintenance and sustenance of the FCOPWA and directly informed the development of the eventual PTs in this study.

Further examination of the CPTs led to the conclusion that the Transactional Model (Lazarus & Folkman, 1984, 1987) offered a 'good fit' with both the common elements contained within these CPTs and the salient emergent findings from the interview evidence. Essentially, the Transactional Model provided a useful means of articulating and explaining 'why' FCOPWA invested so much time in resolving problems and /or dealing with their emotional response to them. Crucially also, the Model provided an explanation of 'how' these actions 'worked to enable the FCOPWA' by elucidating the processes involved and how these assisted in attenuating the principal manifestation of the health inequalities which they face-CVS. This study therefore builds on the existing Transactional Model, extending it and adding to the existing knowledge base by explicating how, when and what circumstances specific problem-focused coping (PFC) and emotion-focused coping (EFC) approaches and strategies 'work' to 'enable the FCOPWA' as part of an adaptive pathway carers might follow.

9.3.3 Achieving research aim 2

Research Aim 2

To determine the validity of the MRT 'resilience' and its contingency 'resilience-building.'

Perceived control over stressors is mediated by ILOC and can reduce physiological reaction to stress (Bollini, Walker & Hamman et al; 2004). ILOC also represents a mechanism that is closely associated with resilience (e.g. Luthans et al., 2006; Masten & Reed, 2005). A key finding of this study is that from the outset of the FCOPWA carers' willingness to remain adaptive to the changing context and circumstances which characterise the AD trajectory remains critical to 'what works.' Furthermore, that successful adaptation includes carers developing their ability to exercise effective control over CVS. Moreover, that this in turn can generate a sense of resilience in carers. Crucially also, the relationship between carers' ILOC and resilience is likely to be reciprocal with gains in one further strengthening the other. Data analysis confirmed the strong association between 'what enables the FCOPWA' and the MRT 'resilience.' It also elucidated how resilience might be achieved by FCOPWA and how this is intrinsically linked to carers' ability to control and manage the health inequalities they face, i.e. dealing effectively with CVS.

This study highlights the fact that without exception carers found themselves compelled to forge their own path independently of formal health and social care providers. This included developing their own ways of building and maintaining resilience. The emphasis that is placed here on exploring the ways in which carers develop resilience by relatively independent means and the prominence that is given to this by this study reflects this finding. Previous authors have voiced concern that research which is focused on resilience should not be based upon an expectation that individuals can achieve resilience alone (Fergus & Zimmerman 2005; Lindstrom 2001; Doll & Lyon 1998). This study shares these concerns and stresses that carers' development of a high level of independence is based on necessity and expedience rather than representing the ideal, responding to the lack of external support, right from the outset of the care journey and thereafter. The later concluding remarks concerning PT5 'Social coping' and the case this presents for the creation of a more 'enabling environment' by health and social care professionals underlines the key point: that resilience needs to be nurtured from without as well as from within.

9.3.4 Achieving research aim 3

Research Aim 3

To establish PTs that account for ‘what works’ ‘how’ ‘for whom’ and ‘in what circumstances’ with respect to ‘what enables the FCOPWA.’

Table 16. Summary of the Program Theories formulated to account for ‘what enables the FCOPWA.’

PT1	‘Carer hope forms part of a wider, collective belief in the potential to learn, adapt to and overcome the challenges presented by AD, as carers evolve to remain resilient despite these challenges.’
PT2	‘Resilience can be significantly enhanced throughout the Early Stage of AD where carers increase internal Locus of Control via the application of problem-focused coping (PFC) to directly mediate the source of stress by addressing the problem at its source.’
PT3	‘Towards the Mid-Stage of AD, FCOPWA come to rely on a dual approach in which problem-focused coping continues to prove instrumental to coping and dealing with solvable problems, while emotion-focused coping becomes necessary to regulate the potential stressors created by unsolvable problems which are largely driven by dementia symptoms.’
PT4	‘Resilience can be significantly enhanced as FCOPWA approach the Mid-stage of AD where carers adopt an increasingly Pragmatic caring style that provides a balance between carer control and attentiveness to PWA’s needs.’
PT5	‘As FCOPWA approach the Later stage of AD, resilience is maintained by adapting to fresh challenges via the EFC strategy ‘Social Coping’ which encourages support-seeking behaviour, while ‘Acceptance’ facilitates coping during the Palliative stage of AD.’

Table 16 provides a summary of the PTs that were established for ‘what works’ ‘how’ ‘for whom’ and ‘in what circumstances’ with respect to the question: ‘what enables the FCOPWA.’ Together with the CMOc’s which accompany them (see Chapter 8) they combine to provide an arguably clear and concise explanatory account of ‘what enables the FCOPWA’ and a comprehensive response to this research question. They emerged following a rigorous process of review and analysis and were selected on the basis of their ability to offer an account of the research question which carried the most explanatory potential in the light of all the literature and evidence that was available to the study.

9.3.5 Achieving research aim 4

Research Aim 4

To determine ‘when’ the PTs work.

While the 2013 G8 summit on dementia was lauded at the time as an attempt to finally recognise the importance of dementia and to put issues, including those of family carers and PWA, on the global

agenda, most progress in the U.K. since then appears to have been made in terms of achieving wider media coverage, rather than anything more substantial (Alzheimer’s Research UK, 2016). Attempts to address the issues surrounding the FCOPWA, particularly the question of its sustainability in the face of health inequalities, such as The 2014 Care Act have attracted criticism. Not least for their basis in a misguided assumption that we are already cognisant of family carers’ complex and changing needs within a care context that is in constant flux.

The RRR served to highlight the complexity surrounding ‘what works to support FCOPWD,’ as well as the lack of consensus regarding the best pathway to follow. The empirical testing phase of this study then proceeded to unpack some of this complexity and in doing so, to offer more specific guidelines for how FCOPWA can be supported via the adaptive adoption of a more definitive set of approaches, strategies and styles of caregiving in order to maintain resilience in the face of significant changes to the care context at specific junctures. The resulting PTs take fuller account of the complexity of the situation carers find themselves in and the associated need to differentiate how carer resilience can be developed and supported across the AD trajectory which is in constant flux (Figure 49).

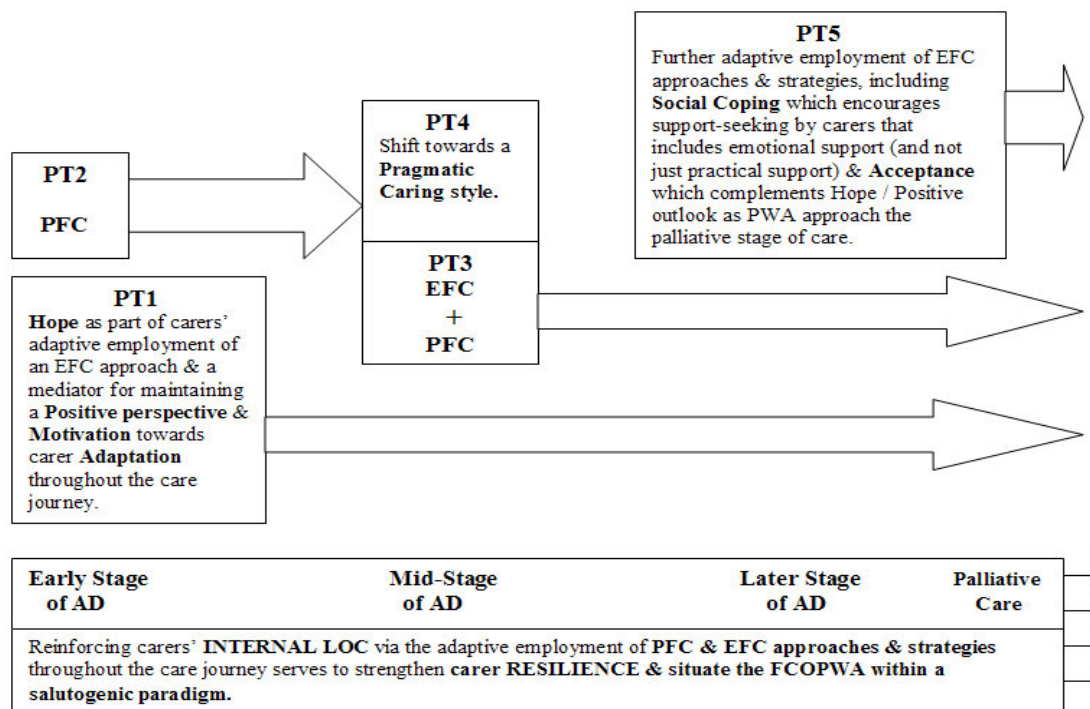


Figure 49. Summary of the adaptive pathway which is based on the Program Theories and can support family carer resilience over the course of the AD trajectory.

While it is acknowledged that individual carers’ experiences of the FCOPWA are likely to differ and that it is important not to ‘pigeon hole’ carers, there is at least a minimum requirement for some level

of guidance regarding how more adaptive pathways can be followed. The relatively high level of specificity contained within the resulting PTs arguably provides clearer guidelines regarding the adaptive pathway FCOPWA can follow, as well as increasing the translational potential of the findings.

9.3.6 Achieving research aim 5

Research Aim 5

To determine whether an additional MRT or MRTs might supersede or be conjoined with the existing MRT 'resilience.'

This study identified three principal demi-regularities which recur repeatedly throughout this study's findings: (i) resilience (ii) coping and (iii) salutogenesis. While the latter two demi-regularities do not replace 'resilience' as central to 'what enables the FCOPWA,' they nevertheless proved critical in respectively providing supportive mechanisms and a supportive mindset and perspective which very much lend themselves to carer resilience. Essentially, these three components collectively provide: the will, the way, the means and the mechanisms, including resilience as the crucial underpinning mechanism, to facilitate the role. Ultimately, enabling FCOPWA to maintain and sustain such care in the long term (see Figure 50 below). How these normally separate and discrete frameworks might be combined to further strengthen carer resilience provides a further potential avenue to explore, particularly with regard to developing a separate, parallel paradigm in which to situate the FCOPWA. This study strongly maintains the view that the traditional positioning of AD and the FCOPWA within the Medical model and its subsidiary 'the burden of care' paradigm lacks appropriateness to illnesses and diseases such as AD that do not lend themselves well to a medicalised approach and an emphasis on pharmacological and / or surgical intervention. Furthermore, that such medicalised paradigms are wholly at odds with the concept of carer resilience and resilience-building which would arguably be much better served by more salutogenic-based paradigms whose focus is on preventing ill health, preserving wellbeing and enhancing quality of life.

Moreover, that the development of a such paradigm, perhaps closely aligned with that which is depicted in Figure 50 below, not only presents a more suitable alternative paradigm in which to situate the FCOPWA, but also the care of people with other diseases that share similar characteristics, i.e. which are similarly chronic and life-limiting (but not life-threatening). Arguably, switching the emphasis towards 'enablement' and the maintenance of resilience despite adverse circumstances offers a considerably more constructive and effective approach than a more medicalised preoccupation with the inevitability of health deficits, incurability, irreversibility and decline, not only for PWA, but also those who care for them.

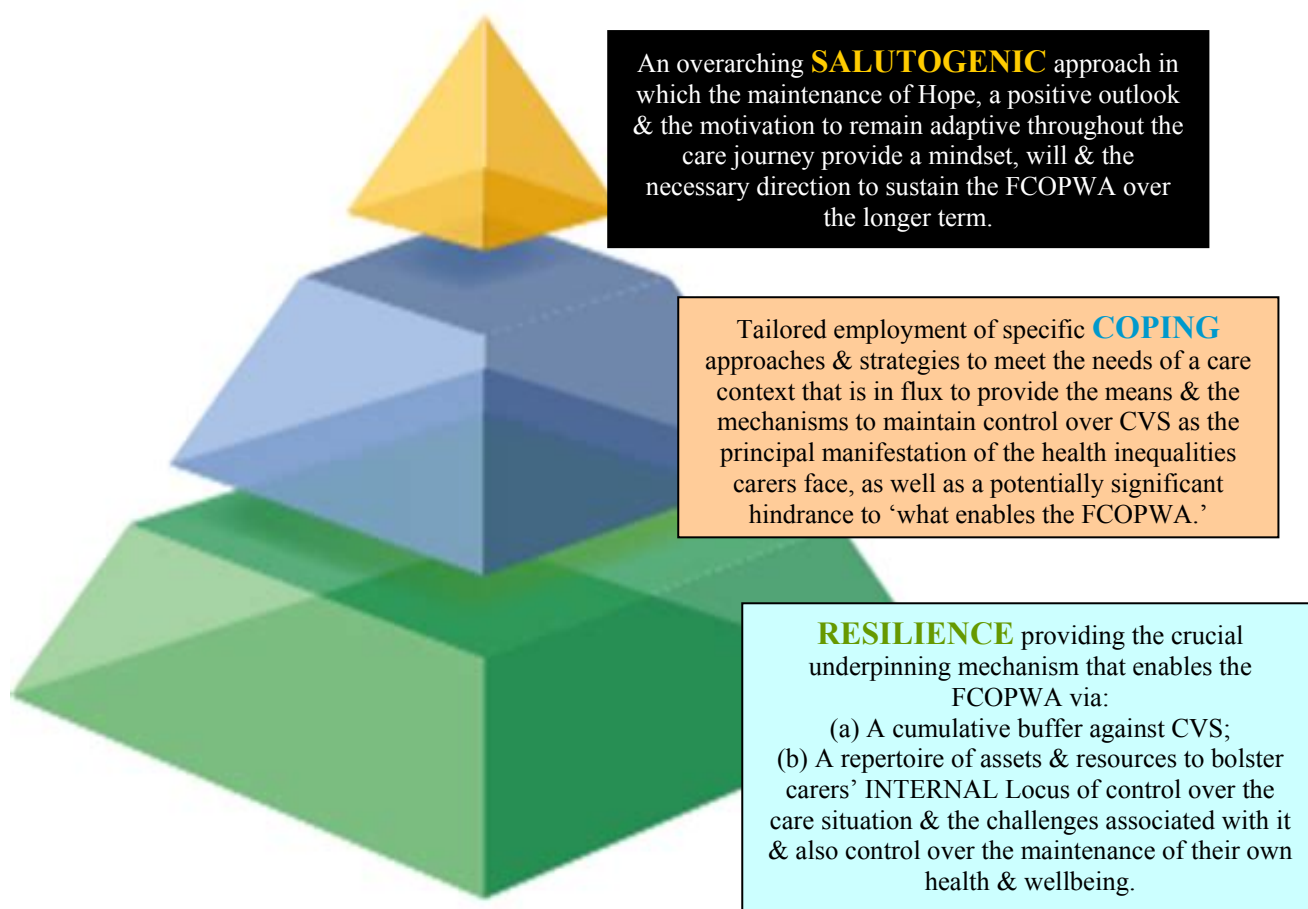


Figure 50. The three principal emergent demi-regularities derived from this study (i) Salutogenesis (ii) Coping & (iii) Resilience and how they combine to provide the will, the way & the means / mechanisms to maintain & sustain the FCOPWA over the longer term.

9.3.7 Achieving research aim 6

Research Aim 6

To determine the validity of the conceptual framework derived from the RRR.

This study singled out those CPTs which possessed the most explanatory potential in response to the research question: 'what enables the FCOPWA' and their inclusion was further warranted by their salience among the principal demi-regularities (see Figure 50 above) to emerge from this study. In keeping with the iterative nature of SR inquiry (Pawson, 2013, p.88), their further refinement via empirical testing culminated in the production of an adaptive pathway which incorporated the PTs. This pathway arguably possesses potential in terms of presenting guidelines, where no clear guidelines were previously available, regarding how FCOPWA can develop and maintain resilience. It also led to the

development of an alternative paradigm in which to more optimally situate the FCOPWA, as well as other, perhaps similar diseases.

However, this does not render the original conceptual framework which was derived from the RRR redundant. On the contrary, much of the evidence gleaned by the carer interviews confirmed the validity of several key aspects of the conceptual framework. However, there were also some notable exceptions that will now be discussed.

9.3.8 Summary of the confirmatory and contradictory evidence that relates to the conceptual framework derived from the RRR

Theme 1:

<p>Theme 1: Supportive social context</p> <p style="text-align: center;"><u>Sub-Themes</u></p> <p>(i) Strong Relational support network (ii) Good carer-PWD relationship (iii) Frequent Service provider liaison & support with family (iv) Family carers & PWD well integrated within a dementia friendly community (v) Regular Voluntary sector support & close links with other carers.</p>
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The interview data revealed how carers' relational support via family, friends and neighbours was extremely patchy. While some carers cited the emotional and practical benefits of close relational support, there was a more or less equal split with at least half of the respondents reporting extremely limited relational support. This underlined the need to ensure FCOPWA can gain access to external emotional support, as well as more practical support designed to promote increased socialisation for both carers and PWA. Instances of extreme carer and PWA isolation were found by this study and unquestionably this exacerbated the health inequalities they already faced. Emotional functioning is important to resilience (Fontes & Neri, 2015), therefore where carers have limited relational support there is a need to find alternative ways to address this. This study revealed how voluntary sector staff and peer support provided important means to address carers' need for emotional support. This study also found that carers would welcome increased opportunities to receive more formal, professional counselling on a 1:1 basis to meet their emotional needs.

The importance of carers maintaining a good relationship with the PWA was further emphasised by this study and given prominence by PT4.

A notable finding was the lack of formal, external support, especially from health and social care, and the need to establish a more collaborative approach that strengthens the carer-PWA-professional

triad. One which fosters a more 'enabling environment' that is conducive to sustaining the FCOPWA by encouraging carers' access to formal support at all Stages of the AD trajectory.

Although a less prominent finding, carers did report how their local community could make an appreciable difference in terms of creating a welcoming environment in which carers and PWA felt encouraged to continue to socialise.

This study reported how the voluntary sector and peer support could play instrumental roles in terms of offering carers emotional support, as well as invaluable knowledge and skills that contributed to 'what enables the FCOPWA.'

Theme 2:

Theme 2: Strengthening Key Psychological Assets available to carer:

Sub-Themes

- (i) Self-efficacy
- (ii) Hope
- (iii) Coping ability

The interview data revealed how FCOPWA felt compelled from the outset of taking on the carer role to rapidly develop autonomy in the absence of any tangible support from formal health and social care systems. This factor provided a catalyst for carers' rapid development of psychological resilience that is focused on strengthening their perceived control over the care situation. In the process, carers developed a strong sense of personal autonomy and a belief in being able to directly affect the course of life events, i.e. carers increased their ILOC and by doing so, strengthened their resilience. 'Hope' and 'Coping' both featured prominently in achieving this and pivotal to 'what enables the FCOPWA.'

Meanwhile, 'self-efficacy' exists as a close proxy for ILOC, particularly where the former is defined as 'the belief that one has the capability to successfully engage in specific actions and exercise control over events affect one's life' (Bandura, 1997). However, LOC more accurately conveys this study's finding that it is crucially carers' perceptions of being able to exercise control over their environment that is most instrumental in mediating role in how they adapt and adjust to a context that is challenging and also in flux. Moreover, how carers need to maintain ILOC in order to avoid its antithesis represented by external LOC and with this the belief that events are a consequence of chance, luck or fate, or to be controlled by powerful others (Rotter, 1966), i.e. health and social care systems. Buddelmeyer and Powdthavee (2016) also noted how an important property of ILOC is grit or perseverance in the face of adversity. ILOC rather than self-efficacy is more closely aligned therefore with this study's emphasis on

the importance to carers of the strength of the relationship between ILOC and resilience in enabling the FCOPWA.

Theme 3:

<p>Theme 3: Maintaining Carer's Physical Health Status</p> <p><u>Sub-Themes</u></p> <p>(i) Perceived level of health (ii) Objective measures of health (iii) Adherence to a healthy, balanced diet (iv) Regular physical activity (v) Perception of generally good quality / quantity of sleep</p>
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While the Medical model may continue to be prone to drawing a distinction between psychological and physical conditions that reinforces the concept of a 'mind-body' dichotomy, this study strongly argues the need for the close bond that exists between carers' physical health and psychological health and wellbeing to be more widely acknowledged and efforts redoubled to assist both. It represents a fallacy to make over-simplistic dissociations between carers' physical and psychological wellbeing and this study emphasises the importance instead of strengthening carers' psychological resilience in order to directly mediate carers' overall health and wellbeing. The saliency of the health inequalities faced by FCOPWA revealed by this study highlight how the AD care context can generate a unique variant of stress which impacts on both the psychological and physical health of FCOPWA. The combination of FCOPWA's experience of stress over a particularly long time course that can extend up to eighteen years (Clark, 2000) and the unique variability and unpredictability of challenges which occur on an almost daily basis, derived principally from AD symptoms and how these manifest themselves, provide fertile conditions for CVS (Herman, 2013; Katz, 1981). CVS is recognised as being distinct and separate from other forms of stress, e.g. acute or chronic stress, and generated by contexts where there is a continual and chronic exposure to highly variable and unpredictable stressors. This makes such stressors difficult to adapt to. Left unchecked, CVS can be especially debilitating, leading to symptoms that resemble clinical depression (Herman, 2013). Such symptoms are commonly reported in FCOPWA and recognised as a trigger for premature cessation of FCOPWA (Hirst, 2005).

The association between psychological resilience and physiological wellbeing has previously been confirmed by studies such as Bollini et al.'s (2004) which found that ILOC can mediate physiological reactions to stress leading to lower cortisol production. This study contends that intervention that is both carer-directed and externally supported and aimed at enabling carers to increase the control,

management and attenuation of CVS, remains pivotal to ‘what enables the FCOPWA.’ The findings of this study in no way denigrate the importance of the original Theme 3 sub-themes (see Box-out above), however this study’s identification of CVS as the principal manifestation of the health inequalities faced by FCOPWA, together with the finding that carer adaptations which enhance ILOC can crucially augment carers’ perceived control over stressors. Furthermore, how this lends itself to strengthening carer resilience and providing a protective buffer against CVS. These findings all drew attention to the need to view the larger picture in which the FCOPWA is set, including the need to situate interventions designed to support carers within a more salutogenic-based paradigm where carers may be set to benefit from the greater emphasis on strengthening carers’ psychological wellbeing in order to mediate physical health.

Theme 4:

<p>Theme 4: Safeguarding Carer’s Quality of Life</p> <p><u>Sub-Themes</u></p> <p>(i) Opportunities to experience of Positive affect (ii) Maintenance of Affect balance (iii) Subjective experiences of life, living & domains of life such as work, leisure & family remain generally positive (iv) Finding self-development, Growth & Meaningfulness in life through the care experience</p>

This study highlights the importance of the need for FCOPWA to maintain their experience of positive affect despite the generally reduced opportunity to socialise and engage in pleasurable activities, including hobbies, which such caregiving can induce. In particular, this study advocates the need for carers to be encouraged to embrace Social coping (PT5) as an EFC strategy, especially for its capacity to encourage support-seeking behaviour that facilitates the creation of opportunities to socialise and engage in pleasurable activities that promotes positive affect. Additionally, how this can enhance quality of life (QOL) for both the carer and the PWA. Furthermore, how this can deliver significant benefits to carers in terms of addressing CVS by bringing emotional benefits, including stress relief.

PT1 provides an account of how ‘Hope’ is intrinsic to ‘what enables the FCOPWA,’ instilling in carers a positive outlook and a mindset that is predicated towards the motivation and belief in carers’ potential to develop ways to adapt and overcome the challenges presented by AD care. Additionally, how ‘Hope’

crucially instils in carers an adaptive, overarching approach to the FCOPWA that encourages the adoption of a generally positive outlook, even despite adverse circumstances. 'Hope' and its capacity to promote positive outlook was also identified as instrumental to the emotion regulation achieved by PT3, facilitating positive appraisal of potentially adverse events. However, this study also makes a clear distinction between how 'positivity' is typically demonstrated by FCOPWA and how it is often portrayed by the 'positive psychology' movement. In particular, that carers' adoption of hope and positive outlook form part of a more pragmatic and 'down to Earth' approach to the FCOPWA in which the challenges presented are handled rationally, but where there is nevertheless a bias towards achieving success in overcoming them. How positivity is interpreted within the context of the FCOPWA should not be confused with positive psychology's more idealistic view: that it somehow confers the capacity to 'flourish' despite adversity and this study remains wary of drawing such a conclusion.

Close links also exist between QOL and salutogenesis (health creation) which combined encapsulate the core components of health promotion (Lindstrom, 1994). Meanwhile, salutogenic models can provide tools for the enhancement of QOL (Eriksson & Lindstrom, 2007), further illustrating how QOL and salutogenesis tend to go hand-in-hand. This study has already identified salutogenesis as critical to 'what enables the FCOPWA,' therefore where QOL and its enhancement further promotes salutogenesis to bolster carers' health and wellbeing, it needs to be encouraged. Hence, this study's emphasis on increasing opportunities to enhance QOL via Social coping (PT5). Moreover, this study highlights how the predominant Medical model and its subsidiary the 'burden of care' paradigm needs to be replaced by a more constructive and appropriate salutogenic-based paradigm in which there is a deliberate focus is on preventing ill health, preserving wellbeing and enhancing QOL.

