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" Even when I'm telling it – it sounds so unbelievably bizarre! "

A realist evaluation of self-management behaviours in dementia family caregivers with long-term conditions

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A thesis submitted to the University of Huddersfield in partial fulfilment of the requirements for the degree of Doctor of Philosophy

The University of Huddersfield

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DEDICATION

This work is dedicated to all those who have and continue to provide care for a family member with dementia. I sincerely hope the findings of this research contribute positively towards your own care. A personal dedication to Auntie Afroz and Uncle Fakhruz Zaman, for their relentless love and dedication in providing care for my Great Aunt.

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ABSTRACT

Family members of those with dementia are often referred to as 'invisible' or 'hidden' patients due to their unmet and often unidentified health and care needs. Poor self-management of caregiver health has negative consequences for the caregiver, the care-recipient and health and social care systems worldwide. With a rising prevalence in long-term conditions due to an ageing population and a limited amount of health resources, it makes it increasingly important to understand and address the self-management support needs of such vulnerable populations. This research was conducted to investigate the self-management behaviours of individuals who have long-term health conditions, who are also the primary caregiver of a family member with dementia.

Using a Realist Evaluation design, a realist evidence synthesis was conducted to guide the development of an interview schedule. Informal discussions with three third-sector caregiver support service managers also informed data collection. Twelve in-depth, semi-structured interviews were conducted with adult male and female dementia family caregivers in the north of England. Data were analysed using Template Analysis; the principles of Realist Evaluation (TARMATO framework) were used to develop the final template into context-mechanism-outcome configurations of barriers and facilitators to caregiver self-management behaviours. The findings from this analysis informed a second qualitative study involving interviews with six third-sector service providers and re-interviewing four of the original caregiver participants for further insight into potential support strategies arising from the data.

Behavioural and psychological symptoms of dementia (such as wandering behaviours or aggressive and attention-seeking behaviours) appeared as a dominant mechanism in contextualising dementia caregiving as an all-consuming role and contributed to numerous losses (such as the loss of 'self') in the caregiver. This resulted in negative self-management outcomes for the caregiver, such as a lack of adherence to medication and recommended treatment regimes, reduction in arranging and attending medical appointments and even an overall lack of acknowledgment of their long-term conditions and self-management needs. Emerging findings also reveal other mechanisms that act as barriers to self-management, such as health beliefs and attachment styles that are embedded within the complexity of this hidden patient population. Additionally, the study highlighted the utility of the policy-oriented and practice-based frameworks, such as the Quality and Outcomes Framework of primary care in the UK, as a potentially useful tool if used qualitatively in third-sector settings. Holistic methodological frameworks such as the one employed in this study are recommended for future research in this field.

Readers of thesis are encouraged to combine these findings with their own knowledge and experience in order to reflect upon the implications of dementia caregiving on the life of a family caregiver with long-term conditions of their own. Involvement of the researcher as an intentional agent in the research process will propel the evolutionary thought process integral to the 'science of realist evaluation'.

DISSEMINATED FINDINGS AND ESTEEM

Conference presentations

Zaman, N. (2019). "Even when I'm telling it – it sounds so unbelievably bizarre!" Dementia family caregivers and long-term health conditions: Evidence-based policy or policy-based evidence? *International Association for Critical Realism: 22nd Annual Conference.* University of Southampton, Southampton.

Zaman, N. (2016). Caring for carers with long term conditions. *Postgraduate Research Festival.* University of Huddersfield, Huddersfield.

Publications

Zaman, N. (2016). Supporting self-management of long-term health conditions in family members of dementia patients. In H. Gavin, S. Hanson & S. Ward (Eds.), *Celebrating the work of postgraduate researchers in the School of Human and Health Sciences.* (p. 23). Huddersfield: University of Huddersfield.

Competitions

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Zaman, N. (2017). Gravestone Scaffolding. *3 Minute Thesis Competition.* University of Huddersfield, Huddersfield.

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LIST OF ABBREVIATIONS

ADI	Alzheimer's Disease International
ADL	Activities of Daily Living
AIHW	Australian Institute for Health and Welfare
BMA	British Medical Association
BPSD	Behavioural and Psychological/Psychiatric Symptoms of Dementia
CDC	Centers for Disease Control and Prevention
CMO	Context-Mechanism-Outcome
EBM	Evidence-Based Medicine
e.g.	exempli gratia (for example)
DH	Department of Health (changed name to DHSC in 2018)
DHSC	Department of Health and Social Care (known as DH before 2018)
DWP	Department for Work and Pensions
GP	General Practitioner
GPC	General Practitioner's Committee
GRADE	Grading of Recommendations Assessment, Development and Evaluation
HOC	House Of Care
IADL	Instrumental Activities of Daily Living
LTC	Long-Term Condition (plural: LTCs)
MRC	Medical Research Council
NHP	Nottingham Health Profile
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NSI	Nutrition Screening Initiative
OADR	Old Age Dependency Ratio
ONS	Office for National Statistics
PWD	Person/People with Dementia
QALYs	Quality Adjusted Life Years
QOF	Quality and Outcomes Framework
RCGP	Royal College of General Practitioners
RCT	Randomised Controlled Trial (plural: RCTs)
SF-36	Short-Form-36
TIA	Transient Ischaemic Attack
UK	United Kingdom
USA	United States of America
WHO	World Health Organization
YOC	Year Of Care

CHAPTER 1: INTRODUCTION

1.1 Overview of Chapter 1:

This chapter introduces some of the central concepts contained within this study. It defines key terms and highlights key background literature, policy and practice considerations. The chapter also contains a reflexive account of the researcher's/author's interest in the topic and initial approach towards the study. The chapter concludes with overarching research aims, an overview of the structure of the thesis and a chapter summary.

1.2 Background

The methodological principles underpinning the design of this research are theory-led and policy-driven; therefore, references to literature and policy must be viewed in light of the timeline of the study. Data collection began in 2016 therefore introductory literature and policy contained within the chapters prior to data collection reflect this timeline; where possible, updated references to show continued relevance have also been provided. The policy and related guidelines informing the methodological structure of this research are based on health and social care policy within the United Kingdom (UK) with a particular focus on the National Health Service (NHS) in England. The names and abbreviations of the UK's main healthcare guiding and governing bodies referenced within this thesis have been presented in Table 1:

Table 1   UK healthcare: governing and guiding organisations

Name	Abbreviation used in thesis
British Medical Association	BMA
Department for Work and Pensions	DWP
Department of Health and Social Care (Department of Health prior to name change in 2018)	DHSC (DH prior to 2018)
Medical Research Council	MRC
National Institute for Health and Care Excellence	NICE
NHS Employers	–
Royal College of General Practitioners	RCGP

Table 2 provides UK-based working definitions of the key terms as they have been used in this thesis. It also provides frequently used national and international synonyms of these terms and highlights which term has been used consistently in this thesis.

Table 2   Defining key terms within this thesis

Term(s) used	UK-based definition(s)	Synonym(s)
Caregiver or family caregiver or dementia family caregiver	Adult who provides unpaid care for a family member (spouse, parent, parent-in-law), who would deteriorate or remain unable to manage without their help, due to the presence of Dementia (DHSC, 2016; NHS England, 2018g, RCGP, 2014, World Health Organization [WHO] 2015a) **Note:** receiving state benefits such as 'carer's allowance' does not exclude a caregiver from the category of 'unpaid' (DHSC, 2016; DWP, 2018; Wanless et al., 2006).	Informal and/or unpaid caregiver/carer
Caregiver/ Caregiving burden	The physical, social, emotional and financial impact of caregiving (Brodaty & Donkin, 2009; Fengler & Goodrich, 1979)	_
Dementia	A neurological, long-term health condition which can be caused by many different illnesses that directly or indirectly affect the brain such as Alzheimer's disease.	_
Long-term condition or long-term health condition	Health conditions for which there is at present no cure and must be managed with ongoing medication, therapies and self-management behaviours (DH, 2015b). Cardiovascular disease (stroke, heart attack), diabetes, chronic respiratory diseases, cancers are examples of LTCs that result in the majority of premature deaths worldwide (DH, 2015b; WHO, 2005, 2007).	Chronic OR non-communicable condition/disease/ illness
Self-management	Actions taken by an individual to recognise, treat and manage their long-term condition (NHS England, 2014)	Self-care

1.3   Concerns of an ageing population

As a result of the preventive and curative advancements made in healthcare, deaths due to sepsis, infectious disease and fatal childhood illnesses have been reduced, resulting in an overall increased life expectancy, otherwise known as the 'ageing population' (WHO, 2015c, 2017b). The age at which a population or individual is considered to be 'ageing' varies across the globe; WHO (2015c) define an older person as "a person whose age has passed the median life expectancy at birth" (p. 230). Generally, a cut-off age of 60 years and above is used to describe the ageing population (United Nations, 2015; WHO, 2014a). In the UK, the 'old age dependency ratio' (OADR) is used to describe an ageing population; this refers to the number of people of pensionable age (65 years and over) per every 1,000 people of working age (16-64 years) (Office for National Statistics [ONS], 2015, 2017). In 2014, WHO stated that there are 841 million people aged 60 and above; and, by the year 2020 the number of people aged 60 and above will outnumber children aged 5 and below, taking this figure of an 'ageing population' to reach a predicted 2 billion in the next 30 years (WHO, 2014a).

Ageing is a non-modifiable risk factor for many long-term conditions (LTCs), particularly dementia (Kennedy et al., 2014; Niccoli & Partridge, 2012). Dementia presents a global challenge for healthcare systems in the provision of long-term care, thus family caregivers are most often assuming responsibility for their care even though they are "themselves old with possible disease or disability" (WHO, 2015a, p. 1). The global healthcare focus is now on healthy ageing; WHO (2014b, 2017b) state that the capacity of an individual to do this is largely determined by the presence or absence of long-term health conditions and their subsequent health-related behaviours.

1.4 Dementia

Dementia is an umbrella term for a number of illnesses that result in both cognitive and noncognitive impairments; symptoms present as a progressive decline in memory, behaviour and daily functioning (DH, 2013a). Neuropsychological/psychiatric symptoms of dementia, commonly known as behavioural and psychological/psychiatric symptoms of dementia (BPSD) can present individually or collectively in some of the following ways: personal disinhibition and inappropriate behaviour, agitation, erratic motor movements, depression, apathy, aggression, paranoid hallucinations and sleep and dietary disturbance (Cerejeira, Lagarto & Mukaetova-Ladinska, 2012; DH, 2014b; Kar, 2009). Irrespective of the subtype of dementia, BPSD is known to occur in varying degrees, in the majority of dementia patients and can have significant negative health, well-being and safety concerns for people with dementia their caregivers (Ornstein, 2011; WHO, 2015a).

Dementia may be caused by many different types of diseases that can directly or indirectly affect the brain, for example, Alzheimer's disease is currently the most common cause of age-related dementia and contributes to an estimated 60-70% of cases (WHO, 2012, 2018b, 2019). While long-term cardio- and cerebrovascular conditions can cause the second most prevalent subtype: vascular dementia, others can also be caused by lifestyle factors such as the alcohol-related dementias (WHO, 2012, 2017a). Genetically identified forms of dementia, accounting for 0.1% of Alzheimer's disease dementias, are considered rare and tend to occur in young/early onset dementia (dementia before the age of 65) (Duthey, 2013; Paulson & Igo, 2011). Familial Alzheimer's disease is a hereditary autosomal dominant condition usually presenting in people aged between 30-40 years (Duthey, 2013). Sporadic, or nonhereditary

dementias, can be made more or less likely depending on genetic risk factors (Paulson & Igo, 2011).

In 2015 the World Alzheimer's Report stated that there are over 900 million people worldwide above the age of 60 (Alzheimer's Disease International [ADI], 2015); when standardised by age and gender to a western European population, the estimated prevalence of dementia in those above 60 years lies between 5-8% across Asia, Europe, The Americas and Africa (ADI, 2015; WHO, 2012, WHO 2019). Although WHO (2012) is clear that dementia "is not a normal part of ageing" (p. 94), they highlight that the projected increases in prevalence and incidence are mainly due to population ageing which is "occurring at an unprecedentedly fast rate" (WHO, 2015b, p. 1). According to WHO (2019), there are 50 million people worldwide living with dementia and the incidence rate has reached 10 million new cases a year. The global incidence in those over 60 years is estimated to double every 5.9 years (WHO, 2015b). WHO (2015b, 2019) state that although ageing is the strongest risk factor for dementia, other factors such as smoking, alcohol intake, sedentary lifestyle and the presence of one or more long-term conditions increases the risk of dementia. Additional important risk factors include social isolation and cognitive inactivity (Najar et al, 2019; WHO, 2019). The global prevalence of dementia is expected to increase almost two-fold once every two decades, with an estimated 82 million people by 2030, and 152 million people by 2050, living with dementia (Robinson, Tang & Taylor, 2015; WHO 2012, 2019).

Although 63% of all those with dementia live in low-income countries, incidence estimates are lower in low-income countries compared to high-income countries, WHO (2015b) state that this is "largely an artefact, due to the specific diagnostic criteria used" (p. 1). The global cost of dementia care was calculated to be US$ 604 billion in 2010; in high-income countries

this cost was distributed roughly equally between family caregivers and the health and social care services; in low-income countries the cost was predominantly shouldered by family caregivers (WHO, 2015b).

In the UK, dementia prevalence has been calculated mainly using UK-wide census data and Delphi consensus methods; age-standardised estimates from 2014 show that of the 62 million people in the UK, 1.3% are living with dementia and 95% of these people are aged 65 years and over (Prince et al., 2014; DH, 2015a). The prevalence of dementia in the UK is disproportionately higher in women (65%) than in men (Prince et al., 2014). A detailed analysis of the cost of dementia care in the UK is provided in Chapter 3.

Dementia is as much a concern for those who are living with it as it is for those who provide daily care for them (DH, 2014b; WHO, 2012, 2015). Dementia caregiving is unlike caregiving for other conditions due to the progressive nature of its disability and dependence, the duration of the disease, and BPSD (DH, 2014b; WHO, 2012, 2015a).

1.5   Dementia family caregiver: A hidden patient

Dementia family caregivers are referred to as the 'hidden' or 'invisible' patient due to the physical, social, emotional/psychological/mental and financial impact caregiving has on their health (Brodaty & Donkin, 2009; Fengler & Goodrich, 1979, George & Gwyther, 1986). These factors are collectively known as 'caregiver burden' (Brodaty & Donkin, 2009; Hoffman & Mitchell, 1998; Parks & Novielli, 2000; WHO, 2015a). Dementia caregiver burden has been linked to negative health effects and negative health behaviours in the caregiver (Brodaty & Donkin, 2009; Richardson, Lee, Berg-Weger & Grossberg, 2013; Schulz & Martire, 2004; Schulz & Sherwood, 2008). Caregiver burden was initially identified as a health phenomenon

(Townsend, 1957). Interviews with working class men and women revealed that as a result of the changing family and community structure in post-war Britain (such as women spending more time in the workplace), excessive mental and physical demands or a change in employment due to caregiving responsibilities could result in a "strain of illness" (Townsend, 1957, p. 58) in the caregiver.

Christakis and Allison, (2006) studied caregiver mortality after the hospitalisation of the caregiver's spouse in over half a million caregiver-patient dyads enrolled in a medical insurance programme. They found that both male and female spousal caregivers of people with dementia were more likely to die within the year of their spouse's hospitalisation than spousal caregivers of people with other long-term conditions such as cancer or heart disease. However, the cohort was socioeconomically biased and did not provide details of caregiver baseline health status. Christakis and Allison (2006) concluded that better support services, training and assistance for spousal caregivers of those with dementia are required in order to reduce healthcare costs and improve health for both patients and caregivers.

Caregiver burden may also result in negative consequences for the care-recipient. Safeguarding of the person with dementia (PWD) is a rising concern as they become more susceptible to potential neglect and abuse from strained caregivers (Cooper et al., 2009; Reinhard, Given, Huhtala & Bemis, 2008). It has also been noted that healthcare professionals may be reluctant to ask about elder abuse for various reasons such as the potential of the PWD being permanently removed from the family caregiver, or also simply because family caregivers are generally not being perceived as "amoral abusers" (Cooper et al., 2009, p. 3; Oswald, Jogerst, Daly & Bentler, 2004). This "all or nothing" (Cooper et al., 2009, p. 3) approach to safeguarding not only increases risk of abuse and poor care for the care-recipient

but also increases the duration of strain and subsequent ill health for the family caregiver. Those caregivers who are already living with mental and/or physical long-term health conditions of their own may experience more pronounced burden and strain (Brodaty & Donkin, 2009). A dementia family caregiver who is unable to adequately manage their own long-term health conditions will be at an increased risk of potential ambulatory care sensitive conditions which require "potentially avoidable" (Freund et al., 2013, p. 363) emergency care services and support for both the caregiver and the person with dementia (Busby, Purdy & Hollingworth, 2015).

1.6   Healthcare policy and practice in the UK

The government's 2015-16 Mandate to NHS England states the need to provide person-centred care to people with long-term conditions by enabling them to live independently through self-management (DH, 2014a, 2014c).

From a medical perspective long-term conditions require ongoing medication, medication reviews and dose adjustments, physical and physiological monitoring and professionally guided lifestyle changes (DH, 2015b). Primary care is the 'gatekeeper' for the medical management of long-term conditions across many western healthcare systems (Garrido, Zentner & Busse, 2011). In England primary care services, such as general practice, are described as the "front door" (NHS England, 2016a, p. 7, 2018d, para. 1) of the healthcare system. The primary care practitioners found in general practice such as general practitioners (GPs) and nurses are chiefly responsible for the diagnosis, treatment and subsequent monitoring of long-term conditions as well as authorising referrals to specialist and secondary care services (Goodwin, Curry, Naylor, Ross & Duldig, 2010; Greenfield, Foley & Azeem, 2016).

The Quality and Outcomes Framework (QOF) is a voluntary General Medical Services (GMS) contract that remunerates and funds general practices across the UK, based on their achievement of national targets for the management of long-term conditions, public health issues and provision of preventive services (NHS Employers, 2014). Although QOF was introduced in 2004 as a voluntary scheme, over 95% of practices within the UK are a part of this contract (NHS England, 2018e). QOF provides a list of prevalent long-term conditions alongside a checklist of evidence-based management 'indicators' which have been developed by NICE on behalf of the governing healthcare bodies within the UK (NHS Employers, 2014). Indicators are outcome measures that need to be addressed, treated and monitored in order to provide optimal, high-quality, evidence-based medical management for long-term conditions (NHS Employers, 2014).

NICE (2015a) also provides pathways of care for acute and long-term conditions to include dementia. Dementia caregivers do not currently have a separate or very specific pathway outlined by NICE for the identification and management of their long-term conditions (NICE, 2014b, 2015a, 2018a). Based on the Care Act 2014 caregiver health assessments after the diagnosis of their family member are conducted by social services (NICE, 2015c). After the initial assessment, signposting to GPs in the case of deteriorating health or poor self-management occurs via private domiciliary care organisations, third-sector support organisations and Admiral nurses (NICE, 2014b). Admiral nurses are specialist NHS nurses who can provide emotional support and other tangible support and advice to dementia caregivers (DH, 2013b). This system relies primarily on the caregiver reporting their health conditions and concerns (DH, 2014b; NICE, 2013, 2014b, 2015b, 2018a).

For annual capitation calculations, each primary care practice produces an 'Exceptions Report' accounting for patients in whom the QOF indicators were not met due to 'exceptional' circumstances beyond the practice's control, such as failure to attend appointments after three formal invitations (NHS Employers, 2014; NHS England, 2014). Family caregivers tend to fall into the exceptions category as they often report being unable to find time for self-management behaviours such as arranging and attending appointments for themselves (Acton, 2002). They usually do not identify as caregivers at routine GP appointments and are less likely to report long-term conditions than non-caregivers (O'Reilly, Connolly, Rosato & Patterson, 2008). A complete list of the 'discretionary' and 'non-discretionary' criteria used when excluding patients from QOF has been extracted from Campbell, Hannon and Lester (2011, p. e184) and summarised in Table 3.

The Medical Research Council (MRC) emphasise the need for more adequate health assessment tools for dementia caregivers as existing services and support for dementia caregivers are not sufficient or caregiver-focused (MRC, 2014; Newbronner, Chamberlain, Borthwick, Baxter, & Glendinning, 2013).

Table 3   QOF exceptions report: criteria for exclusion

Non-discretionary reasons for excluding patients from QOF calculations	Discretionary reasons for excluding patients from QOF calculations
Patients' refusal to attend appointments after being invited three times in the last 12 months.	Patients for whom it is not safely appropriate to carry out LTC reviews (for example taking the blood pressure of an extremely frail patient).
Newly diagnosed or recently registered patients.	Patients who are already on the maximum approved dose of a medication and treatment cannot be adjusted any further despite a lack of improvement.
Patient's informed dissent	Patients for whom medication cannot be prescribed due to allergies, adverse effects or complete lack of tolerance.
Lack of access and availability of a secondary care or investigative service.	Patients with illnesses that intervene with the treatment of other LTCs (for example cholesterol medication in the presence of liver disease).

The term self-management, has been used to describe those behavioural actions that people with existing long-term conditions take in order to manage the medical and lifestyle factors that will affect their long-term conditions, this includes meeting the QOF indicators through compliance and adherence to medical regimes to include medication, appointments and tests, and adjusting lifestyle behaviours such as diet, exercise smoking and drinking, in

accordance with medical advice (DH, 2012a; NHS Employers, 2014; NHS England, 2014). Whether one chooses to engage in, or, avoid behaviours and activities that promote health, their choice is reflective of a self-management style and therefore "one cannot not manage" (Lorig and Holman, 2003, p. 1). In recognition of these issues a key feature of caregiver health policy is to identify their self-management support needs so that they can "attend to their own health problems and long-term conditions" (DH, 2014, p. 56).

1.7   Reflexivity and the Researcher position

"Reflexivity is the self-appraisal in research" (Berger, 2015, p. 220). It refers to the researcher's personal and philosophical beliefs about their approach to the study. Malterud (2001) state that in all research, and particularly qualitative research, methodological rigour is not obtained by trying to prevent the effect of the researcher but instead by making a "commitment to reflexivity" (p. 484), as "preconceptions are not the same as bias, unless the researcher fails to mention them" (p. 484). Berger mentions that reflexivity should account for three broad categories of the researcher's position relative to the research. The three categories are as follows: 1) reflexivity when the researcher is familiar with the subject and may share the participants' experiences, 2) reflexivity when the researcher has moved from an outsider to insider perspective and 3) reflexivity when the researcher is unfamiliar with the subject and experiences of the participants.

My role in this research overlaps between some of these categories. My experience working closely with allied health and primary care professionals has made me familiar with long-term conditions, their biomedical self-management needs and some of the psychosocial factors

involved when it comes to patients' decision-making behaviours. I was however unfamiliar with dementia, its presentation, deterioration and management. I was also unfamiliar with caregiver health psychology and research. My own academic and professional background has been strongly rooted in a medical model based on positivistic philosophies of science. I came to the topic of dementia caregivers through mortality studies of people with long-term conditions. My assumptions were that increased and premature mortality is largely the result of poor self-management practices combined with limitations within the healthcare and social systems. My objective was that vulnerable populations should be targeted first, and vulnerability to me meant disadvantaged populations, which included social factors such as those from deprived socioeconomic backgrounds, but also those with worse health prognoses and outcomes (such as death) due to age, gender, ethnicity and so on. This led me to discover, as discussed in this chapter, that caregiver populations are more 'vulnerable' as they have higher mortality rates than other caregiver and non-caregiver populations. However, quantitative mortality studies offered little insight into the specific health statuses and self-management behaviours and practices of the deceased and so I decided to embark upon this research. I used a qualitative approach, with the aim to gain the insider, patient-perspective and lived-experience of being both a caregiver and a 'hidden patient'.

Without being branded as "the armchair methodologist and the jobbing researcher" (Pawson, 2013, p. x), if in fact these terms are to be taken negatively, my professional and personal experiences have taught me that healthcare research in particular requires a flexible approach whereby the researcher's philosophical beliefs and the research needs should embrace each other; although it may well be argued that the research needs themselves will only be as apparent to the researcher as the researcher's metaphysical belief system will

allow. I have adopted a realist evaluation approach to this research as it is geared towards tackling complex problems using a bottom-up and policy-driven approach (Pawson, 2013). The realist methodology outlined in this research is based on seminal work from Ray Pawson and his colleagues. This thesis brings together three complex healthcare concerns: 1) long-term health conditions, 2) self-management behaviours and 3) a complex patient population: dementia family caregivers. According to Pawson (2013) the suitability of a realist evaluation approach depends on the complexity of the issue; he outlines a complexity checklist which can help 'diagnose' the level of complexity of the topic under evaluation. This checklist has been detailed in later chapters and explains the rationale behind the approach to this research.

1.8   Overarching aim of research

This research explores self-management behaviours in dementia family caregivers with long-term health conditions. The overall aims are to:

- Understand the lived experience of such caregivers.

- Identify dementia family caregiver support needs with regards to their LTCs.

- Gain a better understanding of the strengths and weaknesses in healthcare policy and practice in the UK with regards to the care of long-term conditions in dementia family caregivers.

1.9   Overview of the thesis

This thesis contains two studies. Study 1 is the main study consisting of interviews with dementia family caregivers; this study contributes to the majority of this thesis. Study 2 is based on the findings of Study 1 and involves interviews with both dementia family caregivers and third-sector support service providers. The research philosophy and design of these studies are contained within Chapter 2. This is followed by a realist review of the literature in Chapter 3 and Chapter 4 describes the specific methods used to collect and analyse the data in the Study 1 (some of which were also transferable to Study 2). Chapter 5 and Chapter 6 present the findings of Study 1. Chapter 7 offers both the methods and findings of Study 2. Chapter 8 discusses the implications of these findings for policy, practice and research, along with a detailed reflection on the research process as a whole from the perspective of the researcher. The reflexive sections in Chapters 1 and Chapter 8 are written in first person, the remainder of the thesis is written in third-person, where the author of this thesis has been referred to as the researcher/interviewer.

1.10 Summary of Chapter 1

Box 1 highlights the key points contained within this chapter.

Box 1   Summary & highlights of Chapter 1

→ Long-term health conditions including dementia are on the rise.

→ Dementia family caregivers are prone to increased morbidity due to caregiver burden.

→ Dementia family caregivers do not have a regulated pathway for the management of their long-term health conditions in the UK.

→ Policy targets aim to identify the self-management support needs of dementia caregivers with long-term health conditions.

CHAPTER 2: RESEARCH PHILOSOPHY AND DESIGN

2.1   Overview of Chapter 2

This chapter details the philosophical underpinning of this research which leads on to the research design.

2.2   Realist philosophy: Context-Mechanism-Outcome

This research has been approached from a philosophical paradigm of realism. Realism is a post-positivist methodological perspective borrowing from the philosophical assumptions of both positivist science and constructivist social science (Bhaskar, 1978, 2008; Harré, 1978, Putnam & Conant, 1990; Collier, 1994; Pawson, 2006b, 2013; Pawson & Tilley, 1997). Due to an extensive lineage, there are inevitable variations in the perspectives on realism; this research is based on Ray Pawson's realism which gave rise to the Realist Science of Evaluation methods such as the realist interview and realist review/synthesis (Pawson, 1996, 2000, 2006a, 2009, 2013; Pawson & Tilley, 1997; Wong, Greenhalgh, Westhorp, Buckingham & Pawson, 2013a; Wong, Westhorp, Pawson & Greenhalgh, 2013b).

Pawson (2013) acknowledges that his own "realist wisdom" (p. 3) and realist approach to evaluation "stand on the shoulders of giants" (p. 12) in realist methodology such as Bhaskar (1978, 1979, 2008), Archer (1995), Elster (2007), Merton (1967), Popper (1992), Campbell (1988) and Rossi (1987). For Pawson, the paradigm of realism begins by redefining social programmes (Pawson, 2013; Pawson & Tilley, 1997). Pawson (2013) states that a 'programme' can mean any one of the following things: policy, legislation, service, intervention, treatment, schemes and so on so forth. The purpose of all these programmes is

ultimately to change the decision-making of the subjects for whom they were intended and therefore they can be classed as a 'social' programme (Pawson, 1997, 2013; Wong et al., 2013b). Pawson and Tilley (1997) state that such social programmes should not be viewed individually, instead they should be viewed as complex social systems which contain macro (structural components such as organisational elements) and micro (agential components involving the individual as an actor) issues. The crux of Pawson's realism is contained within the configuration of reality into 'contexts', 'mechanisms' and 'outcomes' (C-M-O). Pawson (2013) states that a programme will either work or not work because of underlying mechanisms that operate in specific contexts. Pawson (2013), Pawson and Tilley (1997) and Wong et al. (2013b) elaborate on the basic tenets of realist philosophy using the terms 'embeddedness', 'mechanisms', 'contexts', '(demi)regularities' and 'change'. The subsequent sections will explain these terms and outline the basic tenets of Pawson's realist philosophy, highlighting differences and similarities between his perspective and those of his predecessors on what constitutes reality (ontology) and how to generate knowledge (epistemology).

2.2.1 Embeddedness

Pawson (2013) and Pawson and Tilley (1997) emphasise the embeddedness of human action within multiple social processes. This view encompasses the ontological perspective of a "stratified nature of social reality" (Pawson and Tilley, 1997, p. 64). According to this view all systems contain sub-systems and are themselves also a sub-system of another, larger system (Pawson, 2013; Pawson & Tilley, 1997; Wong et al., 2013b). Causation occurs within these systems in both an upwards and downwards motion, and thus C-M-O configurations can be embedded in various forms at multiple levels of this interrelated, interacting system. For

example, the outcome of a particular C-M-O at one layer of the embedded system becomes the context of another C-M-O for the next layer. Pawson (2016a) emphasises that the formulaic configuration of C-M-Os must be treated as an "agile aide memoire" (p. 137) that should help researchers when explaining causal forces. He emphasises that configurational explanations are "unrelentingly plural, highly varied and indeed potentially infinite" (Pawson, 2016a, p. 137). In the field of healthcare, numerous pre-existing contexts can influence a social programme mechanism and vice versa; Pawson (2013) frequently refers to examples of embeddedness from the NHS, which he states is a "beast of an institution" (p. 35). One such example details a "typical patient pathway" (Pawson, 2013, p. 36) in the UK, Pawson names this patient Mrs Long, her healthcare journey has been summarised in Box 2.

Box 2   A patient journey in the NHS adapted from Pawson (2013, p. 36)

→ Mrs Long begins to feel unwell

→ She finally decides to visit the GP when she becomes quite ill

→ The GP considers some differential diagnoses and requests further investigations

→ This means an additional appointment booked with the GP to discuss the results

→ This requires the Mrs Long to first accept these tests and then get them done

→ In the second consultation, the GP decides to refer Mrs Long to a specialist

→ Throughout this entire, unfinished, journey Mrs Long is worried and spends "many fretful hours in waiting rooms and on waiting lists" (Pawson, 2013, p. 36)

In such a case, healthcare programme mechanisms, such as policies of referral and health promotion are being immersed within contexts of commissioning, funding, health inequalities, patient agency and staff work routines to mention a few. While deteriorating

health and its likely impact on Mrs Long's daily life was perhaps the mechanism that urged her to visit the GP in the first place, this mechanism then became the context for the GP requiring further investigations. Pawson (2016a) states that a realist evaluator must "delve into a kaleidoscope of potential configurations and uncover the pertinent and active causal interconnections" (p. 137).

Bhaskar (1979) refers to the "transformational character of social systems" (p. 165) to highlight a significant difference between physical and social systems. According to Bhaskar social systems are constantly transformed through human volition, whereas physical and natural systems do not have their own agency to act. Here Pawson (2013) is tentative in his agreement with Bhaskar, as although the morphogenetic nature of social systems as described by Archer (1995) forms a crucial component of Pawson's own philosophy, he is reluctant to see this as a solid form of demarcation between the two systems. According to Pawson (2013) all efforts made in the name of the natural sciences are a result of social systems. Pawson (2013) states that both social and natural sciences occur in open systems. Pawson highlights that society is in a state of self-transformation and policies and interventions are being immersed in already fluid systems; thus, the intervention can no longer be viewed as an 'instrument' to create change, rather it attempts to change the direction of a constantly changing complex system. However, Pawson (2013) suggests that the change itself cannot be fully predicted or anticipated and thus realists should search for roughly predictable patterns of human behaviour instead, a concept he terms 'demi-regularities'. Pawson (2013) also clarifies his deviation from Bhaskar's view of a stratified reality. According to Bhaskar, reality exists within three "distinct" (Bhaskar, 2008, p. 2) domains (Figure 1): the real, the actual and the empirical.

Figure 1   Domains of reality, reproduced from Bhaskar (2008, p. 2)

	Domain of Real	*Domain of Actual*	*Domain of Empirical*
Mechanisms	✓		
Events	✓	✓	
Experiences	✓	✓	✓

Based on this view, contexts (events), mechanisms and outcomes (experiences) cannot be seen as 'embedded', as reality only appears to exists when all three occur together. Bhaskar's ontological perspective is more objective than pluralistic. According to Bhaskar (1979), contexts such as the "latent structures of nature" (p. 59) are accessed and experienced through empirical evidence which is uncovered through the "malleability achieved in a laboratory" (p. 59) and is therefore something that "social science, in this respect, will be denied" (p. 59). Bhaskar (1979) also states that the social sciences can however find a "analogue and a compensator" (p. 59) from the objective, a-priori evidence gained from the natural and experimental sciences (Bhaskar, 1979, 1998; Pawson, 2016b; Reed, 2008). Pawson (2013) argues against Bhaskar's categorical distinction of reality as he states that it renders realist philosophy "ersatz" (Pawson, 2016b, p. 50). Pawson therefore adopts a more pluralistic ontological position, stating that reality can occur at all levels. What naturally follows from this ontological pluralism is the embrace of epistemological pluralism when it comes to the choice of method with which to obtain knowledge. In Pawson's realism all methods of data gathering and sampling are viable provided that the choice of method "is tailored to the exact form of hypotheses developed" (Pawson & Tilley, 1997, p. 85). The definition of a realist 'hypothesis' and realist 'theory' will be provided later in this chapter.

2.2.2 Mechanism

Pawson (2013) states that "mechanisms are agents of change" (p. 5) and generate specific outcomes within specific circumstances. Thus, mechanisms help explain the reasoning and behaviour of people. The realist understanding of a mechanism is that it is usually hidden as it is 'generative' and not 'successionist' (Pawson, 2013; Pawson & Tilley, 1997; Wong et al., 2013b). Pawson and Tilley (1997) warn against the traditional empiricist view of successive logic (Figure 2, Images (a)-(c)) due to its lack of explanatory power; for example, David Hume's successionist philosophy of 'conjunction' whereby event B can be deemed a cause of event A, if, in empirical observation A is always followed by B (Connelly, 2001; Hume, 2009, 2017; Nuzzolilli & Diller, 2015).

Figure 2   Models of causation, reproduced from Pawson and Tilley (1997, p. 68)
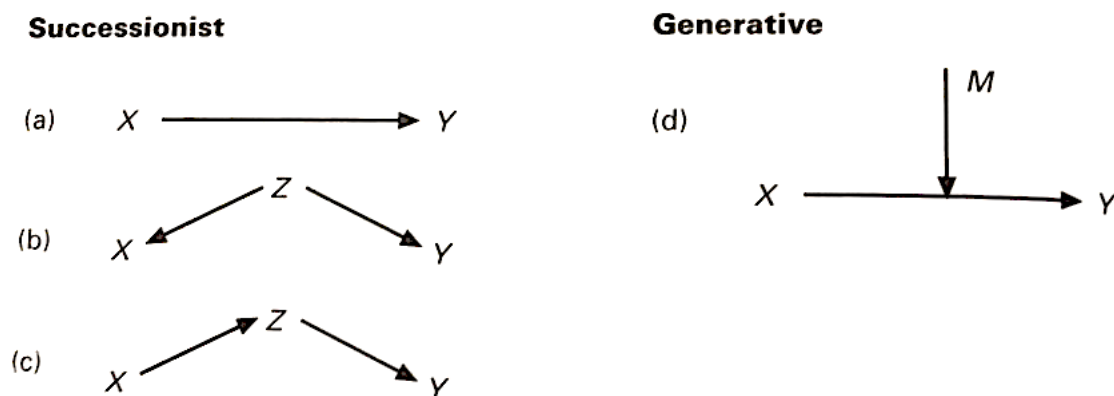
Pawson (2013) emphasises that interventions or programmes themselves do not cause phenomena as complex as human behaviour to change, rather it is the underlying mechanism contained within the contextual factors and 'theories' of an intervention that can either

persuade or dissuade the subject from change; this is precisely the unit of analysis that realism aims to evaluate. Pawson (2016b) refers to the sociological principles of Archer (1995) when defending himself against critics who consider the C-M-O configuration a "conflation of agency and structure under the rubric of mechanism" (Porter, 2015, p. 78). Archer (1995) uses the term morphogenesis to describe the dualistic nature of structure and agency as being "i) analytically separable and; ii) temporally sequenced" (p. 76). Like Bhaskar, Pawson too agrees with Archer's philosophical stance; however, Pawson (2013) emphasises that morphogenesis does not result in a new social system as Archer suggests, as this would place a "cap" (p. 6) on evaluation studies and mean that all social programmes have a "shelf life" (p. 6) which is limited by a temporal and sequential change within the original context in which they were placed. Pawson states that the "social world stumbles between stability and change" and realist evaluation aims to uncover the (demi) regularities that form the "enduring features" (Pawson, 2013, p. 6) of this social seesaw.