A final point is that this study's overall emphasis on the need for carer adaptation and their pursuit of an adaptive pathway via the acquisition of new skills, knowledge, approaches and strategies remains very much compatible with the notion of self-development and growth. However, it is important to note how this is achieved in relatively pragmatic and 'down to Earth' way by carers, rather than via some more elaborate Damascene moment or epiphany that belongs more in the realms of positive psychology.

Theme 5:

Theme 5: Ensuring timely availability of Key
External Resources

Sub-Themes

- (i) Respite care tailored to individual needs
- (ii) Sitting Services & Befriending services
- (iii) Carer training, coaching & mentoring
- (iv) Relevant information & advice
- (v) Group CBT training
- (vi) Mindfulness training

A key finding was that following the AD diagnosis, FCOPWA frequently reported being left mainly to their own devices by formal health and social care services to organise and manage the FCOPWA and that this triggered the need for FCOPWA to establish their own independence and autonomy early on in the care journey. However, this study also emphasises how this becomes expedient for carers rather than representing the ideal and that carers found the lack of formal external support following the AD diagnosis a significant additional challenge they did not anticipate having to face. Given the health inequalities faced by FCOPWA, it is contended that this is unacceptable and that it should not be left to individual carers to ensure they maintain resilience despite facing significant challenges. This study therefore recommended that formal support be made available to FCOPWA at any point along the AD trajectory. Ultimately, a more even balance needs to be achieved between carers maintaining individual autonomy versus the creation of contexts which encourage collective responsibility, including the involvement of formal services.

Furthermore, that formal support systems and structures be designed to create an 'enabling environment' that improves how FCOPWA are supported throughout the care journey. This includes canvassing carers regarding what is most enabling for *them*, rather than simply assuming the answers to this important question are already known. For example, formal support appeared to revolve mainly around a predominantly Medical model-based approach incorporating the promotion of institution-like settings, (e.g. Day care, respite care, hospice care etc.) which were often perceived by carers and PWA to represent precursors to full institutionalisation of the PWA, a scenario which PWA and carers were generally keen to avoid. In addition, formal support was centred on the provision of practical support, however there appeared to be scant provision for much needed emotional support, such as 1:1 counselling.

In summing up, while the RRR found the sub-Themes outlined in Theme 5 above prevalent in the literature and this justified their initial inclusion in the conceptual framework, empirical testing subsequently revealed fundamental, systemic issues surrounding formal external support provision that

first needed to be addressed as a matter of priority. This should include consultation with carers to ensure that support is tailored to meet individual needs, rather than a ‘one-size-fits-all’ generic solution based on gross assumptions and an outmoded approach to carer support that needs to be updated.

9.3.9 Conclusions regarding achieving research aim 6

Research Aim 6

To determine the validity of the conceptual framework derived from the RRR.

Empirical testing uncovered both confirmatory and contradictory evidence for the key components contained within the original conceptual framework derived from the RRR. While much of the evidence gleaned from the carer interviews confirmed the validity of several key aspects of the conceptual framework, there were also some notable exceptions. Furthermore, empirical testing uncovered some of the deeper, fundamental issues surrounding the FCOPWA and ‘what enables it.’

Moreover, the conceptual framework arguably served its additional purpose well, i.e. as a platform and a utility for developing propositions based on the research question which could then be tested empirically.

9.4 The strengths of how Realist evaluation was applied in this study

The RRR took around seven months to complete, far quicker than more traditional review methods. This timeliness assisted the translatable potential of the research by increasing its relevance to contemporary public health needs. It also facilitated the speedy transition of the review’s findings into a workable theoretical framework and CPTs. This ensured the establishment of a robust platform for subsequent empirical testing. Importantly also, this was achieved in a timely manner as a key requirement of such multi-phase projects in order to expedite their completion despite the depth and rigour also demanded of such projects.

A further strength included addressing the notable absence of carers’ voices within many dementia-based studies and in narrowing the gap in knowledge concerning ‘what enables the FCOPWA’ from carers’ own viewpoint. A critical basis for gathering empirical evidence was established by the employment of in-depth interviewing to extract primary stakeholders’ own views based on their lived experiences. This accurately captured carers’ own lived experiences in order to learn at first hand ‘what enables them,’ as well as ‘how,’ ‘when’ and ‘in what circumstances,’ essentially, providing an insight into ‘the real’ (Angus et al; 2006) as an intrinsic part of this realist evaluation.

Much time, energy and rigour was devoted to compiling a substantial data base and in conducting a comprehensive analysis of this. As Pawson (2013, p.xvii) notes: ‘...evaluation research should significantly enlarge its explanatory ambitions...,’ but this comes at a cost in terms of challenge and the

workload it can present to ensure evaluation does not drown ‘under complexity’s menace’ but rather ‘comes up waving’ (Pawson, 2013, p.29). Therefore, while this study unquestionably involved much work in terms of time spent collecting, analysing and interpreting data, this process, despite it being arduous, arguably lent greater robustness to the study’s findings. Crucially, it paved the way for the three key demi-regularities represented by salutogenesis, resilience and coping to emerge as cornerstones of ‘what enables the FCOPWA’ and therefore critical to the evaluation’s overall findings.

The qualitative insights into participants' motivations and experiences achieved by this evaluation can make important contributions to translational research (Ogilvie, Craig & Griffin et al, 2009, p.4), and this is further assisted by the level of specificity that is established by this study regarding ‘what works,’ ‘how,’ ‘when’ and ‘for whom.’ This level of specificity included the formulation of a pathway by which carer resilience might be sustained across the AD trajectory, specifying the assets, resources and approaches that might be optimal at key junctures. Previously, a main concern was that no single trajectory existed regarding resilience that practitioners could recommend (McCubbin et al; 2002). Given that there are likely to be one million primary family carers of PWA in the U.K. alone in the coming years, the need to pinpoint underlying causes and develop strategies associated with ‘what works to support FCOPWA’ is critical and was achieved by this study. As the Frankel Report (Public Health Sciences Working Group, 2004) originally highlighted: ‘understanding causes, identifying strategies and evaluating their impact’ very much lends itself to translational research.

9.5 The weaknesses of how Realist evaluation was applied in this study

For nascent areas of research such as this study where the initial review (i.e. the RRR) reveals a wide spectrum of views but little consensus, this can and did generate a number of potential CPTs, each vying for attention. This was a situation compounded by the uncovering of the MRT ‘resilience.’ As Bonnano (2004) noted: the complexity and variety of human experiences that involve resilience ‘makes the study of resilience apposite but challenging.’ This underlines a key point—that the complexity of resilience makes it no easy option for study, particularly where it is applied to an already under-researched area—the FCOPWA. The empirical testing phase of this study therefore necessarily included a number of CPTs based around a comprehensive conceptual framework. This left a choice between arbitrarily jettisoning potentially crucial hypotheses prematurely or subjecting a wider range of CPTs to empirical testing first in order to make a more reliable and well informed decision regarding ‘hypothesis shedding’ and ‘hypotheses selection.’

However, this decision came at some necessary cost. The focus of SR-based investigations remains on uncovering how ‘processes’ determined by the combination of ‘context’ and ‘mechanism’ operate to generate certain outcomes. This is generally achieved in SR inquiries via three main analytical processes:

(i) realist review (ii) stakeholder consultation (iii) some form of synthesis of the main findings. Normally, the second criterion would be satisfied by the inclusion of a wide range of stakeholders' views, including users, service providers, policy-makers and practitioners to provide a 'rounded view.' The decision to devote additional time and energy towards testing a wider range of CPTs and achieving this by focusing exclusively on carers was not entered into lightly. However, this 'trade-off' was deemed justifiable on the basis that it would permit a fuller and more exacting investigation of the CPTs, while also concentrating this study's efforts more fully on primary stakeholders at the hub of this study.

Furthermore, it was deemed questionable how non-carer views would have made any significant contribution to addressing the research question. The existing literature is already replete with non-carers' views. However, a significant gap in current knowledge exists regarding carers' own views. In terms of addressing the research question, the views of non-carers were gauged to be largely supernumerary in comparison to carers' own views. The decision to devote time instead to investigating the wider array of CPTs represented an acceptable compromise therefore. Moreover, it represented a compromise which would be easy to remedy via the inclusion of a wide range of stakeholders in future follow-up studies, perhaps as part of further iterative testing of the PTs.

A key lesson learned however is that while certain parameters may often be set to narrow the focus of realist evaluation, this can be more problematic for nascent areas of research where there is a lack of consensus and further exacerbated where the initial phases of a study direct researchers down minimally unexplored paths (e.g. adult resilience). Ultimately, this can leave much to be evaluated by a single study that may well demand an ambitious approach and the investment of much time and effort to achieve.

A potential weakness of this realist evaluation that may also be pointed out is its deliberate framing within a positive perspective. However, consistent with the principles of SR, this bias was made transparent from the outset and is justified on the basis that there is a burgeoning need at present, both in the U.K. as well as more globally, for AD research that recognises family carers' strengths and capabilities. Particularly so given the exponential rises in AD prevalence and critical reliance on an ever greater number of family carers to provide the backbone of care.

A further criticism that might be raised is that the selection of participants from the voluntary sector constitutes convenience sampling by overlooking the views of carers who did not request voluntary sector support. However, to counter such criticism participants were selected to include a mixed group, with some regularly attending the Alzheimer's Society branch, but also others who rarely made any contact. That said, future studies might specifically include carers who have no contact with the voluntary sector to ascertain whether there are notable differences.

By the same token, this study excluded carers from BAME communities, while focusing primarily on carers from a specific sub-urban region in the North East of England. Carers' from ethnic minority backgrounds, as well as those from other parts of the country may well experience the FCOPWA differently from those involved in this study. Regional variations regarding availability of services and amenities can be dramatic. Similarly, differences have also been found in carers' experiences in rural versus more urban settings. Future studies might usefully focus more specifically on carers from BAME communities, as well as examine regional and urban / rural differences.

A further point is that while most studies of FCOPWD and resilience are cross-sectional (Dias, Santos & De Sousa et al; 2014), there is a need for more longitudinal studies to record individual carer's resilience and its development from start to finish in relation to the care journey.

9.6 The strengths of the SR approach

A key strength of the SR approach adopted by this study was its ability to address a complex public health issue to produce an explanatory account in response to the research question: 'what enables the FCOPWA' that provided much needed specificity regarding this important question. As Wong (2018, p.2) noted: 'Realist reviews and evaluations are best suited for making sense of complex interventions where context is thought to influence outcomes and answer questions that ask some or all of what works, for whom, in what contexts, to what extent, how and why?' This also involves taking fuller account of the potential for underlying processes or 'invisible program mechanisms' to give rise to causation, including human volition and reasoning, rather than automatically treating these as confounding variables as, for example, more positivist approaches do.

SR strives to maintain a neutral stance towards the PTs that have been drawn up and the avoidance of holding on to hypotheses too preciously via a preparedness to accept evidence that may be counter-factual where such evidence possesses strong validity. SR also avoids epistemological bias by striving to achieve a balance (rather than a polarity) between constructivism and positivism.

Furthermore, SR eschews methodological bias in favour of selecting the most appropriate methods suitable for uncovering (as far as possible) 'the truth' with regard to the research question under investigation, i.e. the tools for conducting research are chosen on the basis of their 'fit for purpose.'

An additional strength concerns SR's attempt to move closer to the 'reality' or 'the truth' regarding how 'real world' phenomena operate by observing the emergent patterns, common threads, social regularities, behavioural patterns etc. within causative chains (Pawson, 2013, p.8). SR also takes into account how these 'demi-regularities' remain inherently variable depending on changing context, including the fluid context denoted by time itself. Moreover, SR strives to move closer to the 'reality' or 'the truth' by focusing on the formulation of grass roots, 'user level' PTs, as opposed to deriving PTs

exclusively from 'upper stream' sources that may otherwise lead to practitioner-led PTs. The translational potential of SR findings is enhanced by the level of specificity and explanatory potential contained within PTs and CMO configurations. Overall, advocates of SR find that it meets a current need for a research approach which is capable of providing the level of specificity required to: (a) unravel social complexity (b) tailor solutions to meet the needs of specific population groups (c) deliver research findings which are sufficiently well specified to permit translational potential to further population groups.

9.7 The weaknesses of the SR approach

Historically, SR has represented 'a methodological approach' or orientation and overarching guide to carrying out research rather than a prescribed protocol per se (Pawson et al; 2005). Previous researchers have sometimes seized on the lack of a definitive protocol as a weakness of SR and a hindrance to its wider adoption as the research approach of choice. This issue continues to be addressed via the introduction of ever clearer guidelines regarding how SR inquiries can be conducted, e.g. RAMASES (Realist and Meta-Narrative Evidence Synthesis-Evolving Standards) updates, RAMASES training materials (e.g. Wong, Westhorp & Pawson et al; 2013) and publication standards guidelines (e.g. Wong, Greenhalgh & Westhorp et al; 2013).

Nevertheless, a challenge at the outset of this study was in finding and adapting a RRR protocol when only two key examples had been published. A similar argument could be raised with regard to the number of PhD studies that included realist evaluation, that examples to provide guidance were relatively scarce at the time this study was commenced. A further challenge lay in completing a realist evaluation with some necessary degree of autonomy as part of PhD and as part of the fulfilment of an academic qualification. As opposed to this task being more equally divided between several team members, as would normally be the case for a commissioned study.

Furthermore, as is consistent with the principles of SR, the fact that the PTs developed by this study are intended to be subjected to further iterative testing might be perceived by some to be a weakness in terms of producing answers which are conditional rather than absolutely definitive. However, this can also be perceived as a strength of SR: that subsequent testing is openly encouraged to garner additional evidence that adds to (or detracts from) the robustness of the findings, as part of the cycle of evaluation science in which hypotheses necessarily undergo further iterative testing that leads to revised theory (Pawson, 2013, p.88).

Moreover, a lesson learned by this study is that establishing the boundaries of investigation and evaluation can be more problematic for nascent areas of research where there is a lack of consensus.

Particularly so where the researcher is simultaneously diverted towards additional, emergent domains of research that further complicates the situation.

9.8 Summary

This study highlights how resilience, its contingency resilience-building can be combined to create a more 'enabling environment' that is more supportive of FCOPWA. Given that the number of such carers is set to rise to one million in the U.K. alone within the next few years and factoring in the million carers who will also be crucially reliant on them, the findings contribute to an urgent need to address how a significant portion of the U.K. population will be supported in future. This includes investigating new ways to support the maintenance of AD care, but crucially also, how to safeguard the health and wellbeing of those who lie at the heart of all this.

Resilience and its contingency resilience-building are also gradually becoming recognised for their potential in helping maintain adult health and wellbeing despite adversity. Previous barriers to exploiting this potential have included: (i) the reductionist view of resilience as a personality trait (ii) a main emphasis on paediatric research (iii) the medicalisation of resilience and its more limited application to adult crises and trauma (iv) nebulous conceptualisations of resilience that complicate rather than elucidate how it operates. In demonstrating the utility of resilience within the context of adult health in this study and crucially also how, when, for whom and in what circumstances this might be achieved, a more clearly delineated pathway is put forward to exploit the broader potential of this powerful resource. This study therefore supports the view that resilience is potentially available to all adults as a life-long, developmental process that is capable of being strengthened from within and bolstered from without by appropriate and timely external support.

Improvements in the context of adult health are not only brought about by drawing up interventions, such as how carer resilience might be developed and sustained, but also by clarifying the risk factors. This study therefore highlights the threat to the maintenance of AD care presented by CVS as the primary manifestation of the health inequalities faced by FCOPWA. Furthermore, how the management and control of CVS throughout the care journey is critical to maintaining carers' long-term health and wellbeing and thereby sustaining the FCOPWA. Moreover, that while carer resilience can provide an important buffer against CVS, it is imperative that it be supported via the creation of a more 'enabling environment' that is achieved through closer carer-PWA-professionals collaboration from the outset of AD care and for the duration of care. While this study found that resilient carers adopted mainly self-governed coping approaches and strategies and caring style, this was principally of necessity rather than representing any ideal scenario. The Prime Minister's '2020 Challenge' (DOH, 2016, p.13) places a clear emphasis on: (a) ensuring family-based care is extended for as long as possible (b) formal support only

becoming more apparent as PWA approach the Later stages of dementia. This study argues these aims are incompatible with each other and that the sustenance of long-term care relies on long-term support that includes both emotional and practical support, especially given the saliency of health inequalities such carers face.

As longevity continues to increase, both in the U.K. and globally, there is now a greater need than ever for life-enhancing approaches to adult health and wellbeing that take this profound demographic change into account. This study contends that the crucial ingredients which may be missing include not only the need for greater specificity regarding the practicalities concerning how resilience can actually be harnessed (see Figure 49), but also how they can be facilitated by their establishment within an alternative, more conducive paradigm, such as that presented earlier in this Chapter (see Figure 50). Ultimately, population health improvement needs to be the goal of translational research (Ogilvie et al; 2009). To this main end, the wider translational potential of resilience and of the alternative, more salutogenic paradigm outlined by this study, needs to be considered in relation to other, perhaps similar population groups. This could include adults with similarly long-term life limiting, but non-life threatening diseases. Moreover, the collective grouping of similarly chronic, life-limiting, but non-life threatening diseases, within such an alternative paradigm to the Medical model arguably holds out the potential to be effective for a much broader spectrum of the population. Additionally, the pathway to resilience detailed here may possess broader utility and perhaps also be of relevance to carers of people who belong to such a collective group.

Similarly, the contention that other, perhaps similar population groups may be also be vulnerable to CVS warrants further investigation to ensure their health and wellbeing is safeguarded. As Wong (2018, p.1) notes: 'The most useful theories in public health research are those that provide explanations, understanding and/or 'predictions' that are transferable from one situation to another.'

Applying this study's findings to a broader, collective population group would also help to justify the practical, logistical, legal and financial investment and effort that would be required. This has direct implications for informing the types of support and intervention that need to be incorporated as part of dementia policy and practice in future, but also the family care of other similarly chronic and life-limiting conditions. Increasing longevity in many countries calls for new and innovative ways to address the public health issues generated by this major and irreversible demographic change. Arguably, current policy and practice places the health and wellbeing of carers and carees in a position of jeopardy and this is avoidable. Left unchecked, this is a situation which not only threatens the premature cessation of family care, but in doing so also generates significant increases to existing formal health and social care costs. Ultimately, strategic investment in carers as part of a salutogenic approach represents not just a moral and ethical public health issue, but also makes sense from a long-term economic standpoint.

9.9 Future research

Ultimately, this represents a single study which covers several important emergent areas of research. These include: enabling the FCOPWA, strengthening adult resilience, the importance of protecting against CVS and the situating of certain diseases and their care within an alternative paradigm to the Medical model. Although this study attempts to move understanding forward with regard to these themes, particularly with regard to their impact on the FCOPWA, further research is warranted to investigate these nascent areas of research in greater depth. Consistent with the principle iterative testing that seeks to build exponentially via ‘...a gradual, progressive, cumulative process of inquiry’ (Pawson, 2013, p.112) there is a need for further iterative testing of the PTs developed here, as well as further investigation of the emergent areas of research which this study highlights. The present study therefore denotes a further step forward along a longer and hopefully further enlightening journey.

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Appendix 1: Initial scoping search RRR

Table 1. 1st literature search: search terms: Database: Google Scholar Abstracts.

<p>'Dementia + carers', 'Dementia + caregivers' 'Dementia +family carers', 'Dementia + unpaid carers' 'Dementia + informal care,' 'Dementia + informal carers,' 'Alzheimer's disease + carers', 'Alzheimer's disease +caregivers', 'Alzheimer's disease + family carers', ' Alzheimer's disease +unpaid carers', 'Alzheimer's disease + informal carers,' Alzheimer's disease + carers' 'caring for people with dementia', 'dementia + support', 'dementia + interventions' 'Dementia + barriers to support'</p>
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Appendix 2: Deductive process leading to identification of sub-Themes by the RRR

Establishing consensus among the disparate findings by noting the observed patterns and uniformities in the literature and in particular, noting the common ground shared by a range of main conclusions drawn from studies involving FCOPWD and drawing up a sub-Theme category label based on all this.

Theme 1: Extending social assets

- (1) Benefits of social support (Roth et al; 2005); dementia & loneliness (Moyle et al, 2011); larger social networks found to be a protective factor against chronic stress and caregiver depression (Kim & Knight, 2008; Gallagher, Ni Mhaolain & Crosby et al; 2011); benefits of family-based psychosocial interventions (Martire et al, 2005); reliance on family & friends to help deal with crises that emerge as part of dementia care (Toot et al; 2013); maintaining high levels of communication between PWD and family members (Walmsley & McCormack, 2013); differences between family members in relation to coping with PWD (Madsen et al; 2013); grandchildren's contribution to care of PWD (Philipp-Metzen et al; 2012); ethnic elders & inertia to seek diagnosis (Mukadam et al; 2011); rural based carers & isolation (Innes et al; 2014; Orpin et al; 2014; Blackstock et al; 2006; Hansen et al; 2005); Rural-urban differences (Tommiss et al; 2007); social isolation, particularly as the intensity and duration of care increases as dementia symptoms deteriorate (Mittelman, Haley & Clay et al; 2006); emotion-focused coping strategies including emotional support from social network reducing caregiver depression (Gallagher, Mhaolain & Crosby et al. (2011).

Conclusion

In terms of 'what works' maintaining a strong and supportive relational network that includes close and extended family, friends and neighbours appears to provide a buffer against carer stress. At the other extreme, weak social support predicts negative consequences for carers' health and wellbeing that may be exacerbated by isolation and loneliness.

(i) Sub-Theme associated with 'what works to support FCOPWD' identified as: 'Strong relational support network.'

- (2) Improving carer-PWD relations, Talking Mats initiative (Oliver et al; 2010); improving communication skills (Eggenberger et al; 2013; McKechnie et al; 2014); use of Talking Mats to improve communication (Murphy et al; 2013); quality of relationship between carer & PWD (Quinn et al; 2009; Ablitt et al; 2009); division of labour and responsibilities among family members (Goldsteen et al; 2007); family solidarity (Arlinghaus et al; 2005); carers learning to 'enter the world' of PWD as part of building new ways to communicate (Trevitt et al; 2006); relational-centred care (Morhardt et al; 2013); quality of relationship between carers & PWD (Singh et al; 2014); poor family functioning at outset predicts higher carer strain (Heru et al; 2006); close relatives as a key resource following diagnosis (Personen et al; 2013); support from carers of PWD to create opportunities for PWD to remain involved in decision-making (Fetherstonhaugh et al; 2013; Smebye et al; 2012); DVD-based training to improve carer-PWD communication (Liddle et al; 2012); importance of good communication between carers & PWD (Savundranayagam et al; 2005); carers developing a non-blame culture towards PWD (Nolan, Ingram & Watson, 2002); positive reappraisal of carer events promotes a positive carer-PWD atmosphere (Hildon, Montgomery & Blane et al; 2009); need to promote equitable relations between carer & PWD (Graham et al; 2006); carers of PWD often face social strain (Tang et al; 2011); weaker carer-PWD relationships provide one of the main precursors to cessation of family care (Shim et al; 2011); importance of good communication between carer & PWD (Kurz et al; 2010); attachment style that is closely inter-related with avoidance coping strategies predicts higher anxiety & predisposition towards cessation of family care (Cooper et al; 2008); poor quality of relationship between carer & PWD

predicts higher rates of anxiety & depression (Mahoney et al; 2005); carer living in locum with PWD predicts higher anxiety but not depression (Mahoney et al; 2005); behavioural management skills helping maintain good relations (Farran, Gilley & McCann et al; 2007; Sorenson, Duberstein & Gill et al; 2006).

Conclusion

In terms of 'what works' maintaining good communications, interaction, handling of potential conflicts maintenance of a good carer-PWD rapport appears crucial. At the other extreme, poor carer-PWD relationships predict compromise to carers' and PWD's wellbeing that may precipitate cessation of FCOPWD.

(ii) Sub-Theme associated with 'what works to support FCOPWD' identified as: 'Good relationship with PWD.'

(3) Formal care networks (Rutherford et al; 2014); dementia care triads (Adams et al; 2005); citizenship practice & social worker relations (Brannelly, 2011); formal services: emotional support needed in addition to practical support (Benbow, Ong & Black et al; 2009); telephone support services (Salfi, Ploeg & Black, 2005); need for joined-up services in rural areas (Winterton & Warburton, 2011); benefits of carer support groups on carers' psychological wellbeing (Chien et al; 2011); improving connectivity between family carers & professional support bodies via trust (Carpentier et al; 2012).