2.2.3 Context

Pawson and Tilley (1997) refer to the works of Sayer (1984) to explain that the relationship between a generative mechanism and its effect is contingent upon the way they are conditioned within the contexts in which they exist. It is this "contextual conditioning of causal mechanisms which turns (or fails to turn) causal potential into a causal outcome" (Pawson & Tilley, 1997, p. 69). All social programmes are immersed into a fluid context, for example if a self-management programme were being used for dementia caregivers, the context the intervention is being immersed in is 'dementia caregiving'; likewise, dementia caregiving is also a generative mechanism influencing self-management outcomes in the wider context of national policies targeting the management of long-term conditions as a

whole. It is the purpose of a realist evaluation to uncover and assimilate the various underlying mechanisms that arise from within these contexts, that would result in specific positive or negative outcomes for self-management. Figure 3 reveals the flow, transferability and accumulation of knowledge through various stages of evaluation research.

Figure 3 **"Elements of realist cumulation", reproduced from Pawson and Tilley (1997, p. 121)**

THEORY

(a) *Methodology:* generative causal propositions

Abstraction

$$C \; M \; O$$

(b) *Analytical frameworks:* programs as rational choice situations

$$C \; M \; O$$

(c) *Middle-range theory:* hypotheses about risk calculations

$$C_1 \; M_1 \; O_1 \qquad C_2 \; M_2 \; O_2 \qquad C_3 \; M_3 \; O_3$$

(a) *Empirical uniformities:* outcomes and regularities in the problem field

$$O_1 \qquad O_2 \qquad O_3 \qquad O_4$$

(b) *Evaluation case studies: CMO* configuration focusing

$$C_1 \; M_1 \; O_1 \qquad C_2 \; M_1 \; O_1 \qquad C_3 \; M_1 \; O_1$$

$$C_4 \; M_1 \; O_2 \qquad C_3 \; M_1 \; O_2$$

$$C_A \; M_B \; O_C \qquad C_D \; M_E \; O_F \qquad C_G \; M_H \; O_I \qquad C_J \; M_K \; O_L$$

Specification

DATA

Pawson and Tilley (1997) explain that the top most layer of knowledge represents the more abstract theoretical contributions to knowledge such as those offered by theorists who explore the key ideas and structural components of social processes, programmes and

interventions. Pawson and Tilley (1997) highlight that the term 'theory' can refer to a number of different elements of knowledge such as those mentioned in Box 3:

Box 3   A "typology of theory" reproduced from Pawson and Tilley (1997, p. 120-122)

1. Methodology

2. General orientations

3. Analysis of concepts

4. Ad hoc or ex post factum interpretations

5. Empirical generalisations

6. Derivations and codifications

7. Axiomatic systems

8. Hypotheses

9. Explanations

10. Paradigms

11. Conceptual frameworks

12. Causal propositions

13. Middle range theories

The second layer of knowledge in Figure 3 involves items 2 to 11 from the theoretical typology (Box 3). It deals with bringing uniformity and generalisability to phenomena by developing analytical frameworks. Pawson states that a classic example of such an analytic framework within social systems is of the economic framework that depends on supply and demand. Similar frameworks form the cornerstone of healthcare policy development that depend on cost-effectiveness of interventions, details of this will be discussed in the next chapter.

The third layer of knowledge refers to Merton's middle-range theories. According to Pawson and Tilley (1997) middle range theories propose that a small range of core concepts or ideas can be used within multiple, specific and different contexts to generate multiple specific and different outcomes. The essence of middle-range realism lies in the fact the C-M-O propositions do not have to start anew with each investigation, rather they should build on existing knowledge generated through previous layers. Thus, the remaining two layers of knowledge owe themselves to middle-range realism; here it is emphasised that uniformities and regularities must not be viewed as "empirical generalisations" (Pawson & Tilley, 1997, p. 125), or the "end product of investigation" (p. 125), rather they are the "raw material" (p. 125) that may be elucidated further through specific realist evaluations.

2.2.4 Regularities and demi-regularities

Pawson (2013) agrees with Bhaskar (1978) that both physical and social systems follow a similar explanatory structure in trying to make sense of complexity by discovering and uncovering patterns. Pawson and Tilley (1997) used the following equation to explain a regularity: context + mechanism = regularity. More recently, Pawson (2013) and Wong et al. (2013b) have adopted a term coined by Lawson (1997): 'demi-regularity'. Jagosh et al. (2011) explain that this term refers to the "semi-predictable" (p. 7) manner in which human agency manifests itself: "'semi' because variations in reoccurring, predictable patterns of behaviour can be attributed to differences in the contextual dimension from one setting to another" (p. 7). Dieleman, Wong and Marchal (2012) explain that this simply means that "certain people tend to behave in certain ways under certain situations" (p. 27); thus, Pawson's mantra for realist evaluation is "what works, for whom and in what circumstances" (Wong, Greenhalgh

& Pawson, 2010, p. 1). The concept of demi-regularities broadens realism's perspectives on the fluidity of behaviour change and human agency.

2.2.5 Change

The realist perspective on structure and agency as outlined by Pawson and Tilley (1997) has been summarised in the following sentences. People are on some level aware of demi-regularities, the resulting choices and limiting social structures within the existing context of their life. This awareness results in some people wanting to change the demi-regularities, however this may not be a fruitful attempt if they do not have the structural support to enable it. Pawson and Tilley (1997) state that this relationship between structure and agency is made more complex and unpredictable as human beings do not always have full knowledge of the contextual conditioning which turn (or fail to turn) the causal potential of underlying mechanisms into outcomes. Therefore, they conclude that realist research should aim to address two key questions, these have been summarised as follows:

1) What are the underlying mechanisms for change and how do they counteract existing social processes?

2) What are the conditions required for change mechanisms to operate and how do they fit within programme theories/contexts?

In order to fully understand these questions further definitions of realist terminology such as, what constitutes a programme theory, is required. These terms will now be discussed in relation to the key principles of the realist science of evaluation.

2.3   The Realist Science of Evaluation

The purpose of a realist evaluation is to elicit what works or does not work for whom and in what circumstances (Pawson, 2013; Pawson & Tilley, 1997). Pawson has named his approach a 'science' of evaluation in order to distinguish it from traditional methods of evaluation which are outcome-driven and often dominated by quantitative methods (Pawson, 2013). Pawson (2013) uses the mnemonic TARMATO to refer to seven elements central to his perspective on realist evaluation, these have been listed in Table 4.

Table 4   Organising principles of realist evaluation, reproduced from Pawson (2013, pp. 85-6)

Theory
Abstraction
Reusable conceptual platform
Model building
Adjudication
Trust-Doubt Ratio
Organised scepticism

2.3.1 Theory

Realist evaluation is theory-driven (Pawson, 2013). Pawson (2013) agrees with Bhaskar (1978) that inquiry should be theory-driven as physical and social systems are always interacting in a complex manner. In realist inquiry theory serves to generate hypotheses that can provide some order to the complexity of the interacting systems. Pawson (2013) states that theory

can guide not only the interest of a researcher but also provide an analytic lens with which to evaluate new theories. Theories can be categorised into four domains, the philosophical theory such as the paradigm of realism discussed above; the research theory, in other words the epistemological approach taken to gather knowledge; the substantive theory which constitutes the grand theories found in particular fields and domains such as psychology and health; and finally, the unit of analysis in a realist evaluation: the programme theory (Wong et al., 2013b).

Pawson (2013) states that the theories upon which realist evaluation hypotheses are built are not the substantive "highfalutin' theories of sociology, psychology or social science" (p. 6). In a realist evaluation 'programme theory' refers to what a programme or intervention embedded within policy and practice is expected to do and how it is expected to work (Wong et al., 2013b). For example, the programme of self-management is high on policy agenda, both for the management of long-term conditions and for the care of dementia family caregivers with these conditions; therefore, this policy 'programme' aims to encourage and promote behaviours in these caregivers that will enable them to take care of their own LTCs. The theories associated with this programme depend on how self-management is monitored within practice and policy regulations and how dementia family caregivers are approaching these self-management behaviours. The contextual circumstances, that is to say, the act of dementia caregiving, determines the mechanisms through which this change will come about. Therefore Pawson (2013) subscribes to a 'context-mechanism-outcome' (C-M-O) configuration in order to evaluate and explain these programme theories. The other three domains of theory are also important in realist evaluations as they develop the knowledge-base that is required to formulate the programme theories (Wong et al., 2013b).

Theories can be termed hypotheses when they are in the stage of refinement and development. Wong et al. (2013b) state that 'initial rough theory' refers to the basic hypotheses that guide evaluation when a more general question is being asked about a programme or "evaluand" (p. 11). Wong et al. (2013b) clarify that an initial rough theory does not have to be conceptualised in a specific C-M-O configuration, they can simply ask realist questions such as the 'what', 'why' and 'how' of the workings of the evaluand. A refined theory or hypothesis aims to elaborate on the initial rough theory using the findings of a realist evaluation. The refinements can be presented in C-M-O configurations followed by narrative explanations.

2.3.2 Abstraction

Abstraction as described by Pawson (2009) is an explanatory tool which reflects the thought process that provides an understanding of the underlying mechanisms of particular phenomena. Much of realist methodology is based on the Mertonian concept of middle-range theories (Pawson, 2006b). Middle-range theories as described by Merton (1949, 1967) are those theories that lie in between the smaller hypotheses (initial rough hypotheses) that are required for "day to day research" (Merton, 1968, p. 39) and the larger (substantive theory), 'grand' "all-inclusive systematic" (p. 39) unifying theories of "social behaviour, social organization and social change" (p. 39). According to Merton (1949, 1968) these intermediate theories serve to provide a level of abstraction that is close to the original empirical data but broad enough to extrapolate an explanation of those findings that are not generalizable from the data or grand theory. Wong et al. (2013b) state that middle-range theories should reflect a level of abstraction that is specific enough to explain a particular case but also general enough to apply across a range of cases or domains.

2.3.3 Reusable conceptual framework

Pawson (2013) states that programmes under investigation often appear to be "one big idea" (p. 92) but contain multiple sub-components. According to Pawson (2013) programmes (such as interventions and policies) that aim to change behaviours do not just aim to incentivise a change; they also:

1) "Select behaviours thought to respond to incentives" (p. 92)

2) "Choose subjects thought to respond to incentives" (p. 92)

3) "Pick incentive levels thought to respond to behaviour, and so on" (p. 92)

Therefore, programmes in the form of policy targets such as 'improved self-management for dementia caregivers' should also have means of "measuring, administrating and publicising the targets" (Pawson, 2013, p. 92). A reusable conceptual platform helps in the 'sense-making' and organisation of realist findings, thus allowing it to contribute towards and refine an existing knowledge base.

2.3.4 Model-building

Pawson (2013) states that refinements to theory should be considered in terms of C-M-O configurations throughout the stage of model-building. Pawson and Tilley (1997) recommend the use of C+M=O tables to show how each refinement provides a growing body of ideas and mechanisms in specific contexts to which the programme theory applies. The conceptual tools of abstraction, adjudication, trust and organised scepticism should be applied when building the model.

2.3.5 Adjudication

Pawson (2013) states that there will always be multiple and contrasting explanations for the mechanism under which a programme does or does not work. A researcher must learn to 'adjudicate' between rival hypotheses using "informed guesswork" (p. 80). Pawson's 'theory of adjudication' rests on Popper's seminal idea that empirical observation alone has "nothing absolute about it" (Popper, 1992, p. 94) and so regardless of the amount of confirmatory data, "undiscovered disconfirmatory" (Pawson, 2013, p. 99) potential exists. Thus, empirical observation always carries potential to falsify a claim. Adjudication, along with abstraction rely on other realist principles such as trust and organised scepticism.

2.3.6 Trust-doubt ratio

In keeping with the stratified nature of realist ontology, Pawson (2013) states that due to the complexity of the evaluand "evaluative knowledge is always partial knowledge" (p. 104) and the "only way to deal with this predicament is to live with it" (p. 104). Pawson refers to the words of Campbell (1988) and Popper (1992) to further explain this concept. According to Campbell (1988), the foundationalist, ontological position of positivism must be substituted using a "holistic, squishy, quasi-foundationalism that I call the 99 to 1 trust-doubt ratio" (p. 105). Pawson (2013) then refers to the words of Popper (1992) to explain why the trust-doubt ratio is essential in complex evaluative science:

> Science does not rest upon rock-bottom. It is like a building erected on piles...when we cease our attempt to drive our piles into a deeper layer, it is not because we have

reached firm ground. We simply stop when we are satisfied that they are firm enough

to carry the structure, at least for the time being. (Popper, 1992, p. 94)

Pawson (2013) clarifies that evaluative model-building does not rest on "indisputable fact"

(p. 105), rather it is the "building of a pontoon bridge above a swamp" (p. 105) of knowledge.

Thus, resulting in the science of theory-driven evaluation that begins by trusting some aspects

of existing knowledge from within this swamp and then proceeding the inquiry by focusing

on others (Pawson, 2013).

2.3.7 Organised scepticism

Finally, Pawson (2013) concludes that all the aspects of realist evaluation science require

organised scepticism where the informed discretion of the researcher is imperative. Pawson

(2013) states that discretionary and disputed concepts are "unavoidable in science" (p. 86).

He emphasises that the review of existing research and practice, and the analysis of emerging

data, necessitates adjudicating between elements of discord in a process of "hypothesis

selection and hypothesis shedding" (Pawson, 2013, p. 161). This process inevitably relies on

organised scepticism as the "superintending force" (Pawson, 2013, p.86).

2.4   A Complexity Checklist

Pawson (2013) states that before embarking on a realist evaluation, the researcher must first

determine whether the research question demands a realist approach to evaluation. As

realist evaluation is intended for complex phenomena embedded within other complex

phenomena, Pawson (2013) offers a "complexity checklist" (pp. 43-44) in order to aid the

'diagnosis' of complexity. The seven elements of the complexity checklist are contained within the acronym "VICTORE" (Pawson, 2013, p. 33) and have been summarised as follows:

1. Volitions

Pawson (2013) urges the evaluators to consider the "choice architecture" (p. 34) of the problem under study. According to Pawson the numerous, multidimensional factors affecting human agency are the first contributor to complexity. What choices do all individuals involved in this complex system have to face? The evaluator is encouraged to map out the "pathways of persuasion" (Pawson, 2013, p. 43) that influence human volition.

2. Implementation

Complex evaluands require time to be implemented or bring about the intended impact. According to Pawson (2013) the greater the time required for implementation the more complex the issue; thus, instructing the evaluator to diligently map out the "implementation chains" (p. 43) of the evaluand from the level of the individual to the level of the institution.

3. Context

Pawson (2013) emphasises the significance of mapping out the micro and macro contexts within which the evaluand is immersed. This involves the profiles and characteristics of all stakeholders along the implementation chain and the wider context within which the evaluand may be found.

4. Time

Temporal mapping is a natural and essential prerequisite of the Mertonian middle-range approach to evaluation research (Pawson, 2013). It requires a thorough review of previous and existing research and practice within the field of study.

5. Outcomes

Here outcomes refer to the mapping of the monitoring systems involved and the issues that may potentially be associated with them during the implementation chain. Pawson (2013) encourages the evaluator to consider whether complex evaluands such as human behaviour, are likely to change due to an intervention for the behaviour or due to the monitoring of the behaviour undergoing intervention. It is also vital to consider the varying and contested perspectives amongst stakeholders.

6. Rivalry

This is one of the most crucial components of realist evaluation as it involves tracing the policy landscape within which the evaluand will be found and considering whether contiguous policies and interventions will impact the volitions of the subjects under study.

7. Emergence

Finally, the evaluator must consider the "potential emergent effects, long-term adaptations, societal changes and unintended consequences" (Pawson, 2013, p. 44) of the evaluand.

2.5   Summary of Chapter 2:

Figure 4 shows the four-step methodological cycle of a realist evaluation using realist methodological principles. The next chapter offers a realist review, which will be used to explore the complexity checklist with regards to the initial rough hypothesis under study: how do individuals manage their own long-term conditions while providing care for a family member with dementia?

Figure 4   Realist Wheel of Evaluation, adapted from Pawson (2013, p. 88)

Programme theories should be elicited through multiple gathering points to include: grey literature, substantive theories, background literature reviews, policy documentation, interviews or discussions with stakeholders and service-providers (Pawson, 2006b; 2013).

Programme theories

Organised Scepticism
+ Reusable conceptual platform:
- Abstraction
- Adjudication
  - Policy discord
- Trust-doubt ratio

Model-building

Revise the hypothesis
C-M-O

Formulate if-then hypothesis

Organised Scepticism
+ Reusable conceptual platform:
- Abstraction
- Adjudication
  - Policy discord
- Trust-doubt ratio

Model-building

Collect data on hypothesis

Multiple methods can be used to collect and analyse data. Pawson (2013) proposes two of his own specific methods:

1) Realist Review (Pawson, 2013; Wong et al., 2013b) and

2) Realist Interviews (Pawson, 1996, 2013; Pawson & Tilley, 1997)

CHAPTER 3: REALIST REVIEW

3.1 Overview of Chapter 3:

This chapter provides the methods and results of a realist literature review. A Realist review, also known as realist synthesis, is a theory-driven and policy-based approach to collecting and synthesising available evidence. The review process has been outlined in detail by Pawson (2013) and Wong et al. (2013a, 2013b). It has two key components: the first part involves a broad review of various different sources of literature; this is followed by a systematic search of the literature for available primary evidence on the topic. This approach to reviewing the literature was chosen for the following reasons:

- It is consistent with realist methodology and developed and recommended by Pawson (2013) for evaluation research.
- It is holistic and aims to cover a wide range of literature in the "swamp" (Pawson, 2013, p. 161) of available evidence.
- It is a policy-driven, bottom-up approach and therefore will allow a detailed mapping of the complexity checklist VICTORE provided by Pawson (2013) as the 'diagnostic' criteria for realist evaluations.

Realist reviews begin with the 'programme theory' rather than the programme/intervention itself, thus the basic unit of analysis of a realist review are the realist theories that give rise to the development, implementation, success and failure of an intervention (Pawson, 2013). As mentioned in Chapter 2, Box 3, a realist theory can refer to a number of different things such as concepts, ideas, explanations, social science theories, empirical research, policy and

practice to mention a few (Pawson & Tilley, 1997). In this research the programme theory refers to theories around self-management and self-management programmes for long-term conditions, care pathways, policy guidelines, as well as dementia family caregiver burden models and health research. A realist review "reconstructs the programme theories…before going to test those theories using available primary research" (Pawson, 2013, p.161).

Pawson (2013) and Wong et al. (2013a, 2013b) outline multiple specific ways to approach a realist review. Wong et al. (2013b) describe the term 'initial rough theory' as an initial idea of a theory that is used to guide a realist review. They state that the initial rough theory may be a programme theory or it may simply be "whatever it is that the question is investigating … and how it is expected to work" (Wong et al., 2013b, p. 11). Pawson (2013) and Wong et al. (2013b) recommend that the elicitation of 'programme theories' should be through multiple sources such as grey literature, policy documents, interviews with key service-providers and formal theories of social science (e.g. behaviour theories). Pawson (2013) acknowledges that when studying complex issues reviewers face an "overabundance of theories…a state of affairs known as 'the swamp'" (p. 161). Although there is "no exact formula to be followed in exiting the swamp" (Pawson, 2013, p. 161), Pawson (2013) offers four strategies that can help develop an optimal set of ideas to test using primary evidence. The four strategies as outlined by Pawson (2013, p. 161) have been summarised below:

1. **Identify a conceptual platform**

Realist reviews are based on the premise that "there is nothing entirely new in the world of public policy and that any specific intervention should be investigated in the light of findings of previous inquiries on the same 'family' of programmes" (Pawson, 2013, p. 161).

2. Engage in hypothesis selection and shedding

Pawson (2013) maintains that "the iron law of complexity says that one cannot review everything" (p. 164) and must exit the swamp of evidence through a process of "hypothesis sifting" (p. 164). In a realist review, a hypothesis can simply be a "reasonable guess" (Wong et al., 2013b, p. 14) at how a context might influence a mechanism to generate a specific outcome. Since not all contextual factors, mechanisms and outcomes can be addressed at once, the reviewer can focus on a particular research question based on policy and research recommendations using the conceptual framework as a guide (Pawson, 2013).

3. Focus on points of policy discord

One way to 'sift' through hypotheses is to focus on areas of 'policy discord' (Pawson, 2013). A realist review aims to provide explanatory accounts of why or why not something will work/ is working; Pawson (2013) states that "in order to maximise explanatory import it is useful to see how the impeding policy looks from both sides of these fences" (p. 166).

4. Develop lines of inquiry breaking down the theory into themes and sub-themes

Pawson (2013) and Wong et al. (2013b) state that where possible programme theories and hypotheses should be broken down into themes/theories and sub-themes/sub-theories. These should then be tested using a systematic search strategy for primary empirical evidence. However, Wong et al. (2013b) specify that it may not always be necessary to outline a programme theory in realist terms of themes and subthemes, in this case the 'initial rough theory' may be sufficient to conduct the review. For the purpose of this research the initial

rough theory has been used as a guide to conduct both the review and the research. The realist review is used to identify the following:

1. Methodological gaps in the field.

2. Areas of research within the topic that have received attention.

3. Programme theories about self-management behaviours in dementia family caregivers with long-term health conditions.

The review first builds a conceptual platform using literature and policy guidance, focusing on areas of policy debate; it then conducts a systematic search of the literature and discusses this in light of the conceptual frameworks and theories of social science. The chapter concludes by identifying a rationale for the aims and objectives of the research.

3.2   Towards a conceptual framework

As recommended by Pawson (2013) a conceptual platform will be developed by combining relevant theoretical and policy frameworks. The next few sections outline the theory and literature on the concepts of caregiver burden and strain that were introduced in the first chapter.

Soon after research defining dementia caregiver burden emerged, burden was categorised in the literature as objective and subjective (Hoffman & Mitchell, 1998; Montgomery, Gonyea & Hooyman, 1985). Objective or primary burden/strains/stressors reflect factors associated with the person with dementia (PWD) such as level of dependency. Subjective or secondary burden, refers to the caregivers' own evaluation of the impact of caregiver burden and is mediated by the caregiver's health.

Objective and subjective strains of dementia caregiving are associated with increased morbidity and mortality in the dementia family caregiver when compared to other caregiver and non-caregiver controls. Schulz and Beach (1999) carried out a four-year cohort study to compare older caregivers of people with dementia to non-caregivers in order to investigate "caregiving as a risk factor for mortality" (Schulz & Beach, 1999, p. 2215). They found that excessive mental and emotional strain as a result of caregiving acts as an "independent risk factor for mortality among elderly spousal caregivers" of people with dementia.

Pinquart and Sörensen (2003), reviewed the literature to assess differences in the physical and psychological health of caregivers and non-caregivers. They found only marginally significant differences in the physical health of caregivers to non-caregivers, however, larger differences in physical health were found when homogenous samples of only dementia caregivers were compared with non-caregivers. The largest difference between dementia caregivers to non-caregivers was found in subjective strains and mental health such as depression, stress and self-efficacy. They recommended that more research for the dementia caregivers' stress process is required in in order to understand their vulnerability and develop tailored support interventions.

There exists variation amongst study results where some show a strong association between caregiver burden and objective strain, whereas others emphasise that subjective measures are more significant in determining caregiver burden and subsequent health needs and physical health outcomes (Hughes et al., 2014). Campbell et al. (2008) demonstrate that subjective strains such as the psychological and emotional impact of an unwanted obligation to provide care, otherwise described as "role captivity" by Pearlin (1983, 2013, p. 19) are stronger predictors of burden than objective stressors. Hughes et al. (2014) state that

although the correlates of objective and subjective burden differ, unmet needs related to the caregiver are a significant contributor to both these aspects of burden.

Inconsistency and variation amongst findings have been attributed to the conceptual and methodological limitations of correlational studies (Roth, Fredman & Haley, 2015). Subjective burden has been correlated with objective burden and has been conceptualised in burden models such as the 'caregiver strain model' proposed by Poulshock and Deimling (1984). Poulshock and Deimling's model illustrates that dementia caregiver strain can either be exacerbated by objective strain and physical and mental morbidity in the caregiver or alleviated through the provision of adequate support and coping mechanisms.

Future research exploring the interactions between the diverse and multiple influences on dementia caregiver-specific outcomes as described by comprehensive stress models such as the Stress Process model conceptualised by Pearlin, Mullan, Semple & Skaff (1990) have been recommended (Campbell et al., 2008; Donaldson, 1997, 1998; Springate & Tremont, 2014; Thompson et al., 2007). For this reason, stress has been selected as a viable realist 'hypothesis' and conceptual basis in the evaluation of caregiver burden and its impact on caregiver LTC self-management behaviours and potential health outcomes. Subsequent sections will explain this stress process and related models in order to identify a suitable conceptual model for this research.

3.2.1 The Stress Process

Pearlin, Menaghan, Lieberman and Mullan (1981) created a model that served to explain how life events, chronic strains and illnesses, and social and cognitive stressors influenced a person's ability to function. Due to dementia's "transforming effect on the patient" (Pearlin

et al., 1990, p. 587) and the subsequent stress-related consequences for the caregiver's physical and mental health, this model was then extended to the 'stress process' in dementia caregivers. A brief overview of the definitions of stress are necessary in order to understand how different models of dementia caregiver stress were developed. Selye (1950) offered a biomedical definition of stress as a "disturbance in homeostasis" (p. 1390) based on the physiological response to stress via the hypothalamic-pituitary-adrenal axis. This biological understanding of stress was based on stimulus-based, animal models of stress and anxiety which are still used in studying the body's response to pharmacological stimuli (Campos, Fogaça, Aguiar & Guimarães, 2013). Selye (1950) used the term 'stressor' to represent the agent causing the 'stress'; thus, 'stress' was defined as a 'reaction' to the stressor. Psychologist Richard Lazarus argued that such positivistic models of stress were unreliable and insufficient in predicting the human response as they did not account for numerous other cognitive and motivational variables such as individual emotions and beliefs (Lazarus, 1966, 1993; Lazarus, Deese & Osler, 1952). It was noted by Lazarus (1993) that sociologists refer to 'stress' as a disturbing stimulus and 'strain' as a collective response.

Pearlin et al. (1990) identified four interrelated, interacting domains that make up the stress process in dementia caregivers. The first domain described the characteristics of the dementia caregiver to include the socioeconomic characteristics, caregiving history, sources of informal support such as family networks, and formal support such as community-based help programs. The second domain includes the stressors, which are further divided into primary and secondary stressors based on whether they stem from aspects directly related to the act of caregiving or the resultant impact of caregiving on the caregivers' personal and

social life. These stressors derive from the multiple factors of burden identified in the landmark study on caregiver burden by Zarit, Reever & Bach-Peterson (1980).

Primary stressors are further divided into objective and subjective aspects of caregiver burden. The objectives measures of burden are directly related to the dementia patient and stress induced from their special care needs. These include the cognitive status of the patient, the behavioural and neuropsychiatric symptoms of dementia, supporting activities of daily living (ADL) such as dressing and toileting, and supporting instrumental activities of daily living (IADL) such as managing finances and housework. The subjective burden describes the caregivers' personal experience of caregiving to include the physical and emotional impact of caregiving and the effect of dementia on the changed caregiver-PWD relationship, which has been described by Pearlin et al. (1990) as "relational deprivation" (p. 587).

Secondary stressors have been divided into role strains and intrapsychic strains which, according to Pearlin et al. (1990), follow naturally from the primary stressors. The role strains are with regards to the roles assumed by the caregiver outside of their caregiving role. The central measure for role strains involves family conflicts and disagreements with regards to taking decisions involving the care of the person with dementia, lack of assistance, receiving unwanted advice and an overall lack of appreciation. Other role strains include the job role, the social role and economic and financial concerns. The intrapsychic strains describe the erosion of, or the barriers to the concepts of 'self' relating to the cognitive and psychological states of the caregiver. One such concept is known as 'mastery', which refers to the levels of perceived control on factors that are considered significant to one's life; another concept is 'self-esteem', which describes judgements made about one's sense of worthiness. Pearlin et al. (1990) repeatedly emphasise that the division of strains and stressors into primary and

secondary categories does not reflect their order of importance or level of impact, rather it reflects the central underpinning of their conceptual model which is that one category of stressors can inevitably lead to another.

The third domain of the stress process describes the mediators of the stress process which include coping strategies and social support. According to Pearlin et al. (1990) coping mechanisms can serve three functions: 1) they can directly address the problem which is creating the stress, otherwise known as 'problem-focused coping' (Folkman & Lazarus, 1980); 2) they can aim to alleviate the psychological distress caused by the stressor, also known as 'emotion-focused coping' (Folkman & Lazarus, 1980); or 3) they can help to find meaning in the situation so that the stress is reduced (Pearlin et al., 1990). The latter appraisal-based meaning-focused coping mechanism had previously been conceptualized by Lazarus and Folkman (1984) and Vitaliano, Russo, Carr, Maiuro & Becker (1985) in their coping theories.

The fourth and final domain of the stress process is the resulting outcomes which encompass the caregivers' physical and mental health, well-being, and ability to maintain their roles as a caregiver. Pearlin et al. (1990) state that treating the outcomes as isolated measures of the stress process would not be an effective approach to understanding the impact of caregiving stress on the caregiver, rather, they suggest viewing the outcomes as interrelated constructs when evaluating the stress response in the caregiver. Such detailed analysis or evaluation of caregiver strain is not always possible in practice, given the current primary care practice guidelines; therefore, exploration of these factors, in relation to self-management and caregiver health, through research on the caregivers' lived experience is imperative.

3.2.2 Stress Appraisal and Coping

In research, the degree of burden caused by primary and secondary stressors are commonly assessed through appraisal processes (Brodaty & Donkin, 2009; Grau, Graessel & Berth, 2015; Volicer, 2005). The theory of appraisal is based on the psychological definition of stress proposed by Lazarus and Folkman (1984) as a "relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (p. 19). Lazarus and Folkman's conceptualisation of stress incorporated the significance of individual agency in determining the response to the stress caused by outside structures. They defined cognitive appraisal as a process through which individuals judge or appraise a stimulus based on its perceived significance to their well-being (Lazarus & Folkman, 1984).

Appraisal was categorised as primary and secondary, based on the identification of the stressor and the subsequent cognitive appraisal process which led to a behavioural or emotional response to that stressor. Much like Pearlin et al. (1990) Lazarus and Folkman (1984) had also emphasised that the use of the terms primary and secondary do not refer to the importance or order of appraisal. Central to this concept of appraisal is the concept of coping, which Lazarus and Folkman (1984) define as "constantly changing cognitive and behavioural efforts" (p. 141) to manage the stresses appraised by the individual. They focused on two main types of coping mechanisms: problem-focused coping and emotion-focused coping. These coping mechanisms, including others mentioned by Vitaliano et al. (1985) such as avoidance-focused coping, where an individual avoids the problem to lower the stress, have been used to study dementia caregivers' styles of coping in relation to their well-being (Lavarone, Ziello, Pastore, Fasanaro & Poderico, 2014).

Along with the stress process, 'stress appraisal' is also a prominent concept in dementia caregiver stress and burden models and is used to explore the caregiver's health and well-being (Lawton, Moss, Kleban, Glicksman & Rovine, 1991; Sörensen & Conwell, 2011). Building on the work of Lazarus and Folkman (1984), Lawton et al. (1991) propose a two-factor model of appraisal for dementia caregivers where if the caregiver identifies a stressor as harmful in the first instance of appraisal then a secondary process of appraisal is commenced. The secondary appraisal involves assessing whether there are sufficient provisions in place to enable coping with the stressor. For dementia family caregivers this translates into the caregiver assessing their ability to continue caring by evaluating the quality of their care with the demands of caregiving. This decision subsequently determines their physiological and psychological health and well-being (Lawton et al., 1991).

Schulz and Martire (2004), used the appraisal process to explain illness and mortality in dementia caregivers. They state that the caregiver's appraisal of their primary and secondary stressors determines their perceived stress and subjective burden. The behavioural and emotional response produced as a result of this burden induces a physiological stress response in the caregiver resulting in morbidity and mortality (Figure 5). In agreement with Pearlin et al. (1990), Schulz and Martire (2004) state that there are numerous feedback mechanisms through which these processes influence each other, and therefore complex interventions and support strategies that target multiple levels of this stress-health model prove more effective than simple interventions targeting either one level of the stress-health process or only one individual from the caregiver-patient dyad.
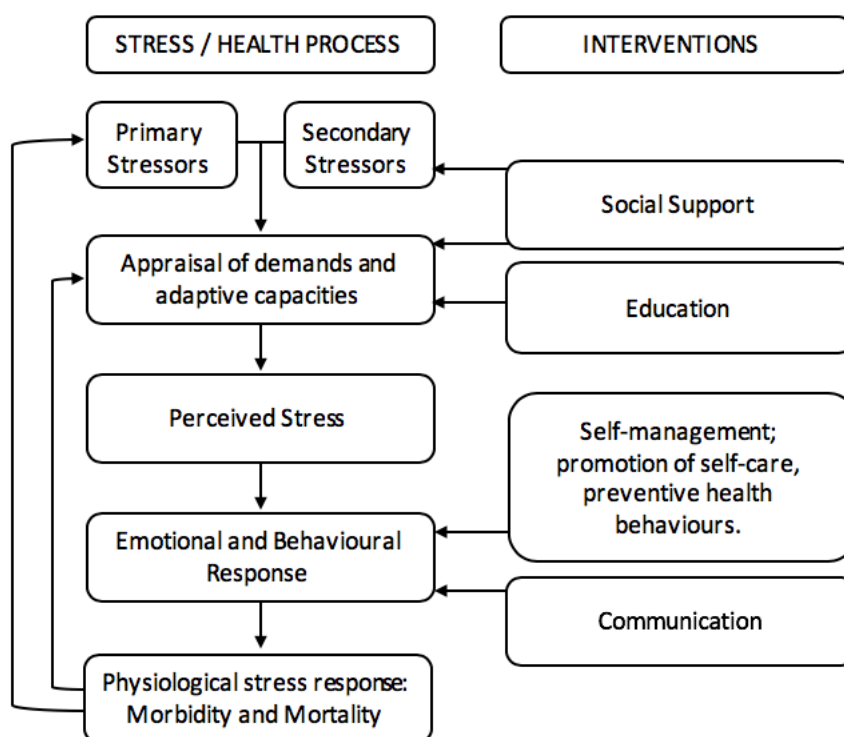
3.2.3 Physiological stress response and morbidity

The physiological stress response which is used to predict caregiver morbidity is mediated by the hypothalamic-pituitary-adrenal axis of the brain; it releases stress hormones such as cortisol and glucocorticoids and other chemical mediators such as catecholamines which modulate the immune response in human beings (O'Connor, O'Halloran & Shanahan, 2000; Guyton & Hall, 2006). In the presence of acute or temporary physical and mental stressors the stress response serves as a protective immune mechanism for the human body as it aims to prevent or repair damage and restore homeostasis through the release of chemical mediators and hormones which induce the 'fight or flight' response (Guyton & Hall, 2006; Mariotti, 2015). The term 'allostasis' was used by Sterling and Eyer (1988) to describe the active processes occurring in the body through which the body is able to maintain

homeostasis despite daily events and changes. The burden of being chronically stressed is likely to induce negative behavioural lifestyle changes such as unhealthy dietary changes, smoking and lack of sleep, thus perpetuating an 'allostatic overload' which can, in the long-term, induce negative physical changes in neural networks of the brain known as 'adaptive plasticity' (McEwan, 2009).

The physiological response to stress in the stress process is also referred to as the 'objective' response (Koolhaas et al., 2011). The subjective response depends on an individual's ability to physically and mentally cope with the stressor also known as adaptive human behaviours or cognitions (Schiffer, Waszak & Yeung, 2015). The brain's adaptive cognitive appraisal system is usually able to cope with short-term stressors, however in the presence of long-term, chronic stress such as that in caregiving and maladaptive cognitions such as catastrophizing and helplessness as reported by dementia caregivers (Ali & Bokharey, 2015), this stress response is magnified and increases the release of the stress hormones (Hannibal & Bishop, 2014). Many long-term conditions are linked to and can deteriorate from chronic stress responses such as cardiovascular illnesses, diabetes, LTCs resulting from stress induced autoimmune disorders, mental and neurological illnesses such as depression and dementia (Mariotti, 2015; Mattei, Demissie, Falcon, Ordovas & Tucker, 2010). The changes occurring through the 'fight or flight' response in the presence of an acute stressor include physiological responses, such as, increased heart rate and blood pressure and increased energy through the release of glucose in the bloodstream (Guyton & Hall, 2006). However, in a chronically stressed state the same chemicals and hormones can serve to suppress, inhibit and even alter, immune function giving rise to physical and psychological morbidity (Morey, Boggero, Scott & Segerstrom, 2015). For example, chronically elevated heart rate or blood pressure as a

result of chronically persistent catecholamines such as adrenaline can induce a chemical and mechanical allostatic overload on the cardiovascular system, leading to or further exacerbating LTCs such as atherosclerotic plaques, stroke and heart attacks (Black & Garbutt, 2002; Goldstein, 1995; Guyton & Hall, 2006; Kumar & Clark, 2009; McEwan, 2005).