Conclusion

In terms of 'what works' frequent service provider liaison and support with family was identified as important, not only to deliver practical support but also emotional support. However, there was a need to ensure good connectivity between formal service providers and FCOPWD. This could be achieved by a variety of means, including telephone contact. There was also a need to ensure that equal partnerships were established between carers, PWD and service providers.

(iii) Sub-Theme associated with 'what works to support FCOPWD' identified as: 'Frequent service provider liaison and support with family.'

(4) Better community integration, Woods et al; 2009); attitudinal change by communities (O'Sullivan et al, 2014); Supportive local communities an asset to dementia care (Blackstock, Innes & Cox et al; 2006); social acceptance of dementia (Robinson et al; 2012); importance of efforts to improve social connectedness & social inclusion for carers of PWD (Daly et al; 2013).

Conclusion

In terms of 'what works' supportive communities encourage acceptance of dementia, inclusion in everyday activities, reduction of stigma and increased social capital among FCOPWD.

(iv) Sub-Theme associated with 'what works to support FCOPWD' identified as: 'Family carers and PWD well integrated within a dementia-friendly community.'

(5) Peer support (Brooks et al; 2014), mutual support groups (Wang et al; 2011); on-line form peer support (McKechnie et al; 2014); interventions involving peer support by voluntary groups (Egdell, 2012); peer group signposting (Robinson et al; 2012); emotional and practical support found in local, informal support groups (McLaughlin & Jones, 2011); low use of computer-based forums (McKechnie et al; 2014); benefits of carer support groups on carers' psychological wellbeing (Chien et al; 2011).

Conclusion

In terms of 'what works' face-to-face meetings, particularly with peers, can provide practical and emotional support to FCOPWD and mutual benefits of improved wellbeing. The voluntary sector provides a useful meeting place and forum for peer support to flourish.

(v) Sub-Theme associated with 'what works to support FCOPWD' identified as: 'Regular voluntary sector support and close links with other carers'

Theme 2: Strengthening key psychological resources available to carers

(1) Coping & locus of control (Bruvik et al; 2013); Carer Control / empowerment (Samsi et al; 2013; Pearce et al; 2012; Nomura et al; 2009); carer autonomy (Lin et al; 2012); sense of coherence in caring (Andren et al; 2008; Valimaki et al; 2014); carer efficacy (Crellin et al; 2014); lack of choice in taking on the carer role-lack of control (Egdell, 2012); increased locus of control linked with peer-led support groups (Kurz et al; 2005); taking on greater degree of decision-making by carers of PWD (Samsi et al; 2013); low sense of coherence associated with higher carer anxiety & depression (Orgeta et al; 2013); self-efficacy & its utility (eHuang, Shyu & Chen et al; 2003); locus of control (Tyrell et al; 2006); self-efficacy of carers (Uei et al; 2013); tailored computer-based interventions may improve carer self-efficacy (Boots et al; 2014); psychosocial interventions & improved self-efficacy of carers (Van Mierlo et al; 2012); The Savvy Caregiver program (Hepburn, Lewis & Tornatore et al; 2007); importance of ability to forward plan, (Ducharme et al; 2011).
Conclusion

Self-efficacy: 'the belief that one has the capability to successfully engage in specific actions and exercise control over events that affect one's life' (Bandura, 1997) features prominently within the literature based around discussions of 'what might work to support FCOPWD.' The benefits to FCOPWD include: higher perceptions of control, empowerment, autonomy, sense of coherence and forward planning, as well as lower rates of anxiety and depression.

(i) Sub-Theme associated with 'what works to support FCOPWD' identified as: 'Self-efficacy.'

(2) Hope moderating psychological distress (Rustøen, Cooper & Miaskowski, 2010); hope instilling positivity (Donovan & Corcoran, 2010); Hope as a key psychological carer resource (Sun, Tan and Fan et al's (2014); positive focus & self-efficacy (Carbonneau et al; 2011); positive health or well being optimal (Antonovsky, 1996).

Conclusion

Hope tended to be encapsulated within research whose focus was on the importance of promoting carer positivity. Although less salient than other psychological constructs such as self-efficacy and coping, hope / positivity often featured within the literature as a potentially important psychological asset in times of adversity. Hope and its contingent hopefulness also represent an antidote to more traditional 'burden of care' models of dementia care which the present study was striving to find a more constructive and positive alternative to. While constructs such as self-efficacy and coping ability can often be represented by the strategies and interventions designed to promote them, hope arguably goes further to instil an attitudinal and motivational belief in being able to maintain and sustain the FCOPWD. Arguably, hope therefore represents an important mindset and perspective that can be adopted by carers that can exert a potentially strong influence on care outcomes.

(ii) Sub-Theme associated with 'what works to support FCOPWD' identified as: 'Hope.'

(3) Coping & coping strategies (Cooper et al; 2012); Perera et al; 2014; Knapp et al; 2013; Moore et al; 2013); START strategy, coping style (Cooper et al; 2014); coping strategies (START program) (Li et al; 2014); Livingston et al; 2014) START program psychological intervention for carers of PWD; coping strategies intervention (START) review (Sommerland et al; 2014); the START program (Knapp et al; 2013); coping (Tetley, 2013); coping (Tottie, 2010); Carer groups psychosocial intervention support (Van Mierlo et al ; 2012); coping strategies (Li et al; 2012); importance of finding ways of coping (Quinn et al; 2008); sense-making & coping, active problem-solving versus avoidance coping (Williams et al; 2014); coping models (Satre et al; 2006); psychosocial interventions for carers of PWD (Gatz, 2007); psychoeducational courses to

support health & wellbeing of carers (Milne et al; 2014); negative impact of avoidance coping strategies (Kim et al; 2007); emotion-focused coping strategies (Iavarone et al; 2014); coping style & carer mood & anxiety (Li et al; 2014), (2012); coping style correlated with anxiety (Cooper et al; 2007; 2006); carers' coping strategies (Egdell et al; 2010); problem-focused coping coaching for carers face-to face & via telephone counselling effective (Nomura et al; 2009); teaching coping strategies (Selwood et al; 2007); submissive approach to coping correlated with carer burnout (Yilmaz et al; 2009); coping (Bruvik et al; 2013); counselling programs that target coping & stress (Kurz et al; 2005).

Conclusion

'Coping ability,' which is succinctly defined by Li, Cooper and Bradley et al. (2012) as 'the process by which people manage stress' features prominently within the literature based around discussions of 'what might work to support FCOPWD.' Advantages conferred to FCOPWD via enhanced coping abilities or strategies include: flexibility and problem-solving, as well as improved management of stress and anxiety.

(iii) Sub-Theme associated with 'what works to support FCOPWD' identified as: 'Coping ability.'

Theme 3: Maintaining carer's physical health status

(1) CAPS (Caregivers for Alzheimer's disease problem scale) monitoring carers' health (Livingston et al; 2005); subjective wellbeing (Hammond et al; 2014); Subjective health of carers (Andren et al; 2005); perceived levels of stress can make a unique contribution to depression (Simpson & Carter, 2013); health self-perceptions and health outcomes (Gross, 1998); psychosomatic factors associated with carer health (Hirst, 2005); depression in carers of PWD (Smith et al; 2011); Depression & distress & c.v.d. link (Mausbach et al; 2007).

Conclusion

How carers perceive and gauge the strength of their ongoing health and wellbeing may be largely subjective. Indices for perceived health are often closely associated with risk factors for health and wellbeing and disease indicators. External and self-monitoring of carers' perceived level of health may be as important as physical measures, particularly where the cumulative effects of chronic stress may take considerable time before they are fully manifest in the form of physical symptoms.

(i) Sub-Theme associated with 'what works to support FCOPWD' identified as: 'Perceived level of health'

(2) Importance of maintaining carers' health in order to sustain family care of PWD via regular contact with G.P. (Downs, Turner & Bryans et al; 2006); psychosomatic links to carers' physical health: depression & distress & c.v.d. link (Mausbach et al; 2007); carers' health status pivotal to maintenance of family care or cessation (Newbronner, Chamberlain & Borthwick et al; 2013); carers' health widely recognised for its importance in helping family carers to maintain the long-term care of a PWD (The Carers Act, 2014).

Conclusion

The strong links between carer stress, the potential repercussions of this on carers' psychosomatic health and how all this influences carers' decision to maintain or cease the FCOPWD make it important that external monitoring and intervention to safeguard carers' health and wellbeing is ensured. This is likely to rely mainly on objective measures of health overseen by carers' G.P.

(ii) Sub-Theme associated with 'what works to support FCOPWD' identified as: 'Objective measures of Health.'

(3) Adherence to a healthy, balanced diet associated with positive coping and strong locus of control in relation to the maintenance of health (Saklofske, Austin & Galloway et al; 2007); self-care via healthy lifestyle choices & carer benefits (Schindler, Engel & Rupprecht, 2012); slow-burning carbohydrates to provide

sustained energy to help counteract the chronic fatigue (Corbin & Strauss, 1988); carers missing out on meals for themselves in order to attend to other daily tasks (Carers UK, 2013); negative coping styles associated with weight gain and maladaptive dietary habits (Pargament, Koenig & Tarakeshwar et al; 2004).

Conclusion

Despite the paucity of research in this area, adherence to a healthy, balanced diet as part of a wider self-care strategy that includes adaptive lifestyle choices may prove valuable in terms of 'working' to support FCOPWD.

(iii) Sub-Theme associated with 'what works to support FCOPWD' identified as: 'Adherence to a healthy, balanced diet'

- (4) Maintaining carers' physical health status, physical exercise & tentative evidence for health benefits (Orgeta et al; 2014); Regular physical activity carries physical and psychological health benefits for carers (Alzheimer's Society, 2015); exercise and reductions in perceived stress (Connell & Janevic, 2009); regular engagement in physical activity and markedly greater well-being in older adults (Steptoe, Demakakos & de Oliveira, 2012); lack of self-maintenance linked to carer burnout (Yilmaz et al; 2009).

Conclusion

Although only a handful of studies have examined the issue of carers' maintaining regular exercise in order to derive longer-term health benefits, the evidence gathered to date suggests that in terms of 'what works to support family carers of PWD' regular exercise may help to safeguard carers' physical health, but importantly also provide psychological benefits that include reductions in perceived stress.

(iv) Sub-Theme associated with 'what works to support FCOPWD' identified as: 'Regular physical activity.'

- (5) Two thirds of FCOPWD potentially affected by some form of sleep disturbance (McCurry & Teri, 1995); achieving good quality and quantity of sleep difficult for FCOPWD (Ornstein & Gaugler, 2012); 'sundowning' phenomenon and adverse effects on carers including sleep deprivation, exhaustion and reduction in perceived ability to cope (Newbronner, Chamberlain & Borthwick et al; 2013); psychological interventions demonstrate particular effectiveness (Schulz, O'Brien & Czaja et al; 2002); meditation and yoga benefits for sleep (Waelde, Thompson & Thompson-Gallagher et al; 2004); inverse relationship between sleep quality and levels of daytime exhaustion impacting especially on older caregivers (McKibbin, Ancoli-Israel & Dimsdale et al; 2005); disruption to sleep patterns in carers has been linked to depression (Simpson & Carter, 2013); improving carer sleep and use of day-care (Zarit et al; 2011).

Conclusion

In terms of 'what works to support family carers of PWD' the imperative for adequate sleep quality and quantity is frequently highlighted in the literature. Given the links between sleep disorders and the onset of depression and the latter's association with cessation of FCOPWD, interventions designed to address this carer issue remain crucial.

(v) Sub-Theme associated with 'what works to support FCOPWD' identified as: 'Perception of generally good quality and quantity of Sleep.'

Theme 4: Safeguarding carer's Quality of Life (QOL)

(1) Pleasant events / experiences-positive affect (Chattillion, 2013); negative affect (Brummett et al; 2006); QOL of carers of PWD (Crellin et al; 2014); increasing carers' ability to perceive positive aspects to caregiving (Liddle et al; 2012); depression negatively correlated with QOL / having a hobby positively correlated with QOL (Bruvik et al; 2012); singing together group activities benefits to carers, Camic et al (2013); targeting

specific components of caregivers' QOL critical to 'what works for FCOPWD' (Gallagher-Thompson & Coon; 2007); positive affect an important protective factor to help offset age associated health losses (Pinquart, 2001); good QOL & positive impact on carers (Schindler, Engel & Rupprecht et al; 2012); promoting positive affect via CBT programs delivered via DVD & carer benefits (Gallagher-Thompson, Wang & Liu et al; 2010).

Conclusion

Perceiving positive affect (feelings of active pleasure) via good quality of life (QOL) activities can exert a positive impact on FCOPWD that also translates into health and wellbeing benefits, including providing a protective factor against depression.

(i) Sub-Theme associated with 'what works to support FCOPWD' identified as: Opportunities to experience positive affect (feelings of active pleasure).'

(2) Safeguarding carers' quality of life (Bruvik et al; 2012); QOL (Ho et al, 2009); factors associated with QOL (Papastavrou et al; 2014); identified carers' QOL highly valued aspect of their lives and important to maintain (Qureshi, Bamford & Nicholas et al; 2000); importance of maintaining QOL & links with health and wellbeing (Argimon, Limon & Vila et al; 2004); The PEAR (Pleasant Events and Activity Restriction model) protective for a number of carer health and QOL outcomes (Chattillion, Ceglowski & Roepke et al; 2013); preoccupation with risk-management of PWD by carers impairs engagement in other activities (Walker et al; 2006); managing decreasing cognitive ability of PWD & maintaining QOL (Grose et al; 2013); carer 'downtime' / breathing space & health benefits (Martinez Cepero, 2012); higher reports of care as burden, older age of carer & longer time spent caring all negatively correlated with QOL (Serrano-Aguilar et al; 2006); safeguarding carers' quality of life, carers social life can suffer, McKechnie et al (2014); maintaining QOL & health benefits (Stirling, Andrews & Croft et al; 2010; Croog, Burleson & Sudilovsky et al; 2006); maintenance of QOL & links with continuance of family care (Coon, Thompson & Steffen et al; 2003).

Conclusion

Despite the possibility of waning opportunities for FCOPWD to continue to engage in QOL activities that promote positive affect, there is a need to strive to maintain positive affect. Not least to ensure a balance against negative affect that may be experienced during times of adversity, including encountering challenges during the FCOPWD.

(ii) Sub-Theme associated with 'what works to support FCOPWD' identified as: 'Maintenance of Affect balance.'

(3) Interventions that help carers focus on positive aspects of caregiving recommended (Toljamo et al; 2012);

low satisfaction with leisure activities correlates with higher inflammatory response-a marker for chronic stress in carers & precursor to developing c.v.d. (Kanel et al; 2014); positive framing mediates the impact of carer stress (Hilgeman, Allen & DeCoster et al; 2007); carers who focus on positive memories shared with the PWD from the past & increased positivity (Shim, Barrosa & Davis, 2012); cognitive reappraisal in which carers are encouraged to review the positives-an effective coping strategy (Nolan & Lundh, 1999).

Conclusion

Maintaining a generally positive outlook & remaining biased towards positive subjective experience of life can promote health and wellbeing benefits for FCOPWD.

(iii) Sub-Theme associated with 'what works to support FCOPWD' identified as: 'Subjective experiences of life, living and domains of life remain generally positive.'

(4) Making sense of dementia (Stokes et al, 2014); safeguarding carers' quality of life-engagement in meaningful activities outside the care setting (Roach et al; 2014); carer meaning found in opportunity to reciprocate

care received from the PWD earlier in life (Rigaux, 2009); finding meaning and growth via the caregiver experience helps to foster positivity (Meuser, Marwit & Sanders, 2004); spouses making sense & adjusting following diagnosis of dementia (Robinson et al; 2005); positive reframing & carers' personal growth (Ott, Sanders & Kelber, 2007).

Conclusion

Finding meaning and growth through the FCOPWD shares links with remaining biased towards the positives to be gained from the caregiving experience. The latter has been identified as a further protective factor against carer stress.

(iv) Sub-Theme associated with 'what works to support FCOPWD' identified as: 'Finding self-development, growth and meaningfulness in life through the care experience.'

Theme 5: Ensuring timely availability of key external resources

(1) Respite care (Downes, 2013), (Phillipson et al; 2013); day respite care benefits & obstacles to access (Robinson et al; 2012); barriers to uptake of respite by carers (Phillipson et al; 2014); a 'one-size-fits-all' approach to respite care provision will not meet needs (Vecchio et al; 2008); benefits to carers of respite care (Tang et al; 2011); day care & carer stress reduction link (Zarit et al; 2011); strategies supporting carers to reduce PWD resistance to attending day care (Nogales-Gonzalez et al; 2014); respite care & carer financial strain (Aggar et al; 2014); use of respite care & maintenance of family care of PWD & need to match services to needs Phillipson et al; 2014); decision aids assist carers to make timely choices regarding uptake of respite care (Stirling et al; 2012); benefits to family carers of taking up respite & care-avoidance of institutionalisation (Parker, Mills & Abbey 2008; Eagar, Owen & Williams et al; 2007; Gaugler, Kane & Kane et al; 2005); low uptake of services by carers of PWD compared with carers of people with other illnesses (Singh et al; 2014); no standard provision of carer support available Flynn et al; 2013); consideration of the need for respite care to support carers (Prince et al; 2012); number of hours spent caring correlated with carer strain (Pinatti de Moraes et al; 2009); uptake of short-term residential care by carers of PWD improved by bespoke staff training in dementia care, design of appropriate activities for PWD & emphasis on benefits to carers (Donath et al; 2009); need for good service co-ordination (Robinson et al; 2009); flexible approaches to respite (Shanley, 2006); 'host family respite' high satisfaction but barriers to be overcome (Boldy et al; 2005); need to promote services to encourage higher carer uptake (Brodaty et al; 2005); advice and signposting of carers towards respite care services could be improved (Egdell, 2012).

Conclusion

The potential benefits to family carers of taking up respite care have been widely reported, including its capacity to help extend family-based care and the avoidance of institutionalisation. However, there may be issues regarding the precise form respite care should take, tailoring of respite to meet individual carer's needs & wider efforts to improve uptake by FCOPWD.

(i) Sub-Theme associated with 'what works to support FCOPWD' identified as: 'Respite care tailored to individual needs.'

(2) Longer term use Sitting / Befriending services may be linked to improvements to carers' psychological wellbeing, including reductions in carer depression (Charlesworth, Shepstone & Wilson et al; 2008); low uptake of befriending services Charlesworth et al (2008); home care support that is bespoke to dementia Rothera et al (2008);

Conclusion

Initial findings indicate that the longer term use of Sitting / Befriending services may be linked to improvements to carers' psychological wellbeing. However, FCOPWD need to be able to trust in the quality of such services before considering its uptake.

(ii) Sub-Theme associated with 'what works to support FCOPWD' identified as: 'Sitting services / Befriending services.'

- (3) Training programs for carers of PWD, e.g. Samuel et al (2014); behaviour management (Gaugler et al ; 2005); carer training via psychoeducational DVD (Gallagher-Thompson et al; 2010); education & training & flexible home care services valued by carers (Toot et al; 2013); education of carers to ensure advanced care planning-need for timeliness (Denning et al; 2011); training programs for carers that offer practical caring skills increasing empowerment (Yeandle & Wigfield, 2011); rehearsal of behaviour management techniques increases carers' self-efficacy and coping skills (Daly, McCarron & Higgins et al; 2013); combining carer training with peer support (Dowrick & Southern for Alzheimer's Society, 2014); need for carer training- lack of caregiving experience provides one of the main precursors to cessation of family care (Shim et al; 2011); gaps in knowledge of Alzheimer's disease by carers (Carpenter et al; 2011); basic education about dementia & development of behaviour management strategies can reduce carer stress (Guerra et al; 2011); education & training for carers 2.5 hours over 5 weeks effective (Gavrilova et al; 2009); carer skills enhancement programs & success (Eayrs et al; 2009).

Conclusion

Training programs for FCOPWD that offer practical caring skills such as behaviour management have been shown to help to increasing empowerment, self-efficacy and coping skills. However, there are issues concerning who should be responsible for such training provision, accessibility for all carers, time available to FCOPWD to attend and ensuring carer training does not replace formal services' continuing role in supporting FCOPWD.

(iii) Sub-Theme associated with 'what works to support FCOPWD' identified as: 'Carer training, coaching and mentoring.'

- (4) Information & support services for carers (Thompson et al, 2007); information for carers soon after diagnosis of dementia (Ducharme et al; 2011); the need for well co-ordinated post-diagnostic support for carers of PWD (Gorska et al; 2013); E.U. funded STAR Web portal offering carers of PWD support (Boyd et al; 2014); need for information for carers following diagnosis (Stokes et al; 2014); ALADDIN computer-based support & networking aid (Torkamani et al; 2014); lack of knowledge / awareness of benefits of ACP (advanced care planning) by carers of PWD (Dickinson et al; 2013); value of information services (Corbett et al; 2012); FCOPWD's information needs are high each time the PWD progresses to a new phase of their illness (McLaughlin & Jones, 2011).

Conclusion

Increasing access to information for FCOPWD can ensure they know about and can navigate key services. Relevant information and advice can also empower FCOPWD to make their own decisions, thereby increasing self-efficacy.

Evidence also suggests FCOPWD may benefit most from a strategic approach to the delivery of information and advice or alternatively, have access to initial guidance which provides specific advice and information to cover specific milestones along the dementia trajectory.

(iv) Sub-Theme associated with 'what works to support FCOPWD' identified as: 'Relevant information and advice.'

- (5) Telephone-based CBT support (Gluekauf et al; 2012); effectiveness of CBT as a therapeutic intervention for carers of PWD (Hall et al; 2012); psychosocial interventions can support carer health & stave off cessation of family care (Brodaty et al; 2003; Spiyker et al; 2008); cognitive reframing-a component of CBT can reduce carer stress (Vernooij-Dassen et al; 2011); psychoeducational training had the broadest effect on carer outcomes (Pinquart & Sörensen, 2006); CBT and links with promoting positive affect (Gallagher-Thompson et al; 2010)

Conclusion

CBT relies on targeted strategies to help people to adopt more adaptive patterns of thinking and behaving. CBT may provide a useful role as a preventative measure that confers protection against the impact of stress on FCOPWD. However, how CBT might be administered to maximise its effectiveness for FCOPWD remains the subject of ongoing research. At issue also is the relative costs involved in delivering CBT with a possible solution being group CBT that might include several FCOPWD as opposed to CBT delivery on a 1:1 basis.

(v) Sub-Theme associated with 'what works to support FCOPWD' identified as: 'Group CBT training.'

- (6) Mindfulness meditation-based interventions (Hurley et al; 2014); Singing therapy groups (Camic et al; 2013); integrating relaxation techniques with psychoeducational interventions may be beneficial to FCOPWD (Pitteri et al; 2013); the beneficial effects of Mindfulness-based stress reduction (MBSR) with FCOPWD (Oken et al; 2010); MBSR can improve carers' self-efficacy (Waelde et al; 2004); efficacy of MBSR in reducing carers' levels of stress (McBee, 2003); MBSR as an effective strategy in the support of FCOPWD (Whitebird et al; 2012).

Conclusion

Mindfulness-based stress reduction (MBSR) represents a version of Mindfulness that is designed to counteract worries about the future. Since such worries are highly prevalent in the context of the care of people living with chronic terminal illnesses such as dementia, this may make MBSR a particularly useful and appropriate intervention that may benefit FCOPWD. Carers' perception of care as 'burden' has often been associated with cessation of FCOPWD, therefore utilisation of MBSR to address carers' catastrophic thinking might prove most beneficial by counteracting such perceptions.

(vi) Sub-Theme associated with 'what works to support FCOPWD' identified as: 'Mindfulness training.'

Appendix 3: Results of RRR for which there was insufficient space to include within Chapter 5

Theme 2: Strengthening key psychological assets available to carers

Theme 2 Sub-theme (i) Self-efficacy

(a) 'What could work to support FCOPWD'

Self-efficacy (SE) is defined here as 'the belief that one has the capability to successfully engage in specific actions and exercise control over events that affect one's life' (Bandura, 1997). Increasing recognition of SE as a modifiable resource is beginning to open up the potential for it to be augmented via external intervention, i.e. SE need no longer be perceived as an 'all or nothing' personality trait which individuals either simply arrive innately equipped with or else they simply do not possess it.

In terms of managing the care of a PWD more effectively, particularly adapting to the variable and unpredictable nature of dementia as it changes along the dementia trajectory (Schoenmakers, Buntinx & Delepeleire, 2010), SE is gaining increasing recognition for its utility (e.g. Huang, Shyu & Chen et al; 2003).

Intrventions designed to improve carers' SE have largely proved successful where these have focused on assisting carers in developing greater control over specific challenges that typically emerge within dementia care contexts, e.g. carer training to develop skills in handling of behavioural problems (Huang, Shyu & Chen et al; 2003) and psychoeducation programs such as The Savvy Caregiver program (Hepburn, Lewis & Tornatore et al; 2007), designed to help carers develop and deploy strategies to manage and cope with the caregiving situation. It is arguable though that this only represents 'the tip of the iceberg' in terms of the potential of SE and internal LOC. While tailored interventions designed to meet specific challenges represent a logical step forward, there is also the broader question concerning how these attributes might be instilled in family carers of PWD at a deeper psychological level that delivers more sustained effects that promote the longevity of family care.

(b) 'What could hinder support for FCOPWD'

SE has long been identified as a potentially important resource individuals can draw upon to meet fresh challenges. However, its significance for family carers whose average age in the U.K. is 65 or over remains at a nascent stage as conceptualisations of this construct begin to shift away from SE representing a relatively fixed personality trait. Hence, research concerning how SE might be utilised as a resource to assist carers of PWD has so far been limited (Gallagher, Ni Mhaolain & Crosby et al; 2011). This suggests that the full potential of SE as a carer asset remains to be realised.

A further issue concerns the mechanisms by which SE might mediate carer’s health and wellbeing. Au, Lai and Lau et al. (2009) reported that SE may achieve this by strengthening internal locus of control (LOC). This finding may prove to be significant given that a loss of internal LOC generally results in adverse effects on carers’ health (Simpson & Carter, 2013; Strong & Mast, 2013).

(c) Specific evidence for factors associated with resilience relating to FCOPWD

Contador, Fernández-Calvo and Palenzuela et al; 2012) reported a direct link between FCOPWD, self-efficacy and resilience. Meanwhile, Gottlieb and Rooney (2004) found that SE may support carer resilience by providing a buffer against negative affect. High SE has been linked to ‘robustness’ which has close associations with resilience (Au, Lai & Lau et al; 2009). Psychological resilience entails perceived control, which results in a sense of personal autonomy and a belief in being able to directly affect the course of life events (O'Rourke, Kupferschmidt & Claxton et al; 2010).

(d) More general evidence for factors associated with resilience relating to FCOPWD

A setback for exploring the possible links between resilience and FCOPWD is that the researchers sometimes employ synonyms for SE that are often close but not precise proxies for this construct. For example, ‘competence’ has been found to be strongly linked to resilience (Fergus & Zimmerman, 2005), while ‘aptitudes’ represents a factor which is focal to Sacker’s (2009) model of resilience.

(e) Candidate Program Theories drawn up based around the RRR evidence

<p>Theme 2: Strengthen Key Psychological Assets</p>	<p>Sub-theme (i) Self-efficacy</p>	<ul style="list-style-type: none"> • Increase confidence to carry out caregiving role via a growing belief in one’s ability to manage the Care situation; • Raise carer perception of controllability over care situation to reinforce carers’ internal locus of control, self reliance, resilience & perceived capacity to master new domains; • SE provides carers with a buffer against negative affect; • SE mediates carers’ health and wellbeing by strengthening internal LOC to positively influence carer perceptions of being able to regulate their health & wellbeing; • Augmenting self-efficacy has been linked with robustness which shares close links with resilience.
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(f) Context-Mechanism-Outcome configuration (CMOc) drawn up from the CPTs

Strengthening carers’ key individual psychological assets, including self-efficacy (C), to facilitate the longer-term maintenance and sustenance of the FCOPWD (O) by a variety of means or mechanisms (M), including supporting carers’ belief in being able to manage and control the care situation and regulate their own health and wellbeing by reinforcing carers’ internal locus of control.

Theme 2 Sub-theme (ii): Hope

(a) 'What could work to support FCOPWD'

In line with the present study Lazarus (1993, p.244) similarly sought answers to a fundamental question that revolves around the FCOPWD: 'what works for those FCOPWD who appear to cope?' In particular: "What enables carers to maintain their psychological integrity? What are they actually doing and telling themselves in an effort to cope?" One plausible answer to such questions revolves around the concept of 'hope' and in particular, the capacity to maintain a sense of 'hope,' even in the face of adversity.

Research since then has gone on to reassert the association between hope and psychological health, particularly its role in moderating psychological distress (Rustøen, Cooper & Miaskowski, 2010). Donovan and Corcoran (2010) highlighted how hope can instil a positive, 'can-do' attitude and mindset in carers that provides a constructive approach to the care situation and an avoidance of undue negativity. More recent research has endeavoured to pinpoint the mechanisms by which hope might be applied. Sun, Tan and Fan et al (2014) identified carer acceptance via a positive framing of the carer role as a buffer against depression. Meanwhile, other research has usefully focused on how hope itself might be promoted. For example, Lohne and Severinsson (2004) suggest that reducing social isolation and increasing LOC may augment feelings of hope.

An operational definition which captures these key elements, particularly the perceived importance of 'hope' in instilling a firm belief, resolute attitude and purposeful motivation to continue to carry out the family care of a PWD is that drawn up by Snyder (2000) in which 'hope' is defined as 'a future goal orientation, the belief that goals can be attained, and the cognitive-motivational beliefs that pathways to goals can be created and pursued' (Snyder, 2000).

(b) 'What could hinder support for FCOPWD'

Previous authors such as Stephenson (1991) had identified 'hope' as a core human resource that remains essential to life and living. In the context of health, 'hope' was also generally recognised for its key role in motivating long-term sufferers of chronic conditions such as stroke (e.g. Bays, 1995) and spinal cord injuries (e.g. Piazza, Holcombe & Foote et al; 1991). However, what remained unclear was how 'hope' essentially functioned as a process within more specific health care contexts, including long-term dementia care. That 'hope' might operate differently and need to be applied differentially is also reflected in the wide range of operational definitions of the concept. Indeed, as recently as 2009 some authors declared that although much research had been conducted around the concept of 'hope,' what was crucially lacking was a deeper understanding of how it might actually be applied as a psychological resource (Tutton, Seers & Langstaff, 2009). A better understanding of the underpinning

mechanisms that help to instil ‘hope’ in different contexts, particularly those in which significant levels of adversity are encountered that might threaten to stifle it, is necessary to capitalise fully on how ‘hope’ might be applied as a psychological resource to support family carers. Although recent research such as Sun, Tan and Fan et al’s (2014) has sought to address this, the issue of how hope might be better promoted and applied to specific contexts and settings remains at an early stage.

(c) Specific evidence for factors associated with resilience relating to FCOPWD

Specific evidence for a link between resilience, FCOPWD and hope was lacking.

(d) More general evidence for factors associated with resilience relating to FCOPWD

Several authors have indicated the strong link between hope and resilience, including Vanistendael (2007) who reported that a hopeful outlook remains essential even under challenging circumstances. In the context of chronic illness Piazza, Holcombe and Foote et al. (1991) found that hope mobilises resources to adapt to changes while Bays (1995) found that hope promotes problem-solving and growth seeking behaviours.

(e) Candidate Program Theories drawn up based around the RRR evidence

<p>Theme 2: Strengthen Key Psychological Assets</p>	<p>Sub-theme (ii) Hope</p>	<ul style="list-style-type: none"> • Hope has a moderating role in alleviating carer stress to help protect carers’ psychological wellbeing; • Hope instils a positive attitudinal orientation towards goals & daily challenges fosters a belief in & Motivation to achieving goals; • Hope encourages positive reframing of the carer role which acts as a buffer against depression; • Hope helps mobilise resources to adapt to changes; • Hope promotes problem-solving and growth seeking behaviours.
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(f) Context-Mechanism-Outcome configuration (CMOc) drawn up from the CPTs

Strengthening carers’ key individual psychological assets, including Hope (C), to facilitate the longer-term maintenance and sustenance of the FCOPWD (O) by a variety of means or mechanisms (M), including instilling a positive attitudinal orientation towards goals and daily challenges, positive reframing of potentially adverse events, promoting the mobilisation of resources and predicating carers towards problem-solving and growth seeking behaviours.

Theme 2 Sub-theme (iii): Coping ability

(a) 'What could work to support FCOPWD'

The earlier discussion of 'self-efficacy' (SE) as a main psychological resource associated with maintaining control over the care situation and hope as means of moderating the impact of stress on carers highlights the potential importance of these two resources. However, a key question concerns how FCOPWD deal with stress once it has breached these two psychological defences. In order to answer to this question interest has turned to a third psychological resource-'coping ability' which is succinctly defined by Li, Cooper and Bradley et al. (2012) as 'the process by which people manage stress.' Coping ability has been highly correlated among the main factors which mediate carer anxiety and depression (ibid).

Importantly also, coping ability and the strategies associated with it represent a potentially overt and learnable skill-set that can be tailored to meet the demands of specific situations. Coping ability would therefore appear to lend itself well to the devising of interventions which are specifically designed to support family carers. Notable among these interventions in the U.K. is 'The START program' (Knapp, King & Romeo et al; 2013), an intervention to support the mental health of carers of carers by identifying individual difficulties and implementing strategies to overcome these. This has so far demonstrated some success in reducing carers' symptoms of anxiety and depression. Li, Cooper and Bradley et al (2012) also highlighted the benefits of carers adopting Problem-focused coping (PFC) strategies as a means to provide a protective factor against stress that might be adapted and supported to meet changing needs as the dementia advances.

(b) 'What could hinder support for FCOPWD'

More specific research concerning the particular coping skills or strategies which may be most appropriate for FCOPWD at different stages along the dementia trajectory remains at a nascent stage with various trials and initiatives currently undergoing appraisal.

In addition, the coping research has focused on 'what does not work' in terms of offering support to FCOPWD. Principal among the more dysfunctional modes of coping are: (a) 'avoidance coping' which essentially involves avoiding attempts to deal with stressors. This has been associated with lower life satisfaction scores and higher caregiver burden scores and has been associated with depression in female carers (Spira, Beaudreau & Jimenez et al; 2007) (b) possessing an insufficient range of coping strategies to deal with the often unique and potentially numerous challenges presented by the care of a PWD (Aschbacher, Patterson & von Känel et al; 2005).

(c) Specific evidence for factors associated with resilience relating to FCOPWD

Specific evidence for a link between resilience, FCOPWD and coping ability was lacking. However, in general, higher levels of carer resilience have often been correlated with individual psychological factors (Dias, Santos & De Sousa et al; 2014). A main question therefore concerns which psychological factors are most crucial to instilling resilience in FCOPWD.

(d) More general evidence for factors associated with resilience relating to FCOPWD

More generally, higher levels of resilience have been linked with effective coping strategies (Sun, 2014; Wilks, Little & Gough et al; 2012).

(e) Candidate Program Theories drawn up based around the RRR evidence

Theme 2: Strengthen Key Psychological Assets available to carer	Sub-theme (iii) Coping ability	<ul style="list-style-type: none">• Coping ability provides a means by which stress can be managed;• Coping ability can mediate carer anxiety & depression;• Coping ability represents an overt & learnable skill set that can be flexibly applied to different situations & allow flexible goal adjustment to help deal effectively with the inherently unpredictable nature of dementia & dementia care;• Coping ability can include Problem-focused coping (PFC) which can provide a protective factor against stress;• Adoption of acceptance-based coping strategies has been shown to be more effective than avoidance-based coping strategies that fail to tackle daily challenges & obstacles that need to be overcome. This has also been demonstrated to alleviate anxiety & stress in the longer term;• Higher levels of resilience are linked with the development of effective coping strategies.
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(f) Context-Mechanism-Outcome configuration (CMOc) drawn up from the CPTs

Strengthening carers' key individual psychological assets, including Coping ability (C), to facilitate the longer-term maintenance and sustenance of the FCOPWD (O) by a variety of means or mechanisms (M), including providing a means by which stress can be managed via Problem-focused coping (PFC) and the adoption of acceptance-based coping strategies, allowing flexible goal adjustment and generally promoting higher levels of resilience.

Theme 3: Maintaining carers' physical health status

Theme 3 Sub-theme (i): Perceived level of health

While the actual physical health status of carers remains crucial so too does how well they perceive their general health. For example, perceived levels of stress can make a unique contribution to depression (Simpson & Carter, 2013).

(a) 'What could work to support FCOPWD'

In keeping with the population in general, how carers perceive and gauge the strength of their ongoing health and wellbeing may be largely subjective. The term 'wellbeing' describes a broader range of markers for carers' overall health that includes physical and mental health and emotional wellbeing (NHS England, 2016, p.8). Indices for perceived health are closely associated with risk factors for health and wellbeing and disease indicators (Kaplan, Goldberg & Everson et al; 1996). In general, perceived health reflects an individual's awareness of symptoms, diagnoses, and performance decrements that are associated with markers for health (ibid). Perceived health acknowledges the psychosomatic relationship between mind and body.

Perceived health may be closely linked with perceptions of emotional wellbeing. How effectively emotions are regulated, including how emotions are experienced and expressed, may provide a key to exploiting the links between health self-perceptions and health outcomes (Gross, 1998). Improving emotion regulation skills might favourably affect perceived health (Middendorp, Geenen & Sorbi et al; 2005). Moreover, directing emphasis and effort further towards improving carers' general health and wellbeing also lends itself to a shift away from currently predominant 'burden of care' models of dementia care which, by contrast, tends towards greater emphasis on the 'inevitability' of carers' health decrements over time. In a similar way, the advice given to carers of PWD by some of the more prominent and influential organisations in the U.K. is beginning to reinforce a more positive message: that the care of PWD is undoubtedly challenging, but that carers can nevertheless make a choice to take steps to maintain their health and wellbeing (e.g. Alzheimer's Society, 2016b). This follows a more salutogenic paradigm in which the emphasis is towards the creation of contexts that generate positive health or well being possible and in which these outcomes are made optimal (Antonovsky, 1996).

(b) 'What could hinder support for FCOPWD'

Self-perceptions of health and wellbeing can have impact on mental and physical health, especially over the long time course associated with dementia. For example, perceived stress can make a unique

contribution to carer depression (Simpson & Carter, 2013), which family carers of PWD are particularly susceptible to (for a review see Hirst, 2005).

However, a moot point concerns which mechanisms are most important in regulating FCOPWD's health perceptions and how these can be better exploited to improve carers' overall health and wellbeing.

(c) Specific evidence for factors associated with resilience relating to FCOPWD

Higher levels of carer resilience have been associated with reduced psychosomatic symptoms that may be partly determined by health perceptions, including depressive symptoms (O'Rourke, Kupferschmidt & Claxton et al; 2010; Clay, Roth & Wadley et al; 2008).

(d) General evidence for factors associated with resilience relating to FCOPWD

The general evidence did not add anything further to the discussion.

(e) Candidate Program Theories drawn up based around the RRR evidence

<p>Theme 3: Maintaining Carer's Physical Health Status</p>	<p>Sub-theme (i) Improving carers' own Perceived level of Health & Wellbeing</p>	<ul style="list-style-type: none"> • Moving beyond the mind-body dichotomy, perceptions of health provide important determinants of physical health, e.g. low perceptions of experiencing stress may provide a protective factor against carer depression; • Emotion-regulation may provide a means to mediate perceived health; • Improving perceptions of health can contribute to a more salutogenic approach to carers' health & wellbeing. • Higher carer resilience is associated with reduced psychosomatic symptoms that may be partly determined by health perceptions.
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(f) Context-Mechanism-Outcome configuration (CMOC) drawn up from the CPTs

Maintaining carer's physical health status by improving carers' own perceived level of health and wellbeing (C), to facilitate the longer-term maintenance and sustenance of the FCOPWD (O) by a variety of means or mechanisms (M), including reducing carers' perceived experience of stress, improving carers' regulation of emotions and encouraging the adoption of a more salutogenic approach to health and wellbeing.

Theme 3 Sub-theme (ii): Objective measures of health

(a) 'What could work to support FCOPWD'

Alzheimer's Society (2014, p.39) make clear the point that for dementia care in the U.K. to remain viable for the foreseeable future the prevention of carer ill health should remain paramount. Further, that a priority should be the establishment of a healthcare system specifically designed to meet family carers' unique health care needs as well as one that is proactive rather than reactive, i.e. preventative

rather than curative. That this is likely to require close integration between the NHS and social care services in some local authority areas to provide quality support that is well co-ordinated is also highlighted by the report. Critical points for the continuance of family care along the carer journey are likely to be influenced by carers' own health (Newbrunner, Chamberlain & Borthwick et al; 2013).

Downs, Turner & Bryans et al. (2006) emphasise the importance of maintaining carers' health in order to sustain family care of PWD via regular contact with G.P. Carers' health status ultimately decides between maintenance of family care or cessation (Newbrunner, Chamberlain & Borthwick et al; 2013). Carers' health is now more widely recognised for its importance in helping family carers to maintain the long-term care of a PWD, a fact which is reflected in recent legislation via The Carers Act (2014) which makes it mandatory for family carers to be eligible for six monthly G.P. health check-ups.

(b) 'What could hinder support for FCOPWD'

Despite its importance and its relevance to 'what works' there is a current paucity of research regarding how carers' health might be maintained and not compromised. Vickland, McDonnell and Werner et al (2011) also point out there is a need to go further to ensure that any intervention designed to address family carers' needs should be differentiated and tailored to meet individual carer's needs, rather than 'rolled out' as a generic, 'one-size-fits-all' set of measures. Arguably, recent initiatives designed to address the need to safeguard carers' health, particularly The Carers Act (2014), are too generic and based around the erroneous assumption that all carers share equal needs. Such a view does not take into account the finding that FCOPWD may endure greater H.i.'s due to the long duration, high degree of variability and profound symptomatology associated with dementia care. In addition, The Carers Act (2014) requires compliance by carers that may demand wider promotion of both the need and the benefits of closer health monitoring of family carers of PWD.

Moreover, given that many family carers of PWD have pre-existing medical conditions of their own to address, even prior to taking on dementia care (NHS, 2015), and that such carers are likely to already have scheduled G.P. appointments to address these, it is questionable whether the provision of an additional carers' health check-up provides any supplementary benefits. A main exception might be where such carers' check-ups specifically targeted family carers of PWD's vulnerability to mental health problems by placing proper assessment and preventative measures to safeguard carers' mental health as a main priority. However, the fact that such a priority is not made explicit by the 2014 Carers' Act arguably leaves mental health prone to omission or liable to be given merely cursory attention, particularly at a time when the mental health services in the U.K. are severely stretched (NHS Providers, 2017).

(c) Specific evidence for factors associated with resilience relating to FCOPWD

Higher levels of carer resilience has been associated with better physical health (Fernández-Lansac, Crespo López Cáceres et al; 2012; Gaiole, Furegato & Santos, 2012; Mehta, Whyte & Lenze et al; 2008).

(d) More general evidence for factors associated with resilience relating to FCOPWD

Payne (2007) lists general health and fitness as factors associated with resilience.

(e) Candidate Program Theories drawn up based around the RRR evidence

<p>Theme 3: Maintaining Carer's Physical Health Status</p>	<p>Sub-theme (ii) Improving carers' access to Objective measures of health</p>	<ul style="list-style-type: none"> • Promotion of carer health and wellbeing is of paramount importance to the maintenance of the FCOPWD & there are demonstrable links between better dementia carer health & resilience; • Formal health care services which are closely integrated can provide a well co-ordinated & proactive approach to ensuring carer health & wellbeing that is based around prevention rather than cure; • Tailored approaches to safeguarding of FCOPWD's health & wellbeing could take fuller account of the salient health inequalities experienced by FCOPWD.
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(f) Context-Mechanism-Outcome configuration (CMOc) drawn up from the CPTs

Maintaining carer's physical health status by improving carers' access to objective measures of health (C), to facilitate the longer-term maintenance and sustenance of the FCOPWD (O) by a variety of means or mechanisms (M), including promoting the vital importance of the maintenance of carers' health and wellbeing to the FCOPWD, closer integration and co-ordination of formal health care services with FCOPWD and the adoption of a proactive approach by such services which takes fuller account of the health inequalities faced by FCOPWD and which places emphasis on prevention rather than cure.

Theme 3 Sub-theme (iii): Adherence to a healthy, balanced diet

(a) 'What could work to support FCOPWD'

In terms of 'what works to support family carers of PWD,' adherence to a healthy, balanced diet would appear to make intuitive common sense and has been identified as a lifestyle choice that is associated with positive coping and strong locus of control in relation to the maintenance of health (Saklofske, Austin & Galloway et al; 2007). Carer self-care remains of vital importance if FCOPWD are to maintain levels of health and wellbeing that allow them to continue to provide dementia care. As Schindler, Engel and Rupprecht (2012) point out, carers who attend to their own fundamental needs place themselves in a stronger position with regard to maintaining long-term care.

Despite the paucity of research in this area, several research initiatives might be suggested that could prove valuable in terms of supporting family carers of PWD. These include exploring the potential for a diet that regularly incorporates slow-burning carbohydrates to provide sustained energy to help counteract the chronic fatigue that is often associated with the physical demands of delivering long-term dementia care (Corbin & Strauss, 1988). Further, since the majority of family carers of PWD in the U.K. are aged 65 years or over (Newbronner, Chamberlain & Borthwick et al; 2013) they may begin to become susceptible to the effects of anaemia which represents the commonest haematological abnormality in older populations (Mukhopadhyay & Mohanaruban, 2002). Since the presence of anaemia can exacerbate feelings of fatigue, a diet that regularly includes good sources of iron such as red meats, green vegetables and fortified foods such as breakfast cereals (NHS Choices, 2016) may also contribute to 'what works to support family carers of PWD.'

(b) 'What could hinder support for FCOPWD'

Carers' adherence to a healthy, balanced diet represents an aspect of carer health and wellbeing which can be all too easily overlooked, particularly by carers themselves. Factors that may lead to such disruption of normal dietary routine can include: (a) the PWD's changing food tastes as an artefact of dementia symptomatology (b) the PWD's often diminishing appetite as dementia advances that is closely linked with the PWD's declining cognitive-behavioural perception of feeling hungry (c) carers' lack of time to regularly prepare healthy, balanced meals with a consequent reliance on convenience foodstuffs (d) carers missing out on meals for themselves in order to attend to other daily tasks (Carers UK, 2013).

In addition, negative coping styles, have been associated with weight gain and maladaptive dietary habits (Pargament, Koenig & Tarakeshwar et al; 2004). Given that in the long term family carers of PWD are likely to become susceptible to a potent combination of factors that may threaten to disrupt diet and that such disruption is also likely to affect the dietary routines followed by the PWD as they become increasingly reliant on the PWD to prepare and provide meals, the question of how to ensure the maintenance of a healthy, balanced diet would become important. Disruption that affects carers' ability to maintain a normal diet may be especially impactful where the carer cohabits with the PWD. While dietary interventions have been researched for PWD (e.g. Shatenstein, Huet & Jabbour et al; 2009), few studies have examined the benefits of similar interventions to support family carers.

(c) Specific evidence for factors associated with resilience relating to FCOPWD

Specific evidence for a link between resilience, FCOPWD and adherence to a healthy, balanced diet was lacking.

(d) More general evidence for factors associated with resilience relating to FCOPWD

The combination of healthy diet and regular physical activity has been found to contribute to resilience in older age (Clark, Blissmer & Greene et al; 2011) and this is relevant since the majority of FCOPWD are aged 60 or over.

(e) Candidate Program Theories drawn up based around the RRR evidence

<p>Theme 3: Maintaining Carer's Physical Health Status</p>	<p>Sub-theme (iii) Adherence to a healthy, balanced diet</p>	<ul style="list-style-type: none"> • Adherence to a healthy, balanced diet has been associated with positive coping & a strong LOC that assist good maintenance of health & wellbeing; • Adherence to a healthy, balanced diet can provide mutual benefits for PWD where meals are prepared jointly; • The regular inclusion of slow-burning starches can increase energy & stamina to help boost carers' energy levels; • Dietary interventions that address increasing risk of anaemia with age can help to maintain adequate energy levels; • Combining a healthy, balanced diet with regular exercise has been found to contribute to resilience.
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(f) Context-Mechanism-Outcome configuration (CMOC) drawn up from the CPTs

Maintaining carer's physical health status by improving carers' adherence to a healthy and balanced diet (C), to facilitate the longer-term maintenance and sustenance of the FCOPWD (O) by a variety of means or mechanisms (M), including regular inclusion of slow-burning starches can increase energy and stamina, guarding against anaemia which can reduce energy levels, combining a good, balanced diet with exercise to promote resilience.

Theme 3 Sub-theme (iv): Regular physical activity

(a) 'What could work to support FCOPWD'

Regular physical activity carries physical and psychological health benefits for carers Alzheimer's Society (2015). With regard to 'what works to support family carers of PWD' the health benefits of regular exercise have been demonstrated in the few studies carried out to date that involved family carers of PWD and include reductions in perceived stress (Connell & Janevic, 2009). More generally, a strong relationship has been found between regular engagement in physical activity and markedly greater well-being in older adults (Steptoe, Demakakos & de Oliveira, 2012). Maintaining wellbeing, which has its basis in psychological health, may help to manage and prevent disease in older adults (ibid). The most probable basis for this is the role of psychological health in supporting immune function. This is also significant given that the majority of FCOPWD are aged 60 or over.