In a regular stress response, the sympathetic nervous system uses steroid hormones such as cortisol and glucocorticoids to regulate metabolic functions and dietary behaviours, such as an increase in appetite, in order to increase the energy levels of the body (Sominsky & Spencer, 2014). Glucocorticoids are also known to reduce sensitivity and impede the function of insulin, which is the hormone that regulates the level of sugar in the blood stream by storing it when levels exceed the normal requirements (Ferris & Kahn, 2012). In a chronically stressed state with accompanying negative health behaviours there may be a lack of energy expenditure thus distorting the supply and demand of energy in the body. The chronic presence of glucocorticoids and cortisol in chronic stress increases the supply of energy whilst also decreasing insulin sensitivity, thus they result in chronically elevated levels of glucose in the blood stream, which can lead to or further deteriorate Type II diabetes (di Dalmazi, Pagotto, Pasquali & Vicennati, 2012). Such biomarkers are used when studying stress and related health effects in dementia caregivers (Allen et al., 2017; Mausbach et al., 2019).

Allen et al. (2017) reviewed 131 studies exploring the impact of dementia caregiving on stress biomarkers and 18 studies exploring the impact of interventions to reduce this stress in dementia caregivers; they found that the hypothalamic-pituitary-adrenal function was reduced and cortisol increased in the majority of studies. They also found that allostatic load was increased in dementia caregivers. With regards to reduction of stress Allen et al. (2017) found that engaging in pleasant activities and the perceived freedom to do so, along with

active coping mechanisms and high levels of self-efficacy helped reduce stress in the caregiver. They concluded however that the evidence was mixed and recommend that caregivers' appraisal, and decision-making processes and coping mechanisms to deal with stress, particularly problem-focused coping, should be explored in more depth as these stress related responses are significantly associated with LTCs and their management in dementia caregivers (Allen et al., 2017).

3.2.4 The conceptual platform

In light of literature and methodological concerns discussed in this chapter the framework (Figure 6) provided by Sörensen and Conwell (2011) will be used along with dementia caregiver policy and care pathways in order to create what Pawson (2013) refers to as a "reusable" (p. 86) or "recyclable" (p. 94) conceptual platform. Such platforms are integral to realist inquiry and evaluation as Pawson (2013) states that:

> "Rather than starting each inquiry from scratch, a stock of recyclable conceptual frameworks is created to distinguish different classes of interventions and to set out their component theories. All evaluations then operate within a common set of programme theories, each inquiry being capable of adding to and refining that framework" (p. 86).

Sörensen and Conwell (2011) conceptualised their dementia caregiver stress process model (Figure 6) by combining the Stress Process model (Pearlin et al., 1990) and the Appraisal model (Lazarus & Folkman, 1984) to predict dementia caregiver health and related behaviours (Figure 6). By combining two key theoretical frameworks in the understanding of the stress-health process in dementia caregivers, Sörensen and Conwell (2011) offer a

comprehensive summary of all the important factors that have been discussed in this chapter as contributors and mediators of dementia caregivers' health and health behaviours. The Stress Process model by Pearlin et al. (1981) has also previously been applied to clinical practice in the UK and was found useful in enhancing the practice of mental health nurses in their assessment of dementia family caregivers (Carradice, Shankland & Beail, 2002); therefore, this model is of relevance to both theory and practice.

Sörensen and Conwell (2011) state that there is sufficient evidence on the effects of dementia caregiving on the general physical and mental health of caregivers. They recommend that future research needs to address the needs of 'vulnerable' caregivers whom they define as those who have pre-existing LTCs. They note that evidence from complex interventions designed to target the multiple stressors affecting caregivers' behaviours show inconsistency in their effectiveness therefore pre-intervention research and assessment would be beneficial in order to elicit the specific health needs of the caregivers. For the remainder of this thesis, the relevance of the various different components of the stress process (Figure 6) will be addressed in relation to the impact they have on the caregivers' LTC health-related outcomes and self-management behaviours.

Figure 6   Stress and Appraisal conceptual model reproduced from Sörensen and
                   Conwell (2011, p. 8)
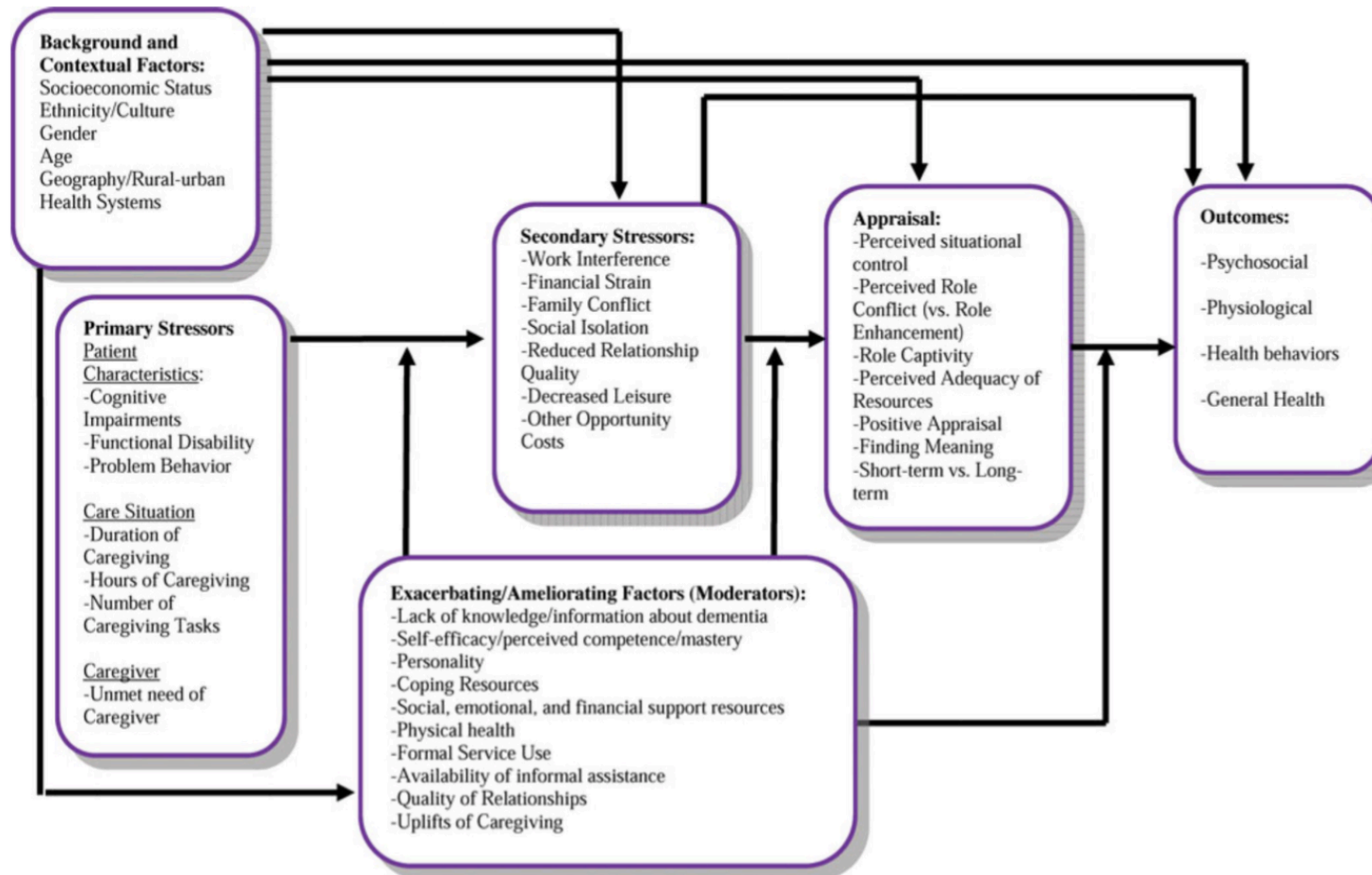
As mentioned in the introductory chapter, the dementia care pathway in the UK is outlined by NICE guidelines. NICE issued the guidance and care pathways for Dementia in 2006, this was known as Clinical Guideline (CG) 42. CG42 was in use until it was updated in 2018 to Nice Guideline (NG) 97 (NICE, 2018a). In preparation for this update, NICE issued a 'guideline scope' summarising the existing care pathway and highlighting areas where "scope for consultation" (NICE, 2015a, p. 1) and improvement remained. Figure 7 shows the summarised pathway of care for people with dementia and their family caregivers as reproduced from NICE (2015a, p. 12).

Figure 7   NICE dementia care pathway reproduced from NICE (2015a, p. 12)
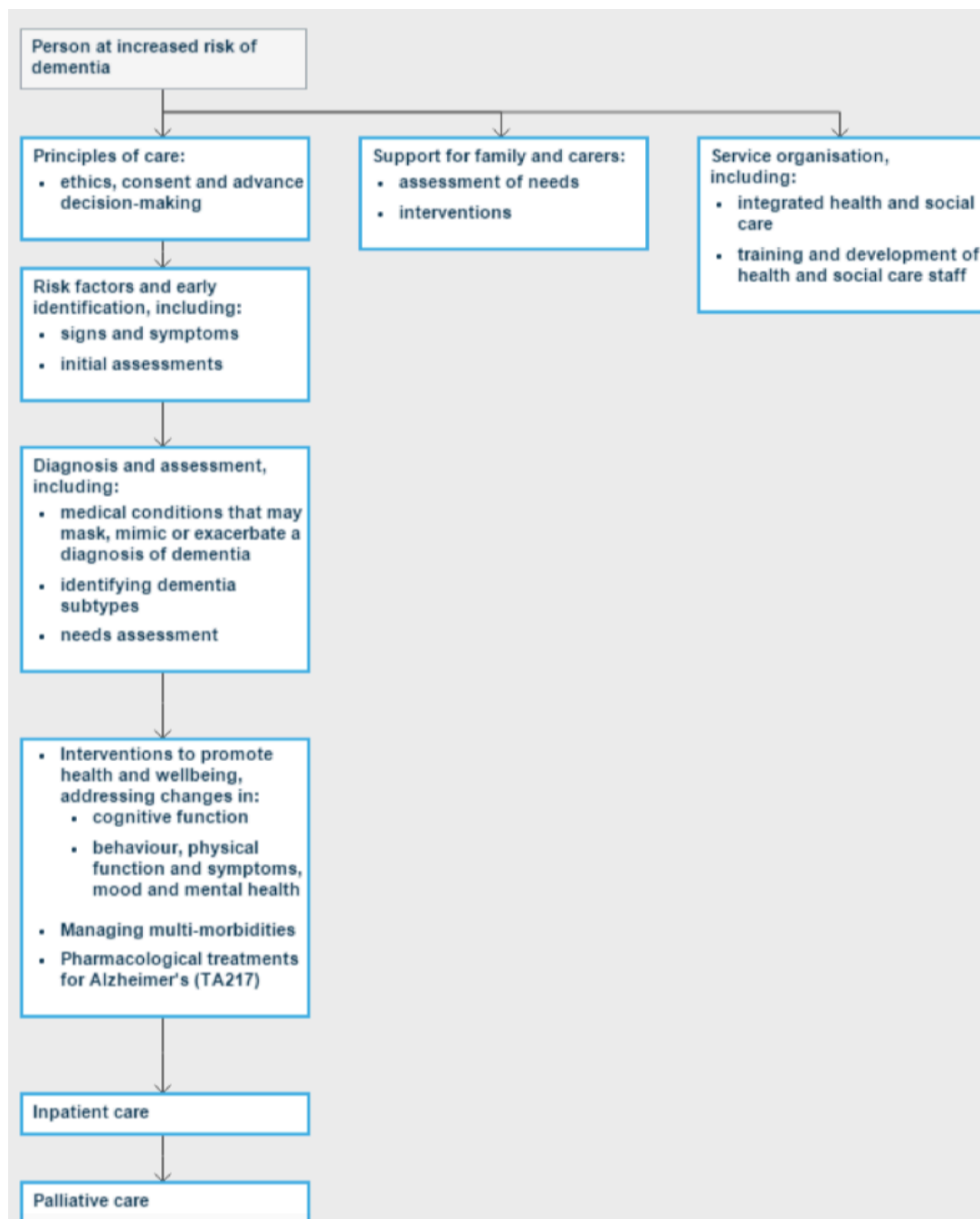
The key care principle that sheds light on how this pathway works for caregiver health needs is as follows:

> Health and social care staff should identify the specific needs of people with dementia and their carers arising from ill health, physical disability, sensory impairment, communication difficulties, problems with nutrition, poor oral health and learning disabilities. Care plans should record and address these needs" (NICE, 2015a, p. 12).

This guideline does not offer specific advice regarding the care of long-term conditions in dementia caregivers; as explained in Chapter 1 the pathway of care for the management of long-term conditions is mainly through the GP in primary care. Therefore, the conceptual framework for this study needs to encompass how policy is translating into practice for dementia family caregivers in the UK. The theoretical framework of Sörensen and Conwell (2011) will allow the study to tie the analysis of these concepts together. Box 4 summarises the key points obtained from the review of the literature thus far (including information from the introductory chapter).

Box 4   Key points from background literature

> → Future research should focus on stress process models
> → NICE's dementia guidelines do not cover specifics on the care of caregivers with long-term health conditions.
> → Primary care LTC management guidelines (QOF) do not have a specific care pathway for dementia caregivers.
> → Dementia family caregivers may easily fall into the QOF exception's category in primary care reports on the management of LTCs.
> → Policy related to primary care must be evaluated to see what works or does not work for the self-management of LTCs in dementia family caregivers.

The next few sections unpick the fundamentals of policy making in NICE guidelines in order to build on and strengthen the methodological and epistemological rationale for the paradigm adopted in this study.

3.3 Evidence-based policy

O'Connell et al. (2018) observed that, globally, self-management support frameworks informing health policy rely heavily on evidence and theory-based literature. WHO state that support tools and interventions for high-risk complex patient populations with long-term conditions should be evidence-based (WHO, 2005, 2017b). WHO define evidence as "systematically developed statements (recommendations) to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances" (WHO, 2005, p. 111).

At the heart of such evidence-informed healthcare frameworks and policies is the adequate appraisal of the quality of that evidence (Rajabi, 2012). NICE guidelines state that they use multiple sources of evidence when informing their guidelines and pathways (NICE, 2012a). Before undertaking further examination of NICE's approach to evidence appraisal and guideline development, a brief philosophical history of what constitutes healthcare 'evidence' is warranted and has been provided in the subsequent sections.

Towards the end of the 20th century, a growing need to incorporate criticality and transparency within medical practice and clinical decision-making led to the advent of 'evidence-based medicine' (Smith & Rennie, 2014). The term coined by Dr. Gordon Guyatt, was based on the earlier teachings and groundwork of his mentor, widely known as the father of evidence-based medicine (EBM): Dr. David Lawrence Sackett (Guyatt, 1991; Guyatt et al.,

1992; Smith & Rennie, 2014; Sur & Dahm, 2011). Although, modern usage of the term refers to a scientific 'model' of clinical practice, it was originally classified as a new medical 'paradigm'; defended on Kuhnian philosophy, it contested for a shift away from unsystematic, unaccountable paradigms of evidence application (Guyatt, 1991).

Soon after its conception, EBM was subject to criticism and debate from the medical and scientific communities; its population-focused, epidemiological underpinnings were deemed insufficient to deal with the intricacies of individual patient problems (Dearlove, Sharples, O'Brien & Dunkley, 1995; Jones & Sagar, 1995; Smith, 1996). Thus, Sackett et al. (1996) issued an article defending the basic tenets of evidence-based medicine as the "conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients" (p. 71). Sackett et al. (1996) stated that 'best evidence' comprises the integration of two parts: "individual clinical expertise" (p. 71) and "best available external clinical evidence from systematic research" (p. 71). However, in what appears to be an attempt to appease holism in translating evidence-based medicine into evidence-based practice, Sackett et al. (1996) describe the scope of the two primary constituents of 'best evidence' as:

Increased expertise is reflected in many ways, but especially in more effective and efficient diagnosis and in the more thoughtful identification and compassionate use of individual patients' predicaments, rights, and preferences in making clinical decisions about their care. By best available external clinical evidence we mean clinically relevant research, often from the basic sciences of medicine, but especially from patient centred clinical research into the accuracy and precision of diagnostic tests (including the clinical examination), the power of prognostic markers, and the efficacy and safety of therapeutic, rehabilitative, and preventive regimens. (pp. 71-72).

Key terms in this quotation have been underlined to highlight that both these facets of evidence rely predominantly on clinical parameters and clinically systematic research, overlooking psychosocial health needs. In order to protect the doctrine from further social polemics, Sackett et al. (1996) added that the definition of evidence-based medicine will "continue to evolve" (p. 72).

3.3.1 Hierarchies of evidence

The next two decades were dedicated to directing the evolution of evidence-based medicine and practice towards an appraisal system based on methodological rigour, transparency and replicability with a clinical focus, which led to the foreseeable conclusion that while all evidence *is* (perhaps) *equal, some* evidence *is* (probably) *more equal than others* (Mallet, Hagen-Zanker, Slater & Duvendack, 2012; McCartney, Treadwell, Maskrey & Lehman, 2016). Thus, a rigorous and ruthless process of grading evidence based on research design and methodology gave rise to hierarchies of evidence where the evidence generated through

primary empirical studies was given more weight. In the year 2000 the Grading of Recommendations Assessment, Development and Evaluation (GRADE) system of appraisal was developed to evaluate evidence for the effectiveness of interventions for patients (Atkins et al., 2005; Blunt, 2015; Guyatt et al., 2011). GRADE assesses the evidence against hypotheses about outcomes such as a treatment having a positive or precisely estimated effect, or no effect at all. GRADE ranks evidence based on methodological hierarchies, to include randomised controlled trials (RCTs) and observational studies. If the evidence-base consists of mainly RCTs then the initial rating is considered 'high', if on the other-hand the evidence-base consists mainly of observational studies then it is ranked 'low'. GRADE does not offer insight into the ranking of a mixed-evidence base. For this reason, Bluhm (2005, 2010) and Blunt (2015) criticise EBM for being a hierarchy of methodologies which either undermines or completely excludes important sources of evidence that inform the clinical and social dimensions of healthcare.

3.3.2 Evidence in the development of NICE guidelines

The development of evidence-based NICE guidelines for the management of long-term conditions further substantiates the claim of methodological biases in EBM as it also subscribes to the GRADE system of quality appraisal. NICE have a Public Involvement Programme team responsible for the involvement of caregivers, patients and service-users in the development of their guidelines (NICE, 2015b, 2018c). However, such individualised involvement is limited to workshops and "informal telephone and email advice" (NICE, 2018c, p. 11). As mentioned earlier, evidence-based practice guidelines for chronic diseases in the UK, particularly in England, are provided primarily by NICE guidelines on behalf of stakeholders such as the Department of Health. A close inspection of the literature

contributing to the evidence of NICE (2016) guidelines for the assessment and management of long-term conditions reveals that out of seventeen literature reviews only one contained mixed forms of evidence to include eleven qualitative studies. The remainder of the evidence-base considered was assessed using quantitative outcome measures and consisted primarily of RCTs. NICE (2016) mentions that the evidence-base informing outcomes were assessed using the GRADE system.

3.3.3 EBM biases

As hierarchies of evidence are an integral component of the evidence-based model it encourages healthcare researchers and stakeholders to invest in deductive, reductionist research designs deemed ontologically empirical and epistemologically objective such as systematic reviews and RCTs. (Burns, Rohrich & Chung, 2012; Broom & Evan, 2007; Scotland, 2012). However, from the onset, and certainly with current public health concerns, the shortcomings of this model in privileging one form of evidence over another is apparent in its inapplicability to the multi-dimensional issues of complex patient populations and multi-morbidities (Greenhalgh, 2012; Greenhalgh, Howick & Maskrey, 2014; Cohen, Stavri & Hersh, 2004; Vlieland, 2002). Reducing the treatment of complex chronic illnesses to "cost and survival" (Beresford, 2010, p. 722) or the health consequences of dementia caregiving to biomarkers of disease and scales of depression offers few practical solutions to the reality and magnitude of the social problem as described by the social models of chronic disease/LTCs, caregiver burden and health behaviours (Allen et al., 2017; Wade & Halligan, 2017).

Greenhalgh et al. (2014) questioned whether evidence-based medicine has become a "movement in crisis" (p. 1) due to its paradigmatic rigidity in rising to the challenges of healthcare complexities. Greenhalgh, Snow, Ryan, Rees and Salisbury (2015) further argued that the evidence-based paradigm subjects patients, particularly those who are also caregivers, to biases which can no longer be addressed or reviewed through empirical research alone. The six biases Greenhalgh et al. (2015) identified have been summarised below:

1) Published literature contains minimal input from patient/caregiver defined outcome measures.

2) The hierarchy of evidence undermines the lived experiences of caregivers and patients.

3) Patient-centeredness is poorly understood and reduced to shared-decision making of treatments and tests.

4) Self-management advice may be ignored as the patients' individual circumstances and corresponding compliance with management plans are not explored in a clinician-led consultation.

5) EBM places greater emphasis on biomedical parameters and underestimates the significance of self-management support.

6) EBM privileges those who actively seek and access care and therefore contributes to healthcare inequalities. Such hidden 'denominators' are removed from primary care lists in their exceptions report.

Such biases challenge the authority of the evidence-based paradigm in informing policies and frameworks of care. As mentioned earlier the EBM paradigm had been defended through Kuhnian philosophy, however, the very nature of Kuhn's reflective philosophy dictates that a "paradigm in crisis" (Kuhn, 1970, p. 84) requires reconstruction that challenges the existing theoretical and methodological applications and generalisations. Kuhn refers to the words of Herbert Butterfield when explaining that a shift in paradigm requires:

> The art of handing the same bundle of data as before, but placing them in a new system of relations with one another by giving them a different framework, all of which virtually means putting on a different kind of thinking cap. (Butterfield, 1957, p. 13).

Unfortunately, the methodological distinctions of current EBM practice continue the quantitative-qualitative dichotomy thus enabling hierarchies of evidence to monopolise health policy and research with only tentative explorations of pluralistic paradigms and mixed-methodologies (Leppink, 2017). According to Pawson (2006b) an optimal solution to the dilemma of the "evidence-based policy to policy-based evidence" (p. viii) cycle is to adopt a realist philosophy and approach to evaluation research.

3.3.4 Political and economic considerations

In addition to the hierarchical categorisation of research methodologies to glean best evidence, the political and economic drive behind tax-funded healthcare systems such as the NHS can serve both as an advantage and disadvantage when informing healthcare policy (WHO, 2004b). While enabling the deduction of population-wide risks proves an advantage, a common disadvantage that stems from allying healthcare priorities with cost is that it

encourages researchers and stakeholders to invest in research designs that subscribe to a positivist paradigm through which cost-effectiveness can be readily determined (Noyes & Holloway, 2004; Ramsay et al., 2015; Thomas, Burt & Parkes, 2010; WHO, 2004b).

With an ageing population and the rising demands of long-term conditions, health economic evaluations are crucial to policy makers (NICE, 2012a). Despite policy targets to improve the quality of care through improved coordination of services, poorly managed LTCs requiring emergency care facilities are still a major concern for healthcare systems worldwide (Busby et al., 2015). This issue remains at the forefront of UK health policy as the NHS continues to face over a decade of austerity (Stuckler, Reeves, Loopstra & Karanikolos, 2017). In the UK, long-term conditions are accountable for 70% of England's health and social care budget, 70% of in-patient bed days and half of all primary care GP appointments (DH, 2012a; DH, 2013a). The estimated increase in people living with three or more long-term conditions in the last decade has been from 1.9 million in 2008 to 2.9 million in 2018 (NHS England, 2018b). This increase in multimorbidity yields a proportionate increase in healthcare expenditure of an estimated £5 billion (DH, 2012a; NHS England, 2018b). NHS England aim to reduce unplanned hospitalisations by making services more 'predictive' in identifying and serving vulnerable patient groups such as dementia caregivers as they are likely to be more susceptible to adverse health outcomes (Coulter, Roberts & Dixon, 2013; Goodwin, Sonola, Thiel & Kodner, 2013; NHS England, 2014, 2018b; The King's Fund, 2010).

3.3.4.1   Economic value of informal caregiving

Informal caregiving is of particular value for economic evaluations in health-promotion support interventions as these interventions may be targeting someone who is either receiving the care or providing the care, and in both cases, the cost-effectiveness of the intervention may be affected in the case of death or morbidity to either the care-recipient or the caregiver (Drummond, Sculpher, Claxton, Stoddart & Torrance, 2015). In 2015, the UK's annual treasury report revealed that the total government expenditure on healthcare services was £134.1 billion (HM Treasury, 2015). In the same year Buckner and Yeandle (2015) provided an updated report on caregivers' estimated economic contribution to government savings. This report updated the findings of the surveys conducted on over seven million caregivers across the UK by the national charity 'Carers UK' on behalf of the Centre for International Research on Care, Labour and Inequalities ([CIRCLE], 2011). In 2011 it was estimated that caregivers contributed £119 billion in savings, which was updated in 2015 to £132 billion, coming close to the cost of a second NHS (Buckner & Yeandle, 2015). A similar pattern in the economic distribution of workload is seen for the provision of dementia care in the UK. In 2014 it was estimated that annual dementia care cost health and social care services £14 billion and informal, unpaid family caregivers £11 billion (Prince et al., 2014). In the words of Schulz and Beach (1999) "although family members perform an important service for society and their relatives, they do so at a considerable cost to themselves" (p. 2215). As established by the current review of the literature, a significant contributor to this cost is the caregivers' own health and wellbeing.

3.3.4.2   Physical health outcome measures

It has been noted that the health outcomes used in policy and evaluations to assess informal caregiver health such as health-related quality of life do not meet the specificity required for effective economic evaluations (Huter, Dubas-Jakóbczyk, Kocot, Kissimova-Skarbek & Rothgang, 2018; Koopmanschap, Exel, van den Berg & Brouwer, 2008). These issues have important implications for research involving dementia caregivers. Due to funding and policy thresholds, the NICE Guideline Development Group state that clinical and cost effectiveness of interventions and treatments should be reported in Quality Adjusted Life Years (QALYs, NICE, 2012b). QALYs view health as a combined function of the quality and quantity of life lived; therefore, they place a higher value on using preference data from generic outcome measures otherwise known as 'preference-based outcome measures' (Coombes, 2010; Prieto & Sacristan, 2003; NICE, 2012b, 2018b).

Preference-based outcome measures, value the public's 'preference' and attitudes for health in terms of health utilities and patient reported aspects of health states such as activities of daily living or pain and discomfort. In favouring generic outcomes, condition-specific psychometric properties of health are neglected (Neumann, Goldie & Weinstein, 2000). Many quantitative studies use generic outcomes such as health-related quality of life, Short-Form-36 or Nottingham Health Profile as outcome measures for the caregivers' physical health (Andrén & Elmståhl, 2008; Bremer et al., 2015; Marziali, McCleary & Streiner, 2010; López, Romero-Moreno, Márquez-Gonzalez & Losada, 2015). Another issue with caregiver health research is the use of burden and mental health scales as primary outcomes measures. One systematic review extracted data from 455 articles to determine which tools and outcome measures are most frequently used to assess dementia caregivers (Jones, Edwards &

Hounsome, 2012). The resulting categories included burden as the most common category researched in caregivers using the Zarit Burden Interview as the most frequently used tool amongst other burden and stress scales. Other categories included mastery, mood, quality of life and social support. 22 out of the 34 scales identified were not specific to dementia caregivers; the only health tool used was the short-form-36 (SF-36).

3.3.4.2.1 Preference-based Outcomes

Preference-based outcome measures are attitudinal scales such as Likert (1932) and Thurstone (1928) scales which gauge peoples' preference and attitudes towards healthcare and health behaviours. These scales were developed under a positivistic paradigm in which the human stress process was described as a direct stimulus-response interaction (Selye, 1950; Watson, 1913). The SF-36 is one of the most frequently used preference-based measures of health-related quality of life due to its perceived usefulness in determining QALYs for health economics research (Lins & Carvalho, 2016). It was developed in a two-year observational study known as the Medical Outcomes Study (Tarlov et al. 1989; Whang, 2013). The study aimed to understand the aspects of the healthcare system that affected the health outcomes in people with long-term conditions and develop tools that would monitor these outcomes and their determinants. This study originated out of a need to restructure the American healthcare system to meet the rising cost demands of LTCs. It was conducted in two phases; a cross-sectional phase with a sample of 22,462 patients, involved evaluating their health and treatment; a longitudinal phase with 2,349 patients from the original sample, involved monitored their hospitalisations, treatment and outcomes of care. The resulting generic tool, the SF-36, was described as "a new paradigm for monitoring the results of medical care" (Tarlov et al., 1989, p. 930).

The SF-36 comprises eight domains to include physical functioning, role limitations as a result of physical problems, pain, health perceptions, vitality, social functioning, role limitations as a result of emotional issues, and mental health (Németh, 2006). SF-36 is considered a valid and reliable health-related outcome measure in people with long-term conditions (Bunevicius, 2017; Kwan et al., 2016; Matcham, Norton, Steer, & Hotopf, 2016; Falide & Ramos, 2000) and in caregivers of people with dementia (Machnicki et al., 2009). However, in a review of 172 studies across thirty-six countries, Lins & Carvalho (2016) question the validity of the SF-36 as used in current research, as they note that there are multiple ways in which the SF-36 total score may be calculated which then gives rise to a measurement bias. They conclude that this methodological systematic error, particularly in studies of patients with long-term conditions, has implications for clinical practice and policy guidelines. Likewise, Jones et al. (2012) recommend exploring and developing dementia caregiver-focused outcome measures instead of generic outcome measures and burden scales when assessing the health of dementia caregivers. Huter et al. (2018) also conclude that the use of QALYs and generic outcome measures reflect methodological obstacles for policy, practice and research as they do not capture the psychosocial benefits of interventions nor do they account for the difference in priorities for older caregivers.

McDowell (2006) claimed that the SF-36 has 'scope' due to its high overall reliability and validity and multiple health domains; however, he states since it is a quantitative measure it struggles to provide in-depth information on each item. The Medical Research Council although still focused on developing generic health outcome measures have started incorporating case studies of specific caregiver needs in their methodological approach to instrument development. The MRC acknowledge that health status alone is not sufficient to

assess dementia caregivers' health needs and a "bottom up" (MRC, 2014, para. 2) approach is required with a rigorous conceptual foundation such as that employed in this research.

3.3.5 Policy discord

The discussion of policy and practice not only highlights the complexity of the issues under study but also that current research paradigms used to guide policy and practice are insufficient and incompatible to identify the unmet needs of vulnerable caregivers. This discussion of policy further highlights a gap in the use of qualitative research methodologies and thus highlights the necessity to adopt a realist, qualitative, approach to self-management amongst dementia family caregivers with LTCs.

3.4   Systematic search

The next stage of this realist review is to conduct a systematic search in order to specifically explore primary, empirical evidence on self-management behaviours in dementia family caregivers with one or more long-term conditions.

3.4.1 Formulating the systematic search strategy

A university librarian with expertise in healthcare literature searching was consulted on two occasions for the development of the search strategy. On the first occasion key literature was searched to identify existing literature and reviews on the subject of self-management in dementia family caregivers with existing long-term conditions. Initially, search terms were brainstormed using pilot search for each keyword to include 'dementia', 'caregiver' and 'long-term condition'. Pilot searches were conducted on Google Scholar, PubMed and SCOPUS to

scope the literature for further key words. An elaborate list of search terms for dementia (25 terms) and self-management (16 terms) was identified from a systematic meta-review (Huis in het Veld, Verkaik, Mistiaen, van Meijel & Francke, 2015). PubMed was scoped for the literature with variations of these terms and it was revealed that the resulting literature was focused on clinical interventions for people with dementia. Between the first and second meetings further literature searching and scoping were done by the researcher and the librarian and a list of terms were identified for comparison. During this process members of the research team were also consulted for their expertise. During the second meeting a final list of terms was agreed (Table 5) and four key search engines for the literature review were selected. A total of two key words were used for dementia, twelve for caregivers and ten health-related terms were identified, to include a mixture of long-term conditions, health needs and self-management. It was found through the searches that caregiver LTCs were often not specified in the title or abstract and therefore for the strategy to be inclusive and comprehensive these terms were separated through the Boolean operator 'OR' instead of 'AND'. The selected search engines included PubMed, Cumulative Index to Nursing and Allied Health (CINAHL), Cochrane Library and PsychINFO.

An English language filter and a time filter to begin the search from 01 January 1990 were applied. The application of the time filter was due to the fact that changes to policy and practice such as the emergence of evidence-based policy making (Guyatt, 1991), caregiver policies (National Health Service and Community Care Act, 1990) and new models and perspectives on care for long-term conditions (Leventhal & Cameron, 1987; Mechanic, 1995; Prochaska & DiClemente, 1992) started near the 1990s. Without the time filter, the literature search graph on PubMed revealed that a surge in research for this topic started from the year

1995, therefore this confirmed that a large volume of literature was not being ignored. The systematic search of the literature reported in this chapter occurred before a research proposal was submitted for ethical approval, therefore the search ended on the 31st December 2015.

Table 5   Search strategy for realist review

Terms for Dementia = 2			
1	dementia	[Title]	OR
2	alzheimer*	[Title]	AND
Terms for Caregiver = 12			
1	caregiver*	[Title]	OR
2	carer*	[Title]	OR
3	caregiving	[Title/Abstract]	OR
4	spous*	[Title/Abstract]	OR
5	partner*	[Title/Abstract]	OR
6	significant other*	[Title/Abstract]	OR
7	offspring*	[Title/Abstract]	OR
8	filial	[Title/Abstract]	OR
9	son	[Title/Abstract]	OR
10	sons	[Title/Abstract]	OR
11	daughter*	[Title/Abstract]	OR
12	adult child*	[Title/Abstract]	AND
Terms for Long-term conditions and Self-management = 10			
1	health	[Title]	OR
2	health need*	[Title]	OR
3	self care	[Title]	OR
4	self management	[Title]	OR
5	long term condition*	[Title]	OR
6	chronic illness*	[Title]	OR
7	chronic disease*	[Title]	OR
8	morbidit*	[Title]	OR
9	comorbidit*	[Title]	OR
10	mortalit*	[Title]	OR

3.4.2 Selection and appraisal of studies

The review quality standards recommend that the selection and appraisal of literature should be based purely on their 1) relevance 2) rigour (Pawson, 2013; Wong et al., 2013a). Wong et al. (2013b) state that the sources selected "should allow the reviewer to make sense of the topic area" (p. 35). Selection based on methodological hierarchies as a basis to exclude evidence has been deemed an 'inadequate' approach to the review. So long as literature is not being excluded solely on the basis of the methodological 'hierarchy' it belongs to, Wong et al. (2013a) permit "using quality standards appropriate to particular kinds of research to appraise documents" (p. 9).

3.4.2.1   Selection of papers

Wong et al. (2013b) recommend that inclusion and exclusion criteria should be reported and data extraction procedures should be clearly outlined in the selection and appraisal process. The inclusion and exclusion criteria have been outlined below in Table 6.

Table 6   Inclusion and Exclusion criteria for Realist Review

Inclusion Criteria	Exclusion Criteria
Published journal articles: qualitative studies, quantitative studies, literature reviews, mixed-methods studies	Guidelines, unpublished literature, other grey literature (as these have already been reviewed in the sections preceding the systematic search)
Self-management interventions for dementia family caregivers with named LTCs. Self-management can include any items that mediate the physical health outcomes and behaviours as illustrated in the conceptual framework	Self-management interventions for PWD; self-management interventions without mention of caregiver LTCs
Dementia caregivers with named physical health conditions (not just mental health conditions)	Caregiver mental health or general health outcomes, or just depressive symptoms, or burden measures
Adult dementia family caregivers: spouses, children, sons/daughters in law	Paid dementia caregivers, professionals, friends

3.4.2.2   Data extraction

As recommended in the literature (Aveyard, 2010, 2016) and agreed by all members of the research team the general data extraction form designed by Hawker, Payne, Kerr, Hardey and Powell (2002) for the assessment of both qualitative and quantitative studies was deemed suitable for such mixed-methods reviews and thus adapted for use (Appendix 1). Sections that were added to this form included: ethics, peer-review, relevance, outcome measures for long-term conditions and health behaviours. The quality appraisal form discussed in the next section was also attached to this form.

3.4.2.3   Quality appraisal

Although methodology-specific checklists were not used to exclude papers, in order to provide transparency of data selection and as an assessment of methodological rigour, it was agreed with the review team that the checklist to review disparate data created by Hawker et al. (2002) will be used. This checklist has been recommended by Aveyard (2010) for use in the assessment of methodological quality of healthcare reviews including both qualitative and quantitative data. The checklist (Appendices 2-3) outlines nine domains to include the abstract and title, introduction and aims, method and data, sampling, data analysis, ethics and bias, findings and results, transferability or generalisability and implications for future research. Each of these items are graded with 10, 20, 30 or 40 points reflecting whether they are 'very poor', 'poor', 'fair' or 'good' respectively. These judgements are based on the assessment protocol devised by Hawker et al. (2002) as seen in Appendices 2-3. This process ensured that while studies were not excluded based on a hierarchy of methodology, the included studies were thoroughly assessed for rigour and the documentation of this through the checklist allowed other members of the review team to independently review the studies and increase the inter-rater reliability of the realist literature review. In order to achieve internal validity, evidence syntheses such as those conducted by NICE (2014a) have a quality code such as '+' or '++' or '−' to indicate whether some, all, or few/none of a quality-checklist criteria have been met respectively, and whether this alters the conclusions of the study. A similar method of coding the quality has been applied in this review. As there were many items on the Hawker et al. (2002) checklist and included four grading criteria, a more elaborate coding template was used as can be seen in Table 7. These codes, as applied to each study can also be found in the detailed discussion of the findings.

Table 7   Quality Codes for Realist Review

Code	Meaning
****	Met all/most criteria in the grade 'good'
***	Met some criteria in the grade 'good' and some in 'fair'
**	Met most criteria in the grade 'fair'
*	Met most criteria in the grade 'poor' or 'very poor' or met no criteria at all

3.4.3   Results

A Prisma flow chart of the results of the literature search can be seen in Figure 8. Titles were screened based on whether they mentioned physical health or self-management interventions in relation to dementia caregivers. Abstracts were screened for relevance based on the inclusion and exclusion criteria, if these were not made clear in the abstract then the full text was retrieved for further review. Three inter-library loans were required from the British Library during the retrieval of a total of thirty-six full-text articles. Full-text articles were screened closely using the selection criteria. A key observation was that studies assessing physical health outcomes in dementia caregivers were labelled poorly in the literature. Twelve studies that implied through their titles and abstracts that caregiver physical health was measured, utilised only generic assessment tools such as the Nottingham Health Profile or SF-36 to assess overall perceived health or health-related quality of life with no mention of baseline health or long-term conditions. Nine studies did not mention named long-term condition in the caregiver and had self-management programmes aimed at the management of dementia for the person with dementia, without measuring specific health outcomes in the caregiver. The references of a total of eight included studies were searched and an additional paper (Janevic & Connell, 2004) was identified from Connell and Janevic (2009). A total of nine studies have been included in this review.

Figure 8   Prisma flow chart for realist review
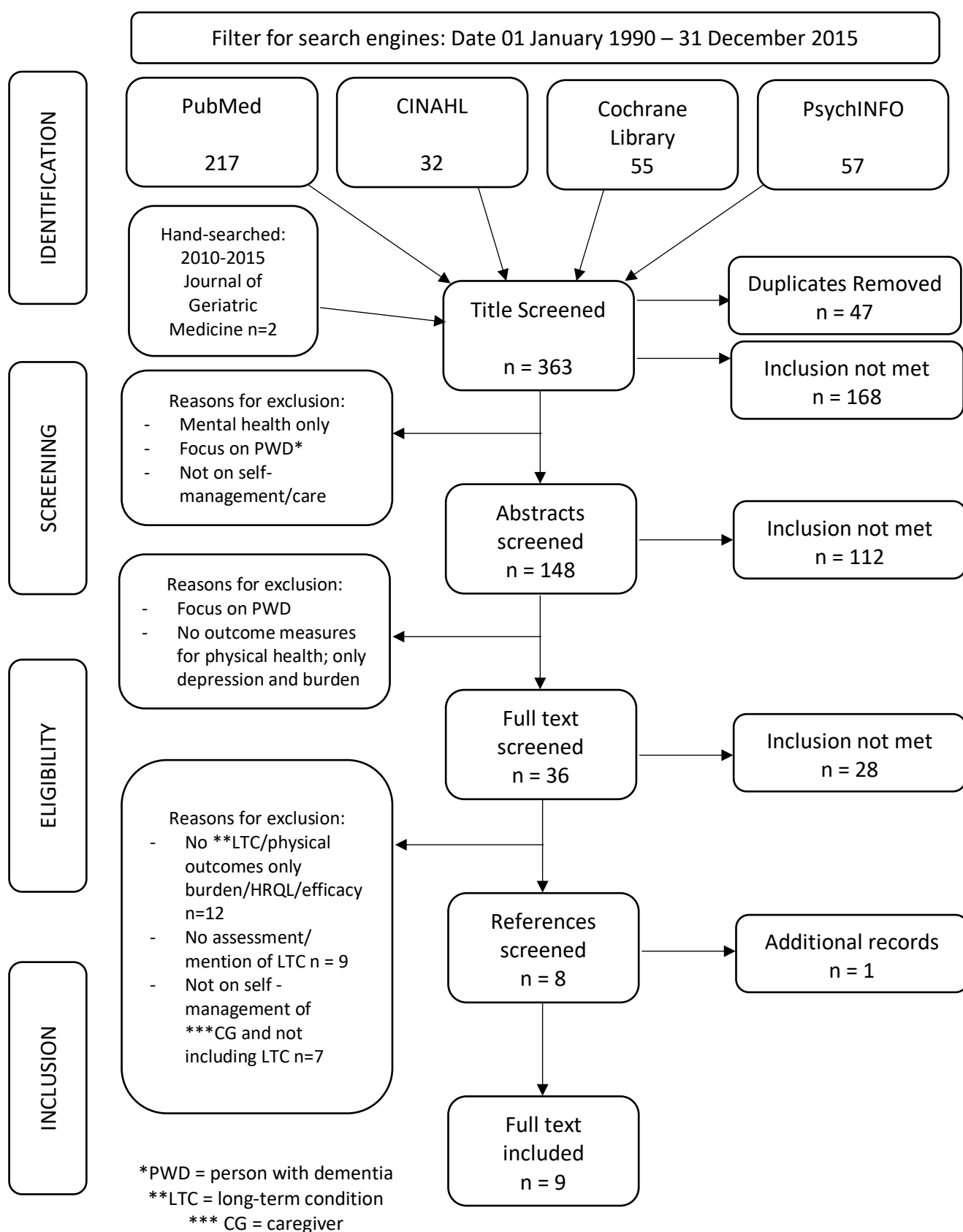
3.4.4   Analysis and synthesis of findings

In realist reviews mechanisms are underlying "causal forces or powers" (Wong et al. 2013b, p. 5). These mechanisms occur in particular contexts to generate specific outcomes (Pawson, 2013; Wong et al., 2013b). A realist review views the analysis and synthesis of evidence as a form of refining the initial theories and grand theories of social science already discussed in previous sections (Pawson, Greenhalgh, Harvey & Walshe, 2005; Wong et al. 2013b). Therefore, the 'unit' of analysis (Pawson et al., 2005) is not the article itself, rather, its role in adding to and refining the existing knowledge upon which the review questions were developed. Thus, as stated by Pawson (2013), Pawson et al. (2005) and Wong et al. (2013b) the analysis and synthesis of a realist review is an explanatory process which aims to address the following:

- What works?

- Whom does it work for?

- What contexts/circumstances does it work in/ apply to?

- In what respects and why does it work?

Realist reviews aim to highlight both theoretical and methodological gaps in the literature (Pawson, 2013). Pawson (2013) and Pawson et al. (2005) recommend presenting the findings of the review using 'if…then' statements about the evidence, for example 'if A then B' or if 'C then D is unlikely or E is possible' to derive the underlying middle range theories. This style of presentation is similar to the use of evidence statements by NICE (2014a) in order to summarise and present their findings. Study characteristics and their relevance to theory building have been summarise in Table 8.

The full form of the LTC abbreviations used in Table 8 have been presented below (in alphabetical order):

- CAD   (Coronary Artery Disease)

- COPD (Chronic Obstructive Pulmonary Disorder)

- CHF   (Congestive Heart Failure)

- CRD   (Chronic Respiratory Disease)

- GIT   (Gastro-Intestinal Tract)

- MI   (Myocardial Infarction – commonly known as a 'heart attack')

- TIA   (Transient Ischaemic Attack)

Table 8   Study characteristics and relevance to theory

Reference to article	Type and place of study	Participant gender, mean age (y), ethnicity	Long-term conditions	Method of analysis	Conceptualisation /stress-health process targeted	Relevance of findings	Rigour
Snyder et al. (2015)	Quantitative USA	Mainly Female, 68 y Caucasian	GIT conditions, respiratory conditions, thyroiditis, TIA, diabetes	Linear Mixed Regression	Pearlin et al. (1990) Lazarus & Folkman (1984) Coping strategies.	Coping strategies may influence the reporting of LTCs and thus potentially impact self-management behaviours	**
Zhu et al. (2015)	Quantitative USA	Mainly Female 65 y Mainly Caucasian	MI, CHF, diabetes, hypertension, COPD, CRD, GIT conditions	Linear Mixed Regression	Pearlin et al. (1990) Depressive symptoms	Caregivers with LTCs reporting more depressive symptoms are more likely to engage in self-management behaviours. Epistemological gap in knowledge-base.	****
Rabinowitz et al. (2010)	Quantitative USA	Only Female 57 y Caucasian & Hispanic	Hypertension, stroke, cancer, respiratory conditions, cardiovascular conditions, diabetes	Multiple Linear Regression	Religiosity as coping strategy	Ethnicity mediates impact of religiosity on negative health behaviours, methodological knowledge gap identified as little insight into reasons for this finding.	***
Furlong and Wuest (2008)	Qualitative Canada	Mainly Female 67 y Caucasian	Hypertension, diabetes, arthritis and others (unnamed)	Grounded Theory	Impact of caregiving burden on self-care behaviours	Self-sacrificing behaviour, lack of knowledge, loss of self, impact self-management behaviours. Advantages of qualitative approach evident, lack of insight into caregiver health status and related medical self-management.	****
Connell and Janevic (2009)	Quantitative (RCT) USA	Only Female 66 y Caucasian	Diabetes, arthritis and others (unnamed)	Hierarchical Linear Regression	Social Cognitive Theory written strategies, verbal persuasion to promote self-care	Written self-management strategies useful in short-term follow-up, maintenance phase of Transtheoretical model needs to be addressed.	****
Janevic and Connell (2004)	Qualitative USA	Only Female 66 y Caucasian	Diabetes, arthritis and others (unnamed)	Thematic Analysis	Subjective appraisal: barriers to self-care	Communication (verbal) support can be both positive and negative in promoting self-management; tangible support not always the main issue	***
Shelton et al. (2001)	Quantitative USA	More Female 74 y Caucasian	MI, CHD, CAD, diabetes, cancer	Linear Regression	Health care cost and utilisation after self-care promotion	Communication, promotion of self-management, regular needs assessment reduces hospitalisation (key policy target)	****
Cahill and Shapiro (1998)	Mixed-Methods Australia	Only Female 61 y No information for ethnicity	Hypertension, CHF, respiratory conditions, cancer, diabetes, arthritis	Thematic analysis; SPSS descriptive statistics	Primary and secondary stressors impact on LTCs	Considers relational comparisons between wives and daughters experience of LTC management while caregiving. Wives more at risk for adverse outcomes and adverse baseline health.	***
Gallant and Connell (1998)	Quantitative (Survey) USA	Male & Female 65 y Mainly Caucasian	Diabetes, hypertension, cardiovascular conditions, arthritis	Regression Causal Model	Lazarus and Folkman (1984) appraisal framework and health behaviours	Subjective burden and multimorbidity not linked to health behaviour; objective burden and depressive symptoms are stronger predictors, both affected by self-efficacy and education.	****

3.4.5 Presentation of findings

Each of the nine studies have been discussed individually. Findings have been introduced using realist '*if-then*' explanatory statements which summarise the crux of the study. Some studies use the term 'self-care' in place of 'self-management', therefore quotations directly reproduced from the study reflect the choice of terminology used in the study.

They first two statements (1a & 1b) derive from studies based on coping strategies as mediators of health outcomes and health-related behaviours in dementia family caregivers with long-term conditions.

3.4.5.1   Realist Explanatory Statement 1a:

** *If* more positive coping strategies are used by the dementia family caregiver *then* caregivers are likely to report fewer LTCs (Snyder et al., 2015).

This population-based study was carried out on a predominantly female Caucasian sample of 226 informal family caregivers of whom 107 were spouses and 98 were filial caregivers of the person with dementia (PWD). The study was conceptualised on the stress and appraisal models proposed by Pearlin et al. (1990) and Lazarus and Folkman (1984) respectively. One hundred and sixty-seven caregivers reported having diagnosed LTCs. The LTCs were identified with the use of a medical questionnaire delivered by a research nurse. The questionnaire asked about the diagnosis of specific named LTCs and the research nurse probed for more information regarding symptoms and diagnoses. The total number of LTCs in each caregiver was calculated and a linear mixed model of regression was used to explore the relationship

between caregiver physical health conditions and caregiver coping strategies. Linear mixed models were used as the study focused not only on physical health conditions but also caregiver mental health and caregiver and PWD characteristics (such as gender, age and education in the caregiver, and duration of dementia in the PWD). Of the 226 caregivers assessed at baseline 135 had at least one follow-up during the five-year period of this longitudinal study.

Caregiver coping strategies were assessed using the revised Ways of Coping checklist developed by Vitaliano et al. (1985). This checklist contains 57 items divided into eight coping domains: Problem-Focused, Seeks Social Support, Avoidance, Wishful Thinking, Blames Self, Blames Others, Counts Blessings and Religiosity. The items are scored from 0-3 where 0 reflects a strategy that is never used, 1 is rarely used, 2 is sometimes used and 3 is regularly used. The analysis revealed a significant interaction between caregiver gender and the use of Blames Others coping strategy and Wishful Thinking and the caregivers' reporting of LTCs as demonstrated by their calculated probabilities being less than 0.05.

Blames Others consists of six items describing the process of blaming others, such as getting angry at others or feelings of being treated unfairly. Wishful thinking consists of eight items such as wishing the situation away or fantasising positive outcomes. Male caregivers with a greater use of the Blames Others coping strategy reported a higher number of LTCs; the opposite pattern was found in female caregivers. Younger caregivers with greater use of Wishful Thinking reported fewer LTCs, with the opposite pattern in older age groups. While the findings are consistent with existing literature such as Kim, Knight and Longmire (2007) in demonstrating an association between coping strategies and physical health, only two of the eight domains were predictive of caregivers reporting LTCs. The study received two stars as

most criteria were met in the domain 'fair' and presentation of results were not consistently or sufficiently explained in the text.

This study was selected for review primarily because it looked at caregivers with LTCs. However, the findings shed little light on the management of these conditions or details about baseline caregiver LTC characteristics. However, one key finding that makes this study relevant to the initial rough theory, pertains to the assumptions (realist hypotheses) that may be drawn about the impact of underreported LTCs on the caregivers' self-management behaviours; in other words, if a caregiver does not report an LTC despite having it, then they will be invisible to an LTC-management support system. Another factor to consider is the method of analysis in such studies; the statistical advantage of using a linear mixed model is that it accounts for missing values, much like an exceptions report produced by primary care practices. However, such population-based quantitative studies do not reveal the reason for participant withdrawal, which would offer more insight into the reality of the lived-experience.

3.4.5.2   Realist Explanatory Statement 1b

*** *If* negative religious coping is used *then* some caregivers may indulge in negative self-management behaviours (Rabinowitz, Hartlaub, Saenz, Thompson & Gallagher-Thomson, 2010).

This study examined the relationship between multiple types of religious coping techniques and their impact on the health behaviours of dementia family caregivers with long-term conditions. The study consisted of 256 Hispanic and Caucasian female caregivers of people with dementia. Cumulative health risk was assessed using health behaviours. Three items of

this measure to include the number of meals, alcoholic drinks and amount of weight gain were taken from the Nutrition Screening Initiative (NSI) scale and assessed using dichotomous yes/no responses. Two additional items addressing weekly exercise and smoking habits were added to the overall health behaviours. Over all, the five-point scale indicated health risks from 0-5 with 0 being low risk and reflecting positive behaviours. Statistically, the regression model, although significant for cumulative health risk with all predictors, showed a low variance of 15%, suggesting that a more comprehensive model is required to establish stronger evidence. Recent studies also reveal poor validity for the use of the NSI scale in assessing risky health behaviours in similar-aged samples indicating a possible methodological flaw in this study as well (Sinnett et al., 2010; Vieira, Assunção, Schäfer & Santos, 2016). After controlling for variables such as age and care-recipient health, results supported the hypothesis that negative religious coping defined as a lack of religiosity, was associated with negative health behaviours in the management of the caregivers' long-term conditions.

Ethnicity provided a moderating effect on this relationship as positive religious coping was not predictive of improved cumulative health risk in Caucasian caregivers though the opposite was observed in Hispanic caregivers. However, as the study was quantitative, only assumptions and inferences can be made as to the reasons behind why these coping methods produced different results in the given sample. The authors suggest that if caregiving and related adversities are seen as a punishment or predetermined event then it could result in the loss of a health locus of control and limit motivation for behaviour change. This study is one of the few in this review that offers insight into ethnic differences between dementia caregiver populations, however, the inferences made in order to explain the differences lack clarity and reliability, resulting in the three-star rating. For example, it was stated that the

cultural significance of religion in the Hispanic population is different to the Caucasian population which may explain the difference in results, however how their culture differs and how dementia caregiving, self-management and health behaviours are conceptualised within this culture was not addressed by the authors. Such inferences make it difficult to ascertain the implications of this study for future research targeting self-management support for specific ethnic populations, thus while negative self-management outcomes were reported, this study provides little insight into the specific contexts and mechanisms that give rise to such outcomes. The findings of this study could be enriched by a qualitative account of the ways in which caregiver agency for self-management is influenced. This study was selected for review as it assessed key long-term conditions and specific self-management behaviours, however, these behaviours did not entail medical self-management and thus this study helps identify an additional gap in the knowledge-base.

3.4.5.3   Realist Explanatory Statement 2:

**** *If* caregivers report more depressive symptoms *then* they are more likely to engage in self-management behaviours such as making and attending doctors' appointments than those who report fewer depressive symptoms (Zhu et al., 2015).

This was a quantitative, population-based, six-year longitudinal study examining five domains of medical care and self-management behaviours: overnight hospitalisations, doctor appointments, outpatient appointments and tests and the use of assistive devices. The caregivers were mainly Caucasian women who were informal spousal and filial caregivers with a mean age of 65 years. A linear mixed model was used to analyse the relationship between caregiver characteristics and PWD characteristics on the caregivers' use of medical

facilities and engagement in self-management behaviours. PWD characteristics such as dependence and comorbidities were found to be statistically insignificant in relation to the caregivers' own health management and thus removed from the model.

Caregiver depressive symptoms were assessed using a Likert scale. Zhu et al. (2015) found that caregivers' own long-term conditions and depressive symptoms were more strongly associated with increased healthcare use and costs instead of the PWD characteristics. An important finding from this study is that while existing research uses interventions to improve caregiver depressive symptoms, there is little research on the impact of improved depressive symptoms on self-management behaviours as depicted by healthcare use and costs. These findings are consistent with other studies revealing an association between increase in depressive symptoms and increase in self-reported poor health, although it is not clear whether poor health increases depressive symptoms in the first place (Harwood, Barker, Ownby & Duara, 2000).

This study identifies a gap in exploring the reasons behind accessing support for self-management. As mentioned before, linear mixed models do not account for the reason in missing values which can be important indicators of the barriers to accessing support for LTCs. Caregivers' own LTCs were also associated with overnight hospitalisations, however, a quantitative account of this linkage does not offer insight into the reasons behind the hospitalisations. If hospitalisations are being caused by inadequate self-management and self-management support of the LTCs then this could have important implications for support interventions. Although this study was thorough in terms of reporting and documenting the research, a methodological gap in the knowledge-base still remains. The findings of this study

highlight that future research, be it qualitative or quantitative, should aim to directly address the caregiver and their needs instead of mediating it through objective measures of burden.

3.4.5.4   Realist Explanatory Statement 3:

**** *If* caregivers experience physical health decline, *then* they are more likely to engage in self-management behaviours (Furlong and Wuest, 2008).

This qualitative study of nine informal spousal caregivers of people with dementia revealed that physical health status is more likely than psychosocial health to encourage self-management behaviours in caregivers. One reason for this was because caregivers were more likely to engage in self-management behaviours when the self-management behaviours could be linked to improved physical health outcomes. A 'normalcy of self' theory was developed in this study using grounded theory methods developed by Glaser and Strauss (1967). An integral component of grounded theory is the development of a 'basic social process' which can help explain the underlying phenomenon of interest in the study (Chapman, Hadfield & Chapman, 2015; Schatzman, 1991; Reed & Runquist, 2007). Basic social processes are defined as "fundamental patterns in the organization of social behaviour as it occurs over time" (Glaser, 1978, p. 106). The basic social process in this study was the theory of 'finding normalcy for self' which provided an explanation for the patterns in self-care behaviours from the lived experiences of dementia caregivers. The three sub-themes or stages identified in 'normalcy for self' were 1) 'living from within', 2) 'reclaiming self-care' and 3) 'making self-care happen'. The progression through these stages were dependent on the following concepts: relational and instrumental support to the caregiver, caregivers' self-management interests, the illness trajectory of dementia and a prominent, emerging concept: 'self-care worthiness'.

Furlong and Wuest (2008) used the term 'self-care' and describe it as those activities that promote or sustain health. They note that caregivers with pre-established self-care behaviours can find normalcy more easily. The unpredictable trajectory of dementia was also linked to a decline in self-care behaviours of spouses, however it was noted that a health decline often triggers self-care behaviours due to a feeling of responsibility towards the PWD. Finally, self-care worthiness, was described as the caregiver's belief regarding the amount of physical, social, emotional and spiritual support they deserved. This was determined by personal judgements or by socially accepted norms of worthiness, in fact, it was reported that many caregivers obtained self-care worthiness through external validation from others including their spouse. The three sub-themes/stages providing a contextual explanation of the constructs of normalcy will now be described in relation to either facilitating or inhibiting self-care behaviours.

'Living from within' was a process through which the caregiver constantly adjusted to the ever-changing lifestyle of dementia caregiving. Three sub-processes were contained within this process. The first sub-process was termed 'learning to be a caregiver'. This explained that if a caregiver had to adjust to their new role through trial and error then they were likely to become more consumed by secondary stressors such household chores and financial duties instead of primary stressors such as dementia caregiving responsibilities. Nonetheless, previous experiences in caregiving did not diminish the need to learn to care for a spouse with dementia. Managing these dual responsibilities left little room for self-care of one's own health and well-being. It was noted however, that caregiver independence prior to becoming a caregiver did play an important role in adjusting to the new lifestyle and subsequently incorporating self-care within it.

The second sub-process was 'mourning change'. This was described as the "loss of reciprocity" (Furlong & Wuest, 2008, p. 1666) from the spouse which further inhibited self-care due to the lack of encouragement, validation and appreciation of the caregiver. The final sub-process of 'living from within' was termed 'self-sacrificing'. This referred to the change in priorities from the self to the PWD. Self-sacrificing behaviour was deemed more likely when there was a "lifetime pattern of always helping others" (Furlong & Wuest, 2008, p. 1666). Self-sacrificing behaviour was not associated with an absence of resources, instead it was experienced more intensely when caregivers refused the acceptance of support. Self-sacrificing behaviour and the refusal of support were however linked to self-care worthiness. The refusal of support existed even in caregivers who had pre-established self-care behaviours.

'Reclaiming self-care', was the second stage of finding normalcy for the self. A critical deterioration in an existing health problem or the emergence of an acute health condition were associated with a 'reclaiming' and move towards self-care in the caregiver. Furlong and Wuest (2008) identify a sub-process called "accepting the disease within the context of self" (Furlong & Wuest, 2008, p. 1667). This explains that self-care is given a priority when the caregiver begins to link their own health outcomes with the ability to sustain long-term caregiving for the PWD:

> If you don't [self-care], you will go right down-hill with them... it is going to be much worse 5 years from now. This is why it is good that I am learning now. (Caregiver quote reproduced from Furlong & Wuest, 2008, p. 1667).

The third and final stage of finding normalcy was called 'making self-care happen'. Three self-care enabling strategies were identified: 'balancing', 'creating routines' and 'getting away'. Balancing involved limiting sacrifices and commitments related to caregiving, though it was acknowledged, in accordance with previous literature (Wuest et al., 1994) that a perfect balance was impossible to strike as "there is always a slight tip of the scale in favour of the welfare of care recipients over caregivers' self-care" (Furlong & Wuest, 2008, p. 1668). Creating routines for both helped when caregivers included the care-recipients' routine into their own self-care routine. However, it was noted that routines that involved both individuals were not as beneficial as independently occurring self-care behaviours as they did not allow the caregiver to feel free of responsibility. Nonetheless, creating routines for both is a more practical and effective strategy when independent self-care activities are not deemed significant by the caregiver, or when the PWDs' safety are in question. Creating routines for both also sustains the spousal relationship, which is beneficial for caregivers' psychological well-being. 'Getting away' self-care behaviours were only possible when the caregiver accepted confrontational behaviour from the care recipient and did not sacrifice one's own health and well-being needs for the care-recipient. This involved accepting respite care, as mentioned by one of the caregivers:

> It is just like when you leave a little kid at day care. They are crying when you go and you are not out the door 10 seconds and they start playing with something. (Caregiver quote reproduced from Furlong & Wuest, 2008, p. 1669).

The importance of getting away is that it acts as a mediator for the potential engagement in self-care activities. Self-care should therefore be viewed as an outcome of getting away. Another important finding of this study was that self-care as perceived by caregivers was only

justified in the presence of physical health problems. By developing the theory of 'normalcy for self' Furlong and Wuest (2008) "close the existing knowledge gap" (p. 1669) on dementia caregiver perspectives for self-care behaviours and conclude that a significant finding of this study is that caregivers did not engage in self-care behaviours until their LTCs declined. However, the study did not outline specific caregiver physical health characteristics beyond the mention that a few of the participants reported LTCs and symptoms such as high blood pressure, high blood sugar levels and weight gain. The study identifies problems with self-management behaviours and underlying concepts giving rise to it, for example self-sacrificing behaviours leading to poor medical management of existing illnesses:

> I am just not feeling as good as I used to. And you see I am diabetic, too. I am not following the diabetic diet and I am not even checking my blood sugars. I should be doing that. I know they are high. (Caregiver quote reproduced from Furlong & Wuest, 2008, p. 1667).

Instrumental support helped make self-care possible for the caregiver by providing physical assistance and respite. Relational support was useful in finding normalcy for the caregiver as it provided emotional support and promoted self-care behaviours in the caregiver. However, emotional and psychological difficulties were not considered important until they became intense, even though, as noted by Furlong and Wuest (2008), the physical health problems, which were considered more important by the caregivers, may have been a result of the emotional decline in the first place. Family and friends were also found useful in promoting healthy behaviours in caregivers, as one reason identified for the loss of self-care, was a lack of healthcare and self-management validation from the spouse with dementia, for example a

caregiver explains the lack of understanding from her spouse with regards to the pain and fatigue she experienced from her arthritis:

> I will say "No I'm too tired." "Oh you're tired," he says, "You will be driving in the car. Let's go!" (Caregiver quote reproduced from Furlong and Wuest, 2008, p. 1665).

This pattern was more strongly associated in the female population; however, the study was conducted on a predominantly female population and therefore doesn't provide much insight into self-care behaviours for men and non-spousal caregivers. Overall, however, this was a well-reported, in-depth study that highlighted the advantages of a qualitative approach in identifying unmet needs, barriers to self-management and support mechanisms in dementia family caregivers. However, while long-term conditions were mentioned in general, details of specific LTC needs were not explored, thus, a knowledge gap remains.

3.4.5.5   Realist Explanatory Statement 4:

**** *If* there is low self-efficacy and higher objective burden *then* caregiver negative health behaviours are likely to be mediated through depressive symptoms (Gallant & Connell, 1998).

This quantitative study of 228 spousal caregivers looked specifically at five items of self-management behaviours to include smoking, alcohol consumption, sleep, exercise and weight management. These items were assessed by constructing a health behaviour change index which was coded dichotomously. A score of zero indicated no change or a positive change, a score of one indicated negative behaviour change. Major LTCs to include diabetes, heart disease, hypertension and arthritis were identified and totalled for each caregiver.

Details on how the illnesses were identified or assessed was not provided and it appears that the diagnosis may have been self-reported by the caregivers. Other measures included objective burden, subjective burden, depressive symptoms and health locus of control through existing quantitative scales; self-efficacy, was measured using self-constructed questions on confidence regarding care for self and care for the person with dementia. A causal structural model was created using exploratory factor analysis for both male and female caregivers which removed the variables of age, LTCs and self-efficacy. The relationship between the measures of social support and subjective burden to the measures of depression and health behaviour change were also found to be insignificant and removed from the model. Figure 9 has been adapted from the final model and shows only the part of the model with the variables that had a negative effect on health behaviours.

Figure 9   Factors negatively affecting health behaviours. Adapted from Gallant and Connell (1998, p. 284)
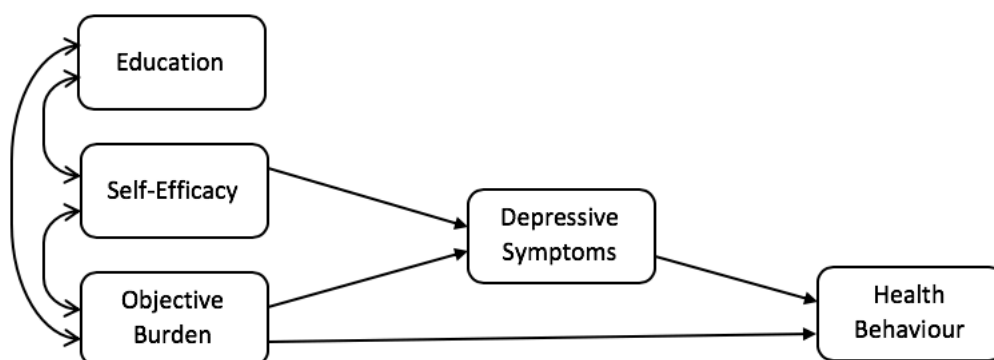
Previous studies have linked subjective burden to caregiver health outcomes as measured by generic scales, this study modelled subjective burden to health behaviours and was unable to establish a link, nor was there a direct link between subjective and objective burden. However, there were links between self-efficacy, education and subjective burden and self-

efficacy and accessing support. In terms of education, 90% of the sample had at least a high-school diploma and 30% had a university degree. The study was modelled on the stress process described by Lazarus and Folkman (1984) and the results support the hypothesis that dementia caregiving has a negative effect on caregiver health behaviours. The authors recommend more research on self-efficacy related to self-management. Overall this was a rigorous study which controlled for specific caregiver characteristics such as length of marriage, mean age and an even ratio of male to female participants. However, the underlying barriers and facilitators behind these associations are yet to be determined and specific LTC medical self-management needs have not been explored. The majority of participants were Caucasian; therefore, the study also does not account for the potential impact of ethnicity on caregiver burden and attitudes to health.

3.4.5.6   Realist Explanatory Statement 5:

**** *If* effective case management strategies are applied, whereby caregivers are regularly provided health assessment and health promotion, *then* this can reduce hospitalisations in caregivers by improving the management of long-term conditions (Shelton, Schraeder, Dworak, Fraser & Sager, 2001).

This quantitative study tested a case management model for patients with dementia and their family caregivers. The case management model involved developing social services in order to support the mental, physical and social needs of the person with dementia and their caregivers. The study hypothesised that regular assessment of caregiver needs would reduce their stress and burden, which would in turn improve the caregivers' health and reduce the need for healthcare utilisation.

The study consisted of 210 dementia caregivers in the case management intervention group and 202 in the control group. Nurse case-managers identified the unmet health and social care needs of caregivers and updated this assessment every 6 months for 1.5 years. Three different linear regression models were used to model the different relationships between the caregiver characteristics, dementia patient characteristics and treatment effects while enrolled in the study.

Overall there were no significant differences between the use of emergency care facilities between the two groups. However, during the study period, the number of caregivers hospitalised from the control group were almost double the number of caregivers hospitalised in the treatment group with an odds ratio of 0.58 marking a significant improvement in reduced hospitalisations in the intervention group. For those who had been hospitalised, the models showed no significant differences between groups in terms of duration of stay or total number of hospitalisations. There were no significant differences in the caregivers' use of emergency services, although, there were more cases of emergency visits in the control group.

Three caregiver characteristics were associated with increased hospitalisations to include: functional limitations as a self-reported measure of their ability to engage in activities of daily living; the presence of congestive heart failure; and age. The interaction between age and LTCs was a significant predictor of hospitalisations, as the impact of the LTCs varied with age. Factors not associated with caregiver hospitalisations included the levels of caregiver burden and stress and unmet service needs. The latter was assessed by the level of assistance required in ADL and IADL by the caregivers; burden and stress were measured using the Zarit Burden Interview and a generic self-reported depression rating scale. Objective stressors such

as dementia severity, functional impairment and BPSD were also not associated with caregiver hospitalisations. The authors concluded that the significant improvement in reduced hospitalisations for the treatment group was due to effective case management of the LTCs of the caregivers.

This study therefore shows that subjective and objective burden measures are not always associated with caregiver health and therefore interventions should aim to directly support the caregiver's unmet health needs. Being a purely quantitative study, methodological limitations do not aid in revealing which aspects of the case management intervention were particularly useful to caregivers and helped reduce their healthcare needs; the study also does not provide specific details of the baseline status of the LTCs present in the caregivers and whether reduced hospitalisations reflected improved health. This study was selected as it was based on the stress-health model and showed that self-management support and communication interventions may reduce hospitalisations, which is a key policy target for LTC management in the UK. However, these quantitative correlates require further exploration through different methods to determine the causal mechanisms behind them.

3.4.5.7   Realist Explanatory Statement 6:

**** *If* caregivers are provided regular verbal and written behaviour change strategies *then* they are more likely to engage in positive health-related behaviour change (Connell & Janevic, 2009).

This randomised-controlled trial involved a self-management intervention to promote exercise-related behaviours amongst 157 female spousal caregivers. The exercise programme was based on Bandura's social cognitive theory and motivational interviewing techniques

(Miller, 1996). Motivational interviewing is focused on activating personal agency as it encourages people to explore their strengths and utilise their decision-making autonomy in order to motivate themselves towards positive behaviour change (Rollnick, Butler, Kinnersley, Gregory & Mash, 2010). Bandura (1977a, 1986) states that neither social structure nor human agency determine the ultimate course of action a person takes, rather, these two factors are mediated by cognitive processes. Social cognitive theory not only explains how people acquire their behaviours but also how people regulate and maintain their behaviour, thus providing a foundation on which to develop behavioural interventions (Bandura, 1989). This is unlike linear models which are based on individual constructs of psychology and place greater emphasis on personal choice and agency in preventing negative behaviours such as the health belief model or the transtheoretical stages of change model (Cockerham, 2005). Bandura (1977b) further developed the social learning theory by adding the concept of 'self-efficacy' to it. Bandura's self-efficacy theory refers to an individuals' belief in their ability to achieve a goal (Bandura, 1977a). Bandura termed this a 'unifying' theory as he claimed it was a major factor to consider in all theories of behaviour change (Bandura, 1977a). His resulting social theory: the social cognitive theory (Bandura, 1986, 1989) was based on a triadic model of causation. In this model, behaviour, cognition, environmental factors and personal factors influence and interact with each other bidirectionally. Bandura clarifies that reciprocal causation does not imply that all factors are of equal weight.

The study aimed to increase the self-efficacy of the participants on an individual level through goal setting, verbal persuasion and modelling their behaviours on that of others. In order to enable modelling of the desired behaviour, participants were shown a video in which other spousal caregivers discussed strategies to implement exercise-related behaviour change in

their caregiving routines. Verbal persuasion was provided by telephone counselling, in which 14 phone calls, progressively decreasing in frequency, were provided over a six-month period. Participants were asked to complete written activity logs, set specific long and short-term exercise goals and monitor them. Of the 157 caregivers, 137 were present at the first follow-up and 130 were present at the second twelve-month follow-up. Reasons for withdrawal were not provided though nine participants who stopped participating in exercise activities stated that it was because they were "too busy" (Connell & Janevic, 2009, p. 176). At baseline there were no differences between the number of LTCs between groups, however there were significant differences in depression scores, with the intervention group having an overall higher depression score than the control. At the first follow-up the intervention group showed significant improvements in exercise-related behaviour change, and at both follow-ups the self-efficacy of the intervention group was significantly higher than the control group. Spousal caregivers in the intervention group showed a significant decline in depressive symptoms. Results also showed that caregivers' perceived stress was significantly reduced, although there were no significant interactions between stress and depression. The authors concluded that since self-efficacy was the only effect size remaining significant at second follow-up, the intervention was marginally successful in producing short-term behaviour change. They recommend that additional research is required to explore the interaction between self-management behaviours and the dementia caregiving experience.

3.4.5.8   Realist Explanatory Statement 7:

*** *If* adequate tangible support and interventions are not useful in bringing about health-related behaviour change *then* research and services should focus on exploring dementia caregivers' perspectives to elicit other unmet needs which may be a barrier to self-management (Janevic & Connell, 2004).

This qualitative study was conducted on 30 randomly selected female spousal caregivers from the telephone-based RCT reported earlier in Connell and Janevic (2009). Participants were interviewed to determine whether verbal support and tangible support, such as respite, were useful in encouraging exercise-related behaviour change. Participants reported the benefits of receiving verbal encouragement from others in order to promote self-management:

> Just the encouragement as far as my daughters went. You know, telling me what I should be doing or how I could be doing it…It makes you more aware of what you are doing. (Caregiver quote reproduced from Janevic & Connell, 2004, p. 76).

Tangible support was discussed based on whether the participant exercised with the person they cared for or whether they preferred exercising alone. Tangible support was provided usually by other family members and caregivers reported that the main barrier to incorporating a regular exercise routine was that tangible support options were not always viable. Some respondents reported that verbal persuasion to exercise felt like "nagging" (Janevic & Connell, 2004, p. 78) and made them feel guilty. Four themes were identified that described the different views caregivers had with regards to receiving support and encouragement for exercise-related behaviour change. The first theme 'self-reliant' described caregivers who enjoyed exercising independently, were self-motivated and

unaffected by lack of verbal or tangible support. The second theme described the 'under supported' caregivers who preferred support and stated that exercise-related behaviour change would have been easier if more support was available. The third theme encompassed the 'well-supported' caregivers who found exercising with others very motivating and beneficial to enabling behaviour change as it allowed monitoring of the change:

> [Having encouragement] helped quite a bit. To have somebody talk about it and encourage and say "have you done it, are you going to do it, when are you going to do it." That kind of stuff. (Caregiver quote reproduced from Janevic & Connell, 2004, p. 81)

The fourth and final theme described 'superfluous' support. This theme represented those who acknowledged the available support they had yet concluded that this support was not the determining factor in achieving exercise-related behaviour change goals; instead, other factors such as the caregivers' physical health and lack of time were considered more important determinants of goal achievement. Since participants of this study were limited to the participants from the RCT, the author acknowledges that they may already have different types of support available to them that may be unavailable to other caregivers in general. Janevic and Connell (2004) conclude that health-related behaviour change interventions and support strategies should ensure that unmet needs are addressed and that alongside encouraging the use of formal support, caregivers should be encouraged where possible to involve of the person with dementia into their self-management regimes.