Addressing the twin issues of timeliness and convenience for family carers who may be intensively involved in the everyday tasks associated with dementia care, evidence points to the success of initiatives that are relatively easy to administer, can be readily engaged in with minimal preparation and offer scope for the PWD to be included also. For example, short daily walks five times a week in the vicinity of the PWD’s own home lasting between 20 to 30 minutes, with the exercise intensity increasing as fitness levels rise (Cerga-Pashoja, Lowery & Bhattacharya et al; 2010).

(b) ‘What could hinder support for FCOPWD’

A main stumbling block concerns how family carers who may be frequently presented with a full itinerary of daily tasks to perform somehow find the additional time and energy to engage in regular exercise. Further, the issue of ensuring that time management and task scheduling can continue to permit regular carer and PWD engagement in exercise remains closely bound up with the parallel concern of how to ensure family carers can maintain regular engagement in pleasurable activities that enhance overall quality of life (QOL) (Schindler, Engel & Rupprecht, 2012). Arguably, the ability to engage in regular exercise is somewhat inseparable from QOL and, in general, both remain complementary to each other, with exercise enhancing QOL for carers of PWD and QOL enhancing opportunities for exercise (Chattillion, Ceglowski & Roepke et al; 2013).

(c) Specific evidence for factors associated with resilience relating to FCOPWD

Full engagement in daily activities (including continued involvement in activities which are not necessarily dementia care related) has been linked with carer resilience (O’Rourke, Kupferschmidt & Claxton et al; 2010).

(d) More general evidence for factors associated with resilience relating to FCOPWD

Exercise can promote self-efficacy (McAuley & Katula, 1998) which has been linked to carer resilience.

(e) Candidate Program Theories drawn up based around the RRR evidence

<p>Theme 3: Maintaining Carer’s Physical Health Status</p>	<p>Sub-theme (iv) Regular physical activity</p>	<ul style="list-style-type: none"> • Regular exercise can reduce carers’ levels of perceived stress; • Regular exercise can improve general wellbeing in older adults; • Maintaining wellbeing, which has its basis in psychological health, may help to manage and prevent disease in older adults by supporting immune function; • Interventions designed to encourage carer exercise may be optimal where they require minimal set-up time or resources & can be fitted in between busy schedules; • Exercise may be usefully combined with pleasurable activities to promote positive affect & enhance QOL; • Continued engagement in daily activities that include non-carer related activities is linked to carer resilience.
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(f) Context-Mechanism-Outcome configuration (CMOC) drawn up from the CPTs

Maintaining carer's physical health status via regular physical activity (C), to facilitate the longer-term maintenance and sustenance of the FCOPWD (O) by a variety of means or mechanisms (M), including, reductions in carers' levels of perceived stress, improving general wellbeing and supporting immune function. Physical activity can be facilitated where it is combined with pleasurable activities to promote positive affect and enhance quality of life.

Theme 3 Sub-theme (v): Perception of generally good quality / quantity of sleep

(a) 'What could work to support FCOPWD'

In terms of 'what works to support family carers of PWD' the imperative for adequate sleep quality and quantity is frequently mentioned in the literature, with up to two thirds of FCOPWD potentially affected by some form of sleep disturbance (McCurry & Teri, 1995). These figures suggest that interventions designed to improve sleep in FCOPWD have the potential to benefit the majority of FCOPWD. Psychological interventions continue to demonstrate particular effectiveness in this regard (Schulz, O'Brien & Czaja et al; 2002).

(b) 'What could hinder support for FCOPWD'

Several main factors associated with dementia symptomatology can often make achieving good quality and quantity of sleep difficult (Ornstein & Gaugler, 2012). Indeed, the prevalence of sleep disturbance in carers of PWD is such that it is estimated to affect two thirds of all carers (McCurry & Teri, 1995). Family carers of PWD face potentially major challenges to regularly 'good' quality and quantity of sleep. Among these the 'sundowning' phenomenon in which PWD may develop changes to normal circadian rhythms manifest in night-time waking, restlessness and wandering is noted for its adverse effects on carers including sleep deprivation, exhaustion and reduction in perceived ability to cope (Newbronner, Chamberlain & Borthwick et al; 2013). A further issue which can often affect carers' sleep quality and quantity is pre-sleep anxiety and an inability to switch the mind off from the day's events and the forthcoming challenges the next day may present, with various remedies suggested including meditation and yoga (Waelde, Thompson & Thompson-Gallagher et al; 2004). Chronic stress can induce emotional, physical and attitudinal exhaustion brought on by continual arousal of the HPA (hypothalamic-pituitary-adrenal) and SAM (sympathetic-adrenal-medullary) axes in response to daily stressors, and is often combined with insufficient resources to cope with continual activation of stress response mechanisms (Gugliemi & Tatrow, 1998). Frequent over-activation of the HPA and SAM axes that provide a key role in regulating sleep via cardiovascular activity and endocrine activity can lead to dysregulation of sleep and chronic sleep disorder (Kato, Montplaisir & Lavigne,

2004). An inverse relationship exists between sleep quality and levels of daytime exhaustion with the most profound impact affecting older caregivers (McKibbin, Ancoli-Israel & Dimsdale et al; 2005). This age effect is significant given that the average age of family carers of PWD in the U.K. is 65 years or over (Newbronner, Chamberlain & Borthwick et al; 2013). In the longer term, disruption to sleep patterns in carers has been linked to depression (Simpson & Carter, 2013). Importantly, carer depression has been well documented as a precursor to cessation of family care (Schoenmakers, Buntinx & Delepeleire, 2010; Gaugler, Yu & Krichbaum et al; 2009; Arai, Sugiura & Washio et al; 2001; Hope, Keene & Gedling et al; 1998).

(c) Specific evidence for factors associated with resilience relating to FCOPWD

Specific evidence for a link between resilience, FCOPWD and sleep was lacking.

(d) More general evidence for factors associated with resilience relating to FCOPWD

Healthy sleep behaviours may have implications for enhancing resilience to current and future stressors and adversities (Pederson, Troxel & Shih et al; 2015).

(e) Candidate Program Theories drawn up based around the RRR evidence

Theme 3: Maintaining Carer's Physical Health Status	Sub-theme (v)] Improving perception of generally good quality / quantity of sleep	<ul style="list-style-type: none"> • Carers' perception of generally obtaining good quality & quantity of sleep can help to counteract daytime exhaustion, promote fuller mental & physical recuperation from prior day-time activities that can in turn provide a protective factor against pre-somnolent anxiety & stress that can lead to sleep disorders; • Prevent chronic sleep disruption from becoming a precursor to carer depression; • Promote uptake of respite care to improve management of carer sleep.
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(f) Context-Mechanism-Outcome configuration (CMOc) drawn up from the CPTs

Maintaining carer's physical health status by improving carers' perception of generally good quality and quantity of sleep (C), to facilitate the longer-term maintenance and sustenance of the FCOPWD (O) by a variety of means or mechanisms (M), including, counteracting daytime exhaustion, promoting fuller mental and physical recuperation and preventing chronic sleep disorders. This can be facilitated by the uptake of respite care.

Theme 4: Safeguarding carer's Quality of Life (QOL)

Theme 4 Sub-theme (i): Opportunities to experience positive affect (feelings of active pleasure)

(a) 'What could work to support FCOPWD'

Following their review of 'what works' for family carers of PWD Gallagher-Thompson and Coon (2007) concluded that among the most effective interventions were those that targeted specific components of caregivers' quality of life (QOL). Qureshi, Bamford and Nicholas et al. (2000) identified carers' QOL as a highly valued aspect of their lives and important to maintain despite the challenges of dementia care. A critical point is that carers' QOL appears to represent far more than a dispensable luxury which can be severely curtailed or put on hold while dementia care is allowed to take full precedence without such a move exacting potentially serious repercussions for family carers' health and wellbeing (Argimon, Limon & Vila et al; 2004).

QOL shares important links with carers' overall health and wellbeing and has intrinsic value for this main reason. So much so that indices of carers' health and wellbeing often amalgamate these factors with QOL to derive an overall measure of carer wellbeing, aka health-related QOL (HRQL) (e.g. Smith, Murray & Banerjee et al; 2005). This strengthens the argument for ensuring carers of PWD can maintain a reasonable QOL as an important means of bolstering their general health and wellbeing. The importance of carers maintaining good QOL cannot be understated.

Moreover, it is now becoming clearer that achieving a reasonable level of QOL need not necessarily involve engagement in lavish, expensive or even time-consuming activities. Rather, there is a growing appreciation of the need to move beyond conceptualisations of QOL that focus on materialism and instead towards the notion that QOL is primarily a subjective experience with close links to the enhancement of general mood state. In particular, positive affect has been identified as potentially instrumental in mediating subjective feelings that can promote long-lasting mood states (Frijda, 2009). These mood states include positive mood states such as happiness and cheerfulness at one extreme which can generally classified as examples of positive affect (feelings of active pleasure). An important distinction is that mood and emotion are generally seen as sub-types of affect, with emotions being more strongly directed toward a specific stimulus, e.g. towards a person, an object, or an event (ibid). Maintaining a general bias towards experiencing positive affect denotes a generally positive adaptation to life and life challenges.

While much of the previous research has focused on interventions designed to reduce negative affect, there has been a recent shift towards a more salutogenic approach in which the focus has switched towards enhancing positive affect to bring about health and wellbeing benefits (Louro, Blasco & Fernandez-Castro, 2015). Regular experience of positive affect has become associated with

enhanced QOL and improved general wellbeing (Aspinwall & MacNamara, 2005). One explanation for the recent focus on promoting wellbeing via positive affect is increasing recognition of positive affect as a state as opposed to a relatively fixed personality trait. Thus, positive affect is now being seen to more widely represent a modifiable mediator of wellbeing (Stauber, Schmid & Saner et al; 2013).

QOL captures two main dimensions: (a) it is represented by the actions or behaviours we perform that promote or constrain the experience of positive affect (b) but it also refers to our subjective perceptions of positive affect or feelings of active pleasure (Lawton, Winter & Kleban et al; 1999). When QOL is considered in the context of health and disease, it is commonly referred to as health-related quality of life (HRQoL) to differentiate it from other aspects of quality of life (Office of Disease Prevention and Health Promotion, 2010). Arguably though, there is a fine line between QOL and HRQOL and it is now increasingly recognised that enhancing the former can exert direct and beneficial effects on the latter, particularly via its meretricious effects on general sense of wellbeing which is largely subjective, but nevertheless increasingly acknowledged as potentially pivotal to overall health (Goldberg, Gueguen & Schmaus et al; 2001). Essentially, frequent experience of positive feelings predicts longevity and health beyond negative feelings (Diener & Suh, 1997). Further, positive affect may also provide an important protective factor to help offset age associated health losses (Pinquart, 2001). It is worth reiterating the importance of this given that family carers of PWD are by virtue of their age generally susceptible to age effects.

The maintenance of a good quality of life (QOL) via the continuation of hobbies, interests and outlets for activities outside the care environment has been shown to exert a positive impact on carers (Schindler, Engel & Rupprecht et al; 2012). This corresponds with increasing evidence for the health benefits gained by carers who manage to maintain a reasonable perceived level of QOL, even despite the demands made on carers' time and energy by caregiving (Stirling, Andrews & Croft et al; 2010; Croog, Burlison & Sudilovsky et al; 2006). Importantly, achieving a ratio in which, on balance, positive affect outweighs negative affect may be most crucial to achieving health and wellbeing benefits (Fredrickson & Losada, 2005). Frequency of experience of pleasurable activities via social activities is linked with positive affect (Watson, Clark & Tellegen, 1988) and may help to maintain a healthy ratio between positive and negative affect. Frequency may also be more important than duration with the mantra 'a little and often' serving FCOPWD best, in addition to being perhaps more realistic and achievable within a generally busy daily schedule.

Carer interventions that specifically target and promote positive affect such as CBT Programs delivered via DVD have so far demonstrated success (Gallagher-Thompson, Wang & Liu et al; 2010). Meanwhile, interventions that tackle the twin problems of ensuring frequent carer experience of positive affect and the removal of obstacles to engagement, e.g. The PEAR (Pleasant Events and

Activity Restriction model), have been shown to be potentially protective for a number of carer health and QOL outcomes (Chattillion, Ceglowski & Roepke et al; 2013).

FCOPWD generally demonstrate high levels of conscientiousness and selflessness that may prohibit what may appear on the surface at least to be self-indulgent activities that seem to detract from caregiving. Interventions designed to tackle this potential obstacle by emphasising both the health benefits to carers and the positive ramifications for continuance of family care have proved effective (Coon, Thompson & Steffen et al; 2003).

(b) 'What could hinder support for FCOPWD'

By contrast, those family carers who experience the perception of being 'trapped' in care responsibilities with no outlets for QOL are more likely to cease the family care of PWD (Gaugler, Yu and Krichbaum et al; 2009; Argimon, Limon & Vila et al; 2004; Lightbody & Gilhooly, 1997). A related finding is that a close association has been found between low QOL and higher levels of burnout and depression (Strong & Mast, 2013; Takai, Takahashi & Iwamitsu et al; 2009).

Despite recognition of the importance to family carers of their maintaining reasonable QOL achieving this in practice shares similar issues to those associated with the maintenance of regular engagement in exercise discussed earlier. The importance of QOL to carers' overall health and wellbeing may well be self-evident. However, finding the time and energy, particularly where these finite resources are already given over to dementia care, can prove somewhat problematic. In terms of 'what works for family carers of PWD' the establishment of care contexts that permit some reasonable level of QOL, ideally for both the carer and the PWD, would appear to be crucial.

Negative mood states such as anger, depression, anxiety and worry can generally be categorised as examples of negative affect (ibid). A general tendency towards experiencing negative affect can be viewed as maladaptive (Louro, Blasco & Fernandez-Castro, 2015), while the chronic experience of negative affective has been strongly associated with psychological distress (ibid).

QOL represents a somewhat nebulous concept. In terms of 'what works' for family carers, it is important therefore to pinpoint the essential components within QOL that carers' promote health and wellbeing. Not least to ensure that carers derive maximum benefits from QOL despite the limitations imposed by caregiving that might limit opportunities for their engagement in it. To this end, the identification of positive affect as a main component of QOL that may be important to carers is arguably deserved of greater recognition.

(c) Specific evidence for factors associated with resilience relating to FCOPWD

Windell and Bennett's (2011) operational definition of 'resilience' includes the criterion 'actively participation in life.' This strongly suggests the need for carers to continue to enjoy regular and continued engagement in social and recreational activities.

(d) General evidence for factors associated with resilience relating to FCOPWD

The general evidence did not add anything further to the discussion.

(e) Candidate Program Theories drawn up based around the RRR evidence

<p>Theme 4: Safeguard Carer's Quality of Life</p>	<p>Sub-theme (i) Opportunities to experience positive affect (feelings of active pleasure)</p>	<ul style="list-style-type: none"> • Positive affect & its maintenance may represent one of the key components within QOL that may be most beneficial to carers in terms of promoting health & wellbeing as part of an overarching salutogenic approach; • Enhancing carers' general subjective mood state via the promotion of positive affect may be more important to sustained health & wellbeing than engagement in costly & time-consuming leisure activities; • Achieving a healthy ratio in which positive affect outweighs negative affect may rely more the frequency of engagement in QOL activities than the duration; • Convincing carers of the potential benefits of maintaining QOL (a) to promote their own health & wellbeing (b) to enable them to sustain the FCOPWD (c) to increase engagement in QOL activities for the PWD may be essential in order to assuage feelings of guilt that may accompany activities normally associated with self-indulgence.
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(f) Context-Mechanism-Outcome configuration (CMOC) drawn up from the CPTs

Safeguarding carer's Quality of Life (QOL) (C), to facilitate the longer-term maintenance and sustenance of the FCOPWD (O) by a variety of means or mechanisms (M), including, ensuring there continue to be regular opportunities to experience positive affect (feelings of active pleasure), promoting health and wellbeing in which QOL is viewed as part of an overarching salutogenic approach and enhancing carers' general subjective mood state. This can be facilitated by convincing carers of the potential benefits to themselves and the PWD of maintaining QOL.

Theme 4 Sub-theme (ii): Opportunities to maintain positive affect (feelings of active pleasure)

(a) 'What could work to support FCOPWD'

As stated above, achieving a ratio between positive and negative affect that is biased towards the former may be important to carers in maintaining health and wellbeing in the long term. This also represents a main point taken up by Pinquart (2001) and seems particularly relevant to family carers of PWD who will experience unavoidable adverse circumstances from time to time that may elicit negative affect. However, while such adversity leading to perceived negative affect cannot be entirely

prevented, what becomes critical is that these perceptions are balanced by activities that promote their opposite based in perceived positive affect.

Moreover, older generations in the U.K. who constitute the majority of family carers of PWD may even be better placed than their younger counterparts regarding their ability to achieve affect balance. This follows from Pinquart's (2001) research which provides evidence suggesting older adults tend to have learned greater emotional maturity. Crucially, this may confer certain advantages with respect to their ability to moderate positive and negative affect to maintain affect balance. Moreover, both highlighting and capitalising on this advantage in older generations of carers denotes a further move away from conceptualisations of dementia care as 'burden' and towards more a salutogenic approach (Antonovsky, 1996) that emphasises what carers can achieve as opposed to dwelling on their perceived inadequacies.

(b) 'What could hinder support for FCOPWD'

However, previous research also points to the fact that carers may need to be made aware of the need to achieve an affect balance and to be proactively engaged in promoting positive affect (Carstensen, Isaacowitz & Charles, 1999). This suggests that the outcome for carers' affect balance cannot be left simply to chance. Rather, carers may need to ensure they cultivate a mindset that is predisposed towards engagement in pleasurable activities from the outset of dementia care and remain actively involved in creating opportunities for these is once again highlighted here. As indicated in earlier discussions, this might also frequently involve the PWD rather than be wholly exclusive to carers per se. The reciprocal dynamic that exists between carers and PWD mean that activities which promote positive affect are likely to be mutually beneficial for the carer and the PWD.

(c) Specific evidence for factors associated with resilience relating to FCOPWD

The main point that despite the time and energy that is taken up with dementia care it is important that carers strive to maintain engagement in activities that promote positive affect as a means to increase overall resilience is made by O'Rourke, Kupferschmidt and Claxton et al. (2010).

(d) More general evidence for factors associated with resilience relating to FCOPWD

Adults' maintenance of opportunities to engage in positive affect needs to be made a higher priority (Carstensen, Isaacowitz & Charles, 1999).

(e) Candidate Program Theories drawn up based around the RRR evidence

<p>Theme 4: Safeguard Carer's Quality of Life</p>	<p>Sub-theme (ii) Maintenance of affect balance</p>	<ul style="list-style-type: none"> • Older adults who represent the majority of FCOPWD may possess greater emotional maturity that confers an advantage in terms of being able to balance positive & negative affect; • This advantage might be exploited to further promote carers' strengths as part of an overarching salutogenic approach; • Maintaining engagement in activities that promote positive affect can provide a means to increase overall resilience but this benefit may need to be more overtly highlighted for FCOPWD to act upon it.
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(f) Context-Mechanism-Outcome configuration (CMOC) drawn up from the CPTs

Safeguarding carer's Quality of Life (QOL) (C), to facilitate the longer-term maintenance and sustenance of the FCOPWD (O) by a variety of means or mechanisms (M), including, reinforcing carers' ability to exploit their emotional maturity to balance positive and negative affect as part of an overarching salutogenic approach and promoting the message that maintaining QOL can contribute to carer resilience.

Theme 4 Sub-theme (iii): Subjective experience of life, living and domains of life such as work, leisure & family remain generally positive

(a) 'What could work to support 'FCOPWD'

Research has examined how the general mindset carers adopt in relation to dementia care can influence care outcomes. For example, Shim, Barrosa and Davis (2012) found that carers who focused on positive memories shared with the PWD from the past, proactively sought out the positive experiences derived from the present care situation, accepted that dementia will bring about unavoidable changes to the carer-PWD relationship and recognised their role in carrying out a very worthy and vital service for someone else went on to report high levels of satisfaction and low levels of perception of care as 'burden.'

The concept of embracing and fostering positivity in the context of dementia has only relatively recently begun to gain momentum. For example, Lin and Lewis (2015) describe positivity as a key concept which needs to be made central to how societies prepare to deal more effectively with dementia in the future, emphasising that it is not sufficient to limit ourselves to tolerating and respecting dementia. Rather, the authors contend we need to move towards dementia inclusive societies in which carers and PWD are encouraged to feel empowered to lead meaningful lives. Further, that this requires an intentional emphasis on strength finding, manifesting through attitudes, beliefs, communication, and behaviours, designed to promote positivity (Lin & Lewis, 2015, p.242).

Arguably also, the life carers lead which surrounds the care situation is equally important in terms of fostering a positive mindset. The maintenance of positivity and positive outlook and perceptions in relation dementia care shares close links with the need for carers of PWD to regularly experience positive affect. Essentially, carers need to be able to maintain some quality of life (QOL), leisure and contact with family in order to experience positive subjective feelings and cognitions within these domains. Arguably also, positive affect experienced within these domains carries latent effects which can extend beyond the initial experience of them to continue to flourish within the care situation also.

Evidence also indicates that positivity can be promoted by holding a predisposition and bias towards it. This has also been described as a 'positivity offset' (Cacioppo, Gardner & Berntson, 1999). A main point is that the potential exists for carers to adaptively adopt a positive mindset towards dementia care. Indeed, several studies have found strong correlations between positivity and increased effectiveness in coping with adverse life circumstances (Fredrickson, Tugade & Waugh et al; 2003; Folkman & Moskowitz, 2000). Further, that daily experience of positivity increases physical and psychological resources (Fredrickson, Cohn & Coffey et al; 2008) that may also confer health and wellbeing benefits.

Additionally, the adoption of a positive outlook and predisposition towards dementia care represents the antithesis of the perception of care as 'burden.' This is a view which is supported by Donovan and Corcoran's (2010) study which found that framing the carer role in a positive way is likely to be more helpful and constructive than dwelling on the negative aspects of care. Although this may seem to represent a truth that is somewhat self-evident, the prevailing view of the family care of dementia continues to be that is fundamentally based on hopelessness and failure (Peel, 2014) and manifest in the predominant 'burden of care' model. Indeed historically, the majority of previous studies of carers of PWD have focused on negative outcomes (Ott, Sanders & Kelber, 2007).

How dementia care is framed and perceived continues to be of immense importance therefore and not least because the perception of care as 'burden' has been strongly linked with earlier termination of home care and patient entry into residential care (Etters, Goodall & Harrison, 2008). In relation to 'what works' challenging prevailing societal attitudes that maintain a view of dementia care as 'burden' would seem to be absolutely fundamental. While ideally such a paradigmatic shift would be universal, extending from how policy-makers might be differentially influenced by a positive outlook with regard to dementia care that is further reflected and supported in the way in which health and social care organisations deliver such policy, there is arguably a need to instil a more positive view in those individuals who remain at the heart of dementia care, i.e. the family carers themselves. Interventions based around this latter premise have demonstrated some success and once again shown that changing people's mindset in relation to dementia care can yield very tangible

and worthwhile results. For example, Nolan and Lundh (1999) found that cognitive reappraisal in which carers are encouraged to review the positives derived from recent caring experiences provides an effective coping strategy. More recently, Hilgeman, Allen and DeCoster et al. (2007) found that positive framing of carers' experiences mediated the impact of chronic stress.

(b) 'What could hinder support for FCOPWD'

Carers who dwell on negative memories and focus on their own unmet needs in the present, blaming dementia care for this, report high perceived levels of care as 'burden' (Shim, Barrosa & Davis, 2012). It is arguable that both the prevailing view of the FCOPWD as 'burden' as well as maladaptive strategies that further promote such a view needs to be challenged if a bias towards mainly negative carer and PWD outcomes is to be avoided.

(c) Specific evidence for factors associated with resilience relating to FCOPWD

Positive subjective experience of life, living and domains of life such as work, leisure and family is more generally associated with 'quality of life' (QOL). QOL is defined here according to the WHO (1997) interpretation: 'individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns-a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment.' Dias, Santos and De Sousa et al. (2014) highlighted the importance of FCOPWD maintaining perceptions of a reasonable QOL as part of efforts to support resilience. Positive cognitions are often associated with a perception of a reasonable QOL. Bekhet (2013) identified positive cognitions as a protective factor against stress for FCOPWD.

By contrast, subjective experience of care as 'burden' has been strongly linked to the cessation of family care of PWD (Etters, Goodall & Harrison, 2008). The potential for resilience to impact on QOL is receiving increasing interest, including from those who formulate health policy and practice (Windell, 2010).