3.4.5.9   Realist Explanatory Statement 8:

*** *If* female caregiver relational status is associated with health effects *then* the overall deterioration of health is likely to be worse in spousal caregivers than filial caregivers (Cahill & Shapiro, 1998).

This mixed-methods study aimed to explore the differences in health outcomes between spousal caregivers and adult daughter caregivers. The qualitative component consisted of in-depth interviews with 60 wives and 31 daughters. Authors acknowledge that since participants were sampled from community-based services it reflects an advantaged population and does not address those 'hidden' from formal services. Caregiver baseline characteristics involved recording the total number of their long-term health conditions and asking them to report on a four-point Likert scale, ranging from 'not at all' to 'yes enormously' whether they thought caregiving affected the management of their LTCs. Nine quality of life items such as fatigue, isolation, family relationships, social life, feelings of entrapment and loss of control were also assessed. Caregivers reported that caregiving seemed to have worsened their existing long-term conditions and given rise to new ones. A key theme which impacted caregivers' reporting of negative health effects included the "24-hour nature of dementia caregiving" (Cahill & Shapiro, 1998, p. 92).

A quantitative assessment of the difference in health effects between spousal and daughter caregivers revealed a significant difference in adverse effects for spouses as compared to daughters. However, there were fewer daughters in the sample than wives and overall the initial and final total number of LTCs found in wives were greater than in daughters. This could be due to the age-related impact of long-term conditions. Authors also acknowledge that

wives were providing significantly longer periods of care than daughters and the care-recipients of the wives had significantly higher levels of cognitive impairment compared to the care-recipients of the daughters. These are confounding factors for a quantitative study, however, the qualitative arm of this study revealed that over time wives are more likely to believe caregiving had a negative impact on their health than daughters. Cahill and Shapiro (1998) conclude that services and policy-makers should engage in detailed explorations of the lived experience of caregiving and its implications for the unmet and changing health needs of spousal caregivers, particularly when their LTCs are known to be deteriorating.

3.4.6 Summary of the findings from the systematic search

Out of nine peer-reviewed studies, six were quantitative including one RCT; two were qualitative and one was a mixed-methods approach including qualitative and descriptive quantitative measures. Ethics was poorly reported across all studies. There was an overall lack of focus on long-term conditions and specific self-management behaviours of those conditions. Health outcome measures in quantitative studies included generic outcomes such as the SF-36. Of the two qualitative studies, one explored the barriers behind 'self-care' and one exploring the perceived benefit of support strategies to enable to 'self-care'. Only one quantitative study explored the mediating effects of ethnicity on coping strategies and including only one comparator ethnicity (Hispanic female caregivers). The mixed methods study was the only one to explore differences in health outcomes from a relational perspective, however this was only for female caregivers. Four out of nine studies used only female participants, four contained a predominantly female population and one contained equal numbers of both male and female participants. More research on male caregivers and ethnic differences is required.

Regression models were used in all six of the quantitative studies, which provided indicators as to the dominant predictors of self-management, however they did not reveal specific details about the barriers and facilitators to self-management or health outcomes. Studies recommended further exploration of these factors through other methodologies as the reasons behind the causality of items relating to health behaviours of caregivers with LTCs remains to be explored. Regression analyses also do not offer explanations for participants who withdrew from interventions aimed at improving health and related behaviours during the research process; exploring these factors would offer insight into the underlying barriers behind self-management and could thus offer valuable findings for the provision of adequate and practicable support for dementia family caregivers. The more recent studies from 2010-2015 are quantitative and as observed through their findings they would further benefit from epistemologically constructivist explorations. The grand theories that were applied across the studies include Bandura's social cognitive theory, Vitaliano et al.'s coping theories, and the most commonly applied were Pearlin et al.'s Stress Process model and Lazarus and Folkman's appraisal model, which further validates the application of Sörensen and Conwell's combined conceptual framework in this research. All studies were conducted outside the UK, seven out of the nine being conducted in the USA, one in Canada and one in Australia. This reveals the gap in research for this topic based on policy and practice in the UK.

3.5 Informal discussions with third-sector service-providers

After the initial review of literature found in the previous sections a research proposal for the realist interview method was designed. Ethical approval (detailed in the next chapter) was obtained to speak to professionals and caregivers. The interview schedule and research aims were discussed with service-providers to ensure end-user relevance of the research as recommended by Pawson (2013). Service managers were consulted through email and telephone to request permission for an informal meeting in order to discuss:

- The scope and relevance of the research

- Pathway of care and assessment for caregivers with long-term conditions

- Existing support strategies for dementia caregivers with long-term conditions

- Health support needs of dementia family caregivers

- Potential for recruitment of participants for this research to include caregivers and professionals through their services

- Ethics procedures involving research with participants recruited through these organisations

One-to-one meetings were held between the researcher and three service managers from three independent third-sector dementia caregiver support organisations. The service managers were selected for these discussions as they were the first port of call when contacting the organisations and were responsible for reviewing any potential research being conducted with either staff or clients within their organisations.

3.5.1 Findings of the service-provider discussions

The discussions revealed that social services and primary care practices both locally and nationally are looking for tools and strategies with which to address the health needs of the dementia caregivers as the existing method of assessments were not targeting specific needs of caregivers with long-term health conditions. Services confirmed that the current care pathway for dementia caregivers is primarily via third-sector support services, who then refer the caregiver to GPs, Admiral nurses and social support services. The services mentioned that caregivers do not often perceive themselves in the role of a caregiver and therefore do not always discuss their own health needs. One service manager specifically mentioned that validated self-management and behaviour tools from the Outcomes Star tool are being informally promoted and used throughout organisations in the UK (Outcomes Star, 2018).

3.5.2 The Outcomes Star tool

The Outcomes Star tools are evidence-based tools designed to support and measure behaviour change in people (MacKeith, 2011). The Outcomes Star tools are now also being used internationally; tools such as the Carers Star and Well-Being Star have been implemented for use across local authorities in the UK since the Care Act 2014 made it mandatory to provide assessments for the promotion of health and well-being of individuals, particularly that of caregivers (MacKeith, 2011, Outcomes Star, 2016, 2018). The Recovery Star is depicted as a star with 10 points which measures outcomes such as mental health, self-care, work and relationships on a scale of 1-10. The five steps identified in the Outcomes Star behaviour change model closely resemble the transtheoretical model of change. The steps include 1) feeling 'stuck' in a problem 2) 'accepting help' 3) 'believing' a behaviour change is

possible and will make a difference 4) 'learning' to overcome setbacks and continue with the change 5) 'self-reliance' occurs when the behaviour change has been established and an individual is confident in sustaining it (Peterson, Ellis, Lorenz & Armbrecht, 2014; MacKeith, 2014). The self-care category of the Recovery Star is graded out of 10 based on this five-point behaviour change 'ladder'. Self-care measures refer to things such as 'a healthy way of life', 'feel better', 'feel awful', 'sense of well-being' and 'look after myself'. The service reported that these measures are subjective and vague for use in caregivers' LTC management. In this particular service, action plans are then decided with the caregiver with regards to the areas they need to develop. These action plans ask the caregiver to write down what they feel is already positive in their behaviour, what they would like to change and how they can make this change.

3.6   Conclusion of the Realist Review

The realist review reveals that there is a gap in knowledge both subject-wise and methodology-wise. The nine empirical studies show that there is a lack of research in this area from a realist, constructivist epistemological position. The earlier discussion on policy and practice also reveal that there is a need for qualitative research into the unmet self-management needs of dementia family caregivers with long-term health conditions. The review also highlights that there is a lack of research in this area in the UK, specifically from a policy-driven perspective. Current pathways and self-management measures for LTCs are not consistent with the LTC self-management guidance outlined by QOF in primary care services. This chapter provides a reusable conceptual platform and rationale for the method of Realist Interviews: a qualitative interviewing technique developed by Pawson (1996, 2013) and Pawson and Tilley (1997). The findings of all the information discussed thus far have been

synthesised using Pawson's complexity checklist described in the previous chapter: VICTORE (Table 9). Each stage has been framed as a question in the left-hand column and then answered using the existing knowledge-base in the right-hand column.

Table 9   Mapping out the complexity checklist before data collection

Volitions What choices do caregivers have to make to achieve LTC self-management?	Acknowledging their needs (service-user discussions) Balancing the needs of the person with dementia and their own needs (Furlong & Wuest, 2008) Learning to prioritise themselves (Furlong & Wuest, 2008)
Implementation What would be the chain of implementation between existing policy and practice in the care of dementia caregivers with LTCs?	Currently the NICE care pathway is not specifically designed to address the many and individual needs of the caregivers. The pathway lacks sufficient clarity for both the service-user and service-provider as evidence shows that patients can easily fall into the exception's categories of primary care LTC management and thus their needs remain unmet (Campbell et al., 2011). Third-sector services, unofficially may be the first port of call in identifying caregiver health needs, but appear to be unaware or

	unequipped with sufficient tools in order to address these issues adequately.
Contexts What situations and circumstances are dementia caregivers immersed in on a daily basis? How could these impact their self-management behaviours?	Empirical evidence thus far does not reveal too much about the lived-experience of dementia family caregivers with LTCs and it will therefore be revealed upon data collection. However, the evidence thus far does point to caregivers being immersed in extremely challenging situations both physically and emotionally. Caregivers appear susceptible to depressive symptoms which may have adverse effects for LTCs and self-management.
Time How have these issues been dealt with previously – for example how effective have self-management programmes been in the past and what are the implications of this for policy-making and practice?	Evidence shows that there appears to be an exception's category similar to that of QOF within the field of research as well. Caregivers who refuse to continue to be a part of research due to increasing responsibilities or a deterioration in the PWD, are omitted from the findings; although these are most likely the people that may offer valuable insight into the challenges of providing care for someone with dementia. Thus far both research and practice

	are unequipped with sufficient knowledge to anticipate or address these loopholes.
Outcomes What monitoring systems would be relevant to self-management in dementia family caregivers? Would changed behaviour be a result of being monitored or a result of the intervention or programme?	Janevic and Connell (2008) highlight that the being monitored/prompted (e.g. by family or friends) itself provides encouragement and motivation for behaviour change. Current LTC self-management monitoring systems are the QOF in primary care, and interventions for lifestyle factors such as diet or exercise in research. Research has not consistently targeted specific medical self-management behaviours that are monitored in practice, particularly from a policy perspective. Policy, practice and research usually do not account for the 'hidden needs' of the 'hidden patients' who may possibly require the most support.
Rivalry What is the current policy landscape within which self-management programmes are embedded, how would these override the actions of stakeholders or service-users?	Current national policy focuses on quantitative economic evaluations and research. These offer little insight into the level of complexity of the issue under study. Qualitative evaluations are needed to highlight the care needs of this seemingly vulnerable population.

Emergence How might an acceptance and improvement in self-management of LTCs change the original context of the situation? What are the chances of the outcome being no change, change or unintended change?	This will be clarified upon collecting data from a qualitative evaluation that can delve into the details of the lived-experience of the caregiver and the factors associated with decision-making for self-management.

3.7   Aims of Study 1

Explore self-management behaviours in dementia family caregivers with one or more long-term conditions.

3.8   Objectives of Study 1

Use the Realist Science of Evaluation and Realist Interview method to interview dementia family caregivers regarding their self-management behaviours as defined primarily by UK policy and practice guidelines.

CHAPTER 4: REALIST INTERVIEWS

4.1   Overview of Chapter 4

This chapter presents the methods used within this study. It begins by providing an outline of the entire approach to include considerations regarding sampling, analysis and study quality. It then provides a detailed description of the exact procedures employed within the realist interview method of data collection and analysis.

4.2   Overview of method

An overview of the procedures undertaken in this study has been provided in Table 10. Details and the rationale behind these procedures will be covered throughout this chapter.

Table 10   Overview of Method of Realist Interview

Realist Approach	Realist Interview Method of Evaluation Science (Pawson, 1996; 2013; Pawson & Tilley, 1997)
Realist interview design	Questionnaires used for conceptual structure: Short-Form-36; Long-Term-Conditions-6 Questionnaire; Quality and Outcomes Framework 2015/16
Realist Sampling	Purposive sampling strategy; main inclusion criteria: adult, primary dementia family caregiver with one or more LTCs. 12 dementia family caregivers: 7 Female (F); 6 Male (M). - Spousal: 4 (F); 4 (M) - Filial (biological): 2 (F); 1 (M) - Filial-in-law: 1 (F)
Realist Recruitment	Council funded third-sector support groups for dementia family caregivers in the Yorkshire and Humber Region.
Realist Analytic framework	Combining realist Analytic Framework (TARMATO and C-M-Os) with methods of Template Analysis.
Realist study quality	Gathering rich explanatory data; pilot interview; independent coding; member-checking in Study 2.
Ethical procedures	University of Huddersfield Research Ethics Committee Approval Ethical guidelines followed: Risk Analysis and Management (University of Huddersfield; 2015); Social Research Association ([SRA], 2003); Principles of Biomedical Ethics (Beauchamp and Childress, 1979; 2013).
Realist presentation of findings	Chapters 5 and 6 present a realist narrative showing C-M-O configurations using verbatim long and short quotes from the data

4.3 Realist interview design

In a paper titled 'theorizing the interview' Pawson (1996) is critical of the traditional structured and unstructured approaches taken to interview design, and presents a theory-driven model for realist semi-structured interviewing. He states that the researcher must adopt a "hypothesis-seeking behaviour" (Pawson, 1996, p. 306) and "channel" (Pawson, 1996, p. 306; Pawson & Tilley, 1997, p. 167) issues that are usually considered confounding biases such as the interviewees' reservations regarding the nature of questions, the influence of the interviewer and the purpose and consequences of the interview (Pawson & Tilley, 1997). According to Pawson and Tilley (1997) the task of the researcher and the craft of realist interview is to "refine theory by teasing out more details from the participants on how their reasoning was influenced" (p. 169). The purpose of a realist interview is to adapt existing theory and policy-driven questionnaires such that the mechanisms that remain hidden in quantitative inquiry due to being "smuggled in, rather implicitly across the pages of the questionnaire" (p. 305) can be gleaned through qualitative inquisition. The political and theoretical frameworks used to guide the development of the interview schedule have been described below.

4.3.1 Quality and Outcomes Framework 2014/2015

The key self-management behaviours that were being explored were those that are routinely monitored through the quality and outcomes framework by primary care in the UK to include components such as medication, appointments, symptom management, smoking and drinking.

4.3.2 Long-Term-Conditions-6 Questionnaire

The Department of Health and NHS' long-term conditions self-management policy included the Quality Innovation Productivity and Prevention (QIPP) workstream (DH, 2012b). QIPP was piloting the long-term-conditions-6 (LTC-6) questionnaire which included six items that were expected to measure whether individuals felt they were receiving personalised care through coordinated services (DH, 2012a). This was recommended to be used in diverse settings such as healthcare research, in order to improve the care of long-term conditions and ensure "maximum benefit and quality of care to patients" (DH, 2012a, p. 19). This was adapted for use in the interview schedule to explore how the dementia caregivers' long-term conditions were being addressed by existing practice and policy. This particular questionnaire was selected due to its prominence in key policy guidelines.

4.3.3 Other questionnaires and contributions to the interview schedule

Based on previous policy literature, most outcome measures used in existing research are preference-based and the SF-36 is a popular tool used in research. The SF-36 comprises eight domains to include physical functioning, role limitations as a result of physical problems, pain, health perceptions, vitality, social functioning, role limitations as a result of emotional issues, and mental health (Németh, 2006). SF-36 is considered a valid and reliable health-related outcome measure in people with LTCs (Kwan et al., 2016; Matcham, Norton, Steer, & Hotopf, 2016; Falide & Ramos, 2000) and in caregivers of people with dementia (Machnicki et al., 2009). The SF-36 and Zarit Burden Interview are the most frequently used tools to assess

dementia caregiver health (Jones et al., 2012). Therefore, the questions regarding the physical, social, financial and emotional impact of caregiving on LTCs along with domains of pain and fatigue management were extracted from these questionnaires. Background details such as age, employment, years of caring, moving due to caregiving and so on, were also collected.

After ethical approval was obtained, expert opinion was sought from an NHS LTC self-management coach and single-point of access professional, based in London. Communication occurred through email and telephone to receive feedback on the interview schedule. This consultation resulted in the addition of a question regarding caregiver hobbies. During the third-sector service-provider discussions sensitivity of the questions were discussed, service-providers emphasised that terms such as 'burden' should be substituted with 'impact'. Table 11 shows the interview schedule.

Table 11   Interview Schedule Study 1

Key Questions	Additional information
Physical/mental/functional – from QOF, SF-36 questionnaire	
What long term conditions do you have?	How long have you had them for?
How many medicines are you taking	Do you take them regularly, how do you monitor your health, smoking, drinking etc.
How long have you been/did you caring/care for?	Assess level of burden (impact), number of hours of care, identify if primary or secondary caregiver
Does your health prevent you from carrying out everyday tasks?	How does caring affect your ability to carry out everyday tasks?
Does being a caregiver affect you from managing your health (QOF Questions)	Taking medication, attending appointments, going to hospital, individual condition-specific QOF questions
How (if ever) often do you experience symptoms from your health condition	What are these symptoms and how do you manage them in relation to caregiving?
How has caring affected you emotionally?	How do you deal with these emotions do they prevent you from taking care of your own health
How has caring affected bodily pain if at all	How much pain? Where? Why? How is it managed? How does it affect your life?
How has caring affected your level of tiredness/fatigue if at all	What effect does this have on your everyday life?
How does your health affect your social/financial life?	How does being a caregiver affect this?
Organisational/health care delivery aspects from LTC-6 questionnaire	
In the last 12 months did you discuss what was most important for managing your own health and the patients' health?	
How would you describe the amount of information you received to manage your and the PWD's health?	
Have you had enough help from your health and social care team to help you manage your health	
Do you think the support and care you receive is joined up and working for you?	
How confident are you that you can manage your own health	
Open-ended narrative	
How would you describe your life and health after becoming a caregiver for someone with dementia	

4.4   Sampling & recruitment

Wray, Markovic & Manderson (2007) state that "each life is unique, no data are ever truly saturated" (p. 1400), and Sandelowski (1995) states that the main goal of qualitative research is to ensure that "a new and richly textured understanding of experience" (p. 183) can be achieved with a small and manageable sample size. Realist inquiry does not confirm or reject hypotheses through data saturation via sample size; instead findings are assessed according to their relevance and rigour to theory and model-building (Emmel, 2013, 2014; Manzano, 2016; Pawson, 2013). This process is based on the researchers use of organised scepticism in abstraction and adjudication of the findings using a trust-doubt ratio that relies on existing theoretical knowledge (including a reusable conceptual platform) and familiarity with the data (Pawson, 2013). Manzano (2016) acknowledges that this may pose a problem for researchers who require sample estimates for research/ethics proposals and therefore estimates can be based on various different criteria such as relevant research and research methodologies. Manzano (2016) and Weiss (1998) emphasise that for realist evaluations sampling should be conducted with a view to maximise variation amongst the participants.

The aim of a realist interview is to obtain in-depth explanatory "fragments" (Emmel, 2013, p. 141) or "nuggets" (Pawson, 2006a, p. 127) of evidence for the formulation of explanatory C-M-O configurations (Pawson & Tilley, 1997; Manzano, 2016). Therefore, guidance for an initial estimate of 10-12 participants was taken from multiple sources, such as an in-depth qualitative study conducted by Taemeeyapradit, Udomittipong & Assanankornchai (2014). The latter study involved interviewing nine dementia family caregivers in order to construct a new caregiving burden scale which was subsequently validated through exploratory factor analysis. Guidance was also sought from literature using related methods of data collection,

sampling and analysis. Polkinghorne (1989) suggests that in exploratory phenomenological studies anywhere between 5-25 participants are sufficient to generate data subject to subsequent thematic analysis. Braun and Clarke (2013) state that, with their experience on thematic analysis, 6-10 participants are deemed suitable for small projects in terms of the generation of patterns within themes. Guest, Bunce and Johnson (2006) examined 60 studies using thematic analysis and concluded that for most research using thematic analysis to gain insight into the shared lived-experiences of a group of individuals, patterns within the data can be detected usually within 12 interviews, though this may be influenced by the heterogeneity of the participants. From a practice perspective, the size of support groups in the three recruiting organisations typically ranged from 10-15 participants, thus making this a pragmatically representative sample of what can be achieved in practice. Thus, a sample of 12 participants was obtained. Table 12 contains the selection criteria:

Table 12   Selection Criteria for Caregiver Interviews

Inclusion	Additional information
Age = 18+,	Adults
Gender: men and women	Married spouses; biological children; son/daughter-in-law married to biological child of PWD
Region: UK	Yorkshire and Humber Council funded third-sector services
Have any and/or multiple long-term health condition(s)	Caregivers had to verbally report that they had been diagnosed (one or more) long-term conditions by a medical professional. List of conditions as outlined by the quality and outcomes framework is provided through the information sheets.
Currently caring for a family member with dementia	Patient being cared for by the caregiver must have definite diagnosis of dementia as reported by the caregiver. Caregiver must self-report being primary caregiver of PWD.
Capacity to consent	Participants will be assumed to have capacity to consent if they can read and understand the participant information sheets and give informed consent for the interview.

The sampling strategy included delivering participant information sheets (Appendices 4-5) and flyers (Appendix 6) to the third-sector recruiting organisations who then passed this information on to the caregivers at the support groups. The recruiting bodies also invited the researcher to attend some support groups in order to personally introduce the research and provide the relevant information. Seven participants were recruited by the researcher visiting the support groups, the remaining participants were recruited directly by the services and their contact details were provided to the researcher. Interviews were carried out in the participants' home while someone was taking care of the PWD. Interviews normally lasted between 1-2 hours. Interviews were transcribed verbatim by the researcher.

4.5   Ethics procedures

Prior to the commencement of the study ethical approval was gained from the University of Huddersfield's 'School Research Ethics Panel' (SREP). A template of the components within this form can be found in Appendices 7-9.

Measures were taken to ensure that the researcher was safe when visiting the participants at their house. The researcher provided a mobile phone number and expected interview beginning and end times to the main supervisor and a family member or friend; they were informed of the completion of each interview after the researcher left the participant's house.

Five key issues as outlined in the guidelines by the Social Research Association ([SRA], 2003) were addressed:

1) Informed consent

Written informed consent was obtained from all research participants. Informed consent was obtained in a number of ways: participants were verbally briefed during the recruiting process and prior to the commencement of the interview. They were also provided with the participant information sheets and asked to sign the written consent form provided by SREP (Appendix 10). The NHS Constitution, delivered on behalf of the Department of Health, state that in accordance with the Equality Act of 2010, effort should be made to present people with an equal opportunity to participate in approved research (DH, 2015c). Published guidelines on mental capacity and consent including The Adults with Incapacity Act 2000, Medicines for Human Use Regulations 2004 and Mental Capacity Act 2005 clearly specify that any participant should be helped as much as possible in making the decision to be a part of research (HRA, 2018b). The Mental Capacity Act also clearly states in its first principal that "a person must be assumed to have capacity unless it is established that he lacks capacity" (Department for Constitutional Affairs [DCA], 2007). Clinical tools to assess participants' mental capacity to give consent for treatment are available however were not required for this research as they are designed for clinical trials where consent to pharmacological therapies is required. Although the research was non-invasive, under the Health Research Authority (HRA) it cannot be deemed non-intrusive as it is interview based and therefore requires consent (HRA, 2018a; NHS England, 2016c; NRES, 2011).

There are two stages in the Mental Capacity Act 2005 that help determine whether an individual lacks capacity. Stage 1 requires proof of an impairment to the mind or brain which may include: "dementia, significant learning disabilities, long-term effects of brain damage, physical or mental conditions that cause confusion, drowsiness or loss of consciousness, delirium, concussion, symptoms of alcohol drug use" (DCA, 2007, p. 44). Stage 2 emphasises that these impairments may not necessarily affect the individual's ability to make decisions and therefore if they can understand, retain and use the verbal or written information provided to them regarding the decision to participate in research, and then express their choice through clear communication then they are considered mentally capable of making their own decision and giving consent. In the case of a participant lacking capacity the MRC and the Research Ethics Committee (RES) of the HRA recommend that a participant information sheet should be provided to a consultee (family/friend/professional) who can assist the participant in understanding the information and enable them to make an informed decision about participating in the research (HRA, 2018a). These were made available to the participants via the recruiting bodies but were not used as all participants read and understood the information sheets and gave verbal and written consent. The participant information sheets were designed used the templates provided by the University of Huddersfield and in accordance with the MRC and RES guidelines (HRA, 2018a). The guidance regarding consent, capacity and information sheets for this research came from the RES 2011 (formerly known as the National Research Ethics Committee [NRES]) and HRA 2015, however, their websites have been updated since and the references reflect the links and access to the updated sources.

2) Data protection

During data collection electronic audio and paper copies of all data were stored in a locked cabinet in a private office on the premises of the University of Huddersfield and on the researcher's private, password-protected computer. The participants and organisations were informed that interviews would be recorded and verbatim quotes would be used in the thesis and any disseminated findings in papers or conferences. Participants were informed that the data will be archived securely at the University of Huddersfield and eventually destroyed in accordance with University policy.

3) Confidentiality

Participant confidentiality was fully respected. Anything spoken/delivered outside of the interview/data collection setting time and space was not used towards the research. However, participants were informed that if sensitive information was revealed and anything was identified in the interviews that would indicate harm to the participant or the PWD, then the recruiting services would have to be informed. Participants were informed that findings from the interview would be disseminated under pseudonyms for the caregiver and all those mentioned in the interview by the caregiver. Participants were informed that information regarding ethnicity, age, gender and family structure would contribute to the research, although the services and specific location would remain anonymous. The information sheet asked participants to provide a contact detail such as a phone number or email address to their organisation that could be passed on to the researcher. Participants were also given the choice to ask the recruiting services to arrange a meeting with the researcher if they were not comfortable providing contact details.

4) Anonymity

Participants' names and the names of all those mentioned by the participant have been kept anonymous through the use of pseudonyms.

5) Right to withdraw

It was made clear to participants, both verbally and in writing, that they can suspend or stop the interview or withdraw from the study prior to the commencement of data analysis.

Along with autonomy the remaining three ethical principles of justice, beneficence and non-maleficence as developed by the philosophers Beauchamp and Childress (1979, 2013) were also considered throughout the research in the following context:

6) Justice: All participants were treated equally and considered fairly in accordance with the selection criteria and the Equality Act 2010 as previously mentioned.

7) Beneficence: This research intended to benefit the health and health-related quality of life of dementia family caregivers by hoping to inform clinical practitioners, policy-makers and researchers. In doing so, it would also be of benefit to global healthcare systems and healthcare economy.

8) Non-maleficence: Although the focus of the study was the caregivers' self-management behaviours in relation to their long-term conditions, it was highlighted by the recruiting organisations that discussions about caregiving can become emotionally upsetting; participants were informed of support services available to them should they decide to seek additional support after the interview. Participants also retained full rights, in such a case, to

suspend or stop the interview or withdraw from the study, though this situation did not arise. Effort was made by the researcher to end the interviews on a positive note.

Participants were also informed that should they reveal sensitive information that may endanger their life or health or that of their family member with dementia then in the first instance the recruiting services will have to be informed. Three out of the twelve participants made references to previous suicidal thoughts or attempts. The researcher first asked whether the participant would like to stop the interview, however all participants stated that these were issues of the past and that they would like to continue. For the remainder of the interviews the participants did not seem distressed or affected by this; the researcher then informed the main supervisor and the services through which the participants were recruited straight after the interviews. The services stated that they were aware of two cases where actual suicide attempts had been made, but that these were very long ago. All these participants had regular weekly contact with the services, nonetheless the services made a note in the participants' files and contacted them immediately through telephone explaining that the main purpose of the call was to gain feedback on the researcher and the interview, so as not to unnecessarily concern the participants. The services informed the researcher of the safety and well-being of the participants thereafter. Table 13 below shows what the participants said with regards to suicide. Karen's suicide attempt scenario was not in relation to her current caregiving situation with her husband; it was in relation to her previous caregiving experience with her father (with dementia) over two decades ago.

Table 13   References to suicide in three caregiver interviews

Karen (Spousal Caregiver)	I did have a breakdown years ago when my dad was alive and like the doctor said "it's like a pack of playing cards and eventually it just goes like that [hand gesture cards falling]" and it did. I'll be quite candid I did try and commit suicide because of that – and now I think "well how stupid!". I'm glad I didn't make a very good job of it (laughs) – otherwise I would have missed my lovely great-grandchildren!
Robert (Spousal Caregiver)	I couldn't afford it [expenses of caregiving and external caregiving support]. No – age 63, £30 000 to go for a loan, you'd be talking 20 years to pay it back with interest – so if Council hadn't have done it we'd still have to struggle through that door – so I couldn't have coped 7 days a week in here – you know what I mean? I'd be hanging through a raft! But like I said people [who do not accept external support for caregiving] are silly – like I say they've [Council] been great to me!
Daniel (Filial Caregiver)	I did fleetingly think about it [suicide] – not plan it but I was just "oh I can't do it anymore"– but then you think "if I'm not here who's going to look after mum!" – so you just carry on and then it [suicidal thought] just goes away!

4.6   Realist analytic framework

The analytic framework included the generation of C-M-O configurations from the data using the principles and tools contained within realist evaluation as described by Pawson (2013) and detailed in Chapter 2. As Manzano (2016) notes, the methods of realist analysis are not a definitive or separate stage of research involving "trudging out a few themes constructed from multiple subthemes and labelling them as contexts, mechanisms and outcomes" (p. 18). Realist analysis is an iterative process and realist data construction must continue alongside the presentation of quotes (Manzano, 2016; Pawson & Tilley, 1997). Pawson and Tilley (1997) state that analysis should be "organised around the development of CMO propositions" (p.

182). Pawson (2013) and Pawson and Tilley (1997), generally uses thematic analysis to organise the data into such compositions, although they do not specify a specific structured approach in doing so.

Template Analysis belongs to the family of thematic analysis. It is a specific and structured form of thematic analysis particularly useful for theory-driven research using semi-structured and in-depth interviews (Brooks et al., 2015). Braun and Clarke (2006), King (2004, 2012), King and Brooks (2017) and Thorne (2000) state that thematic analysis is not just a means to an end as argued by some authors such as Holloway and Todres (2003) or Ryan and Bernard (2000), rather it follows a robust six-step process that lends itself to a distinct method in its own right. King (2012) described Template Analysis as a technique that fits into a wide array of philosophical positions, including realism. King and Brooks (2017) outline a six-step approach to coding, clustering and arranging the themes in a hierarchical pattern in the design of a template. A brief description of the terms used in thematic analysis is as follows: a code is a label attached to themes; themes imply repetition of an account across multiple participants; a-priori themes are those that have been pre-identified by the researcher in theory-driven research; clustering refers to the grouping of emerging themes and a-priori themes into meaningful categories that are ordered in a hierarchical fashion of broad to narrow. The six-steps of Template Analysis have been explained with reference to this research in Table 14:

Table 14   Six stages of Template Analysis (King, 2012; King & Brooks, 2017)

6 Stages of Template Analysis	Actions taken:
1) Familiarisation with data	• Researcher conducted all interviews one to one • Listened to recordings and transcribed interviews verbatim (usually same day as interview) • Read through transcripts once more after transcription and before coding
2) Preliminary coding	• Code interview data to identify all ideas that may populate a-priori themes (existing themes) • Code interview data to identify all areas relevant to research question (emerging themes)
3) Clustering	• Emerging and existing a priori themes are clustered into groups and hierarchies of broader → narrower themes.
4) Producing initial template	• Develop and organise clusters and themes into an 'initial template'
5) Developing template	• Apply this initial template to further subset of data and edit as required
6) Final template	• Design final template in accordance with how the data will be analysed and presented in the findings

4.6.1 Template development

The general a-priori themes included medications, appointments, pain, fatigue, physical, social, emotional, financial impact of caregiving and service and system issues from the LTC-6 questionnaire. Table 15 shows how the interviews were used in order to develop the initial template for the first twelve caregiver interviews.

Table 15 Design of a basic template

Interviews	Stage of template development
Spouse (Karen, Vanessa, Maria, Emily)	Initial template designed (Karen)
Spouse (Andrew, James, Robert, Ethan)	↓
Filial (Anna, Janice)	Template developed
Filial interview (Daniel)	↓
Filial (Daughter-in-law heron referred to as filial (in-law) caregiver) (Maya)	Completed draft of template for further realist analysis & presentation

In order to keep the focus of the analysis on 'the influence of dementia caregiving on self-management behaviours', interviews were initially reviewed for all aspects relating directly to self-management as understood by the researcher. These were based mainly on the a-priori constructs of medical management. Key quotes from each interview were copied and pasted onto a separate document. A small note and code were placed alongside the quotes to remind the researcher which cluster they belonged to and their relevance to the overall research question. Each interview was reviewed and coded a second time to identify other factors and emerging themes that related to self-management. This included those factors that did not directly emerge from aspects of medical management and those that contributed to the overall stress process but didn't appear to directly impact self-management. Table 16 shows how the initial template was developed using Karen's interview. Here, the conceptual framework was particularly useful in drawing inferences between mechanisms and outcomes.

Table 16   Development of template using Karen's interview

	Cluster/broad theme	Key themes/ sub themes	Description
Barriers to self-management and self-care of LTCs	Integrative theme	Dismissiveness, focus on care-recipient	Overall attitude to health and self-needs

	Medical management	• Reporting long-term conditions
		• Appointments
		• Lack of knowledge/doesn't ask or acknowledge
		• Symptoms
		  - Pain
		  - Fatigue
		• Perceptions/understanding of self-management
			Barriers were encountered in these areas with regards to approaching, considering and carrying out self-management behaviours related specifically to key aspects of medical management.

	Issues with support	• Support for care recipient
		  - Previous/others experience
		  - Coping mechanisms
		    ▪ Strength of relationship
		    ▪ Inner strength/perceived competence
		  - System issues
		• Support for caregiver
			There were barriers to support for both the care recipient and caregiver. as mentioned by caregivers support for the care-recipient also provided a means of respite and support for the caregiver. key barriers to care-recipient support were positive coping mechanisms. Although these mechanisms helped caregivers cope with the caring process, they proved a barrier to accessing/accepting support.

	Impact of dementia caregiving	• Lack of focus on self - Focus of interview on care-recipient needs • Impact on time – demands of dementia caregiving • Impact on memory • Impact on emotions	Time-management was a key issue with dementia caregiving. Karen's husband in particular was physically dependent on her as he was wheel-chair bound. This had implications for her ability to find and make time for herself. Her emotional health also influenced her motivation and ability to care for herself. Karen mentioned that due to the pressures of dementia caregiving she often forgot things.
	Other/secondary stressors	• Previous caregiving experiences • Emotions experienced • Health worries	Karen had significant experiences of caregiving, although it provided her strength and experience, she mentioned it had also taken a toll on her overall health. As a result of caregiving Karen reported feeling worried about developing other health conditions, particularly dementia.
Facilitators	Council support	• Group activities • Self-management support	Creative group activities were identified by the care-recipient as essential to maintaining health and well-being.
	Self-care behaviours		Positive self-care behaviours as a result of being a responsible caregiver were apparent
	Suggestions		Suggestions were made on how services could be improved to help caregivers

After Karen's interview, Vanessa's interview was added to the template. Appendix 11 shows the additional modifications that were made. Additional changes were made to the template after Maria's interview was coded onto this template (Appendix 12). After Maria's interview no major changes were made to the key themes of the overall template. Emily, Andrew, Robert, James and Daniel's transcripts added to the existing themes (Appendix 13). Once all interviews had been mapped onto the template some themes and subthemes were reorganised and reworded in order to improve the coherence and accuracy of the template (Figure 10). Realist organising principles were applied to this template in order to construct a final template in the form of context, mechanisms and outcomes. This final template has been divided into two separate templates Final Template 1 and Final Template 2 (Figure 11), these can also be found at the beginning of Chapter 5 and Chapter 6 respectively where the discussion of their themes will take place. It is evident from Figure 11 that many themes appear several times in both templates, this is because these were the demi-regularities that were found within the data-set. For example, BPSD was a mechanism that influenced multiple self-management outcomes therefore it appears multiple times. In realist terms repeated themes are demi-regularities which show the embedded nature of C-M-Os within each other (Pawson, 2013); in terms of Template Analysis "themes which permeate several thematic clusters" (King and Brooks, 2017, p. 35) are referred to as integrative themes.

Figure 10   Applying realist principles to template to generate C-M-O

This can be both mechanism and outcome mention separately as theme 'other C-M-O'

These are specific behavioural outcomes – should be moved to outcomes theme, link with the causal mechanisms mentioned below.