(d) General evidence for factors associated with resilience relating to FCOPWD

The general evidence did not add anything further to the discussion.

(e) Candidate Program Theories drawn up based around the RRR evidence

<p>Theme 4: Safeguard Carer's Quality of Life</p>	<p>Sub-theme (iii) Subjective experience of life, living & domains of life such as work, leisure & family remain generally positive</p>	<ul style="list-style-type: none"> • Carers who proactively seek out the positives gained from the care experience report higher levels of overall satisfaction & low perception of care as 'burden;' • Fostering positivity within dementia care is also important from a wider societal perspective, particularly if dementia is to become properly accepted & integrated; • Positivity shares close links with positive affect so that activities that promote the latter can also assist the former; • The adoption of a general, purposeful bias towards positivity-'positivity offset'-can enhance the ability to cope with adversity; • Positive cognitions can provide a protective factor against stress for FCOPWD & can be derived from QOL & in particular the capacity for QOL to instil resilience; • Positivity represents a constructive shift away from predominant perceptions of care as 'burden.'
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(f) Context-Mechanism-Outcome configuration (CMOc) drawn up from the CPTs

Safeguarding carer's Quality of Life (QOL) (C), to facilitate the longer-term maintenance and sustenance of the FCOPWD (O) by a variety of means or mechanisms (M), including, reinforcing carers' ability to exploit their emotional maturity to balance positive and negative affect as part of an overarching salutogenic approach and promoting the message that maintaining QOL can contribute to carer resilience.

Theme 4 Sub-theme (iv): Finding Self-development, Growth and Meaningfulness in life through the care experience

(a) 'What could work to support FCOPWD'

Various studies have demonstrated that finding meaning and growth via the caregiver experience helps to foster positivity in spite of adverse circumstances (e.g. Meuser, Marwit & Sanders, 2004). Reframing the care experience has been found to make a significant contribution to carers' personal growth (Ott, Sanders & Kelber, 2007) and it seems likely that such reframing includes positive reframing, as discussed in sub-theme (iii) above.

Giuliano, Mitchell and Clark et al (1990, p.2) define 'meaning' in the context of caregiving as, "positive beliefs one holds about one's self and one's caregiving experience such that some benefits or gainful outcomes are construed from it." Both cognitive and affective factors appear to facilitate meaning in caregiving (for a review see Noonan & Tennstedt,1997), including making sense and coherence from life despite the challenges it presents as an adaptive cognitive state of mind.

Ideas and ideologies can exert a powerful influence on both cognitions and behaviour to promote very real and positive, salutogenic health outcomes. For example, Farran, Keane-Hagerty and Salloway

(1991) found that growing and gradually finding meaning through caregiving provided positive dimensions to the experience that can provide a protective factor against carer stress. Moreover, Noonan, Tennstedt & Reblsky (1996) found there may be mutual benefits for the PWD in terms of successful care outcomes derived from carers maintaining a positive mindset in which recognising growth and finding meaning in the experience.

Sorenson et al. (2006) found that in terms of effective interventions, psychoeducational training generally had the broadest effect on improving caregiver outcomes. More specifically, the potential value in targeting dysfunctional thoughts via cognitive-behavioral interventions with caregivers has been emphasised (Losada et al; 2010). Nevertheless, relatively few caregiver-intervention studies have focused on amending dysfunctional thoughts despite this representing a potentially effective cognitive-behavioral strategy (Wilz et al; 2011). This suggests that within family dementia care contexts much progress remains to be made regarding efforts to replace negativity and its consequences with something more positive and constructive.

(b) 'What could hinder support for FCOPWD'

Critics might argue that the notion of finding meaning and growth via dementia care seems somewhat naïve and based around the kind of idealistic mantra normally propagated by those of a more humanist persuasion (e.g. Block & Billings, 1998). Strong negative emotions and cognitions such as helplessness and fear are commonly experienced among Carers of PWD (Markut & Crane 2005). Therefore finding ways in which carers of PWD can find positivity, self-development, meaning and growth represent more than wishful idealism but arguably a necessity.

(c) Specific evidence for factors associated with resilience relating to FCOPWD

Payne (2007) cites 'finding meaning' in the care situation as a factor associated with resilience. Cohen, Colantonio and Vernich (2002) also found that 'finding meaning' in the FCOPWD corresponded with carer resilience. 'Finding meaning' also has also been found to represent a useful and adaptive coping strategy (Noonan, Tennstedt & Reblsky,1996).

(d) More general evidence for factors associated with resilience relating to FCOPWD

Sanders (2005) reported that 'personal growth' and 'a sense of accomplishment' were not uncommon among FCOPWD and associated with positive outcomes gained from dementia care.

(e) Candidate Program Theories drawn up based around the RRR evidence

Theme 4: Safeguard Carer's Quality of Life	Sub-theme (iv) Finding Self- development, Growth & Meaningfulness in life through the care experience	<ul style="list-style-type: none"> • Finding meaning and growth via the caregiver experience helps to foster positivity in spite of adversity; • Both cognitive and affective factors appear to facilitate meaning in caregiving, including making sense and coherence from life despite adversity; • Finding growth & meaning in the care experience shares close links with the adoption of a salutogenic approach to the FCOPWD; • Interventions designed to amend carers' dysfunctional thoughts about the care experience might be delivered via psychoeducational initiatives such as CBT; • Finding meaning in the care situation is linked to carer resilience.
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(f) Context-Mechanism-Outcome configuration (CMOC) drawn up from the CPTs

Safeguarding carer's Quality of Life (QOL) (C), to facilitate the longer-term maintenance and sustenance of the FCOPWD (O) by a variety of means or mechanisms (M), including, finding meaning and growth via the caregiver experience and making sense and coherence from life despite adversity. These factors can facilitate the adoption of a salutogenic approach as well as reinforce carer resilience.

Theme 5: Ensuring timely availability of key external resources

Theme 5 Sub-theme (i): Respite care

(a) 'What could work to support FCOPWD'

Nolan, Ryan and Enderby et al (2002) highlighted carers' dependency on external resources and called for a more inclusive vision of dementia care via a fresh paradigm in which external services designed to support carers might be more closely integrated. In terms of 'what works to support family carers of PWD' the availability and ease of access to external resources would seem intuitively to be vital. A fundamental issue that relates to this concerns who should take the main initiative in terms of instigating support and whether external services adopting a largely passive role is sufficient to meet carers' needs. The voluntary sector, particularly Alzheimer's Society, has grown at an exponential rate to occupy a gap in service provision between users and providers. Arguably though, external services need to become far more proactive with regard to this, even perhaps adopting more of an outreach approach to ensure carer access and uptake. Perhaps also, increasing the scope and range of such outreach may require a rethink regarding our use of terminology, i.e. reverting to calling 'carers' simply 'family members' instead rather than feeling compelled to identify them by some other label.

Respite care in which carers of PWD are provided with a period of time away from the regular responsibility for care provision is perhaps one of the most widely recognised services generally available to family carers. The potential benefits to family carers of taking up respite care have been widely reported, particularly its capacity to help extend family-based care and the avoidance of

institutionalisation (e.g. Parker, Mills & Abbey 2008; Eagar, Owen & Williams et al; 2007; Gaugler, Kane & Kane et al; 2005). The benefits of respite care also extend to improving carers' quality of life (QOL) (Winslow, 1997). As discussed in theme 4 above, there is a strong argument for asserting the importance to both carers and PWD of maintaining a reasonable level of QOL. In terms of 'what works,' the potential of respite care cannot be understated therefore.

(b) 'What could hinder support for FCOPWD'

Despite the advantages that might be gained by FCOPWD from increasing the uptake of formal services a relatively recent survey conducted with family carers in the U.K. reveals that less than half of all family carers (47%) reported being offered any support at all (Dowrick & Southern for Alzheimer's Society, 2014). This suggests that carers who remain passive and who largely anticipate that services will be advertised to them when they become available are likely to be limited in terms of the formal services they receive. A related issue is highlighted by Moriarty, Sharif and Robinson (2011) who noted the problem of inertia towards carer services uptake, particularly by minority groups in the U.K. who may feel there is a lack of inclusion reflected in existing policies and practices designed to offer external support.

A further issue concerns the level of integration that exists between external services to facilitate relatively seamless accessibility of external resources by family carers. Peel (2014) highlighted the systemic problems within the U.K. with both accessing, and navigating, health and social care services. Arguably, this represents a situation that is likely to have been exacerbated by the recent devolution of care responsibilities to local councils (Kane & Terry for Alzheimer's Society, 2015). Relevant to this point also is the need to ensure greater transparency regarding those services which are available to family carers (Livingston, Leavey & Manela et al; 2010).

A moot point concerns the extent to which voluntary sector organisations are effective in bridging the gap between the informal, family-based dementia care environment and the formal environment responsible for the provision of carer support. Moreover, the positioning of the voluntary sector as mediator between FCOPWD and more formal services may even be counter-productive in terms of leaving such services somewhat systematically distanced from carers. Further, that such a move serves to reinforce the notion that there a 'gap' between carers and formal services that needs to be filled rather than making any real attempt to remove the gap (for a review see Moreira, O'Donovan & Howlett, 2014). Indeed, a main conclusion of Knapp et al's (2012) systematic review of dementia care costs and outcomes was that poor coordination of health and social care provision and financing represented serious and fundamental issues to be addressed.

An additional factor which is associated with the generally low uptake of services by FCOPWD is that carers quite frequently do not perceive themselves as 'carers.' Rather, they continue to identify themselves according to their previous relationship with the PWD, i.e. as 'wife', 'husband', 'long-term partner,' 'son' or 'daughter.' This point was raised by Molyneaux et al. (2011) who criticised the use of the term 'carer' as inappropriate in terms of capturing the role actually performed by family in relation to PWD and reinforcing a polarity between them as if the 'carer' and 'cared for' resided at the opposite ends of some notional scale. The authors argue that this is divisive rather than integrative. Arguably also, the term 'carer' conveys the imputation that responsibility for caregiving mainly resides with the family member rather than representing a task which is shared with formal authorities who can offer support.

The full potential for respite care 'to work' for family carers remains largely untapped in the U.K. (Greenwood, Habibi & Smith et al; 2015). While there has been some focus on the lack of take up of such services by certain sub-populations of dementia carers (e.g. McDonnell & Ryan, 2013; Yeandle, Bennett & Buckler et al; 2007; Dilworth-Anderson, Williams & Gibson, 2002), more recent reports highlight the fact that the under-utilisation of respite care by carers in the U.K. is likely to represent an endemic problem which also affects the wider, majority dementia carer population (Greenwood, Habibi & Smith et al; 2015).

The evidence suggests that in order for respite care to 'work' in the U.K. there are several key issues which remain to be resolved. Included among these is the lack of clarification regarding the precise form respite care should take. The NHS Outcomes Framework for 2013 (Department of Health, 2012) placed emphasis on the provision of carers' downtime (time set aside when carers need not be actively engaged in the care role) via temporary support but fell short of specifying exactly how this support would be delivered. Without a clear mandate for how temporary support can be achieved, delivery is likely to become haphazard and of limited effectiveness. This is borne out by various reports. For example, under current guidelines almost 90% of councils in England stipulate that carers are only eligible for formal service provider support once their needs become critical or substantial (Association of Directors of Adult Social Services, 2014). In practice this means that many carers only receive respite care support once they have reached crisis point. Arguably, systems need to be in place to ensure such interventions are preventative rather than reactive, particularly with respect to maintaining carers' health and wellbeing in order to promote the continuation of family care. Service providers' policy towards respite care, particularly carers' eligibility to access it, needs to be reviewed if it is mainly accessed following a crisis, by which time the accumulation of stress has already impacted on carers' health and wellbeing. Lack of information made available to carers of PWD that

would otherwise enable them to make informed choices regarding respite care uptake also represents a main issue here (Greenwood, Habibi & Smith et al; 2015).

A further point is that there needs to be stricter guidelines regarding the quality of respite care available. This has been blamed at least in part for the relatively low uptake of this service in many parts of the U.K. (Newbronner, Chamberlain & Borthwick et al; 2013). A related point is that satisfaction survey data garnered in relation to carers' experiences of respite care services in the U.K. that might assist both in gauging and ensuring the quality of such services appears to be under-utilised (Greenwood, Habibi & Smith et al; 2015). In addition, respite care needs to be made affordable without compromising on the quality of the service available to carers (Dowrick & Southern for Alzheimer's Society, 2014).

Moreover, carers of PWD represent a very diverse group of people (Hirst, 2005). A factor recognised by the government published report 'Carers and personalisation: improving outcomes' (Simpson & Murray-Neill for DoH, 2010). Therefore generic guidelines for how respite care should be delivered are likely to fall short of meeting individual carer's needs. More research is needed therefore regarding how tailored respite care that meets carers' personal needs can be delivered. For example, forms of respite that may vary according to (a) duration, ranging from a single day or evening to several weeks at the other extreme (b) location, i.e. based at a hospice or centred round home-based care or in some instances there are opportunities for carers to go on bespoke vacations where all the actual care is provided by a third party (c) type, i.e. the carer leaves the PWD in the care of others or alternatively, the carer remains with the PWD but the provider takes over the actual care. Arguably, within the current respite care system there is scope for greater consideration of a far wider range of tailored respite care plans designed to meet individual carer's needs and which take greater account of the wide variety of contexts different dementia carers find themselves in.

At a more fundamental level there is also now discussion of the appropriateness of the term 'respite care.' A constructivist analysis of the term 'respite' reveals how it may convey the impression that carers are receiving temporary relief from some form of otherwise continuous onslaught or attrition. Arguably, such connotations are more suited to the context of 'war' than to 'dementia care.' Moreover, they may serve to reinforce the prevailing perspective of dementia care as 'burdensome,' thus upholding the predominant 'burden of care' models. As discussed in earlier chapters, if the family care of PWD in the U.K. is to continue to not only remain as the backbone of dementia care, but to actually become increasingly so due to the rising prevalence of the disease, then such models are at best unhelpful. Particularly in terms of promoting the family care as 'workable,' i.e. maintainable and sustainable in the long-term. Alternative terms to 'respite care' include 'replacement care' (e.g. Alzheimer's Society, 2016b, p.7), which at least focuses on the exchange of roles with someone else

temporarily taking over the primary carer’s position. However, arguably the temporary and transitory nature of the arrangement is not best conveyed by the term ‘replacement.’

(c) Specific evidence for factors associated with resilience relating to FCOPWD

Respite care has demonstrated effectiveness in extending family care of PWD (Eagar, Owen & Williams et al; 2007) and this might be viewed as evidence for its potential to enhance carer resilience. However, Payne (2007) points out that carer support to facilitate resilience is frequently reactive rather than pre-emptive with carers often only seeking help once a crisis has already been reached with a prime example of this being the availability of respite care (Eagar et al; 2007, Parker et al; 2008).

(d) General evidence for factors associated with resilience relating to FCOPWD

The general evidence did not add anything further to the discussion.

(e) Candidate Program Theories drawn up based around the RRR evidence

<p>Theme 5: Ensure timely Availability of Key External Resources</p>	<p>Sub-theme (i) Respite care tailored to individual carer needs</p>	<ul style="list-style-type: none"> • A more proactive approach is needed by FCOPWD as well as by formal service providers to ensure services are made more widely available & that their uptake is scaled up in support of the FCOPWD; • Respite care can extend the duration of FCOPWD, afford opportunities for carers to engage in valuable QOL activities & enhance carer resilience; • Respite care needs to become far more flexible to allow tailored respite care plans to be drawn up to meet individual carer’s needs and which take greater account of the wide variety of contexts different dementia carers find themselves in; • ‘Replacement care’ rather than ‘respite care’ may provide a more accurate reflection of the nature & purpose of this service to encourage its uptake, as well as to frame the service within a more salutogenic framework & away from the perception of dementia care as ‘burdensome.’
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(f) Context-Mechanism-Outcome configuration (CMOc) drawn up from the CPTs

Ensuring the timely availability of Respite care (C), to facilitate the longer-term maintenance and sustenance of the FCOPWD (O) by a variety of means or mechanisms (M), including, wider opportunities for carers to engage in valuable QOL activities which can in turn promote carer resilience. This can be facilitated by a more proactive approach to uptake by FCOPWD and by formal service providers ensuring Respite care is made more widely available and tailored of to meet individual carer’s needs.

Theme 5 Sub-theme (ii): Sitting / Befriending services

(a) 'What could work to support FCOPWD'

Although further research is needed to establish the full benefits that might be attained by carers of PWD by utilising such Sitting or Befriending services, initial findings indicate that their longer term use may be linked to improvements to carers' psychological wellbeing, including reductions in carer depression (Charlesworth, Shepstone & Wilson et al; 2008). Ultimately, carers need to feel secure in the knowledge that the PWD will be left in good care in order for the service to work as intended, i.e. to afford the carer some 'downtime,' as well as to offer the PWD a change in terms of socialising and making conversation. In terms of 'what works' Sitting services, like Respite care services, potentially at least have much to offer family carers of PWD.

(b) 'What could hinder support for FCOPWD'

Sitting services and Befriending services are beset with some of the same issues associated with respite care services. In particular, the lack of a wider availability of these services, particularly for FCOPWD who are based in more rural areas (Tommis, Seddon & Woods et al; 2007; Innes, Blackstock & Mason et al; 2005). A further issue relates to the affordability of such services. While a range of local councils in the U.K. provide a Sitting service for carers, these are often time-limited, usually for six months only. Sitting services offer a far more economical alternative to residential care, but more needs to be done to ensure all family carers of PWD can access Sitting services (The Health Foundation, 2011). Further, perceived inflexibility, lack of responsiveness and preconceived notions of sitting services as too generic rather than personalised according to individual needs all present significant barriers to the uptake of such services (e.g. Phillipson & Jones, 2011).

(c) Specific evidence for factors associated with resilience relating to FCOPWD

Specific evidence for a link between resilience, FCOPWD and Sitting or Befriending services was lacking.

(d) More general evidence for factors associated with resilience relating to FCOPWD

Evidence exists to indicate that the uptake of Sitting / Befriending services by FCOPWD can provide a protective factor against depression (Charlesworth, Shepstone, L., Wilson et al; 2008). This is significant given that depression is a marker for cessation of family care of PWD (Mittelman, Haley & Clay et al; 2006) and the stated outcome for resilience in the present study is the 'maintenance and sustenance of FCOPWD.'

(e) Candidate Program Theories drawn up based around the RRR evidence

<p>Theme 5: Ensure timely Availability of Key External Resources</p>	<p>Sub-theme (ii) Sitting Services & Befriending Services</p>	<ul style="list-style-type: none"> • The longer-term use of Sitting / Befriending services can provide a protective factor against carer depression; • Interventions that help to safeguard carers' mental health & wellbeing can contribute to carer resilience by delaying cessation of FCOPWD; • Sitting / Befriending services tailored to individual needs to facilitate wider socialisation for both the carer & the PWD to provide mutual benefits.
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(f) Context-Mechanism-Outcome configuration (CMOc) drawn up from the CPTs

Ensuring the timely availability of Sitting Services / Befriending Services (C), to facilitate the longer-term maintenance and sustenance of the FCOPWD (O) by a variety of means or mechanisms (M), including, providing a protective factor against carer depression and facilitating wider socialisation for both carers and PWD.

Theme 5 Sub-theme (iii): Carer training, coaching and mentoring

(a) 'What could work to support FCOPWD'

The available evidence indicates that some form of carer training could very well make a useful contribution to 'what works to support FCOPWD.' Training programs for carers that offer practical caring skills have been shown to help to increasing empowerment (Yeandle & Wigfield, 2011). For example, the rehearsal of behaviour management techniques can help to increase carers' self-efficacy and coping skills (Daly, McCarron & Higgins et al; 2013). Farran, Gilley and McCann et al (2007) and Sorenson, Duberstein and Gill et al (2006) also reported the mental health benefits to carers of interventions designed to assist family carers in dealing with some of the behavioural changes in the PWD wrought by dementia. Meanwhile, Dowrick and Southern for Alzheimer's Society (2014) cited the further advantages associated with the strong networking and peer support developed as a result of carers coming into contact with their fellow carers while attending such training courses. While the lack of opportunities for FCOPWD to engage in various forms of training was a criticism by some researchers only a short time ago (e.g. Rosa, Lussignoli & Sabbatini et al; 2010), more recent evidence indicates that in the U.K. there opportunities have since increased.

For the present at least, any carer training remains an option which family carers can take up. However, this is reliant on carers having advice about such training, being signposted towards it and having the means and willingness to devote time and energy to it. Further, carer training is often only available via local Voluntary sector organisations where these are available and where provision and access is possible. Essentially, carer training in the U.K. currently remains haphazard and patchy.

Arguably, this represents a missed opportunity where it is designed to empower FCOPWD rather than replace the need for formal health care involvement. This represents a main point taken up by Dowrick and Southern in a report prepared for Alzheimer's Society in 2014 which examined constructive ways in which dementia care might be changed. However, the authors concluded that to date the U.K. has been slow to realise the potential benefits of empowering family carers with the voluntary sector taking a lead. A moot point concerns whether the Voluntary sector currently possesses the means to take up this mantle fully. Further, whether there should in fact be more formal services' involvement in such processes.

There are some key issues that remain to be resolved with regard to family carer dementia training. This includes deciding who should provide such training, what precise form such training should take and remaining mindful of the need to ensure carer dementia training provision represents an equitable arrangement in which formal health-care providers perceive the training context as an opportunity to forge closer links with family carers rather than to further distance themselves from carers once such training is completed.

(b) 'What could hinder support for FCOPWD'

The majority of FCOPWD are stepping into the unknown with regard to dementia care and this feeling of moving out of one's depth may deepen as carers advance further along the dementia trajectory (Carers Trust, 2015). Few carers come readily equipped with the requisite knowledge and skills needed to address the many and various challenges dementia can bring. Arguably, this presents a dilemma since on the one hand family carers are expected to simply take up the reins and get on with the carer role while on the other managing dementia care well can often prove challenging, even among those with previous caregiving experience. The relatively unique nature of dementia, including its long time course, unpredictable and variable symptomatology and the profound changes it engenders in the PWD arguably call for quite specialised knowledge and skills. A main argument concerns how family carers should acquire and develop such specialist skills. Moreover, whether it is indeed ethical or fair for formal health care providers to anticipate that family carers will accept a large part of the responsibility for day-to-day care without any formal training and indeed, how much involvement formal providers should have. That there is some ambiguity concerning how much training and coaching FCOPWD should be offered is also reflected in The Social Care Institute for Excellence's (SCIE) recent decision to switch the focus of their E-learning courses which were formerly available to family carers since 2009 (SCIE, 2009) to formal care workers.

(c) Specific evidence for factors associated with resilience relating to FCOPWD

Dias, Santos and De Sousa et al. (2014) found links between FCOPWD, educational support about dementia and dementia care and called for educational support to help facilitate carer resilience.

(d) General evidence for factors associated with resilience relating to FCOPWD

The general evidence did not add anything further to the discussion.

(e) Candidate Program Theories drawn up based around the RRR evidence

<p>Theme 5: Ensure timely Availability of Key External Resources</p>	<p>Sub-theme (iii) Carer training / coaching / mentoring</p>	<ul style="list-style-type: none"> • Training that includes the development of practical skills can enhance carer empowerment & carer self-efficacy; • Training in behavioural management techniques can assist carers' mental health; • Training can facilitate carer networking to improve peer support; • Educational support about dementia & dementia care can facilitate carer resilience.
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(f) Context-Mechanism-Outcome configuration (CMOc) drawn up from the CPTs

Ensuring the timely availability of Carer training / coaching / mentoring (C), to facilitate the longer-term maintenance and sustenance of the FCOPWD (O) by a variety of means or mechanisms (M), including, the development of practical skills which can enhance carer empowerment and carer self-efficacy and facilitate carer networking that increases peer support.

Theme 5 Sub-theme (iv): Relevant information and advice

(a) 'What could work to support FCOPWD'

While the effects of more generic carer education may be limited (Kurz, Wagenpfeil & Hallauer et al; 2010; Pinquart & Sörensen, 2006), the majority of interventions that were better tailored to meet the more specific needs of FCOPWD have been shown to improve carers' well-being and coping ability (Gallagher-Thompson & Coon, 2007; Chee, Gitlin & Dennis et al; 2007). In particular, information and advice that focuses on carers' development of social, problem-solving, or cognitive components appears to be most beneficial.

Several studies also highlight the importance of FCOPWD receiving the best information and advice concerning the availability of services, how to access and utilise Voluntary sector support, network with peers and gain relevant information about dementia pathology (Edelman, Kuhn & Fulton et al; 2006; Van der Roest et al., 2009).