These BPSD quotes are not direct barriers to specific self-management behaviours; instead they highlight the causal mechanisms that give rise to them and create multiple losses in the caregiver's life → move to mechanisms and separate into different types of BPSD related loss.

BARRIERS TO SELF-MANAGEMENT

1. Medical self-management & self-care
Barriers directly related to LTC/physical health
1.1 Reporting long-term conditions & general health
1.2 Appointments
1.3 Medication
1.4 Symptoms
   1.4.1 Reporting symptoms
   1.4.2 Pain
   1.4.3 Fatigue
1.5 Lack of knowledge/doesn't ask or acknowledge
1.6 Understanding/perception of self-management
1.7 Risky health/care behaviours
   1.7.1 Sleep
   1.7.2 Exercise
   1.7.3 Weight
   1.7.4 Smoking
1.8 Lack of support/validation from care recipient

2. Lack of focus on self & own needs
2.1 Focus of interview / conversation
2.2 Demands of dementia caregiving
   2.2.1 Hours of care
   2.2.2 Impact on routine
      2.2.2.1 Doubled work/role conflicts
      2.2.2.2 BPSD and daily unpredictability

3. Emotional Stress
3.1 Lack of motivation/energy to care for self
3.2 Loss of a person/relationship
   3.2.1 Loss of intimacy/companionship
3.3 Resentment/unfairness
3.4 Hopelessness

4. Financial Stress

5. Barriers to support/system issues
5.1 Barriers to support for care recipient
   5.1.1 Support not sensitive to nature of dementia
   5.1.2 Negative experience of respite
      5.1.2.1 High cost/poor quality care
   5.1.3 Hassles/delay accessing respite/caregiving support
   5.1.4 Fragmentation of services; information/communication issues
   5.1.5 Guilt
   5.1.6 Strength of relationship/uplifts of caregiving as barriers to accepting support
   5.1.7 Perceived lack of choice

5.2 Issues with caregiver support & self-management
   5.2.1 Hassles/delays/lack of time
   5.2.2. Lack of carer-led/ individualised needs assessment
   5.2.3 Lack of recognition and routine monitoring
   5.2.4 Fear of being watched

6. Other stressors
6.1 Health worries

FACILITATORS TO SELF-MANAGEMENT

7. Different ways of approaching/accessing medical management/care

8. Overcoming negative health/self-management behaviours
8.1 Using memory aids and if-then strategies
8.2 Prompts & support from family
8.3 Other coping strategies

9. Positive health care behaviours
9.1 Exercise
9.2 Smoking

10. Caregiving as incentive to improved self-management (using focus on care recipient as incentive to care for self)
10.1 Appraisal of long-term capacity to care

This is a causal mechanism not a direct barrier

This along with other aspects of caregiver burden can be merged with the causal mechanisms instead.

Realist Analytic Principles

Adjudicating and Abstraction: the demands of caregiving provide the main causal mechanism that related to the specific self-management behaviours - links should be made through quotes to show mechanism-outcome relationships. Rival hypotheses are present such as health beliefs – in some cases these can be linked to the caregiving role.
Themes such as lack of focus on self can be mechanism or outcome – related or unrelated to caregiving however through majority of data using trust-doubt ratio links between caregiving and this theme can be made.

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Figure 11   Final Template 1 and 2

Final Template Part 1   Context and Causal Mechanisms

PRIMARY CONTEXT: CONTEXTUAL CONDITIONING OF DEMENTIA CAREGIVING

THE 24-HOUR ROLE
  Perceived greatest contributor to burden

KEY MECHANISMS

CAUSAL POTENTIAL OF BPSD & RELATED DEPENDENCE	CAUSAL POTENTIAL OF BARRIERS TO EXTERNAL SUPPORT
Demands of dementia caregiving: Extra work (mental & physical)	**Barriers to support for PWD**
■ Disruption/lack of routine	■ Perceived adequacy of available support for PWD by caregiver
o Switching to the past	o Support not sensitive to nature of dementia
o Difficult/attention-seeking behaviour	o Denial/lack of acknowledgment of dementia by PWD
■ Difficulty accomplishing tasks	o High cost – poor quality care
o Lack of acknowledgement of dementia by PWD	■ BPSD, worry and stress
o Difficult/attention-seeking behaviour	■ Guilt
■ High levels of dependency of PWD	■ Marital bond & religious coping
o Merging identities	■ Finding meaning
	■ Financial benefits
Prioritising PWD	
■ Due to unpredictability, risk and danger	**Barriers to support for caregiver's health needs**
■ Due to emotional attachment	■ Lack of caregiver-led needs assessment as perceived by caregiver
o Difficult/ manipulative behaviour	■ Lack of routine monitoring as perceived by caregiver
	■ Fear of being watched
Prioritising Self	■ Lack of recognition of own caregiving role
■ Due to unpredictability, risk & danger	
■ Emotional Detachment & role captivity	

Final Template Part 2 Self-management OUTCOMES and other C-M-Os

OUTCOMES: BARRIERS TO SELF-MANAGEMENT BEHAVIOURS

MEDICATION	APPOINTMENTS	SLEEP, REST & SYMPTOM MANAGEMENT	SMOKING	DRINKING
BPSD	**BPSD**	**BPSD**	**Role captivity**	**Respite use**
→ Disruption of routine	→ Unpredictability & difficult behaviour	→ Wandering and escaping	→ Loss of motivation	→ Loss of meaning
		→ Reality perceptions		
→ Fear of escaping		→ Unaware and lack of understanding		
	→ Loss of own identity & motivation			
→ Double (extra) work		**PRIORITISING NEEDS OF PWD (due to dependency)**		
→ Prioritising PWD	**PRIORITISING NEEDS OF PWD (dependency)**	→ Ignoring/undermining own needs	**SEXUAL BEHAVIOURS**	
		→ Worries & lack of sleep	→ Loss of a relationship and emotional detachment	
LACK OF CO-RESIDENCE				

PRIORITISING NEEDS OF PWD & Other mechanisms & outcomes

→ Lack of focus on self
  o Lack of reporting LTCs/ probing caregiver to reveal LTCs
  o Unable to talk about self
  o Lack of self-management support seeking behaviours
→ Beliefs and Perceived significance/consequence of a lack of self-management
  o Medical-related behaviours
  o Symptoms – attributing symptoms to old age
  o Exercise – self-perceptions of 'good' self-management

OUTCOMES: FACILITATORS TO SELF-MANAGEMENT BEHAVIOURS

→ Prioritising person with dementia
→ Deterioration in health
→ Fear of dementia
→ Prompts and support from family
  o Prioritising PWD
→ Use of memory aids
→ Goal-oriented strategies/behaviours

4.7   Realist study quality

Pawson and Tilley (1997) recommend the use of a pilot interview to ensure quality in the interview techniques. King and Brooks (2017) recommend independent coding to improve the reliability of the overall analysis. Overall preliminary and independent coding was conducted on five of the twelve transcripts. Besides the main researcher (Researcher 1, Table 17), independent coding was carried out by three members of the supervision team (Researchers 2-4, Table 17). Table 17 has been provided in order to help explain how a researcher's background can influence the interpretation of results in qualitative data analysis.

Table 17   Researchers involved in coding

Researcher	Role/ (background)	Expertise/ influence on analysis	Focus of preliminary coding & other comments
Researcher 1 (Author of thesis)	Researcher/ Interviewer (healthcare, clinical/medical)	Biomedical model of care, long-term conditions management, patient adherence/compliance issues	Beliefs and attitudes to self-management, implications for primary care practice
Researcher 2 (Supervisor)	Researcher (applied public health research; psychology)	Chronic pain, long-term conditions; self-management, semi-structure interviews, Template Analysis	Understanding aspects novel to dementia caregiver self-management and implications for practice
Researcher 3 (Supervisor)	Researcher (research methodology; psychology; health)	Template Analysis, hermeneutic phenomenological analysis, health psychology, primary care	Interpretations of verbal and non-verbal language to understand participants hidden meanings and perceptions of self-management
Researcher 4 (Supervisor)	GP, researcher	Long-term conditions, self-management, primary care and public health concerns	Probe for underlying mechanisms to highlight further issues that explain the influence of dementia caregiving

Figure 12 shows how the different perspectives added to the preliminary coding of the pilot interview:

Figure 12   Preliminary coding of pilot interview by researchers

Barriers to self-management

How confident are you about your health currently? About managing your health on your own – 'self-management'?

Lines 3-8 Well I felt fine until I had me check-up you know I felt fine until I went to that (laughs) then sort of put kibosh on it. But I feel fine but I'd say apart from feeling a bit tired. But I'm sleeping okay at night.
And I still take me two kiwi fruits (laughs) before I go to bed and its working (laughs).

Beliefs about what is important for self-management: sleep, diet – but *laughs* therefore dismissive attitude to self-care.

Doesn't want to admit how bad it is: denial / dismissive of medical management; *repeats* 'feel fine' as if to reassure self.

How often do you experience symptoms from your health conditions symptoms that bother you?

Line 106 No, I don't really – no I don't. (very quick and abrupt response)

Lines 170-175 The only pain I feel is when I have to keep shoving up the slope going home – I've got a bruise on my arm here and I don't know how I've done it … I don't know whether I've done it pushing him up – yeah. I do gets aches and pain well its only to be expected cos I've got a metal plate in my ankle and sometimes that's the pain I get oh and then I take my arthritis pills – I've got them yeah, I do.

Says no to any symptoms dismissively, then later talks about impact of these symptoms. (Defensive? Protecting competence to care?)

Just remembered she has arthritis - even though specifically asked about it, a few times before – dismissive towards LTCs.

EXTRACTS FROM KAREN'S TRANSCRIPT

Researcher 1 had clinical experience with patients who were susceptible to poor self-management of long-term conditions as a result of underlying limiting beliefs and psychological issues. Researcher 1 was aware of the impact that poor adherence and compliance to medical advice had for secondary care and emergency services and the subsequent quality of life for the patient. Researcher 1 thus focused on highlighting limiting health beliefs and dismissive attitudes to self-management as strong indicators of poor management of long-term health conditions.

Researchers 2 and 3 were experienced with caregiver research, self-management research and the research methodology employed in the study. Researcher 3 had particular expertise in hermeneutic phenomenological research methods and the interpretations were focused on choice of language and other non-verbal cues to demonstrate the dismissiveness in attitudes to health. Researcher 2 was experienced in applied research and was focused on deriving the aspects of dementia caregiving that influenced this dismissiveness and its potential implications towards the management of the caregiver's health condition.

Researcher 4 highlighted other issues that may result from the dismissive attitude to health. Reflecting on his experience of patients in general practice he suggested that perhaps the interview questions should probe further to investigate underlying issues behind acknowledging long-term conditions and self-management as caregivers often did not consider poor self-management behaviours a major concern to their health. Researcher 4 acknowledged that the data gathered through the in-depth interviewing techniques employed in this research would most likely highlight these issues, however, in keeping with realist methods a few direct and probing questions would help focus the interview and help in "teasing out more details" (Pawson & Tilley, 1997, p. 169), for example:

"Have you ever declined a test or some treatment because you were worried about who would look after your spouse?" (sample probing question by Researcher 4).

Quality-checks on preliminary coding and template development

It was after the pilot interview that the researcher along with members of the research team agreed that elements of discourse analysis such as non-verbal cues, pauses, laughter, crying and so on so forth, should be included as they provide insight into the caregivers emotional and mental state. After Karen's interview, further interviews were carried out and four other transcripts were independently coded by the researchers. A meeting was arranged to discuss the preliminary codes and emerging themes with the researchers. Prior to the meeting it was recommended that Researcher 1 should draft an initial template using three or four interviews in order to highlight any issues with the analysis procedure. It was recommended that the interviews selected for this initial draft should be diverse in order to cover as many themes as possible.

Figure 10 shows the first attempt at the development of an initial template by Researcher 1. This was made using the first three interviews which included a female spousal caregiver, male spousal caregiver and female filial caregiver. The template was annotated by the other three researchers prior to the meeting.

It was noted that dismissiveness and a lack of focus on the self was prevalent throughout the interviews despite the measures taken to keep the questions focused on the caregiver. These were highlighted as potential integrative and emerging themes. It was also discussed that BPSD appeared to have a key role in determining the caregiver's ability to focus on themselves and carry-out self-management tasks for their long-term health conditions.

Researcher 2 emphasised that due to the richness of the data and deviating focus of the caregivers throughout the interviews, the focus of the analysis must be consistently reflected

upon in order to understand how dementia caregiving influences the caregiver's beliefs and attitudes towards self-management and their long-term conditions. It was advised that in writing up the findings constant links must be made to other themes and aspects of the interviews in order to provide a coherent account of the overall influence that dementia caregiving has on the caregiver's health and health management. The pilot interview, subsequent independent coding on various other transcripts and supervisory discussions were the key measures of ensuring quality in data collection and analysis.

Figure 13   First attempt at template development in early stages of coding
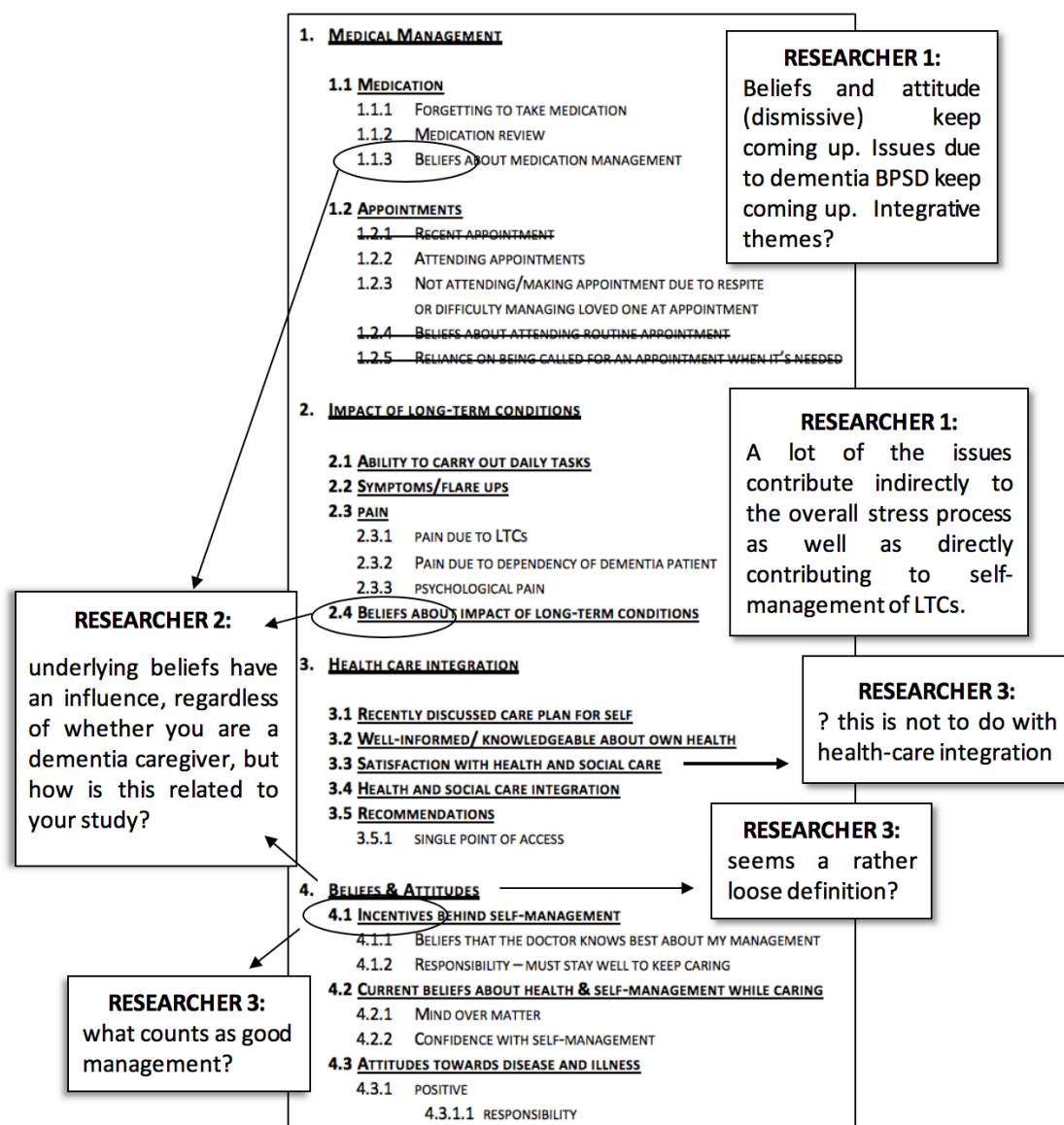
CHAPTER 5: PRESENTATION OF FINDINGS (CONTEXT AND MECHANISMS)

5.1 Overview of Chapter 5:

The findings have been presented thematically based on their division into contexts, mechanisms and outcomes. This chapter contains Final Template Part 1 as seen in the previous chapter (Figure 11). The themes (demi-regularities) working within the context of dementia caregiving have been presented in this chapter; the self-management outcomes resulting from these mechanisms will be follow in Chapter 6 (Final Template Part 2). Table 18 details the characteristics of the caregivers, further relevant details will be presented case-wise while discussing the themes.

Table 18   Caregiver characteristics

Caregiver Pseudonym	Caregiving Relationship & Gender & Age (years)	Ethnicity	Total number of LTCs	Type of Dementia of PWD & years caregiving
Karen	Spousal female 69	Caucasian	3	Alzheimer's 5
Emily	Spousal Female 73	Caucasian	3	Alzheimer's 3
Vanessa	Spousal Female 78	Caucasian	7	Alzheimer's 4
Maria	Spousal Female 77	Caucasian	4	Alzheimer's 2
Andrew	Spousal Male 69	Caucasian	3	Alzheimer's 13
Ethan	Spousal Male 79	Caucasian	3	Alzheimer's 7
James	Spousal Male 73	Caucasian	3	Alzheimer's 8
Robert	Spousal Male 63	Caucasian	2	Alzheimer's 4
Anna	Filial Female 64	Caucasian	3	Alzheimer's 10
Janice	Filial Female 52	Caucasian	2	Alzheimer's 4
Daniel	Filial Male 67	Caucasian	3	Alzheimer's 4
Maya	Filial (in-law) Female 59	South Asian	2	Alzheimer's 4

As all interviews were transcribed verbatim, the grammar and vocabulary of the quotes presented here are in their unedited form. Table 19 has been provided to aid the understanding of a reader unfamiliar with the nuances and vernacular of the participants' regional dialects. The Latin expression '[sic]' has been used within quotations to indicate where grammatical errors have been retained intentionally as they represent the verbatim speech of the participants.

Table 19   Words used by participants

Word/expression	Meaning
Cos	Because
Nowt	Nothing
Owt	Anything
What have ya	Things like that
Ye/ya	You

Realist construction of data involves looking at fragments of text beyond their demi-regularities and patterns, an act Pawson refers to as "digging for nuggets" of evidence (Pawson, 2006a, p. 127; Pawson, 2006b, p. 90) which may be placed within wider C-M-O configurations (Manzano, 2016, Pawson, 2013, Pawson & Tilley, 1997). As most quotations are long, important and powerful sentences that contain the crux of the message have been underlined in places, to help the reader focus on these 'nuggets' as well as demonstrating the key significance of the quotation for the researcher. Focal elements of dementia caregiver burden such as the physical, emotional, social and financial strains and stressors have also been underlined to reveal how burden manifests under BPSD. These issues will weave together the embedded mechanisms that influence self-management behaviours as seen in the next chapter. As recommended by Pawson (2013) and Pawson and Tilley (1997), C-M-O tables are used to help construct the realist data to show the relationship, i.e. the contextual conditioning, causal potential and embeddedness of these mechanisms and outcomes within each other.

Final Template Part 1   Context and Causal Mechanisms

PRIMARY CONTEXT: CONTEXTUAL CONDITIONING OF DEMENTIA CAREGIVING	
THE 24-HOUR ROLE Perceived greatest contributor to burden	
KEY MECHANISMS	
CAUSAL POTENTIAL OF BPSD & RELATED DEPENDENCE	**CAUSAL POTENTIAL OF BARRIERS TO EXTERNAL SUPPORT**

Demands of dementia caregiving: Extra work (mental & physical)
 	
 ▪ Disruption/lack of routine
     o Switching to the past
     o Difficult/attention-seeking behaviour
 ▪ Difficulty accomplishing tasks
     o Lack of acknowledgement of dementia by PWD
     o Difficult/attention-seeking behaviour
 ▪ High levels of dependency of PWD
     o Merging identities
 	
 Prioritising PWD
 ▪ Due to unpredictability, risk and danger
 ▪ Due to emotional attachment
     o Difficult/ manipulative behaviour
 	
 Prioritising Self
 ▪ Due to unpredictability, risk & danger
 ▪ Emotional Detachment & role captivity
	Barriers to support for PWD
	
	 ▪ Perceived adequacy of available support for PWD by caregiver
	     o Support not sensitive to nature of dementia
	     o Denial/lack of acknowledgment of dementia by PWD
	     o High cost – poor quality care
	 ▪ BPSD, worry and stress
	 ▪ Guilt
	 ▪ Marital bond & religious coping
	 ▪ Finding meaning
	 ▪ Financial benefits
	
	 Barriers to support for caregiver's health needs
	
	 ▪ Lack of caregiver-led needs assessment as perceived by caregiver
	 ▪ Lack of routine monitoring as perceived by caregiver
	 ▪ Fear of being watched
	 ▪ Lack of recognition of own caregiving role

5.2   Contextual conditioning of dementia caregiving

This study began with the overarching context that caregiving for dementia results in worse health, wellbeing and mortality outcomes for the family caregiver than most other forms of caregiving. It was mentioned in Chapter 2 that it is the "contextual conditioning of causal mechanisms which turns (or fails to turn) a causal potential into a causal outcome" (Pawson & Tilley, 1997, p.69). The next section highlights that the wider context of dementia is such that it 'conditions' the caregiver to find themselves in an all-consuming new role. The multiple mechanisms that give rise (or fail to give rise) to this contextual condition will be discussed in the remainder of the themes within this chapter. Table 20 shows the overarching C-M-O configuration that reveals the context in which specific LTC self-management behaviours were influenced.

Table 20   C-M-O Overarching research question: context revealed

Context	Mechanism	Outcome
Role consumption is the primary reason WHY the context of dementia caregiving is different to other caregiving contexts (see next theme: The 24-hour role)	HOW is role consumption brought about? Which causal mechanisms within dementia caregiving give rise to (or do not give rise to) this context?	WHAT implications do the resulting mechanisms have on outcomes for LTC self-management? (potential influences discussed in this chapter; specific examples given in next chapter).

5.2.1 The 24-hour role

With the exception of one filial caregiver (Janice) all caregivers' immediate response to the amount and hours of daily care provided was that dementia caregiving was a 24-hour, full-time role. A lack of co-residence as in the case of the filial caregivers, or the use of temporary external support services such as regular respite services, did not appear to alter this view. Some sample responses from both male and female, spousal and filial caregivers have been provided below.

> All the time – it's a hundred percent! (Ethan, Spousal Caregiver)
>
> Twenty-four hours – all day and night. (Maria, Spousal Caregiver)
>
> With this you're on a twenty-four-hour a day job. (Daniel, Filial Caregiver)
>
> I'm on call twenty-four hours a day. (Anna, Filial Caregiver)

Anna stated that a lack of co-residence made it harder for her to provide the care and thus impeded more on her time.

> At least if they live with ya [sic], if anything goes wrong you can be there and sort it out but at the moment I might get a phone call in the middle of the night. (Anna, Filial Caregiver)

Janice was the only caregiver who calculated her caregiving hours and reported that she provides "probably 15 or so" hours of care as a daily average as she also has to go to work. However, Janice's later responses indicated that even at work she is constantly worried about her mother; based on the definition provided by WHO (2004, 2015) showing mental and emotional concern also contributes to the caregiving role.

I worry about mum being there on her own and I think it's added stress cos you can't

do anymore to help her because you're working fulltime (Janice, 47-48)

All caregivers were asked which aspect of caregiving out of social, emotional, financial and physical, had the most impact on them, the unanimous response was "emotional". This theme reinforces the knowledge that dementia caregiving is a strenuous all-consuming activity. The next theme will demonstrate instances from the caregiving experience that may contribute to this, such as BPSD and emotional attachment.

5.3   Mechanism: Causal potential of BPSD and related dependence

In order to understand some of the presentations of the behavioural and psychological/psychiatric symptoms of dementia (BPSD) mentioned in this section, an overview of the key types of BPSD and typical presentations of memory-loss and cognitive decline have been provided here. Most types of BPSD that result in delusions are due to the BPSD of 'misidentification' or 'agnosia' (Hamdy et al., 2017). This can be a misidentification of a familiar object or a familiar person (including oneself). One of the major causes of this is that the time perceptions of the PWD have been altered due to the nature of cognitive decline, thus, depending on the stage of dementia, they may retain strong memories of the past while forgetting the current reality (El Haj & Kapogiannis, 2016). Alterations in perception can lead to delusions, paranoia and emotional disturbances such as depressive symptoms or feelings of guilt in the PWD as they try to make sense of their current surroundings (Holt & Albert, 2006; Cipriani et al., 2013). BPSD also presents in the early stages as 'boundary ambiguity' and 'manipulative' or 'attention-seeking behaviours'. 'Boundary ambiguity' refers to the situation where family caregivers are unaware of the psychological and/or physical

presence of the PWD in their family roles and responsibilities; it is a significant predictor of depression in dementia family caregivers (Boss, Caron, Horbal & Mortimer, 1990). The terms 'manipulative' or 'attention-seeking' behaviours are often used interchangeably and refer to those BPSD that are perceived by caregivers to be done deliberately by the PWD; the cause of these behaviours is uncertain and they may be linked to other BPSD such as disinhibitions (Huang, Wang & Liao, 2017; Koder, Hunt & Davison, 2014; Tunis, Edell, Adams & Kennedy, 2002). Due to the uncertain trajectory and progressive nature of dementia, people with dementia do not lose all mental capacity, memory and cognition at once and therefore boundary ambiguity, manipulative behaviours and related BPSD are often unpredictable and unclear (Hannah et al., 2018).

5.3.1 Demands of dementia caregiving: Extra and doubled work (mental & physical)

As mentioned in previous chapters, dementia places unique demands on the caregiver due to BPSD and/or the high levels of dependency which itself is often caused by BPSD. The sub-themes within this theme contain long explanatory accounts of the caregivers' lived experiences with BPSD. Key points for reflection particularly the physical, emotional, social and financial burden of dementia caregiving have been underlined to reveal how burden manifests under BPSD. These issues are important as they will weave together the embeddedness of mechanisms that create barriers to self-management behaviours.

5.3.1.1   Disruption/lack of routine

The data revealed that two particular forms of BPSD cause a lot of disruption in a family caregiver's daily and nightly routine. These have been documented within Final Template Part 1 as 'switching to the past' and 'difficult/attention seeking/manipulative behaviour'. This theme provides detailed examples of both these BPSD in relation to the impact they have on the caregivers' routine and different aspects of caregiver burden.

5.3.1.1.1   BPSD: Switching to the past

The PWD switching to a previous reality was mentioned across many cases and was a major source of emotional and physical disturbance for both filial and spousal caregivers. Some caregivers reported that the PWD would shift between multiple realities in the past thus causing distress to both the caregiver and themselves. Daniel summarised the experience of caregiving for a PWD with such symptoms:

> You're not in a position to plan properly – because nothing's going to be the same – you can't tell somebody with dementia "tomorrow at four o'clock you're going to be doing this" – so you don't know what you're going to be doing at four o'clock cos you don't know what they're going to do at four o'clock! <u>You're tied by what they're doing</u> – so all your plans are thrown out the window because once that one goes – it has a <u>knock-on effect</u> – suddenly your little plan like maybe going to the bank or something – it's for Thursday and once Thursdays gone that little plan's gone and then you have to get a reminder, "oh I've got to pay that and I thought I'd dealt with that" and you haven't and <u>then you get a bit anxious</u> and then you – it has a knock-on effect all the time (Daniel, Filial Caregiver)

Daniel's repetition of 'it has a knock-on effect' provides a good example of the embeddedness of mechanisms and the domino-effect they create. He continued to explain the nature of BPSD, particularly switching to the past as a cause of this inability to plan.

> Their memory goes but they're not a four year old every day they're a thirty odd year old one day and a sixteen year old after dinner – or they might be a ninety year old after dinner – so it's finding out where they are and trying to talk to them – try and provide them with the experiences they had as a thirty year old or as a fifteen year old – trying to imagine what they'd have been doing – not as a fifteen year old today but as a fifteen year old fifty odd years ago – which luckily I'd have been able to sort of relate to as an eight year old or a three year old! (Daniel, Filial Caregiver)

Switching to the past was accompanied by a number of other BPSD such as changes in perception, paranoia and delusions. A rather distressing account of this was provided by Maria, as she explained the events that followed when her husband sat on the sofa next to the window, which he believed was a train:

> Quite a lot of the time on an evening he thinks he's on a train – and he doesn't know how to get off the train and he thinks he's going to miss the stop – because he wants to get off at his home. And – it sounds weird doesn't it? He says "they'll [mum/wife] be expecting me home for my tea!" – and if I can convince him that he's safe and I know when we're going to get off the train – then no problem – but then I have to ring his wife; I have to ring his mum! (Maria, Spousal Caregiver)

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The entire scenario shows an unpredictable nightly routine, which Maria pointed out later carries on to the next day; all of this is made worse by the emotional impact of the cause of disruption. The consequences of being unable to 'convince' the PWD can result in difficult and dangerous situations for both the PWD and the caregiver, such as, the PWD escaping or becoming violent as documented in the other themes. This symptom has numerous consequences on all domains of caregiver burden, these will be explored in other themes. Maria continued to explain the impact of dementia on her husband's behaviour:

> Sometimes he knows that he has a wife and he thinks that since he's here with me he's being disloyal – I say "I'm going to ring Jenny to come over" – he says "who's Jenny?" I say "your daughter" he says "no because I don't want her telling my wife I'm having this affair!" I have to pick up whether it's his wife he's anxious about or his mum. I'll say "do you want me to ring your wife?" He'll say "yes ring her but don't tell her that I'm here with you". So, I have to go into the kitchen and make these telephone calls and have a chat away (laughs). I'll say "no she's fine, your mums quite happy that you're here and they'll see you tomorrow" – and it's just living a (laughs/cries) – it just sounds so – even when I'm telling it – it sounds so unbelievably bizarre! Until anybody's lived with it – you just cannot –! Just the pressures of ringing his mum/wife every night! (Maria, Spousal Caregiver)

This again shows how unpredictable a family caregiver's routine can become in the context of dementia caregiving. The PWD's responses are also unpredictable and can vary drastically with a sudden, unexpected and rapid decline in their condition. A key point to note is how the maladaptive cognitions related to memory-loss present themselves to the caregiver, rendering them with a lack of control on the caregiving situation. For example, Maria had

mentioned during the interview that not only does her husband not recognise her but he considers his own reflection in the mirror an "intruder", all of which are related to delusions of misidentification. However, this does not appear to impact his understanding or acceptance of having a daughter once he has been reminded of her, such a disease trajectory, particularly when marked by unexpected and severe decline, is inevitably difficult to make sense of on a daily basis. Not only is Maria's routine affected by this behaviour, but the emotional impact of such situations, as evident from her crying, are significant.

5.3.1.1.2   BPSD: Difficult/attention-seeking behaviour

Another example shows more clearly how BPSD can distract the caregiver from attending to their own basic activities of daily living. This BPSD may be related to either attention-seeking behaviours or it may be a manifestation of BPSD related to disinhibitions, distress, irritability or aggression.

> I went to have a wash and Janet's [PWD] pulling wall paper off the wall – so you see
> I've got to stop her doing that – and she smashed her glasses – this last week we've
> gone through three pairs. So, you know it gets stressed with all these situations and
> you could easily blow your top and that sort of thing. So, you have to keep calm.
> (Andrew, Spousal Caregiver)

This loss of control and unpredictability of BPSD can evidently become the cause for the all-consuming nature of dementia caregiving. Andrew's situation also reveals the impact of BPSD on the financial domain of caregiver burden as he mentioned later that glasses are not cheap to replace. It is quite often this demanding nature of BPSD that acts as the mechanism which makes caregivers prioritise the PWD. Another point to note is that Andrew related his

experience in a rather calm manner which could possibly be a reflection of his own personality, but can equally suggest how quickly a caregiver 'normalises' the experience and perhaps submits to this new and unpredictable life. Table 21 shows the realist construction of this theme by breaking the broader mechanism of BPSD down into smaller more focused C-M-Os. The final row shows the cumulation of this evidence into a broader middle-range theory as seen in the template.

Table 21   C-M-O Disruption of Routine

Context	Mechanism	Outcome
BPSD: switching to previous reality and/or attention-seeking behaviour	Uncertain + unpredictable + demanding needs of PWD + dangerous situations	Constant disruption of routine + loss of time + loss of control + damage control required = role consumption
Loss of control of PWD and loss of control of time	Damage control and prioritisation of PWD essential; unable to plan	Prioritise managing BPSD & the PWD over self and own needs
Dementia caregiving: BPSD & dependence	Assuming full responsibility for and prioritising the PWD's tasks due to BPSD	Role consumption & lack of time for self (and potentially self-management)

5.3.1.2 Difficulty accomplishing tasks

The last quote of the previous theme showed how BPSD can make it difficult for the caregiver to accomplish their own tasks. This theme refers to how BPSD can make the tasks of caregiving more arduous. The primary underlying BPSD mechanisms responsible for this theme relate to the 'lack of acknowledgement of dementia by PWD' and 'difficult or attention seeking behaviour'. Examples have been provided below explaining these sub-mechanisms.

5.3.1.2.1 Lack of acknowledgement of dementia by PWD

Due to the nature of the illness many people with dementia do not understand, acknowledge or accept that they have dementia. This can make caregiving difficult. In dementia caregiving this results once again in prioritising the PWD, as the caregiver often feels that they must assume final responsibility for the task being completed.

Anna described a situation whereby her mother retained some capacity in decision-making but was unable to fulfil her financial duties and would not admit that she had dementia. Her lack of cooperation made it difficult for Anna to accomplish caregiving tasks and therefore had consequences on the amount of caregiving tasks she had and her ability to manage her time:

> Anything to do with memory loss or dementia she won't admit that there's a problem there. There's [sic] things like bills and she won't have bills paid by direct debit because that's the olden – it's a generational thing so I've got to help sort her bills out and insurance policies and things like that. And she won't let me have power of attorney either – so you know that's an ongoing situation (laughs)! (Anna, Filial Caregiver)

Janice, also mentioned a similar situation with her mother, which made it difficult for her to manage her workload:

> Ask mum if she thinks she's got some problems with her memory. She doesn't think she's got dementia and she's 100% convinced that the doctor thinks he can cure her! It's a little bit frustrating cos she says she'll do something then she doesn't remember and then things get left and left and she gets worked up and upset about it. We're just going over power of attorney at the moment – we mentioned it about two three years ago and she never did anything about it. (Janice, Filial Caregiver)

This issue is of particular concern to filial caregivers who do not co-reside with the PWD due to their role conflicts. Anna and Janice were both married and had other responsibilities. Anna had a son with a mental health condition and although he was not dependent on her, she added that it was an extra worry. Janice had a full-time job and mentioned that she had offered for her mother to live with her but since her mother refused to acknowledge the dementia, she would not agree to live with Janice and her husband.

5.3.1.2.2   Difficult/attention-seeking behaviour

BPSD such as perceived manipulative behaviour or attention-seeking behaviour also makes it difficult to accomplish simple tasks with the PWD. This can become both physically and mentally exhausting for the family caregiver. James also stated that it "got" to him when he was unable to ascertain whether his wife was being deliberately manipulative or whether it was the dementia. He gave an example of how it made helping her with simple tasks of daily living difficult:

I'm under pressure! Like that day <u>I was feeling really poorly and Pam was mushing me</u>

<u>about</u> – she sprayed her toothbrush all over my t-shirt – that weren't the thing that

bothered me – it was just that look on her face – just <u>petulant child</u>! <u>That got to me</u>!

She was just looking at me like "stuff you – so what! I'm not gonna do it!".

(James, Spousal Caregiver)

Table 22 shows the potential mechanisms involved in prioritising the PWD.

Table 22   C-M-O Difficulty accomplishing tasks

Context	Mechanism	Outcome
PWD lack of acknowledgement of own condition/needs + lack of understanding and cooperation with caregiver	Caregiver assumes responsibility for and prioritises PWD and their needs	Difficult + time consuming to get simple tasks done (role consumption) = even less time and energy for self and self-management

5.3.1.3   High levels of dependency

The previous themes addressed how the physical workload of a dementia family caregiver

can increase significantly as even simple tasks become difficult to accomplish particularly in

an irregular and unpredictable routine. This theme shows that in dementia caregiving, the

caregivers' responsibilities are not limited to physical acts of care due to dependency. A major

cause of dependency is BPSD and memory-loss related behaviours. Thus, the caregiver has to

also *think* on behalf of the PWD. Dementia caregiving thus consumes not only physical space

but considerable amounts of mental energy and space as well. The natural consequence of

this, in light of the mechanisms leading to prioritisation of the PWD, would be that the

caregiver eventually loses the ability to focus on themselves. Karen explained how she sometimes forgot her own tasks and chores because of this very issue:

> I do forget sometimes but I think it's the whole <u>pressure of remembering for two</u>. (Karen, Spousal Caregiver)

Anna offered a filial perspective on the dementia family caregivers' doubled workload:

> You've got <u>two lots of everything</u> – you've two lots of paperwork – two lots of everything besides your own! (Anna, Filial Caregiver)

5.3.1.3.1 Merging identities

Daniel also provided a filial perspective on the matter, his response seemed to show the combined effect of both Karen and Anna's responses:

> All my chores and tasks are my mother's chores and tasks, it's not just caring – its thinking. In a home the nurses are there and all they're doing is caring for the people – they're not thinking about where the money's coming from, they're not thinking about who's gonna be cleaning all the bedding – who's gonna be ironing the clothes – they're not thinking about all this and my bloody head's going woo woo woo woo! (Daniel, Filial Caregiver)

This shows that in dementia caregiving the caregiver begins to slowly assume responsibility for both physical and cognitive processes of the PWD's life. While Anna mentioned that her chores and tasks are doubled, Daniel's response indicates how the caregivers' identity or role can begin to merge with the PWDs'. This can also lead to prioritisation of the PWD as the

boundary between what is done for the self and what is done for the PWD blurs due to increasing cognitive decline and dependence. Table 23 shows how these mechanisms can result in a prioritisation of the PWD which in turn results in the caregivers' loss of self and their own self-management needs.