Evidence also suggests FCOPWD may benefit most from a strategic approach to the delivery of information and advice or alternatively, have access to initial guidance which provides specific advice and information to cover specific milestones along the dementia trajectory. This would allow provision to be tailored more according to the needs demanded by particular contexts and situations. For example, Egdell (2012) found that advice and signposting of carers towards respite care services could be improved and might prevent the escalation of chronic stress in carers during the later stages of dementia. A further and perhaps overlooked advantage of formal health-care providers remaining involved with family carers in the strategic provision of such information and advice throughout the dementia trajectory is that such a measure could help to maintain closer links between formal services and individual carers. The strategic delivery of information and advice would also avoid inundating carers with a surplus of advice and information at the outset of dementia care which may prove overwhelming as well as daunting. Receiving appropriate advice and information in the right quantities is clearly important at the outset of the carer journey in order to begin to establish a basis from which to build increasing competence and self-efficacy (Yeandle & Wigfield, 2011). One way in which significant milestones might be drawn up to ensure FCOPWD receive the right level of information at the right time might be to focus on the finding that FCOPWD's information needs are high each time the PWD progresses to a new phase of their illness (McLaughlin & Jones, 2011).

That the receipt of relevant information and advice by FCOPWD is important is underlined by one of Alzheimer's Society's 2015-16 main mission statement cited in their review report, that there is a burgeoning need to increase access to information so that people affected by dementia are empowered to make their own decisions and take control of their lives. Practical ways in which Alzheimer's Society have endeavoured to achieve this is via a combination of Helpline support, as well as an increasing range of magazine bulletins, guide books and Website support.

(b) 'What could hinder support for FCOPWD'

FCOPWD are seldom well equipped at the outset of dementia care with the requisite knowledge and skills to carry out the carer role and this equally applies to information and advice concerning dementia care. Service care providers should not assume that carers are able to discover relevant information themselves. To this end, it is essential that signposting of services and support navigating the options available are properly addressed (Peel, 2014). Currently, FCOPWD may receive a quantity of information following an initial diagnosis of dementia, after which contact with formal services and the provision of information and advice becomes infrequent.

(c) Specific evidence for factors associated with resilience relating to FCOPWD

Specific evidence for a link between resilience, FCOPWD and relevant information and advice was lacking.

(d) More general evidence for factors associated with resilience relating to FCOPWD

Indirect evidence for the potential for relevant information and advice to enhance FCOPWD resilience comes from the finding that this can enhance carer empowerment (Yeandle & Wigfield, 2011) and carer self-efficacy (Daly, McCarron & Higgins et al; 2013).

(e) Candidate Program Theories drawn up based around the RRR evidence

Theme 5: Ensure timely Availability of Key External Resources	Sub-theme (iv) Relevant information, advice, education	<ul style="list-style-type: none">• Advice & information that is tailored to meet the specific needs of FCOPWD has been shown to improve carers' well-being, coping ability & competency;• Information and advice can empower FCOPWD to make their own decisions, take control of their lives & improve self-efficacy to increase resilience;• Information and advice that focuses on carers' development of social, problem-solving, or cognitive components appears to be most beneficial;• Information and advice that improves access to services, including Voluntary sector & peer support, demonstrate effectiveness in supporting FCOPWD;• The strategic provision of information and advice throughout the dementia trajectory can ensure the right information is received at the right time & could facilitate closer liaison & continuity between FCOPWD & formal service providers.
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(f) Context-Mechanism-Outcome configuration (CMOc) drawn up from the CPTs

Ensuring the timely availability of relevant information, advice and education(C), to facilitate the longer-term maintenance and sustenance of the FCOPWD (O) by a variety of means or mechanisms (M), including, developing social and problem-solving skills and improving access to services including Voluntary sector and peer support which can contribute to improving carers' well-being, coping ability, competency and control. This can be facilitated by the strategic provision of information and advice throughout the dementia trajectory.

Theme 5 Sub-theme (v): Cognitive behavioural therapy (CBT)

(a) 'What could work to support FCOPWD'

Brodsky et al (2003) concluded that beneficial psychoeducation interventions for carers of people living with neurodegenerative disorders are urgently needed. In this regard, a main avenue which has been explored for its potential to offer support to family carers of PWD is Cognitive Behavioural

Therapy (CBT). In general, CBT uses targeted strategies to help people to adopt more adaptive patterns of thinking and behaving, which leads to positive changes in emotions and decreased functional impairments (Coffey, Banducci & Vinci, 2015). CBT has been used to treat a number of psychiatric disorders ranging from anxiety and depression to obsessive-compulsive disorders and personality disorders. Strategies include identifying and challenging problematic thoughts and beliefs, scheduling pleasant activities to increase environmental reinforcement, and aversion therapy (Beck, 2011).

While the rationale for the inclusion of CBT alongside other measures that might 'work to support FCOPWD' centres around its potential to alleviate the anxiety and stress frequently associated with dementia care, its role as a preventative rather than a remedial measure is of particular interest. This coincides with the finding that FCOPWD may often be exposed to chronic stress and moreover, this can predicate the premature cessation of family care (Hirst, 2004). Moreover, it is claimed that by addressing underlying psychiatric disorders, CBT actually contributes to improvements to people's quality of life (QOL) (Coffey, Banducci & Vinci, 2015). This draws some relationship therefore between CBT and Theme 4 (QOL) discussed earlier.

Until relatively recently, psychoeducation training such as CBT enjoyed burgeoning popularity and endorsed by numerous studies (Butler, Chapman & Forman et al; 2006). These positive findings were also reflected in studies that more specifically examined the effectiveness of CBT as a means to support FCOPWD. For example, Pincus and Sörensen's (2006) meta-analysis of caregiver interventions found that psychoeducational training had the broadest effect on carer outcomes. Meanwhile, Gallagher-Thompson et al's analysis (2010) found that CBT could go further to not only reduce carer stress but importantly also, achieve its opposite by promoting positive affect.

(b) 'What could hinder support for FCOPWD'

However, there is now greater realisation of the need to tailor interventions that rely on CBT to meet the needs of different clients and different disorders. Further, that as a therapy CBT's effectiveness or otherwise may be greatly dependent upon how the technique is applied and whether it is appropriate and efficacious for the treatment of the particular disorder for which it has been prescribed.

Moreover, there is now a better understanding of the need for clients to be prepared to fully commit towards the therapy in order for CBT to work effectively (Coffey, Banducci & Vinci, 2015).

Arguably though, the most pressing issue in the U.K. concerns the ability of 2012 Health and Social Care Act to live up to its promised aim of ensuring that people's mental health is placed on an equal footing with physical health (Mind, 2013). MIND's (2013) report into the accessibility and effectiveness of talking therapies in the U.K., including CBT, found many deficiencies that included limited access,

unacceptably long waiting times for referral, insufficient number of sessions and inconsistent quality between different therapy providers. Specifically addressing FCOPWD, Rosa et al's (2010) study found that there was limited availability of psychological interventions.

(c) Specific evidence for factors associated with resilience relating to FCOPWD
 Specific evidence for a link between resilience, FCOPWD and CBT was lacking.

(d) More general evidence for factors associated with resilience relating to FCOPWD
 Psychoeducational programs such as Cognitive behavioural therapy (CBT) have been shown to exert the broadest impact on carer outcomes (Pinquart and Sörensen, 2006). CBT can include training carers to develop vital cognitive skills that (a) challenge dysfunctional thoughts (b) encourage positive reframing and (c) enhance behavioural skills such as adaptive coping. The effectiveness of CBT as a strategy for mediating depression is likely to be important to FCOPWD who are in general have a vulnerability to depression (Hirst, 2005). As a protective factor against stress and a potential means to promote positive affect (Gallagher-Thompson et al; 2010)
 CBT appears to embrace the kind of qualities one might associate with facilitating resilience.

(e) Candidate Program Theories drawn up based around the RRR evidence

Theme 5: Ensure timely Availability of Key External Resources	Sub-theme (v) CBT Training	<ul style="list-style-type: none"> • CBT that is tailored to FCOPWD's needs can provide a protective factor against stress by modifying perceptions of stress & challenging & controlling negative, upsetting thoughts; • CBT can increase positive affect (feelings of active pleasure); • Such qualities signal that CBT has the potential to facilitate FCOPWD resilience.
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(f) Context-Mechanism-Outcome configuration (CMOc) drawn up from the CPTs
 Ensuring the timely availability of CBT Training (C), to facilitate the longer-term maintenance and sustenance of the FCOPWD (O) by a variety of means or mechanisms (M), including, providing a protective factor against stress by modifying carers' perceptions of stress, challenging and controlling negative, upsetting thoughts and increasing positive affect.

Theme 5 Sub-theme (vi): Mindfulness training

(a) 'What could work to support FCOPWD'

Although there are strong associations between Cognitive Behavioural Therapy (CBT) and other forms of psychoeducation interventions such as Mindfulness, the latter tends to be more specifically directed towards addressing carers' dysfunctional thoughts. Further, Mindfulness-based stress reduction (MBSR) represents a version of Mindfulness that is designed to counteract worries about the future. Since such worries are highly prevalent in the context of the care of people living with chronic terminal illnesses such as dementia, MBSR would appear to represent a most appropriate intervention to be employed with FCOPWD. The nature of dementia, including its prolonged trajectory and the profound neurodegenerative impact it inflicts on PWD, ultimately culminating in mortality, mean that FCOPWD may be especially vulnerable to catastrophic thinking. This is borne out by several studies, including Markut and Crane's (2005) which found that catastrophic thinking involving strong negative emotions such as helplessness and fear are commonly experienced and expressed among FCOPWD.

Research conducted by Oken et al. (2010) into the effects of MBSR with FCOPWD demonstrated its effectiveness proved in (i) helping carers to understand their personal reactions to stress (ii) teaching skills that provided a means to modify stress reactions. Earlier research by Waelde et al. (2004) found that MBSR can improve carers' self-efficacy while McBee (2003) reported its efficacy in reducing carers' levels of stress, somatic problems and improve perceived levels of satisfaction with caregiving. More recently, studies have found support for MBSR as an effective strategy in the support of family carers, including Whitebird et al. (2012) while Paller et al. (2015) found that MBSR delivered over the course of 8 weekly sessions was effective in improving not only carers' general wellbeing and mood, but also proved effective for PWD who jointly attended the sessions. This was manifest in reduced levels of stress, improved mood and the removal of the reflexive tendency to react to potentially stressful situations in habitual but maladaptive ways.

(b) 'What could hinder support for FCOPWD'

Research to date suggests MBSR represents a worthy addition to 'what works to support family carers of PWD.' However, there remains a need for future studies to investigate MBSR further: (a) longitudinal studies to establish how long the beneficial effects of MBSR endure, particularly given that sustained benefits may be largely dependent on carers' willingness to continue to practise the skills learned during training (Paller, Creery & Florczak et al; 2015) (b) larger scale studies to confirm the findings to date (Hurley, Patterson & Cooley, 2014).

(c) Specific evidence for factors associated with resilience relating to FCOPWD

Specific evidence for a link between resilience, FCOPWD and Mindfulness training was lacking.

(d) More general evidence for factors associated with resilience relating to FCOPWD

Mindfulness training can provide useful strategies for controlling negative thoughts (Cheng, Lam & Kwok et al; 2012), teach skills that help carers better understand and moderate their personal reactions to stress (Cheng, Lam & Kwok et al; 2010) and prevent catastrophic thinking that can lead to undue anxiety, stress and fear (Markut & Crane, 2005). Its potential to provide a further protective factor against carer stress and promote self-efficacy (Waelde et al; 2004) suggest Mindfulness-based stress reduction (MBSR) may have a role to play in maintaining carer resilience.

(e) Candidate Program Theories drawn up based around the RRR evidence

<p>Theme 5: Ensure timely Availability of Key External Resources</p>	<p>Sub-theme (vi) Mindfulness training</p>	<ul style="list-style-type: none"> • Mindfulness-based stress reduction (MBSR) can help FCOPWD to understand & modify their personal reactions to stress to prevent catastrophic thinking; • MBSR can improve FCOPWD’s general wellbeing and mood; • MBSR can promote self-efficacy in FCOPWD; • By providing a further protective factor against carer stress and promoting self-efficacy MBSR may have a role to play in maintaining carer resilience.
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(f) Context-Mechanism-Outcome configuration (CMOc) drawn up from the CPTs

Ensuring the timely availability of Mindfulness training (C), to facilitate the longer-term maintenance and sustenance of the FCOPWD (O) by a variety of means or mechanisms (M), including, modifying carers’ personal reactions to stress, preventing catastrophic thinking, improving general mood and wellbeing and promoting carers’ self-efficacy.

Appendix 4: Summary of Candidate Program Theories (CPTs) derived from the RRR.

Theme 1: Supportive social context

Theme 1 Sub-Theme 1: Strong Relational support network

Potential Mechanisms & How they might enable the FCOPWD

- Reducing social isolation removes a potential trigger for carer depression;
- Reliable alliance support reinforces ability to cope;
- Division of labour reduces number of hours engaged in daily care by a single family member to alleviate the intensity of care for each individual;
- Shared responsibility permits contingency plans to be made & duties reorganised to allow adaptation to meet sudden changes to the carer situation, facilitating carer recovery from adverse events;
- Adaptive emotion-focused coping (including emotional support from others, acceptance & positive reframing) provide a protective factor against carer stress.

Theme 1 Sub-Theme 2: Good relationship with PWD

Potential Mechanisms & How they might enable the FCOPWD

- Reduce potential social tensions alleviates anxiety / stress;
- Building a stronger rapport & mutual trust supports a more harmonious atmosphere around the care situation;
- Reduce likelihood of misunderstandings leading to behavioural management issues that can otherwise promote high levels of stress;
- Positive reappraisal of carer events promotes a positive carer-PWD atmosphere.

Theme 1 Sub-Theme 3: Potential Mechanisms & How they might enable the FCOPWD

- Foster the notion of the caregiving role as being family oriented approach by health professionals & inclusive of family members who are seen as valued for their contribution;
- Closer integration between formal services & carers to ensure practical Advice, information & signposting can be made available without much delay to permit a rapid response to carers' & the PWD's needs;
- A proactive policy by formal service providers to try to ensure carer health & wellbeing remain paramount, including emotional support.

Theme 1 Sub-Theme 4: Carers & PWD well integrated within dementia friendly community

Potential Mechanisms & How they might enable the FCOPWD

- Remove social stigma attached to dementia encourages acceptance of carers & PWD within the community reducing potential anxiety / tension;
- Facilitate socialisation within the community to encourage wider social support & wider engagement in social activities to enhance quality of life.

Theme 1 Sub-Theme 5: Regular Voluntary sector support & close links with other carers of PWD

Potential Mechanisms & How they might enable the FCOPWD

- Provide a less formal & potentially more inviting pathway to access information, advice, support & training relevant to both the carer & the PWD;
- Reduce social isolation & increase emotional support to remove potential triggers for carer depression;
- Promote resilience of carer via mutual support, camaraderie & carer solidarity;
- Increase the potential for rapid dissemination of new or emerging advice.

Theme 2: Strengthening Key Psychological Assets

Theme 2 Sub-Theme 1: Self-efficacy

Potential Mechanisms & How they might enable the FCOPWD

- Increase confidence to carry out caregiving role via a growing belief in one's ability to manage the care situation;
- Raise carer perception of controllability over care situation to reinforce carers' internal locus of control, self reliance, resilience & perceived capacity to master new domains;
- Self-efficacy (SE) provides carers with a buffer against negative affect;
- SE mediates carers' health and wellbeing by strengthening internal LOC to positively influence carers' perceptions of being able to regulate their health & wellbeing;
- Augmenting SE has been linked with robustness which shares close links with resilience.

Theme 2 Sub-Theme 2: Hope

Potential Mechanisms & How they might enable the FCOPWD

- Hope has a moderating role in alleviating carer stress to help protect carers' psychological wellbeing;
- Hope instils a positive attitudinal orientation towards goals & daily challenges fosters a belief in & motivation to achieving goals;
- Hope encourages positive reframing of the carer role which acts as a buffer against depression;
- Hope helps mobilise resources to adapt to changes;
- Hope promotes problem-solving and growth seeking behaviours.

Theme 2 Sub-Theme 3: Coping ability

Potential Mechanisms & How they might enable the FCOPWD

- Coping ability provides a means by which stress can be managed;
- Coping ability can mediate carer anxiety & depression;
- Coping ability represents an overt & learnable skill set that can be flexibly applied to different situations & allow goal adjustment to help deal effectively with the inherently unpredictable nature of dementia & dementia care;
- Coping ability can include Problem-focused coping (PFC) which can provide a protective factor against stress;
- Adoption of acceptance-based coping strategies has been shown to be more effective than avoidance-based coping strategies that fail to tackle daily challenges & obstacles that need to be overcome. This has also been demonstrated to alleviate anxiety & stress in the longer term;
- Higher levels of resilience are linked with the development of effective coping strategies.

Theme 3: Maintaining Carer's Physical Health Status

Theme 3 Sub-Theme 1: Perceived level of carer health

Potential Mechanisms & How they might enable the FCOPWD

- Moving beyond the mind-body dichotomy, perceptions of health provide important determinants of physical health, e.g. low perceptions of stress may provide a protective factor against carer depression;
- Emotion regulation may provide a means to mediate perceived health;
- Improving perceptions of health can contribute to a more salutogenic approach to carers' health & wellbeing.
- Higher carer resilience is associated with reduced psychosomatic symptoms that may be partly determined by health perceptions.

Theme 3 Sub-Theme 2: Objective measures of health

Potential Mechanisms & How they might enable the FCOPWD

- Promotion of carer health and wellbeing is of paramount importance to the maintenance of the FCOPWD & there are demonstrable links between better dementia carer health & resilience;
- Formal health care services that are closely integrated can provide a well co-ordinated & proactive approach to ensuring carer health & wellbeing that is based around prevention rather than cure;
- Tailored approaches to safeguarding of FCOPWD's health & wellbeing could take fuller account of the salient health inequalities experienced by such carers.

Theme 3 Sub-Theme 3: Adherence to a healthy, balanced diet

Potential Mechanisms & How they might enable the FCOPWD

- Adherence to a healthy, balanced diet has been associated with positive coping & a strong LOC that assist good maintenance of health & wellbeing;
- The regular inclusion of slow-burning starches can increase energy & stamina to help boost carers' energy levels;
- Dietary interventions that address increasing risk of anaemia with age can help to maintain energy levels;
- Combining a healthy, balanced diet with regular exercise has been found to contribute to resilience.

Theme 3 Sub-Theme 4: Regular physical activity

Potential Mechanisms & How they might enable the FCOPWD

- Regular exercise can reduce carers' levels of perceived stress;
- Regular exercise can improve general wellbeing in older adults;
- Maintaining wellbeing, which has its basis in psychological health, may help to manage and prevent disease in FCOPWD by supporting immune function;
- Interventions designed to encourage carer exercise may be optimal where they require minimal set-up time or resources & can be fitted in between busy schedules;
- Exercise may be usefully combined with pleasurable activities to promote positive affect & enhance QOL;
- Continued engagement in daily activities that include non-carer related activities is linked to carer resilience.

Theme 3 Sub-Theme 5: Perception of generally good quality / quantity of sleep

Potential Mechanisms & How they might enable the FCOPWD

- Carers' general perceptions of obtaining good quality & quantity of sleep can help to counteract daytime exhaustion, promote fuller mental & physical recuperation from prior day-time activities that can in turn provide a protective factor against pre-somnolent anxiety & stress that can lead to sleep disorders;
- Prevent chronic sleep disruption from becoming a precursor to carer depression;
- Promote uptake of respite care to improve management of carer sleep.

Theme 4: Safeguarding Carer's Quality of Life

Theme 4 Sub-Theme 1: Opportunities to experience positive affect

Potential Mechanisms & How they might enable the FCOPWD

- Positive affect & its maintenance may represent one of the key components within QOL that may be most beneficial to carers in terms of promoting health & wellbeing as part of an overarching salutogenic approach;
- Enhancing carers' general subjective mood state via the promotion of positive affect may be more important to sustained health & wellbeing than engagement in costly & time-consuming leisure activities;
- Achieving a healthy ratio in which positive affect outweighs negative affect may rely more on the frequency of engagement in QOL activities than the duration;
- Convincing carers of the potential benefits of maintaining QOL may be essential in order to assuage feelings of guilt that may accompany activities which might be regarded as forms of self-indulgence that detract from dementia care. Such benefits include: (a) promoting carers' health & wellbeing (b) enabling carers to sustain the FCOPWD (c) increasing engagement in QOL activities for the PWD.

Theme 4 Sub-Theme 2: Maintenance of affect balance

Potential Mechanisms & How they might enable the FCOPWD

- Older adults who represent the majority of FCOPWD may possess greater emotional maturity that confers an advantage in terms of being able to balance positive & negative affect;
- This advantage might be exploited to further promote carers' strengths as part of an overarching salutogenic approach;
- Maintaining engagement in activities that promote positive affect can provide a means to increase overall resilience but FCOPWD may need to be made more fully aware of these potential benefits in order to capitalise on them.

Theme 4 Sub-Theme 3: Subjective experience of life, living & domains of life such as work, leisure & family remain generally positive

Potential Mechanisms & How they might enable the FCOPWD

- Carers who proactively seek out the positives gained from the care experience report higher levels of overall satisfaction & low perception of care as 'burden';
- Fostering positivity within dementia care is also important from a wider societal perspective, particularly if dementia is to become accepted as an integral part of communities;
- Positivity shares close links with positive affect so that activities that promote both may prove mutually beneficial;
- The adoption of a general, purposeful bias towards positivity-'positivity offset'-can enhance the ability to cope with adversity;
- Positive cognitions can provide a protective factor against stress for FCOPWD & can be derived from QOL & in particular the capacity for QOL to instil resilience;
- Positivity represents a constructive shift away from predominant perceptions of care as 'burden.'

Theme 4 Sub-Theme 4: Finding Self-development, Growth & Meaningfulness in life through the care experience

Potential Mechanisms & How they might enable the FCOPWD

- Finding meaning and growth via the caregiver experience helps to foster positivity in spite of adversity;
- Both cognitive and affective factors appear to facilitate meaning in caregiving, including making sense and coherence from life despite adversity;
- Finding growth & meaning in the care experience shares close links with the adoption of a salutogenic approach to the FCOPWD;
- Interventions designed to amend carers' dysfunctional thoughts about the care experience might be delivered via psychoeducational initiatives such as CBT;
- Finding meaning in the care situation is linked to carer resilience.

Theme 5: Ensuring timely availability of key external resources

Theme 5 Sub-Theme 1: Respite care tailored to individual carer's needs

Potential Mechanisms & How they might enable the FCOPWD

- A more proactive approach is needed by FCOPWD as well as by formal service providers to ensure services are made more widely available & that their uptake is scaled up to enable the FCOPWD;
- Respite care can extend the duration of FCOPWD, afford opportunities for carers to engage in valuable QOL activities & enhance carer resilience;
- Respite care needs to become far more flexible to allow tailored respite care plans to be drawn up to meet individual carer's needs, taking greater account of the wide variety of contexts FCOPWD find themselves in;
- 'Replacement care' rather than 'respite care' may provide a more accurate reflection of the nature & purpose of this service to encourage its uptake, as well as to frame the service within a more salutogenic framework & away from the perception of dementia care as 'burdensome.'

Theme 5 Sub-Theme 2: Sitting Services & Befriending Services

Potential Mechanisms & How they might enable the FCOPWD

- The longer-term use of Sitting / Befriending services can provide a protective factor against carer depression;
- Interventions that help safeguard carers' mental health & wellbeing can contribute to carer resilience;
- Sitting / Befriending services tailored to individual needs can facilitate wider socialisation for both the carer & the PWD to provide mutual benefits.

Theme 5 Sub-Theme 3: Carer training / coaching / mentoring

Potential Mechanisms & How they might enable the FCOPWD

- Training that includes the development of practical skills can enhance carer empowerment & carer self-efficacy;
- Training in behavioural management techniques can strengthen carers' mental health;
- Training can facilitate carer networking to improve peer support;
- Educational support about dementia & dementia care can facilitate carer resilience.

Theme 5 Sub-Theme 4: Relevant information, advice, education

Potential Mechanisms & How they might enable the FCOPWD

- Advice & information that is tailored to meet the specific needs of FCOPWD has been shown to improve carers' well-being, coping ability & competency;
- Information and advice can empower FCOPWD to make their own decisions, take control of their lives & improve self-efficacy to increase resilience;
- Information and advice that focuses on carers' development of social, problem-solving, or improved cognitions appears to be most beneficial;
- Information and advice that improves access to services, including Voluntary sector & peer support, demonstrate effectiveness in supporting FCOPWD;
- The strategic provision of information and advice throughout the dementia trajectory can ensure the right information is received at the right time & could also facilitate closer liaison & continuity between FCOPWD & formal service providers.