Table 23   C-M-O High levels of dependency of PWD

Context	Mechanism	Outcome
Cognitive loss + BPSD	Increased mental + physical dependence	Prioritising PWD Merging identities
Prioritising PWD	Merging identities	Loss of self
Merging identities + Prioritising the PWD	Loss of self	Lack of acknowledgement of own self-management needs

5.3.2   Prioritising PWD

Previous themes discussed how BPSD and high levels of physical and cognitive dependence can cause a significant increase in workload through which caregivers have little time and energy left for themselves; the C-M-O tables were used to display the various configurations in which this creates a situation where managing the PWD and their symptoms and needs is prioritised by the family caregiver. This theme further explores, and explains through specific cases, other mechanisms and sub-mechanisms that are linked to the prioritisation of the PWD.

5.3.2.1   Prioritising PWD due to unpredictability, risk and danger

The person with dementia switching to a past reality was a common experience amongst the participants (Emily, Maria, Daniel, Maya). The cases below show how switching to the past resulted in dangerous behaviours in the PWD that would naturally cause a loss of time, routine and energy in the caregiver thus causing them to prioritise the PWD.

Maria mentioned that there had been multiple occasions when her husband managed to leave/escape the house and head in the direction of his maternal home. The following account highlights the causal potential of such a living-context on the physical, emotional and financial domains of caregiver burden. It also once again shows the unpredictability of a caregiver's daily/nightly routine. It also highlights the kind of danger the PWD can get themselves into and how such incidences may *condition* the caregiver to constantly prioritise the PWD.

> We were having those very <u>high winds – really cold wet rainy night</u> – I looked everywhere round the house around the garden but couldn't find him! I put my coat on and <u>I set off and ran</u>! Literally running down the road looking for him but he was too far ahead for me to be able to see him. I came back home and rang the police – they picked him up on the motorway he was going 'home' – <u>he had walked 4.5 miles</u> to the motorway! And he'd gone out in his pyjamas and he was carrying his slippers in his pyjama bottoms! And that happened a couple of times! We've had the police out twice <u>late at night looking for him</u> so now I keep the door locked 24/7! I keep the keys in my pocket but I have the sensors fitted on the doors just in case – you know, as an added precaution. (Maria, Spousal Caregiver).

Maria's account reveals that dementia requires the caregiver to be constantly alert and aware; this had specific implications for Maria's medical self-management behaviours, these will be discussed with the 'outcomes' in the next chapter. Maya revealed a similar situation when she was explaining the physical toll it took on her as she had to carry out her household chores either when her mother-in-law was asleep or being supervised by another family member. She provided two examples of this situation, one in relation to escaping which has been provided below and another in relation to dangerous behaviours related to misidentification which follows after this quote.

> I was cleaning the kitchen so I left the door open to let the air come and let it dry – but she [PWD] says "I'm going to my mum's!". She put the coat on and starts walking outside! I just ran after her and I says [sic] "I'm coming with you to see your mum!" – "No you go back home!" she says to me "I know where my mum lives I go by myself, you go back!". I says "no but your mum says I have to come with you to see her because I haven't seen her for a long time so I'd like to go and see your mum and dad", "alright then, come on then" she says (laughs). So I went with her and I was trying to divert her back another road so we can come back home but she says "no we don't go that way, that's not my mum's house!" I had no mobile and I had to get contact with my husband – so we went down and I said "your house is not coming, it's all these pubs and shops" and she says "it's still further down it's not here" so we carried on – there was a paper-shop – he [shop owner] was Asian and he knows my husband because he buys papers every day from him and I said "my mum's not well can I use your phone to ring home?" But first he was surprised you know and I says "please let me use your phone I'll pay you how much it costs money or whatever for your phone

bill" – so he says "no, no it's okay you can use it" – so he let me use the phone – I rang my husband straight and says "you better come down straight we are in the shop! I'm trying to keep her in the shop!" (is breathless; pauses to cough) – so I kept her in the shop until my husband came. (Maya, Filial (in-law) Caregiver)

As mentioned earlier these accounts have been left in their long, raw form to give the reader a sense of the chaos as the caregiver relates their experience. The elements of discourse such as laughing, crying, pausing, can provide insight into their stream of consciousness and reflect the panic and emotion they had experienced at the time. Maya revealed her experience with very few pauses in between sentences; by the end of her account she was breathless and coughing almost as if she had relived the situation of running after her mother-in-law and trying to convince her to stop. Her detailed explanation of the conversation with the owner of the paper-shop also reveals her feelings of helplessness and uncertainty at the time as she quickly calculated the possibility of obtaining support and understanding from him. Maria and Maya's accounts show how rapidly and unexpectedly a dementia family caregiver loses control of a situation and faces an onslaught of negative emotions and physical strain. The loss of control impacts their ability to control their own routine, and doubles their workload as they have to work around the PWD; thus, after stopping to breath and recollect her thoughts, Maya finally completed her answer to the original question asked of her with a simple sentence:

That's why I don't clean when she's around (laughs) – we have to lock all the doors and that. (Maya, Filial (in-law) Caregiver)

Continuing from Maya's account, she also revealed that she has to wake up at three o'clock in the morning in order to finish cooking all the meals before her mother-in-law wakes up at seven o'clock. Maya explained that her mother-in-law can recognise some items in the kitchen but due to 'misidentification' of objects she no longer remembers how to use them correctly and instead uses them the way they would have been used in her youth or childhood. This resulted in a number of dangerous situations as revealed by Maya, one of these accounts have been provided as follows:

> Then one day she says "I'm going to make tea" but I was in the bathroom so she put the kettle on – you know where you put the kettle on the electric – but she put it on the gas fire – turned the gas on and it was a fire (laughs)! That's why I don't let her go near the kitchen – I just do the cooking before she comes down so it makes it easy for me, so she doesn't come in the way – that's why I get up early and do all this before I start (laughs) – so it's a hard life (laughs)! (Maya, Filial (in-law) Caregiver)

Maya's frequent laughing may be a coping mechanism which allows her to deal with the "hard life" in which she must prioritise her mother-in-law due to BPSD.

5.3.2.2   Prioritising PWD due to emotional attachment

Cognitive decline and BPSD result in the loss of a person (the PWD) and the loss of a relationship; however, although caregivers lose the person in mental form, the emotional attachment of the relationship and resulting sense of duty remain. Although, it will become evident in later themes that where the emotional attachment can keep a caregiver in the

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caregiving role, the loss of a person may also create 'emotional detachment'. In this theme, Emily explains why despite all the difficulties of managing BPSD she continues to provide care:

> Caring for someone with dementia is different to caring for someone with anything else. Uh, if you're caring – I know it might sound umm not very nice this – but when you're caring for someone with cancer – that person is still there – they have an illness but they are still there! Person with dementia – they're not there! You're caring for the person that they used to be – you love them. We'd had a good life together, we'd just managed to have us [sic] golden wedding before he started going really downhill.
>
> (Emily, Spousal Caregiver)

5.3.2.2.1   Difficult/manipulative behaviour

Similar to James' experience mentioned earlier, Janice stated that sometimes it was difficult to ascertain whether her mother was being deliberately uncooperative, and that this took a toll on her emotions. This quote also shows, as with previous quotes that caregiving can be made a difficult task for the caregiver by the PWD's BPSD. Janice's statement reveals that her mother, as perceived by her, had a difficult personality even before dementia, however now, more than ever Janice must maintain a "sympathetic" view:

> Unfortunately, my sister and I are a bit like punch bags but you really don't know what's mum being mum and what's dementia, and we're not qualified to know that either really so we do tend to struggle! It's frustrating because you've got this sympathetic view and you try and look after her and sometimes she'll let you and sometimes she'll push you away and for all you know sometimes she's taking the mick!
>
> (Janice, Filial Caregiver)

The unpredictable and uncertain illness trajectory of dementia makes it difficult for the caregiver to determine where dementia begins and where the PWD's personality ends. This symptom is similar to role ambiguity, where it is difficult to ascertain the PWD's level of cognitive absence and presence, thus making it difficult to ascertain the PWD's decision-making and sense-making capacity. The influence of this symptom is that the caregiver has to prioritise the PWD regardless. Table 24 shows the relationship between the mechanisms discussed within this theme.

Table 24   C-M-O Embeddedness of mechanisms (1)

Context	Mechanism	Outcome
BPSD: Switching to the past	Dangerous, unpredictable, risky behaviour	Prioritise the PWD
Dementia (difficult & attention/seeking BPSD; + cognitive decline & other BPSD)	Emotional attachment, relationship/marital bond, sense of duty as family	Remain in the caregiving role → prioritise PWD
Prioritising the PWD	BPSD + cognitive decline + emotional attachment	Numerous implications for self & self-management (revealed in next chapter)

5.3.3 Prioritising Self

While the previous theme shows how BPSD and resulting dangerous behaviours cause the caregiver to prioritise the PWD, this theme shows how the same mechanism can result in the opposite outcome for the caregiver, thus making the following sub-theme an integrative mechanism.

5.3.3.1 Prioritising Self due to unpredictability, risk & danger

The next two quotes are from Emily. The first quote explains how Emily came to know about the deterioration in her husband's condition and how this resulted in her making some life-changing decisions. Emily revealed this experience when she was asked whether the financial strains of caregiving were impacting her ability to care for her own long-term conditions. Emily explained how one of the early signs of the deterioration of her once "responsible" husband's condition was that he started going to the bookies instead of his part-time job.

> (Lowered tone) <u>Part of the problem</u> was that Eddie [PWD] gambled all our money away <u>(laughs)</u>! I were [sic] <u>getting letters</u> saying bills weren't being paid cos <u>he used to pay all the bills</u> you see. I looked at the last bank statement and he'd withdrawn six-hundred pound in one month! He was going into the bookies! I had to take his card off him – he wasn't going to give it me at first so I had to give him an <u>ultimatum</u> – I said "well it's either you gave me your card or we sell the house, split the money – you take yours and I take mine and we <u>split up</u>!". He went upstairs for ten minutes, came back down and gave me his card! That were <u>a bit of a worry</u> were that – I <u>couldn't physically stop him</u> and he got us into a bit of <u>debt</u> as well you know – <u>I had to take a loan</u> out to pay it off – but I uh <u>managed to turn it around</u> – and that's when we found out he were getting worse! (Emily, Spousal Caregiver)

Through this account, Emily has revealed a number of domains of caregiver burden that may have been affected by her husband's unexpected BPSD. While already adjusting to the new role of caregiving, her workload was unexpectedly doubled in an area she was unfamiliar with (managing finances). This was accompanied with a sense of shock and loss of the person her

husband used to be. Emily appears to trivialise the matter as she laughs and calls it a 'bit' of a worry, perhaps as a coping mechanism. Her statement also highlights potential emotional strains as she had to give her husband an "ultimatum" that may have ended their marriage. The next quote reveals the reason why Emily finally agreed to accept external support for caregiving for her husband and was essentially forced to prioritise herself when his rage and violence became uncontrollable.

> He gets up at two o'clock in the morning – gets dressed to go out – and you know <u>you have to coax him back</u> into bed. He's starting to get a bit violent – he were trying to get climb up the coffee table – he were trying to smash the window to get out – I had to lock the doors or else he'd have gone out – and he were running around the house trying to get through the windows – and I tried to get him down off the coffee table and he turned around and <u>grabbed me</u> – which is not like – you know <u>it wasn't like him and that frightened me</u>. The last time he started getting violent again – he was running around the house looking for a hammer – he was going to <u>break the door down, smash the windows</u> and he went into the cubby hole where all the tools are and I have five hammers (laughs) – I have five hammers there and he looked at them but he didn't pick them up – <u>he didn't associate those objects with a hammer</u> – he just said "hammer" but he didn't realise they were hammers – so he didn't pick them up. And he's running up and down the stairs – so in the end I rang my daughter and <u>I were upstairs on the toilet with my mobile (laughs)</u> – I daren't pick up – he wouldn't let me pick the phone up – I picked the phone up to ring and he snatched it out of my hand and he's <u>shouting and bawling</u> and I'm in the toilet with my mobile texting <u>(laughs)</u> and he's shouting "I know what you're doing!". (Emily, Spousal Caregiver)

5.3.3.2   Emotional detachment & role captivity

Robert explained how his wife's BPSD had become so dangerous that he could not travel with her in the car. This lack of independence and loss of the person his wife used to be, resulted in him becoming emotionally detached.

> I did go through that trough of feeling resentful. I just felt as if I was a prisoner myself because my life had changed – things that you couldn't do. I think the biggest turning point for me were going on the dating sites to be honest – because I can talk to people even if it's only for a short time – even if they'll only take me for my money – I mean it's great – I have great fun with it! People will say it's wrong because, I mean, I'm still married to Brenda, I shouldn't be on there – and dating sites, they'll ask "well what are you on here for if you're still married?" I say "I'm looking for friendship" – which I am! I've still got a pulse! I've still got needs! I've still got feelings – so does all that stop then? I mean me and Brenda – separate beds, separate bedrooms – so I'm a married man but a single man in a way – I can move on. You know if Brenda had died four years ago right –
>
> **Researcher: Nobody would say anything to you?**
>
> No, but because Brenda's still here in a physical body – but like I said they [acquaintances] don't understand Brenda's condition! It's like dropping off a cliff – Brenda's lost everything – everything's gone – there's nothing left really for her to lose – she can't walk, she can't go to the toilet, she can't feed herself. It's worse than a child – because a child learns! Brenda doesn't learn – she's unlearning – but she's unlearnt everything! (Robert, Spousal Caregiver)

Robert also went on to explain how most caregivers do not use the abundance of support and respite available to them due to emotional attachments, thus making it difficult for services to provide support. Table 25 shows the interaction between the mechanisms involved in prioritising the self.

Table 25   **C-M-O Embeddedness of mechanisms (2)**

Context	Mechanism	Outcome
BPSD (loss of control/ disinhibition behaviours, role ambiguity) + cognitive decline = role consumption	Life/physically/financially threatening situations	Family caregiver is forced to prioritise self
BPSD & cognitive decline	Loss of a person & relationship	Detachment from PWD
Detachment from PWD + prioritising self (due to danger/risk)	Encourages service use (lowered level of guilt as caregiver acknowledges lack of choice)	Implications for self & self-management (more time and energy for self)

5.4 Mechanism: Causal potential of barriers to external support

This theme explores the barriers to caregivers acknowledging, accessing and accepting external support either for the management of the PWD or to address their own self-management and support needs. Support for the PWD includes private and domiciliary care services, day-care services, at-home care services, permanent care services, caregiver support groups/chats amongst other third-sector support services, social services and/or Admiral nurses. Support for the caregiver includes their consultations with primary and secondary health and social care professionals, Admiral nurses and/or third-sector service providers.

The significance of accepting support for the PWD can be gleaned from Maria's following quote:

> If Matthew [PWD] gets help that in turn helps me as well – because it's more through his illness that I need help you know. (Maria, Spousal Caregiver)

Table 26 shows the causal potential of such barriers with regards to the caregivers' ability to acknowledge, care for and attend to their own needs.

Table 26   C-M-O Barriers to accessing support

Context	Mechanism	Outcome
External support services available to dementia family caregivers	Barriers to accessing support (as described in subsequent themes)	Role consumption, less time and energy for self and self-management

It will be revealed in the next chapter how attitudes to support can serve as both barriers and facilitators to the family caregivers' self-management behaviours.

5.4.1 Barriers to using support for PWD

This theme reveals the barriers to using available support for the care of the PWD, as perceived by their family caregivers.

5.4.1.1   Perceived adequacy of available support

Due to the high levels of dependency in dementia, manifestations of BPSD in the PWD, and emotional attachment between the caregiver and the PWD, caregivers naturally felt that they were best suited to provide optimal care for the PWD. This resulted in concerns regarding the

quality of support being offered by professionals who did not know or understand the PWD's specific needs and demands.

5.4.1.1.1 Support not sensitive to nature of dementia

Daniel mentioned that his previous experiences of professionals working at respite centres prevented him from sending his mother to them.

> Even the social workers know nothing about dementia, nothing about Alzheimer's – they just assume "oh yeah they forget things" and it's just generally thought of – like the social worker when my mother was in respite and she said "oh she forgets" and I said "they don't forget everything!". She said "hold on what do you mean?" and well I says "my mother she used to get in the car and she had a stick to walk with and she used to put in front of her between her legs and I told her not to do that and I showed her to put it down the side of the seat – I told her three times and did it always – so she's learnt and she can work things out!" just because she's no memory doesn't mean she can't do things now! If you let them do it they can work things out as long as it's short – because that moment in time, they're just as clever as you! (Daniel, Filial Caregiver)

5.4.1.1.2 Denial/lack of acknowledgement of dementia by PWD

Anna had previously mentioned how her mother's denial of dementia resulted in a doubled workload. She also mentioned that this was a barrier to using a popular self-management support service as the service required the caregivers to attend with the PWD.

No [don't go to support group] – because my mum – that's for people with dementia – so my mum won't go – my mum will not admit that she's got dementia! (Anna, Filial Caregiver)

5.4.1.1.3   High cost – poor quality care

Maria and Karen expressed their disappointment in terms of the quality of care being received for the amount they were paying. This deterred them from considering respite services. As mentioned before, care demands for dementia are so high and specific that it is natural for a caregiver to feel wary of services, particularly if they have been inconvenienced by them in the past; the decision of accessing or accepting support is made more difficult when the caregivers' expenses are strained.

I got cross when no carers turned up cos I said "I don't expect preferential treatment but I expect the same line of treatment as people that don't pay!". (Karen, Spousal Caregiver)

Karen explained that on a few occasions she had to make visits to the support organisations to lodge formal complaints that she was not receiving the care she had been promised. Karen also spoke of the financial drain dementia caregiving has on her savings. Confronting the system not only deters Karen from considering external support for her husband but it also creates more physical stress and hassle. This had implications for Karen's self-management behaviours as she later stated that external care would be required if she wanted to attend hospital appointments for herself; these barriers to external support-seeking behaviours therefore create more work and less time. Maria also felt that the quality of care being

provided was not worth the amount being spent on it, although unlike Karen, Maria was in a far more affluent position.

> Well there'll be people [not paying] in that respite home that are getting exactly the same care that Matthew is getting – probably drunk all their lives – probably haven't worked – I don't know!? (Maria, Spousal Caregiver)

Maria's response also indicates that as a close family member the caregiver's own standards of quality caregiving are most likely significantly high, and they would rather provide quality care at the cost of their own needs than pay for care that is, according to them, substandard. However, as Maria later acknowledges, her reluctance to accept respite is also due to emotional barriers. Table 27 shows how these mechanisms can result in negative respite use and inevitably a lack of time for caregiver self-management.

Table 27   C-M-O Embeddedness of mechanisms (3)

Context	Mechanism	Outcome
Adequacy of support services as perceived by caregiver	Caregiver-PWD relationship; knowledge and understanding of BPSD in dementia (by services); quality & expenses	Lack of use of support services for PWD
Lack of use of support services for PWD		Role consumption; potential lack of time for self and self-management

5.4.1.2   BPSD and PWD distress

Caregivers expressed concern regarding the distress the unfamiliarity of a new environment and new people causes the PWD. They explained that this often resulted in worsening of the PWD's BPSD and required a longer recovery time when they returned home. Daniel explained how the use of respite services affected his mother:

> It always takes her about <u>two to three days</u> to get over <u>a spell of respite</u> – because although you are surrounded by people – <u>you're surrounded by mad people</u> and they are acting really strange – if you <u>can't process people acting really strange</u> in your head then it makes it even worse. She can't understand what I say but at least <u>what I say is based around what she says!</u> (Daniel, Filial Caregiver)

Spousal caregivers like Karen and Maria also explained their anxiety regarding the use of respite:

> I don't think I want to send him into respite because I don't think it'd do for him quite honestly. They say it's a change for you and what have ya [sic] but <u>I'd be more worried about him if he was in respite</u> – if he was okay, if he weren't pining – because <u>he will pine!</u> (Karen, Spousal Caregiver)

> I know <u>he doesn't settle when he's in these places</u> – you know <u>when he's at the respite – that kind of worries me.</u> (Maria, Spousal Caregiver)

This barrier is not just related to the caregivers' own reservations regarding respite or the PWD. Emily explained that after the distressing display of violence when her husband was looking for a hammer to break the doors and windows in order to escape, her daughter

suggested the use of respite in order to give her a break. This experience was described under the causal potential of BPSD forcing the caregiver to prioritise themselves. However, as evident from Emily's following quote, respite services for dementia cannot guarantee support due to the unpredictability of the PWD's BPSD:

> She [daughter] said "we'll get him into care for two weeks and then you can have a rest". So, my son-in-law took us down and that was at about twelve o'clock – three o'clock they rang me up – I had to take him home – they couldn't cope with him. They said they couldn't cope and I had to go back and fetch him! (Emily, Spousal Caregiver)

The respite service Emily mentioned was not unfamiliar to her or her husband and had been used before, this therefore reveals how difficult it is to meet the unique and highly demanding support needs of people with dementia and their caregivers by support services. This example also highlights how accepting external support carries the potential to immerse the caregiver deeper into role consumption as they are now not only concerned about the welfare of the PWD during respite and their recovery after respite but are also to remain more vigilant, or as Anna stated previously "on-call twenty-four hours a day". Thus, accepting or accessing support does not necessarily provide the caregiver with the freedom to make definitive plans with their time. Such experiences may understandably make the caregiver reluctant to access respite. Table 28 shows the interaction between these mechanisms and outcomes in various C-M-O configurations.

Table 28   C-M-O Embeddedness of mechanisms (4)

Context	Mechanism	Outcome
Dementia	BPSD	Lack of guaranteed respite + distress to PWD + continued distress to PWD after respite
Reluctant to access/accept external support services	Lack of guaranteed respite + distress to PWD + continued distress to PWD after respite	Role consumption

5.4.1.3   Guilt

As mentioned in earlier themes, emotional attachment can create guilt which leads to the prioritisation of the PWD's needs and may also alter the perceived adequacy of available support for the PWD. This theme provides exclusive examples of guilt as a direct barrier to accessing or accepting support services even when the family caregiver realises its inevitability.

> The Admiral nurse wants me to go look at various homes – respite homes and just get a feel for them – so I haven't taken that step – so these are the emotions of the next step of it – it's just the emotions of the next big leap. (Maria, Spousal Caregiver)

Daniel and James expressed their guilt on using respite services:

> I just feel as though I've let her [wife/PWD] down. (James, Spousal Caregiver)

I felt like I was letting her [mother/PWD] down by putting her in the home at the

weekend. (Daniel, Filial Caregiver)

Table 29 shows the interaction between the mechanisms of guilt and emotional attachment

with regards to accessing or accepting external support for the care of the PWD.

Table 29   C-M-O Guilt and emotional attachment

Context	Mechanism	Outcome
Close family	Emotional attachment + guilt	Reluctant to access or accept external support
Reluctant to access or accept external support	Prioritising PWD	Role consumption

5.4.1.4   Marital bond & religious coping

As dementia commonly occurs in old age, one barrier to accessing external support for

spousal caregivers is acquired through a sense of duty towards the long marital bond they

once shared, which can often be tied to their religious beliefs as well. These coping

mechanisms may support the caregiver mentally and thus prevent them from acknowledging

the need for external support; however, it can also create feelings of role captivity and

perceived lack of choice.

I've been <u>married 51 years – can't just dump him, can I?</u> You know, I have to look after

him <u>it's my duty</u> to look after him! (Emily, Spousal Caregiver)

Karen's views were similar to Emily's:

> 50 years is a long time and I just feel I'd be doing him a disservice. (Karen, Spousal Caregiver)

Andrew mentioned a sense of duty coupled with guilt as he considered what his wife would do for him if the situation had been reversed:

> If it were the other way around my wife would do the same or probably do better! (Andrew, Spousal Caregiver)

Ethan and Maya both mentioned that religiosity helped them cope with the emotional difficulty of providing dementia caregiving:

> I've just got to do my best and I don't find it a problem – there's probably quite a lot of love there we've a bit of faith – we go to Church most Sundays umm, which helps, (Ethan, Spousal Caregiver)
>
> My day starts from remembering God – whatever situation I do [sic] – always remember first God and then start your work and you don't feel stressed – your day feels just normal. (Maya, Filial (in-law) Caregiver)

Much like Ethan, "you just have to keep going" and similar phrases were repeated by most caregivers throughout their interviews, usually in the context of external care not being a morally viable option. The two quotes above show that coping mechanisms may not only help caregivers overlook the extreme difficult and dangerous situations that arise due to the PWD, but can also prevent them from reaching out to support services providing external care by

continuing to do their "best" regardless of "whatever situation". Table 30 summarises the causal potential of this theme:

Table 30   C-M-O Marital bond and religious coping

Context	Mechanism	Outcome
Dementia common in old-age	Strong marital + religious duty Religious coping	Less likely to access support
Less likely to access support	Prioritise PWD and marriage	Role consumption more likely

5.4.1.5   Finding meaning

As explained earlier, the contextual conditioning involved in caregiving for dementia is primarily defined through role consumption which gives rise to further, vertically linked causal mechanisms such as merging identities and prioritising the PWD. This theme describes the complex interplay between the latter two mechanisms and the mechanisms mentioned in the previous two themes such as marital bond, religiosity and guilt. Many caregivers, both filial and spousal, mentioned giving up hobbies, being isolated from family, friends and social activities, giving up work opportunities or retiring early and relocating amongst the many changes they had to make as a caregiver. Dementia family caregivers thus redefine their life roles and purpose to being a caregiver for a family member with dementia. Therefore, 'finding meaning' in this new role also acts as a barrier to accessing or accepting support as the caregiver begins to wonder they would do if the PWD was no longer with them.

Following from Karen's previous quote, she continued that it would not only be a disservice to her husband but also to herself if she were to consider long-term respite services for his care:

> And I would be doing myself a disservice! I would be lost too – I mean they say "it's hard work bla bla bla" but I like taking him with me – and I mean somebody's watching him for me now but he's still with me – I can't envisage going out without him quite honestly – can you imagine after all that year together we did everything together so yeah, I'd be completely lost – won't know what to do! (Karen, Spousal Caregiver)

Maria explained that although it may not make sense to deal with the intensity of BPSD on a daily basis, the option of respite does not necessarily add quality to the caregivers' life either.

> You sort of think "why am I giving myself all this stress and anxiety?" – you know "just walk away, just walk away" and then I think "why do I want to walk away? Where would I walk to?!". (Maria, Spousal Caregiver)

Table 31 shows that the causal potential of this mechanism lies in the impact it may have on the caregiver when they are no longer in the caregiving role. Specific examples of this with regards to self-management behaviours will be provided in the next chapter.

Table 31   C-M-O Finding meaning and merging identities

Context	Mechanism	Outcome
Role consumption	Merging identities	Caregiver loses own identity and sense of self
Loss of own identity and sense of self due to long-term lack of involvement in own life after becoming a caregiver (finding meaning in new role)	Fear of losing new identity and role as caregiver	Reluctant to accept external support

5.4.1.6   Financial benefits

Robert was the only caregiver from a lower socio-economic status compared to the others. He received considerable monetary benefits from the local authority and stated that he went through the various difficulties and inconveniences of home renovation to accommodate his wife's rapid functional decline as he depended on her for the financial benefits of being a dementia family caregiver. Therefore, although he readily accepted external support from professional caregivers in his home, he was reluctant to consider permanent respite or other respite services delivered mainly outside his house.

When I thought she [PWD] were going in the home permanent – I accepted that then, but I had to go out to work then – so finding a job at sixty-two – you know what I mean? So I'm lucky I don't have to do that now – but if owt happens to Brenda I'd have to – you know what I mean – cos I wouldn't have enough to live on – you know if all the benefits stop – in 8 weeks all the benefits stop – like now I don't pay council tax – zero rated but if I lived on my own – it would be a £1000 I'd have 25% knocked

off not all of it, you know what I mean? So financially they do us – I'm full of praise for them they've got it down – to me like I say Council is brilliant – absolutely! (Robert, Spousal Caregiver)

Robert's case was a unique example of a barrier to accessing permanent external support within this particular sample. His case offers interesting insights to the contextual conditioning of socio-economic status in the decision-making process of family caregivers. It also raises questions about the quality and adequacy of care being provided to the PWD at various stages of their illness. For example, a caregiver may prioritise the care and well-being of the PWD so that their health remains well enough to keep them at home, this may increase the impact of role consumption. On the other hand, the PWD may become vulnerable to abuse and mistreatment as their condition deteriorates and the caregiver loses patience with their behaviours and symptoms. In Robert's interview, examples of both these situations were apparent, although, the former situation did not result in role consumption as Robert felt emotionally detached from his wife due to her condition, and thus willingly accepted temporary respite and at-home care services whenever possible. This allowed Robert to indulge in new hobbies and activities such as gaining a driving licence, taking horse-riding lessons and having time and money to socialise. Table 32 shows the C-M-O configurations deduced from this example.

Table 32   C-M-O Socioeconomic status

Context	Mechanism	Outcome
Lower socio-economic status	Qualifies for significant financial support → numerous benefits, improved lifestyle	Reluctant to access permanent support
Reluctant to access permanent support	Prioritise PWD	Role consumption and less time for self + Improved care for PWD less/more time for self (depending on other mech
Reluctant to access permanent support	Prioritise PWD + emotional detachment	More time and energy for self + improved or worse care for PWD (depending on situation)

5.4.2 Barriers to support for caregiver's health needs

This theme reveals some of the barriers as perceived by caregivers that prevented them from accessing or accepting support that has been designed for them, for example support from the GPS or Admiral nurses.

5.4.2.1   Lack of caregiver-led needs assessment as perceived by caregiver

When asked whether they had care plans and LTC needs addressed by professionals, caregivers stated that the care plans discussed were usually just about the PWD. They stated

that questions did not appear to focus on specific personal needs of the caregiver, and were usually with regards to the needs of the caregiver in relation to their caregiving role:

> It's only just recently that carers are deemed to be human beings – and this is where the downfall is because we have got needs of our own. (Anna, Filial Caregiver)

> I haven't had any help from them [health and social care] really – I have a care plan for my mum – an emergency care plan but that's for my mum, I haven't had a care plan for myself. (Anna, Filial Caregiver)

When asked if his LTC needs were being assessed or addressed through the caregiver assessments, Robert stated:

> Well [in Carer's Assessment] questions like you know – "do you get depressed?" "Can you cope with the situation?" – but it's all around depression – it's all around coping with situations. (Robert, Spousal Caregiver)

When asked specifically about support from Admiral nurses Robert explained that they usually asked about support required for caregiving. He also added later that most of this support he had arranged prior to their assessment and he had to go through a lot of hassle in order to obtain it.

> See I don't have an Admiral nurse because when I were talking to them they said you don't really need us now because you've got everything in place – which were kind of by me. (Robert, Spousal Caregiver)

Vanessa also explained that she stopped contacting the Admiral nurses as they appeared to only ask questions regarding caregiving needs:

> I haven't rung them [Admiral nurse] since they sort of ask you a lot of questions – we seem alright, we don't need any help, we've got a toilet downstairs – you know that sort of thing. (Vanessa, Spousal Caregiver)

5.4.2.2   Lack of routine monitoring as perceived by caregiver

Along with a lack of personalised assessments, caregivers also stated that assessments were infrequent. Daniel echoed a similar experience to Vanessa in the previous theme, he added how assessments were sporadic and did not address LTC, health or personal needs:

> Saw her [Admiral nurse] twice in four years When she'd came the second time I'd forgotten I'd seen her before – she reminded me and said "oh you're doing a very good job carry on" (Daniel, Filial Caregiver)

Karen also mentioned being unable to remember the caregiver assessment as it had been when she first started caregiving, five years ago:

> You tend to forget it would be at the beginning I had the carer assessment for me.
> (Karen, Spousal Caregiver)

Vanessa, expressed that she wanted more support directly from the GP instead of the Admiral nurse regarding her own health:

Doctors aren't doing enough – but you see they have enough on haven't they? (Vanessa, Spousal Caregiver)

5.4.2.3 Fear of being watched

This theme refers to a concept that upon in-depth reading of the data, was indirectly alluded to by some, but only mentioned directly by Karen. Much like other caregivers, Karen described a BPSD related incident where she lost her patience when her husband refused to step out of the car:

> It wasn't a 'shout' shout you know? It was a "if you don't help me get you out of that car you'll have to stay there. I'll come back in five minutes I'm going into the house!" – it was technically about going into another room when you're cross and that's what I did. (Karen, Spousal Caregiver)

Karen explained that this incident resulted in someone reporting her to the Admiral nurse for her behaviour towards her husband, which subsequently prevented her from requesting their services again.

> I don't know whether it's the woman across the road who had something to do with social work but she obviously knew who to get in touch with – and <u>I got a ticking off</u> really – and he [Admiral nurse] never got into contact after that. So, I thought "well I don't feel like phoning you if you don't phone me! You're the one that's supposed to be looking after me and you weren't!". So I thought I can look after myself rather than have somebody like that who can come and tick me off or not support me really. <u>I didn't feel supported.</u> (Karen, Spousal Caregiver)

5.4.2.4　Lack of recognition of own caregiving role

Anna had previously stated that there was a lack of recognition of the caregiver's needs from healthcare services, however she also suggested that a major barrier to caregivers catering to their own needs is a lack of recognition of their own needs from the caregivers themselves:

> Because for a long, long time I didn't perceive myself as a carer. It's a generational thing as well – because in years gone by daughters used to look after the parents. (Anna, Filial Caregiver)

Table 33 shows the C-M-Os related to a lack of acknowledgement and recognition of the caregiving role.

Table 33   C-M-O Lack of acknowledgement and recognition

Context	Mechanism	Outcome
Dementia family caregiver with LTC(s)	Caregiver perceived only as caregiver not as a hidden patient with own health needs	Lack of caregiver-led needs assessment + lack of routine monitoring + lack of recognition of own needs by caregiver = Unaddressed LTC self-management needs of dementia family caregiver
	Caregiver perceived only as patient with LTC and not as caregiver	Fear of being watched + unaddressed social, emotional, financial needs related to self-management = doesn't utilise/accept support + support not effective for caregiver with unmet needs

5.5   Conclusion to Chapter 5

This chapter discussed the potential of numerous mechanisms that are likely to result in role consumption for the caregiver which in turn will impact their time, energy and motivation for self-management. The chapter also considered that some of the same causal mechanisms may potentially have the opposite impact on the caregiver should the contextual conditioning of the mechanism change. Table 34 shows the key research questions that were outlined at the beginning of the chapter and how the findings presented within this chapter have answered those questions.

Table 34   C-M-O Overarching research question: mechanisms revealed

Context	Mechanism	Outcome
Role consumption is the primary reason WHY the context of dementia caregiving is different to other caregiving contexts	HOW is role consumption brought about? Which causal mechanisms within dementia caregiving that give rise to this context?	WHAT implications do the resulting mechanisms have on outcomes for LTC self-management
Overarching context of research: Caregiver LTC self-management while caregiving for a family member with dementia	The primary active mechanism within dementia that links most mechanisms together is the impact of BPSD on the family caregiver	Lack of time Lack of energy Lack of motivation Lack of organisation/routine Lack of recognition of needs Lack of service use for PWD & Self Prioritising the Self

CHAPTER 6: PRESENTATION OF FINDINGS (OUTCOMES)

6.1   Overview of Chapter 6

This chapter shows how the causal potential of dementia caregiving mechanisms and other mechanisms prevent a dementia family caregiver from engaging in LTC self-management behaviours. The quotes have been presented using Final Template Part 2.

Final Template Part 16: Self-management OUTCOMES and other C-M-Os

OUTCOMES: BARRIERS TO SELF-MANAGEMENT BEHAVIOURS				
MEDICATION	**APPOINTMENTS**	**SLEEP, REST & SYMPTOM MANAGEMENT**	**SMOKING**	**DRINKING**
BPSD → Disruption of routine → Fear of escaping → Double (extra) work → Prioritising PWD **LACK OF CO-RESIDENCE**	**BPSD** → Unpredictability & difficult behaviour → Loss of own identity & motivation **PRIORITISING NEEDS OF PWD (dependency)**	**BPSD** → Wandering and escaping → Reality perceptions → Unaware and lack of understanding **PRIORITISING NEEDS OF PWD (due to dependency)** → Worries & lack of sleep → Ignoring/undermining own needs	**Role captivity** → Loss of motivation **SEXUAL BEHAVIOURS** → Loss of a relationship and emotional detachment	**Respite use** → Finding meaning

PRIORITISING NEEDS OF PWD & Other mechanisms & outcomes

→ Lack of focus on self
    o Lack of reporting LTCs/ probing caregiver to reveal LTCs
    o Unable to talk about self
    o Lack of self-management support seeking behaviours
→ Beliefs and Perceived significance/consequence of a lack of self-management
    o Medical-related behaviours
    o Symptoms – attributing symptoms to old age
    o Exercise – self-perceptions of 'good' self-management

OUTCOMES: FACILITATORS TO SELF-MANAGEMENT BEHAVIOURS
→ Prioritising person with dementia → Deterioration in health → Fear of dementia → Prompts and support from family   o Prioritising PWD → Use of memory aids → Goal-oriented strategies/behaviours

6.1.1 Medication

This theme outlines all the mechanisms that act as barriers to caregivers taking their own LTC medication.