Theme 5 Sub-Theme 5: CBT Training

Potential Mechanisms & How they might enable the FCOPWD

- CBT that is tailored to FCOPWD's needs can provide a protective factor against stress by modifying perceptions of stress & challenging & controlling negative, upsetting thoughts;
- CBT can increase positive affect;
- Such attributes signal that CBT has the potential to facilitate FCOPWD resilience.

Theme 5 Sub-Theme 6: Mindfulness Training

Potential Mechanisms & How they might enable the FCOPWD

- Mindfulness-based stress reduction (MBSR) can help FCOPWD to understand & modify their personal reactions to stress to prevent catastrophic thinking;
- MBSR can improve FCOPWD's general wellbeing and mood;
- MBSR can promote self-efficacy in FCOPWD;
- By providing a further protective factor against carer stress and promoting self-efficacy, MBSR may have a role to play in maintaining carer resilience

Appendix 5: Ethical Approval for study



Professor Kathleen McCourt, CBE FRCN
Executive Dean

This matter is being dealt with by:

Dr Nick Neave
Director of Ethics
Faculty of Health & Life Sciences
Northumberland Building
Newcastle upon Tyne
NE1 8ST

18th March 2016

Dear Mark

Faculty of Health and Life Sciences Research Ethics Committee

Submission Code: HLS-PHW151616

Title: What builds resilience in family carers of people with dementia?

Following independent peer review of the above proposal, I am pleased to inform you that Faculty approval has been granted on the basis of this proposal and subject to compliance with the University policies on ethics and consent and any other policies applicable to your individual research. You should also have recent Disclosure & Barring Service (DBS) if your research involves working with children and/or vulnerable adults.

The University's Policies and Procedures are available on the ELP; Organisation name: HLS0002: Research Ethics and Governance

You may now also proceed with your application (if applicable) to:

- NHS R&D organisations for approval. Please check with the NHS Trust whether you require a Research Passport, Letter(s) of Access or Honorary contract(s).
- NHS or Social Care Research Ethics Committee (REC). [They will require a copy of this letter plus the ethics panel comments and your response to those comments].

You must not commence your research until you have obtained all necessary external approvals.

The University strongly advises that the supervisor accompany the student when attending an external REC.

All researchers must also notify this office of the following:

- Any significant changes to the study design, by submitting an 'Ethics Amendment Form'
- Any incidents which have an adverse effect on participants, researchers or study outcomes, by submitting an 'Ethical incident Form'
- Any suspension or abandonment of the study;

We wish you well in your research endeavours.

Yours sincerely

J. Reynolds
Dr Joanna Reynolds
Faculty Ethics Coordinator: Department of Public Health and Wellbeing

Vice-Chancellor and Chief Executive
Professor Andrew Wathey

Northumbria University is the trading name of the University of Northumbria at Newcastle.

Appendix 6: Participant Information Sheet



Faculty of Health & Life Sciences

Study Title: What works to support family carers of people with dementia?

Investigator: Mark Parkinson (Public health researcher at Northumbria University).

Participant Information Sheet

You are being invited to take part in this research study. Before you decide it is important for you to read this leaflet so you understand why the study is being carried out and what it will involve.
Reading this leaflet, discussing it with others or asking any questions you might have will help you decide whether or not you would like to take part.

What is the Purpose of the Study

Not enough is known about the best ways in which family carers of people who are living with dementia can be supported. This is despite increases in the numbers of family carers and increasing reliance on them. An evaluation will therefore be conducted to gather family carers' views on the main research question: 'What works to support family carers of people living with dementia (PWD)?' This will be carried out using in-depth interviews with family carers of PWD. The Project will address several key questions:

- (i) which factors remain crucial to supporting family carers of PWD in order to maintain and sustain family care of PWD and which hinder it?
- (ii) how do family carers' needs change as the dementia advances?

Why have I been invited?

You have been invited to take part because the study will investigate what works to support family carers of people who are living with dementia. The study places great importance on family carers' own views in relation to this question, hence your involvement in the study. In particular, the study will focus on family carers of people who are living with Alzheimer's disease and who provide the main unpaid support. It is recognized that you may not formally label yourself as a 'carer' but you will have been looking after someone with Alzheimer's disease for a minimum of 12 months already. You will be living in the North East region. You will also be aged 50 or over since this age group represents the age of the majority of family carers of people living with dementia in England at present.

Do I have to take part?

Taking part in the study is purely voluntary and you are free to withdraw from the study at any point by informing the researcher or the researcher's principal supervisor, Professor Susan Carr at Northumbria University. Any data already submitted will be deleted. At the beginning of the study you will be given the option of providing a unique identifier. You may use this to withdraw from the study by emailing the researcher with this identifier and your data will then be removed without prejudice. If you would like to withdraw from the study, you must do so within four weeks after the completion of the study. After this time, the results may have been analysed and it will not be possible to withdraw your data.

What will happen if I take part?

You will be asked to take part in an interview lasting up to approximately one and a half hours at a venue of your choosing. However, the interview time can be shortened should you need to be called away to attend to the caree. During the interview you will be asked to talk about your experiences of being a family carer. This will span from the time you began this up until the present time. It is recognised that the subject matter of the interview is of a sensitive and personal nature. Therefore you are under no obligation whatsoever to answer any questions you would prefer not to comment on. If at any time you wish to pause or cease the interview, you can request this and your request will be immediately granted. The interview questions will be based around the main research question listed above, but the interview will also allow you the opportunity to speak freely about any other issues that you feel may be important in relation to how family carers of people living with dementia might best be supported. The interview will be recorded using a voice recorder or MP3 recorder. This will be switched on at the beginning of the interview and switched off once the interview has been concluded. This is to enable the researcher to later examine the main points raised during the interview in further depth and detail.

Once the interview recording has been taken away and examined in further detail and depth by the researcher you will be asked to meet with the researcher on a second, separate occasion for approximately 15 minutes to view the findings and to offer your views and comments on them to ensure that they accurately reflect what you meant to say during the original interview. This will also ensure that you are not misquoted in error or that the researcher has misunderstood any of the points that you raised.

What are the possible disadvantages of taking part?

The interview and the follow-up meeting will take up some of your time. In addition, it is acknowledged that discussing the role of being a carer and the challenges this can bring may mean raising sensitive issues.

What are the possible benefits of taking part?

The planned research is of potential benefit to family carers, but also to people who are living with dementia through its main aim of improving knowledge and understanding of what works to support family carers of PWD.

Will my taking part in this study be kept confidential and anonymous?

Your confidentiality will be assured by the following means: no personal data such as names and contact details will be taken. At the start of the study you will be given a unique participant identifier number that will ensure your anonymity. Data will be anonymised and your individual answers will not be identifiable.

Your data will be stored on a password protected computer in an encrypted folder and will be kept for 6 months before being destroyed after the Project and thesis submission deadline of October, 2017. All identifiable paper records will be stored in a locked filing cabinet, accessible only to the research team and all electronic information will be stored on a password-protected computer. All of the information you provide will be treated in accordance with the Data Protection Act. All electronic and paper data will be destroyed 6 months after completion of the project (i.e. April, 2018). There is a possibility that the Project findings and / or thesis may be published in a scientific journal, or at a conference, however your personal information or data will not be identifiable in such instances. If the Project findings and / or thesis are published your data may be stored for up to 7 years before being destroyed. If you decide to withdraw from the study before the study has been completed then all electronic and paper records related to you will immediately be destroyed.

What will happen to the results of the study?

The data collected in this study will be used for the fulfilment of a Medical Research Council research funded Project that may help to inform future policy and practice in relation to how family carers of people who are living with dementia are supported. In addition, the Project will serve as the main thesis as part of the fulfilment of a PhD in Public Health.

Once the study has been completed in September, 2017 you will be debriefed on the research you have completed to provide you with feedback. In addition, once they are known, the general findings of the study can be e-mailed to those participants who request this on the separate debriefing form that will be given for you to sign.

Who is Organizing and Funding the Study?

The Project is funded by the Medical Research Council and organised by Fuse (Centre for translational research in public health, based at Newcastle University) & Northumbria University (Department of Health & Life Sciences).

Who has reviewed this study?

This study and its protocol have received full ethical approval from the Department of Public Health & Wellbeing Ethics Chair: Dr. Joanna Reynolds, in accordance with the Faculty of Health & Life Sciences Ethics Committee.

Contact for further information: Mark Parkinson (Lead researcher)

m.parkinson@northumbria.ac.uk

or Professor Susan Carr (Principal Project Supervisor) sue.carr@northumbria.ac.uk

Independent information or advice about the project can be obtained by contacting: Mrs. Laura Ritson / Mrs. Terry Lisle (Fuse Centre Administrators):
e-mail: fuse@newcastle.ac.uk

Appendix 7: Participant Consent Form



Faculty of Health & Life Sciences

INFORMED CONSENT FORM (for participant to retain)

Project Title: **What works to support family carers of people with dementia?**

Principal Investigator: **Mark Parkinson.**

*please tick
where applicable*

I have carefully read and understood the Participant Information Sheet.

I have had an opportunity to ask questions and discuss this study and I have received satisfactory answers.

I understand I am free to withdraw from the study at any time, without having to give a reason for withdrawing, and without prejudice.

I agree to take part in this study.

Signature of participant..... Date.....

(NAME IN BLOCK LETTERS).....

Signature of researcher..... Date.....

(NAME IN BLOCK LETTERS).....

Appendix 8: Participant Consent Form (Researcher's copy)



Faculty of Health & Life Sciences

INFORMED CONSENT FORM (for researcher to retain)

Project Title: **What works to support family carers of people with dementia?**

Principal Investigator: **Mark Parkinson.**

*please tick
where applicable*

I have carefully read and understood the Participant Information Sheet.

I have had an opportunity to ask questions and discuss this study and I have received satisfactory answers.

I understand I am free to withdraw from the study at any time, without having to give a reason for withdrawing, and without prejudice.

I agree to take part in this study.

Signature of participant..... Date.....

(NAME IN BLOCK LETTERS).....

Signature of researcher..... Date.....

(NAME IN BLOCK LETTERS).....

Appendix 9: Voice Recording Consent Form



FOR USE WHEN TAPE RECORDINGS WILL BE TAKEN

Project title: **What works to support family carers of people with dementia?**

Principal Investigator: **Mark Parkinson.**

I hereby confirm that I give consent for the following recordings to be made:

Recording	Purpose	Consent
Voice recordings via MP3 recorder.	<i>To enable a faithful and accurate account of the interview to be recorded and to allow the researcher to analyse the responses in greater detail once the interview has been concluded.</i>	

Clause A: I understand that the findings from the interview recording will be verified by me during a 15 minute follow-up meeting to make sure that these provide an accurate reflection of my expressed views.

Tick or initial the box to indicate your consent to Clause A

Clause B: I understand that the recording(s) may be published in an appropriate journal/textbook or on an appropriate Northumbria University webpage. My name or other personal information will never be associated with the recording(s). I understand that I have the right to withdraw consent at any time prior to publication, but that once the recording(s) are in the public domain there may be no opportunity for the effective withdrawal of consent.

Tick or initial the box to indicate your consent to Clause B

Signature of participant..... Date.....

Appendix 10: Risk Assessment 'Lone Interview'

Northumbria University General Risk Assessment Form 1

DATE: 20th January, 2016 ASSESSOR: Mark Parkinson LOCATION: Interview Room at Newcastle Carers' Trust ASSESSMENT: INTERVIEW_01

AREA/ACTIVITY Conducting a Face-to-face Interview

Item No	Activity/equipment/materials, etc.	Hazard	Persons at risk	Severity	Likelihood	Risk Rating H 20-36 M 12-18 L 1-10	Control Measures Required	
	An interview/survey will be conducted on a face-to-face basis in a designated interview room at Newcastle Carers' Trust. The interview will be conducted using a semi-structured interview schedule. Information given will be recorded	The participant might have difficulty locating the testing room/ investigator and become stressed	participant	1	1	L	Instructions on how to locate the building/testing room, and investigators work phone number are provided in advance. Most participants will be familiar with the building & its layout but this should not be automatically assumed in every case.	A

via an MP3 voice recorder & also via annotations to a timeline by the interviewer to chronicle key events / issues pertinent to the study.							
	The participant might become emotionally / psychologically overwrought.	Participant	8	8	8	The investigator will pause the interview, switch off voice recording equipment & ask if the participant would like to take a break from being interviewed. Subsequently, the participant will determine themselves whether they wish to proceed with the interview or terminate the session prematurely. Participants will have such requests immediately granted & also be given the option to withdraw access to any data already recorded if they feel that the sensitivity of such information is too great to be divulged in retrospect.	A
	A participant might ask for feedback concerning their individual responses to questionnaires, surveys, interviews etc. Refusal might cause offence.		1	1	L	The participant information/brief/debrief sheet makes it clear that individual feedback is not provided, only general feedback is given.	A

		The participant may be become frustrated at the time taken to complete the interview.		1	1	L	Participants will be briefed on the approximate duration of the testing before they consent to take part. Breaks will be allowed.	A
General Control Measures:							Strict adherence to the agreed protocol. Newcastle Carers' Trust Staff and principal Project supervisor informed when interviews are taking place and institutional mentor contact details are kept on record.	A

To be completed by the Manager undertaking the risk assessment

Name: Mark Parkinson

Job Title: Lead Researcher

Signature:



Date: October, 2015

To be completed by the Senior Manager

I consider this risk assessment to be suitable and sufficient to control the risks to the health & safety of both employees undertaking the tasks and any other person who may be affected by the activities.

Name: Professor Susan Carr

Job Title: Project Supervisor

Signature:

Date: October, 2015

NB – If Senior Managers do not agree that the risk assessment is suitable and sufficient then the assessment must be reviewed.

Appendix 11: Risk Assessment Form 'Lone Working'

Northumbria University

General Risk Assessment Form 2

DATE:20th January, 2016 **ASSESSOR:** Mark Parkinson **LOCATION:** Interview Room at Newcastle Carers' Trust
ASSESSMENT AREA/ACTIVITY GENERIC LONE WORKING RISK ASSESSMENT

Item no.	Activity/equipment/materials, etc.	Hazard	Persons at risk	Severity	Likelihood	Priority H 48-100 M 20-40 L 0-16	protective measures required	Result*
1	Lone Working	Physical assault	Interviewer	1	1	L	a) Ensure that interviewer who will be required to work alone has effective means of communication, i.e. mobile phone. Staff at the centre where interviews will be conducted will be notified in advance when & with whom an interview an interview is being conducted. The Project Supervisor will also be notified of the location & time of any interviews with the interviewer reporting back at a predetermined time to notify that the interview has been concluded.	A

				1	1	L	<p>b) The interviewer will not knowingly go to any location where there have been ongoing incidents of aggravation, aggression or danger due to environment, time of day, crime, politics or specific groups of people and must acquaint themselves with the background and local conditions by making general enquiries with colleagues.</p> <p>c) Self Risk Assessments: Interviewer to regularly assess the situation in which they are conducting interviews and feedback issues immediately direct to Project Supervisor</p> <p>d) Interviewer will use log in/out procedures with reception at interview location so that all staff can be contacted at all times and details of actions to take where an employee fails to report back at the end of a visit or does not respond to a check call or visit.</p>	T
				1	1			T
								A

*Key to Result: T = Trivial risk; A = Adequately controlled; N = Not adequately controlled; U = Unable to decide

Northumbria University – Risk Assessment Form

To be completed by the manager undertaking the risk assessment

Name: Mark Parkinson

Job Title: Lead Researcher

Signature:



Date: October, 2015

To be completed by the Senior Manager

I consider this risk assessment to be suitable and sufficient to control the risks to the health & safety of both employees undertaking the tasks and any other person who may be affected by the activities.

Name: Professor Susan Carr

Job Title: Project Supervisor

Signature:

Date: October, 2015

NB – if senior managers do not agree that the risk assessment is suitable and sufficient then the assessment must be reviewed.

Appendix 12: Post Interview Participant Letter



Dear participant,

Your participation in this study is greatly appreciated. However, it is recognised that some of the topics that have been discussed are both personal and sensitive. Therefore once the interview has been concluded if you feel that it may be helpful to talk to Liz Williams then she has kindly provided her contact number which is: (0191) 427 5443.

Thank you.

Kind regards,

A handwritten signature in black ink, appearing to read "Mark Parkinson".

Mark Parkinson (researcher).

Appendix 13: Participant Debrief Form



Participant code:

PARTICIPANT DEBRIEF

Name of Researcher: Mark Parkinson (Public health researcher at Northumbria University).

Name of Supervisor: Professor Susan Carr (Principal Project Supervisor)

Project Title: What works to support family carers of people with dementia?

1. What was the purpose of the project?

A key issue is that the number of people who are diagnosed with dementia is rising in the U.K. and this is likely to continue into the near future. This will lead to a greater reliance than at any time in the U.K.'s history on family carers to help care for people who are living with dementia. However, at present there is little agreement about how family carers can best be supported to carry out this vital role, whether different carers have different needs or how carers' needs change as time goes on. Looking at what has already been written about this subject in the past led to the theory that support in five main areas might be crucial-(a) social support (b) support with general health, sleep and diet (c) support with mental health and wellbeing (d) support to continue to enjoy a good quality of life (e) finding out which services might offer the best support to carers and making them widely available to carers as a matter of priority. It was thought that if these five areas could be properly supported this might help family carers to become stronger and more resilient and therefore better able to look after their own health. It is very important that family carers achieve this because a healthy carer is in general a more effective carer. However, it was important for the research to also ask family carers themselves what they thought was vital to providing them with support.

Overall, the study hopes to find out:

- Whether these five areas are the ones that need the most support or if there other areas that also need to be considered;
- Whether building carer strength and resilience through these five areas offers the best way forward;
- How different types of support might be needed by carers during the different stages of dementia;
- Whether different types of carer (husband, wife, son, daughter etc.) may have different needs when it comes to providing them with support.

2. How will I find out about the results?

Once the study has been completed and the data analysed, approximately 12 weeks after taking part, the researcher can email you a general summary of the results. If you wish to receive these results please provide an e-mail address in the space below so that the researcher can contact you:

_____ @ _____

3. Have I been deceived in any way during the project?

No. However, it could be argued that the researcher's theories may have been explained to you before the interviews took place. Although the researcher had developed some theories about what might work to support family carers of people who are living with dementia, it was important to also find out what family carers themselves thought about this question. To ensure that family carers were not swayed in their opinions by what the researcher thought or believed it was necessary to only reveal these theories more fully once the interview with you was concluded.

4. If I change my mind and wish to withdraw the information I have provided, how do I do this?

If you wish to withdraw your data then email the investigator named in the information sheet within 1 month of taking part and give them the code number that was allocated to you (this can be found on your debrief sheet). After this time it might not be possible to withdraw your data as it could already have been analysed.

The data collected in this study may also be published in scientific journals or presented at conferences. Information and data gathered during this research study will only be available to the research team identified in the information sheet. Should the research be presented or published in any form, all data will be anonymous (i.e. your personal information or data will not be identifiable).

All information and data gathered during this research will be stored in line with the Data Protection Act and will be destroyed 12 months following the conclusion of the study. The study is scheduled to be completed by 30th September, 2017. If the research is published in a scientific journal it may be kept for longer before being destroyed. During that time the data may be used by members of the research team only for purposes appropriate to the research question, but at no point will your personal information or data be revealed. Insurance companies and employers will not be given any individual's personal information, nor any data provided by them, and nor will we allow access to the police, security services, social services, relatives or lawyers, unless forced to do so by the courts.

If you wish to receive feedback about the findings of this research study then please contact the researcher at **m.parkinson@northumbria.ac.uk**

This study and its protocol have received full ethical approval from Faculty of Health and Life Sciences Research Ethics Committee. If you require confirmation of this, or if you have any concerns or worries concerning this research, or if you wish to register a complaint, please contact the Chair of this Committee (Dr Nick Neave: nick.neave@northumbria.ac.uk), stating the title of the research project and the name of the researcher:

Title of the research project: **What works to support family carers of people with dementia?**

Name of the researcher: **Mark Parkinson** (Public health researcher at Northumbria University).

Appendix 14: Interview Schedule

[Interview Schedule]

Theme 1: Relational support network

Q1: How much help & support do you receive from other family members?

- **Hours per week on average & by whom?**
 - **How important is this help & support?**
 - **Why is it important / not important?**
 - **Can you give some examples?**

Q2: How much do you rely on the help & support of friends & neighbours within the community?

- **How does this help you?**
- **Can you give some examples?**

Q3: How much do you rely on help and support provided by Community organisations such as allotment associations, swimming sessions, art classes, bowling, badminton, music societies, film clubs, etc.?

- **In what ways do they help you?**

Q4: How well do you feel supported by the NHS / G.P. (Service provider support) for yourself?

- **Can you give some examples?**
- **What sort of things should the NHS / G.P. consider in relation to the support of carers?**

Q5: How well do you feel supported by social services?

- **Can you give some examples?**
- **In your opinion, how could this support be improved**

Q6: How well do you feel supported by your G.P. with the dementia side of care?

- **Can you give some examples?**
- **How important is this help & support?**

Q7: Have you exercised your right to a 6 monthly carer health check-up to make sure that you remain healthy while caring?

- **If not, why not?**

Q8: In what ways do you rely on Voluntary support e.g. from organisations like Alzheimer's Society?

- **Can you give some examples?**
- **If not, why not?**

Q9: When you go out into your local community, how do people generally react to dementia & people with dementia? Can you give some examples?

- **In your view, what could be done to improve / build on this?**

Theme 2 Sub-Theme 1: Key Psychological Resources available to carer: Self-efficacy

Q1: (a) When you first found out about the dementia diagnosis how confident did you feel about caring for your

_____ **(insert relationship)?**

(b) How confident do you feel **Now** about caring for your _____ ?

- **How has this changed?**

Q2: How easy or difficult is it to feel in control of the situation when you are caring for a PWD?

- **Can you explain why this is?**

Q3: What **helps you to stay** in control of the situation when you are caring for a PWD?

Q4: Can you give some examples of how you **plan ahead** for the next day?

Q5: How important is it to plan well ahead when caring for a PWD?

Q6: How easy is it to block out bad thoughts when you are caring for a PWD?

Q7: What needs to be done to improve how carers are supported in the future?

Theme 2 Sub-Theme 2: Key Psychological Resources available to carer: Hope

Q1: How important is ‘Hope’ and being hopeful when you are caring for a PWD?

- **Can you explain why?**

Q2: As a carer what things do you do each day to help you to stay positive?

Theme 2 Sub-Theme 3: Key Psychological Resources available to carer: Coping Ability

Q1: As a carer, what kind of things do you rely on to help you to cope each day?

Q2: If carer support was to be improved what changes could be made to help you to cope even better?

Q3: How easy is it to change your plans when circumstances suddenly change?

Q4: How often do you look for outside support (e.g. NHS, Social services, Voluntary organisations) to help you?

- **Can you give some examples of instances when you look for outside support to help you?**

Q5: People sometimes say, ‘always look on the bright side.’ As a carer, how easy is it to do this in practice?

Theme 3: Maintaining Carer's Physical Health Status

Q1: How well do you feel in general, on a day-to-day basis?

- **Has this changed since you became a carer? In what ways?**

Q2: How often do you visit your G.P. on average?

Q3: How would your G.P. rate your general health?

Q4: Has when and what you eat most days changed since you became a carer?

- **In what ways?**

Q5: In general, have you gained / lost or stayed the same weight since you became a carer?

Q6: List any activities, including walking, that you do each week that involve exercise (outside of caring for a PWD?)

Q7: How would you rate the overall quality of the sleep you get most nights?

- **Has this changed at all since you became a carer?**

Q8: Do you generally feel alert and energetic during the day?

- **Has this changed at all since you became a carer?**

Theme 4: Safeguarding Carer's Quality of Life

Q1: How often do you take part in hobbies & interests each week?

Q2: How many of these activities involve some sort of social get-together with others?

Q3: Are these activities as regular as they used to be?

- If not, why not?
- How could this situation be improved?

Q4: What things do you do to make sure that there is a balance between carrying out chores each day and having some time to relax?

- How important is this to you?

Q5: How would you rate your overall quality of life right now?

- Has this changed since you became a carer?

Q6: On balance, is being a family carer a positive or a negative experience?

- Can you explain why?

Q7: What things have you learned since becoming a carer?

Theme 5: Ensuring timely availability of key external resources

Q1: Have you ever used or considered using:

(a) *Respite care?*

- If so, how often?
- In what ways is it important to you?

(b) Have you ever used or considered using: *Sitting Services / Befriending services?*

- If so, how often?
- In what ways is it important to you?

(c) Have you ever used or considered using: *Carer training / coaching / mentoring / information, advice, education?*

- **If so, what kind of carer training etc. did you do / receive? (or would like to do / receive)?**
- **(d) Have you ever used or considered using: *CBT Training*?**
- **(e) Have you ever used or considered using: *Mindfulness Training*?**