6.1.1.1   BPSD

Disruption of routine, fear of the PWD escaping and doubled/extra workload were the mechanisms resulting from the contextual conditioning of BPSD in dementia. These mechanisms prevented the caregiver from taking their medication in a number of different ways as demonstrated in the sections that follow.

6.1.1.1.1   Disruption of routine

Emily explained how BPSD such as following the caregiver around disrupts her routine when she tries to take her medication.

> I get into bed, come back downstairs to take me [sic] medication and then he comes back down again and then we're up and down – so that's when I forget to take the medication. (Emily, Spousal Caregiver)

Maria explained that on a morning she tried to incorporate her own medication routine with her husbands, however she acknowledged that since BPSD is unpredictable, she cannot always ensure that this routine is maintained:

Obviously if he's been very disruptive during the night – we don't have that routine – so I have to be in that routine otherwise I will forget – and have done! (Maria, Spousal Caregiver)

Maya explained that her medication must be taken at regular intervals post-prandial. She mentioned being so busy with her caregiving tasks that if this routine was disrupted then she would not take her medication.

I forgot to take the tablets because I have to take the tablets by the food time – but when it's passed you know two hours I thought oh I can't be bothered to take it now because I'm not eating anything now! (laughs). (Maya, Filial (in-law) Caregiver)

6.1.1.1.2 Fear of PWD escaping

BPSD not only made caregivers forget their self-management tasks but in Maria's case it also determined which medications she was able to take. Alongside physical LTCs Maria also had a history of anxiety and depression; throughout the interview she had frequently mentioned that these conditions were triggered by the emotional impact of her husband's dementia and BPSD. However, since Maria had to remain vigilant at night, she avoided taking medication that made her drowsy.

The antidepressants I'm determined not to take them unless I really, really have to do – because of the side effects. They talked about sleeping tablets – cos I had really bad episodes of not sleeping for quite a few weeks on end – and that was one time I went to the doctor and because of the caring situation they couldn't give me sleeping tablets because <u>I have to be alert during the night</u> – so in that regard I suppose I don't

take certain medication because of the impact it could have on Matthew [PWD]. (Maria, Spousal Caregiver)

6.1.1.1.3   Doubled/extra work

As previously stated by Anna, dementia family caregivers have "two lots of everything", this also includes having two lots of multiple long-term conditions to manage. As a result of having to manage two medication routines, caregivers like Robert and Maya explained that this could sometimes be confusing and medicines could accidentally get "mixed up". Robert mentioned how he had once accidentally taken his wife's medicine instead of his own, Robert's frequent laughter in this sentence may indicate his views on the significance of medical self-management.

> Oh I took Brenda's [Alzheimer's medicine] once (laughs) – it doesn't do much for your memory (laughs)! (Robert, Spousal Caregiver)

Maria mentioned that besides forgetting to take her medication on time due to a disrupted routine, she has also forgotten to take her medication due to it being "mixed up" with her mother-in-law's medication.

> I take them regular but um last year I did forget to take sometimes – you know I missed a couple of times my diabetes one because I have to look after my mum's medicine as well and I keep forgetting because (laughs) it was mixed up (laughs). (Maya, Filial (in-law) Caregiver)

In keeping with realist interviewing techniques, such matters were probed further. Maya was the only caregiver of South Asian ethnicity and her family structure and living situation possibly reflected cultural norms. She stated that she lives with her husband, sister-in-law and mother-in-law (PWD). Maya mentioned that both her husband and sister-in-law also have multiple long-term conditions and therefore she makes sure that along with her mother-in-law's medication she places their medication next to their breakfast in the morning. When asked why she did not follow a similar routine for herself, Maya acknowledged that she prioritises the needs of her family before her own, though she did not clearly explain the reason behind her lack of self-management.

> (Laughs) They [family] are more important for me. But because I keep it ready but I just forget because I left it in the fridge my medicine – it was one of those things I forgot. (Maya, Filial (in-law) Caregiver)

6.1.1.1.4   Prioritising PWD

Although BPSD caused an understandable disruption in routine, some scenarios revealed that caregivers, despite realising the impact of BPSD were not prioritising taking their own medication first. One possible mechanism that can give rise to this situation is the contextual conditioning of BPSD which permanently keeps the PWD at the forefront of the caregivers' priorities. Both Emily and James provided examples of how BPSD makes the self-management tasks of the PWD so difficult that they no longer remember to take their own medication.

> Because his medication is so riveting you know – I have to break tablets in half – I have to make sure he gets his tablets – so sometimes I forget to take mine. (Emily, Spousal Caregiver)

James experienced similar difficulties when managing his wife's medications and subsequently forgot his own:

> Because I make sure that Pam takes hers, and get her into bed and I forget – and on a morning – she takes one pill on a morning does Pam – which I think is the anti-depressant – I put it on my hand and make her take it off my hand – and she puts it in her mouth and I have a cup of water – and I went into this drawer one day and there's three of these pills in there – she weren't taking it – she were chucking it under her tongue – then when I went back out – so then we had a little mind game battle – "have you swallowed it?" – "yes" – "come on swallow it!" – <u>getting her to swallow it</u> – but I do all that and then I forget to take my own bloody pill! If I remember I take the aspirin and one of the naproxen – if I remember – I take it then and if I don't then just leave it till the next morning. <u>Um – I don't want to not take the aspirin</u>. (James, Spousal Caregiver)

Unlike other caregivers, such as Robert who joked about a lack of adherence to his medication, the final sentence in James' response indicates that perhaps he was wary of coming across as irresponsible, and therefore felt it necessary to explain that he does value his medication. However, James mentioned a number of occasions where, due to a lack of self-management, his rheumatoid symptoms had flared up considerably and his movement and mobility were significantly restricted; he also stated later that he loses motivation to care for himself when his wife is away in respite care. However, James' overall self-management behaviours did not showcase a lot of attention to his own healthcare needs, regardless of his wife's respite.

1.1.1.1 Lack of co-residence

As mentioned earlier a lack of co-residence made things just as difficult if not more so for filial caregivers, as they were always "on-call" and checking in with the PWD to ensure that they are safe and to remind them to carry out certain ADL, IADL and self-management tasks. A similar situation was evident in Daniel's case, who visited his mother at night to make sure she had taken her medication and in doing so, he often forgot to take his own medication.

> It's [dementia caregiving] not something you do normally in your life is it – so it's just – I'm either not where – when I remember I'm not there where the pills are – it might be at home and I remember at ten o'clock at night – "ah I'm not there" – so quite often I've missed them. (Daniel, Filial Caregiver)

6.1.2 Appointments

This theme outlines all the mechanisms that act as barriers to caregivers arranging their own LTC appointments.

6.1.2.1 BPSD

6.1.2.1.1 Unpredictability and difficult behaviour

BPSD and related dangerous or unpredictable behaviours also made it difficult for caregivers to attend their own appointments. Arranging respite or temporary care was not always easy nor reliable as seen in previous themes. Andrew explained how it can become difficult for him to attend his appointment with his wife:

You know, going to the doctors with Janet [PWD] – it's a difficult thing – because in the reception area if she starts shouting and bawling or going on them – it's – it's a bit of an embarrassment. It's alright if you arrive at ten-fifteen for your appointment and you go in at ten-fifteen but if you're twenty minutes later or an hour – I can't leave her in the car because you know she might get out and uh so it's very difficult to arrange them sort of things. (Andrew, Spousal Caregiver)

Robert revealed a similar situation:

She opens my door – she gets hold of the door handle and pulls it – so it's a bit dangerous in the car – she unlocks my door – with being in the front. I don't take her in the car anymore. (Robert, Spousal Caregiver)

Karen had been one of the caregivers to mention that inconveniences and hassles associated with arranging external care were limiting factors in her ability to attend or arrange her own LTC appointments, though she appeared to underestimate and be dismissive of the time restraints:

No, no, I should be able to [go to the doctor] I mean if I had to go to the hospital I'd have to get a sitter in – I mean the doctor's not so far away it's – I could leave him for half an hour, I wouldn't leave him for longer. (Karen, Spousal Caregiver)

Karen mentioned that she could occasionally ask her neighbour to watch her husband, but due to BPSD she could only manage for a short time before he became agitated and started looking for her. Maria on the other hand was worried due to her husband's continuous attempts at escaping:

I wouldn't go down to the surgery and leave him here. I'd be frightened these days he'd make some attempt to escape you know (laughs). (Maria, Spousal Caregiver)

6.1.2.2   Loss of identity and motivation

All caregivers expressed that the emotional aspect of dementia caregiving was the most difficult, however Daniel further explained that dementia can emotionally and mentally weigh the caregiver down so much so that they no longer feel motivated to do anything for themselves.

It's like <u>your carrying someone else's misery</u> if you like – and that affects ya and you don't want to do anything for yourself – so things get behind and gets more behind and you've got more things to do and you don't know which one to do first (laughs)! I don't know whether it's depression or whether it's just – self-worth – when you're caring – but I didn't know what to do with it – so yeah. I said "oh I can do that tomorrow" – and everything just builds up and builds up and builds up and then you get yourself into trouble worse than you ever thought. So it's – pulling yourself together! (Daniel, Filial Caregiver)

6.1.2.3   Prioritising needs of PWD

The amount of physical and mental dependency of the PWD due to BPSD and memory-loss behaviours meant that caregivers would more often than not consider the impact their own self-management would have on their caregiving routine. For example, Anna mentioned a number of times in the interview that she needed to have her knee replaced but was afraid

that the post-surgical recovery would impede on her ability to be available to provide care for her mother.

> Oh regularly [missed appointments or not booked]! Yeah – I should go to the doctor's now because of the pain in my knee but I'm putting it on hold because of my mum [PWD]. (Anna, Filial Caregiver)

Maria's response also revealed that she always considers the impact her self-management tasks will have on her caregiving routine and therefore is often dismissive of her own needs:

> It comes down to Matthew again cos you'll probably put off doing things because of what consequence it might have down the line for his care – I can't think of an instance (pause 10 seconds) – for example "do I really need to see the doctor? No I'll leave it till next week see how it goes next week" I don't know – it's always back to thinking about what impact it's going to have on the way our lives are run really. (Maria, Spousal Caregiver).

Janice was one of the few caregivers to acknowledge her LTCs and related needs, however she also admitted that she prioritises her mother's needs above her own:

> I had quite a few problems uh over the last twelve to eighteen months – I've been clinically diagnosed with IBS and I had some kidney stones and I'm due for a thyroid test – I usually do it once every twelve months but – I had a lump in my breast last year but that was a cyst so that was fine. On the whole I think I am the kind of person that kind of puts myself on the backburner and looks after everybody else. (Janice, Filial Caregiver)

6.1.3 Sleep, rest and symptom management

When asked about symptoms and fatigue, a lack of sleep and rest came up as emerging self-management needs, particularly when LTC symptoms were not under control. This theme details the various barriers to the caregivers' sleep and rest behaviours.

6.1.3.1   BPSD

6.1.3.1.1   Wandering and escaping

James explained that his wife frequently got out of bed at night and that disrupted his routine. Like many caregivers he mentioned that once woken up it was difficult to get back to sleep. This itself had a number of different dementia caregiving related causal mechanisms.

> A bad night might be 2 hours – cos we're up that many times and I stay awaken – sometimes I'm still awake when she's starting to get out of bed again! (James, Spousal Caregiver)

Although previously Robert had stated that caregiving for dementia is worse than providing care for a child as the PWD is always "unlearning", other caregivers found it easier to explain the demands of dementia caregiving by drawing parallels with the tasks involved in providing care for an infant or child. Similar to how Maria had explained the need for vigilance during the night, Emily and Daniel also stated that even when they did get sleep they were still subconsciously alert.

It's like when you have a baby! You don't sleep so well – you're listening for them all the time – it's exactly the same when you're caring for dementia! (Emily, Spousal Caregiver)

Daniel also explained that he had complaints from neighbours due to the alarm system he had installed to keep his mother from escaping, however he revealed that things can escalate into dangerous situations for a PWD and therefore he had no choice:

So your brain goes all mashed – it's full time – you try to sleep – be awake and asleep at the same time – so that's why we put a catch on the door that makes the noise. (Daniel, Filial Caregiver)

6.1.3.1.2   Reality perceptions

BPSD related to 'switching to the past' not only made it difficult for caregivers to sleep but also took a toll on their emotional well-being as described by Maria and Daniel. As mentioned before, Maria's husband considered himself newly married and did not identify her as his wife, resulting in the following situation:

You know going to bed on a night – he goes to bed usually an hour to an hour and a half before I go because you know I'm not his wife and I really shouldn't be in his bed (laughs)! (Maria, Spousal Caregiver)

Daniel on the other hand experienced a similar situation for the opposite reason:

> She wakes me up – because I look like my dad – I have to try and explain to a deaf woman who thinks her husband's turning her out of her own bed – put her back in there – quite often when I used to put her to bed and leave her she used to sound disappointed and say "don't you love me anymore?". (Daniel, Filial Caregiver)

Maya and Vanessa also mentioned how the PWD's lack of awareness of their current reality prevents them from getting sleep and rest.

> They [PWD] don't realise you're poorly – they don't seem to realise – you know? You know what I mean? They just – "are you getting up now? Are we going out?". (Vanessa, Spousal Caregiver)
>
> I have a rest little bit in the afternoon for half an hour or one hour – you know because I get up at three a.m., just a little – but sometimes she [PWD] doesn't let me have a rest because she thinks what am I doing here!? If she starts talking I just open my eyes. (Maya, Filial (in-law) Caregiver)

6.1.3.2   Prioritising the needs of the person with dementia

6.1.3.2.1   Worries and lack of sleep

Unsurprisingly, caregivers had many worries on their mind regarding the long-term care of the PWD. Disrupted sleep often triggered these worrying thought processes and resulted in more stress and lack of sleep. A few examples have been provided below.

It's very unusual to sleep the whole night through – some nights you get none at all – very much hit and miss. I get very stressed because I switch on but I can't switch off – Matthew sleeps generally fairly well – I can usually get him back to sleep but then I struggle to get back to sleep. (Maria, Spousal Caregiver)

Vanessa explained the thoughts that enter her mind when she is awake at night, her final sentence reveals that she perhaps uses a combination of 'wishful thinking' and 'avoidance' to cope with the stressful emotions and feelings:

Well I lie awake thinking about stuff you know – like I should say if Adam's to go in a home or anything like that – but you just have to carry on and hope it isn't eh? (Vanessa, Spousal Caregiver)

Janice's case revealed the impact dementia can have on extended family structures and how this too can impact the primary caregiver. Janice explained that her mother's dementia and difficult and manipulative behaviours had started to strain her sister's marriage and she would worry not only for her mother but also the consequences of her mother's behaviour for her sister and her sister's daughter, whom she stated she was very close to:

I'm not sleeping because I'm worrying about my niece and I'm worrying about my mum [PWD] and I'm worrying about my sister! (Janice, Filial Caregiver)

6.1.3.2.2   Ignoring/ undermining own needs and prioritising PWD

This theme revealed that caregivers can undermine their own needs and continue to provide care despite physical limitations and symptoms of pain and fatigue.

For example, when Vanessa was asked about her own ADL, she stated the trouble she has with simple tasks, however later in the interview she revealed that she manages to carry out difficult manual handling tasks and ADL for her husband.

> **Researcher: Does your health prevent you from carrying out everyday tasks?**
>
> I couldn't start vac'ing [vacuuming] house up – <u>I've a job enough making bed</u> and doing – yeah – yes it does!
>
> **[Later during interview: discussion regarding support from occupational health and having rails added to bathroom]**
>
> I have to help him get bath – I have to help him in and wash him and then help him – you know he couldn't do it himself – no I have to help him get back out. (Vanessa, Spousal Caregiver)

Similarly, Andrew who was initially dismissive of his arthritis explained why he can no longer do gardening which used to be his hobby, however he added quickly that this does not limit him from managing the numerous and difficult caregiving tasks for his wife, whose BPSD as mentioned before resulted in a lot of distressing and aggressive behaviours such as peeling wall paper or breaking glasses.

> Well – with having my hip – I can't just bend down to pick things up off the floor so easily. <u>But apart from that</u> I can manage. I have to put a thing and kneel on and push myself up because I haven't got strength in my hip that I used to have you see. <u>But apart from that</u> – <u>looking after Janet – I can manage</u>. (Andrew, Spousal Caregiver)

Andrew's response indicates that this mechanism may be linked back to previous mechanisms such as 'fear of being watched'. Andrew may have been reluctant to appear as though he lacked competence in caregiving which may also explain his dismissiveness towards his LTCs and related symptoms.

6.1.4 Smoking

6.1.4.1   Role captivity and loss of motivation

Continuing with Andrew's case, he was the only caregiver to mention that he had started smoking for the first time in his life at the age of 65 when his wife's BPSD got more difficult to manage, resulting in feelings of resentment and role captivity.

> You get very stressed with this job – you know you've got to be able to calm down otherwise you feel you're getting out of control.
>
> **Researcher: Smoking has a negative impact on your health conditions though?**
>
> Well, no it [smoking] isn't good – but the thing is – I know this isn't a good answer but the thing is you know – you've worked all your life and you end up just being a carer you've got no real life (very hesitant; lips trembling, almost crying). So – you know – death's not far around the corner – so why bother if you've got a drudgery of a life?
>
> (Andrew, Spousal Caregiver)

Although Andrew once again appeared conscious of giving "good" answers in the interview, he was overwhelmed with emotion while discussing his current life as a spousal dementia caregiver.

6.1.5 Drinking

6.1.5.1 Finding meaning

Previously 'finding meaning in caregiving' and 'guilt' had been identified as barriers to respite. James explained how sending his wife to respite occasionally made him more upset as he not only felt guilty but also no longer knew what to do while she was away. It should be noted that going from a hectic unpredictable routine to complete loneliness can itself be a disruption in 'routine' for caregivers, many of whom have sacrificed jobs, hobbies, friends and a social life for their caregiving role. Thus, respite does not necessarily result in positive behaviours in a caregiver unless they have goal-oriented provisions in place.

> It's loneliness – and I don't think I'm neglecting myself – I'm eating well enough – but I were drinking too much – I know that – being by myself "ugh go on I'll have another one". I know why – cause what else is there to do? It [drinking] helps you to sleep – well it does initially but then it doesn't – you just don't sleep you have weird dreams. (James, Spousal Caregiver)

6.1.6 Sexual behaviours

6.1.6.1 Loss of a relationship and emotional detachment

Robert explained how the loss of his relationship affected his sexual health, wellbeing and behaviours. Much like Andrew, Robert was also conscious of what would be appropriate to reveal in his answers, though this appeared to be more a consequence of him previously being stigmatised by his own family for revealing his feelings.

How frank can I be with you so I don't upset ya? [Doesn't wait for reply]. You see, we [him & wife with dementia] don't have a sexual relationship – we haven't had one for over four years. (Robert, Spousal Caregiver)

Robert proceeded to explain his annoyance at other caregivers, particularly women who were reluctant to use respite services due to a sense of marital duty.

I just say "for goodness' sake get a life!" – same as a lot of women – same as a lot of young lasses I talk to on the internet (laughs) – they're all drop dead gorgeous women, they really are but they say: "I want an older man" I say "why do you want an old man? why don't you want a young man?!" They'll say "because I caught him in bed with my best friend" and every woman's got the same tale – they must have the same guy writing the script for everybody! (Robert, Spousal Caregiver)

Robert's next quote reveals a potential mechanism that allows him to emotionally detach; he explained that he finds it easy to "move on" and therefore gives the same advice to women who are unable to overcome emotional attachments:

I'll say "well move on" – I had two wives – both had sex with other men, both – we had a divorce, my second wife left – I mean I'm being bad now aren't I because I'm doing the same to Brenda! (Robert, Spousal Caregiver)

Robert then referred to an incident he had mentioned earlier about a sexual relationship he had formed with a lady he met at a pub. This and the subsequent quote reveal how Robert struggles with stigma within his own community but is not afraid to address his needs. However, with Robert this was resulting in indulging in risky sexual behaviours. Sexual

behaviours were not included in the interview schedule as they are not measured in primary care as an LTC indicator, however risky sexual behaviours may give rise to more LTCs and are an important public health concern. Additionally, a lack of addressing one's sexual needs and the resulting impact on well-being can take an emotional toll on the caregiver as Robert had previously also mentioned that had it not been for the monetary support provided by the Council and the emotional support obtained through the dating websites he would be "hanging through a raft" due to issues pertaining to role captivity.

> But like I said they don't understand Brenda's condition, they don't realise how bad she is – I mean that one lady did – cos it were for one night – but you don't get many people that go on to my wavelength – so when you go home today – I'm *not* the norm! I'm not the norm (laughs). I've come out of the church [quieter tone] – <u>you don't wanna know why really – well</u>, I can tell ya – because I were unfaithful to Brenda at Christmas – so I reported myself to Church and pastor weren't amused with me – he said "if you'd have felt guilty" – I says "I don't feel guilty" and I says "I'm looking for more" I said "I want a friend with benefits" – and he weren't amused with that either – you know because my marriage vows should mean a lot more. (Robert, Spousal Caregiver)

Robert constantly demonstrated an awareness that speaking about personal matters might either be perceived as offensive to the researcher or might make him appear immoral, however he did not wait for a response before continuing to reveal personal matters. This may reflect the loneliness dementia family caregivers feel which manifests as a need to talk, which many caregivers (Karen, Anna, James, Janice) stated was a benefit of the interview as they felt it had been a "cathartic" experience.

6.2 Prioritising needs of PWD and other mechanisms & outcomes

6.2.1 Lack of focus on self

A lack of focus on oneself was first evident when caregivers struggled to report their LTCs and continuously spoke of the needs of the PWD instead of their own. As mentioned in the previously, after the pilot interview, questions were refined and made more explicit in order to clarify that they were asking about the caregivers' own health and needs, however caregivers continued to speak about the PWD. This demonstrated that most dementia family caregivers were unable to focus on themselves or address and acknowledge their own needs.

6.2.1.1   Unable to talk about self

After Karen listed her LTCs, she was asked about their onset and duration and she immediately started talking about the duration of her husband's diagnosis instead. Karen responded in a similar fashion when she was talking about her medications as well.

> **KAREN (Spousal Caregiver)**
>
> **Researcher: Have you had these [aforementioned long-term conditions] for long?**
>
> (Very quickly) How long has it been since his diag– uh (misunderstood the question).
>
> **Researcher: What medicines do you take, if any?**
>
> I take that cod liver oil capsule and B12 - and I'm still giving him B12 cos I know, I don't know whether there's been any improvement in him (talking about her own health becomes general as she starts talking about him, shows focus and priorities)
>
> How do you cope when you begin to feel low or negative again?

To be quite candid I don't know it just doesn't happen maybe I think of the positive

side straight away – I mean I have thoughts sometimes (hesitant to finish sentence

referring to previous suicide attempt again) – I give him a hug – if he seems low I give

him a hug.

As Karen's was the pilot interview, effort was made to make the questions as clear to the

caregiver as possible. However, much like Karen, Vanessa still started referring to her

husband's medication even though she was clearly being asked about her own.

VANESSA (Spousal Caregiver)

Researcher: Have you ever forgotten to take your own medicines due to that stress?

Well you see that's another thing – he never remembers to take them – I've got to tell

him – and I can put them there and he says he's taken them and he hasn't.

When filial caregivers were asked about their LTC appointments and monitoring they instantly

referred to the PWD's appointments and LTC-management instead.

ANNA (Filial Caregiver)

Researcher: When you need them [GP] like when you went for your osteoarthritis or

when you went for your blood pressure –

I have to ring – my mum goes for a twelve-monthly check for her medication and the

doctor goes through that with her.

DANIEL (Filial Caregiver)

Researcher: Did you ever miss or delay booking any of your *own* appointments because of all these caregiving responsibilities?

No no nothing – nothing to do with mother I'd never miss.

MAYA (Filial (in-law))

Researcher: Have you missed any of your own appointments for your *own* health?

No, I've never missed – when it's her appointment we have to tell that I've got appointment so you have to come with me because she won't go to doctor's.

6.2.1.2 Lack of reporting LTCs/probing caregiver to reveal LTCs

A lack of recognition of one's own needs was evident from the onset of the interviews. When asked about their long-term conditions, most dementia caregivers initially forgot or did not acknowledge some or all of their long-term conditions even after specific LTC names were provided through verbal and written prompts. This was also despite the fact that the caregivers had been identified by the recruiting organisations as having one or more long-term conditions; they had read the participant information sheets and been briefed regarding the purpose of the interview. Caregivers appeared to undermine the significance of their health and LTCs by using humour and an overall dismissiveness in tone and language. There could be a number of potential underlying mechanisms behind this, such as the caregiver being focused on the PWD; the caregiver feeling reluctant to admit compromised health in-case their competence to care is judged; the caregiver's health beliefs and knowledge regarding LTCs; these mechanisms have been discussed later. This theme shows how considerable probing was required from the researcher for the caregivers to admit,

acknowledge or remember all their long-term conditions. The accounts have been presented case-wise below. A lack of recognition of one's own needs is a significant barrier to self-management as it could potentially mean that caregivers may also 'forget' to reveal LTCs in front of health professionals, with whom they have limited contact under tight time constraints.

For example, Karen forgot to mention three of her other LTCs even after being specifically prompted multiple times. She later remembered these conditions when discussing symptoms and physical difficulties of providing care for her husband.

> **KAREN (Spousal Caregiver):**
>
> Irritable bowel and Hiatus hernia I think and yeah, yeah and a bad temper sometimes (laughs). (Does not mention other LTCs)
>
> **(Researcher asks probing questions regarding symptoms & pain from LTCs much later in the interview)**
>
> I've got a bruise – it's only a little one there – I don't know whether I've done it pushing him up. Well it's only to be expected cos I've got a metal plate in my ankle and that's the pain I get – oh and then I take my arthritis pills! But no I don't think that I've nothing that I go "oh!" (clutches chest to imitate heart attack pain; laughs).

Karen's description of her pain is indicative of her dismissive attitude towards her own health needs as she has to cater to the needs of her husband who is wheel-chair bound. Karen dismisses her symptoms as a natural consequence of her ankle surgery but does not consider that the pain may indicate that she should reduce the amount of physical exertion on her body. Although mentioned in jest, her final sentence indicates that for her to take symptoms

seriously they would have to be very serious and potentially life-threatening, much like a heart attack.

Vanessa revealed a similar dismissive attitude when asked about her conditions

> I have osteoporosis and I have something else – (pause 5 seconds) – oh I can't think – that might be it then eh? (Vanessa, Spousal Caregiver)

Likewise, Emily also forgot to mention some of her long-term conditions and spoke dismissively of her transient ischaemic attack (TIA). TIA's occur when blood flow to the brain is blocked often due to blood clots forming in blood vessels that have been narrowed by fatty deposits (Guyton & Hall, 2006). This condition is therefore often associated with ongoing long-term cardiovascular conditions. TIA's present with the same symptoms as a stroke however they do not last as long as a stroke (Guyton & Hall, 2006). The short period of duration does not reflect reduced seriousness and TIA's indicate that the patient is susceptible to stroke and further cerebrovascular events in the future (Guyton & Hall, 2006). Hypertension is considered one of the most significant modifiable risk factors for TIAs (Guyton & Hall, 2006; Kumar & Clark, 2009); Emily did not mention that she had hypertension until she was specifically asked about it. She spoke of her TIA as though it was an acute event and unrelated to her long-term health and other LTCs.

> **EMILY (Spousal Caregiver):**
>
> I had a TIA [transient ischaemic attack] about four year/ five year ago now and that's the only thing that's wrong with me really. (Does not mention other LTCs).
>
> **Researcher: So, are you taking any medication for blood pressure?**

Yeah blood pressure – blood thinner and an atorvastatin – a statin you know for uh – cholesterol.

Silent, asymptomatic long-term conditions such as hypertension or high cholesterol were frequently dismissed by dementia caregivers. Maya, Ethan and Andrew also undermined the presence and implications of these LTCs.

Ethan's initial response to having any long-term conditions was an abrupt "no". However, after being probed about the medications he takes, he revealed:

Oh – only high cholesterol and blood pressure but its only very marginal. (Andrew, Spousal Caregiver)

Ethan later dismissed his own health issues as playing an insignificant part in his caregiving role due to largely being asymptomatic:

(Laughs) I'm not concerned about my health – it's a minor detail I'm afraid – it's not bothering me. (Andrew, Spousal Caregiver)

Similarly, after much probing and when asked specifically about named LTCs such as hypertension and arthritis Andrew explained the state of his LTCs:

ANDREW [Spousal Caregiver)

Researcher: Have you had any surgeries?

I had a hip replacement due to my arthritis but I don't suffer from arthritis as such.

Researcher: What about blood pressure?

Well – only slightly it's not an issue with doctors or owt like that.

Andrew later revealed that the arthritis, which had created the need for a surgical hip replacement now made it difficult for him to carry out some activities of daily living and engage in his hobbies, which shows that in this response he had undermined the impact of this LTC. Andrew's response also highlights that medical opinion plays a significant role in determining his attitude towards his long-term conditions, which was not necessarily the case with all dementia caregivers.

Maya, on the other hand, although acknowledged that she had hypertension was dismissive in her response about its management as she did not appear to realise the pathophysiological implications of high blood-pressure but only related it to the amount of stress she felt.

> It's okay, blood pressure's not too bad because I calm down myself, I don't take pressure or anything you know, I take a day as it comes, I don't worry too much (laughs). (Maya, Filial (in-law) Caregiver)

Maya repeated a number of times throughout the interview that she doesn't "worry too much" and takes it "a day as it comes". The repetition and tonality of such, seemingly self-assuring statements were indicative in themselves of her reluctance to acknowledge the reality of the situation when it came to managing her own health and well-being whilst also managing her caregiving responsibilities. Her views however could also be reflective of her own health philosophy. Although she later acknowledged that her lack of attention to her LTCs had resulted in an emergency appointment with the doctor.

6.2.1.3 Lack of information

A lack of information regarding the self-management needs of LTCs and other health conditions, was evident in the data-set. This can be both a behavioural outcome resulting from a lack of time and focus on oneself due to the contextual conditioning of dementia caregiving; or it can be a behavioural mechanism that results in poor self-management in the context of health-beliefs. Some examples have been provided below. The responses indicated that caregivers were not inclined to ask about their needs either.

> I have some eye drops for a non-specific allergy – don't know what it is, cos it were at it this week and I thought it's winter! What's in winter to – you know that I've had to get these eye drops? (Karen, Spousal Caregiver)

Vanessa, who had multiple gastric long-term conditions mentioned on a number of occasions that she did not know how to manage her medications or diet.

> **VANESSA (Spousal Caregiver)**
>
> I have vitamin B12 – for what, I don't know!
>
> I know things I can't eat, but a lot of them I don't know – you know, what I do eat.
>
> Is that for hiatus hernia ah – no I don't know what they call 'em (laughs) – but I took box lid [to pharmacy] and I said "can I have some more of these?".
>
> Being able to look after myself – oh well I'm not that good – cos I never know what's gonna happen!

During the interview Vanessa was asked to rate her bodily pain on a scale of 1-10 with 10 being the highest, this analogue scale is commonly used in primary and community care settings by health professionals. Vanessa's response indicates that she does not understand the assessment procedures and does not try and find out about them either. This will naturally result in poor or inaccurate assessments. Her response highlights that perhaps people with long-term conditions need probing to ensure they understand what is being asked, this is particularly important with dementia caregivers who are already susceptible to a lack of focus and attention towards their own needs.

> Ah well – you see I can't really – they ask you that in hospital – "what's your pain?" – you don't know what they mean! (Vanessa, Spousal Caregiver)

Daniel was the only caregiver whose response indicated that perhaps there was a lack of clear communication and follow-up that resulted in his lack of knowledge. However, even his response shows that he did not make a personal effort to inquire about this and waited to be contacted by professionals instead.

> Oh, I haven't had those [steroids for RA] for nearly 12 months now cos they warned me that that could be – see there are so many different feedbacks – first of all they said I couldn't have more than one, and then she said I could have one every week – but nobody's sent for me?! (Daniel, Filial Caregiver)

The greatest indicator that caregivers were not trying to inquire about their health and address their health-needs was in the following quotes from filial caregivers.

Never thought about it [getting arthritic joint pain checked]. (Maya, Filial (in-law) Caregiver)

I never really thought about it [getting help for own health issues]. (Daniel, Filial Caregiver)

My health!? I don't really request any help or anything like that. (Janice, Filial Caregiver)

6.2.2 Beliefs and perceived significance/consequence of a lack of self-management behaviours

Upon further probing, caregivers' responses revealed that their perceived significance of certain self-management behaviours was an additional barrier to self-management. Previously Robert had joked about his wife's Alzheimer's medication having no impact on him; and Andrew had stated that he probably would not be taking his medications had he not been in a caregiving role. This theme further highlights issues pertaining to caregivers' perceptions and beliefs regarding self-management behaviours.

6.2.2.1 Medical behaviours

Daniel revealed that although he missed his medicines while he was away at his mother's house, he also did not believe in "taking pills" as he feared their side effects:

I've never been quite keen on taking pills. I read all the side effects and they are

bloomin' frightening – I said [to doctor] "I'd rather have the pain than take these risks

– heart failure, umm, bad joints – bad joints! This is what it's supposed to cure!".

[Doctor says] "Oh well it's been very successful" I said "I don't care – what if I'm 'that'

person?! – I could even die because of these damn things – so no!" (Daniel, Filial

Caregiver)

Ethan and Karen mentioned that since their medication does not seem to have a significant

impact on their health or life they are lenient with their adherence.

One for BP, one for cholesterol; aspirin to stop a stroke and two for prostate so that it

doesn't grow – and I miss them sometimes – it's pure inefficiency really – because I'm

doing other things – because I forget. It's not life or death – any of them (Ethan,

Spousal Caregiver).

Once again, in Karen's response, further probing revealed that the ultimate mechanism

underlying all of these beliefs is most likely still the mechanism of prioritising the PWD:

I think if mine were life threatening I'd be more careful. **[Researcher: Why?]** Because

it's life threatening! If something happens to me who's going to look after him? (Karen,

Spousal Caregiver)

6.2.2.2   Symptoms – attributing symptoms to old age

Other than undermining symptoms due to prioritising the PWD as seen in a previous theme,

caregivers also undermined and were dismissive of their symptoms as they perceived them a

natural consequence of ageing. However, when they spoke of their medicines and other LTCs

it became apparent that their symptoms were most likely linked to their LTCs and not just a natural part of the ageing process. For example, Karen was taking medicine for urinary incontinence which was related to her irritable bowel LTC. However, Karen dismissed her symptoms by saying:

> I do suffer a bit with my bladder actually but that's I think that's what all us women do especially when you get to menopause. (Karen, Spousal Caregiver)

Similarly, Emily's back pain was linked to long-term arthritic issues with her sacroiliac joint, however she dismissed it by saying:

> Well that comes anyway with age. Uh I mean I've always had a weak back – yeah my sacroiliac – I've always had problems with that. I do wear a belt around the back – but uh it doesn't stop me doing anything. (Emily, Spousal Caregiver)

Her response indicates that physical work aggravates her symptoms, however she was quick to add that these issues did not prevent her from any of her physical caregiving activities.

Vanessa had cataracts in both eyes which were seriously affecting her vision. Cataracts occur when the lens develop cloudy patches which obscure vision and eventually lead to blindness (NHS, 2017). In rare cases cataracts may occur in infancy or early childhood but most cataracts are age-related and occur in the elderly (NHS, 2017). However, the cause behind age-related cataracts is not clear and a number of risk factors have been linked to their development. These risk factors include the presence of certain LTCs such as diabetes or hypertension, prolonged use of steroid medication and risky health behaviours such as smoking and drinking (NHS, 2017). Of these risk factors Vanessa has hypertension and prolonged use of steroids

due to her osteoporosis, however, Vanessa dismissed her cataracts and their impact on her daily life as a normal process of ageing:

> Oh no it's too early [to operate] – but it's like now I can't see the same even though I've got my glasses and when go in a shop I can't see there – you know – its old age lass (laughs)! (Vanessa, Spousal Caregiver)

Likewise, Maria also laughed and said her arthritic pain symptoms do not prevent her from carrying out caregiving tasks.

> Not really [prevents from caregiving] just old age pains you know – pain in the neck and pain in the back (laughs). (Maria, Spousal Caregivers)

6.2.2.3   Exercise – self-perceptions of self-management

This theme demonstrates caregivers' self-perceptions of what constitutes adequate self-management of their long-term health conditions. It also reveals barriers to self-management behaviours such as exercise, however the theme emerged from questions regarding medical self-management of LTCs rather than specific exercise related questions. Through their responses most caregivers indicated that they considered general non-medical behaviours more important for the maintenance of their health than specific medical-related self-management tasks. Exercise, sleep and relaxation were spoken about most frequently and considered important by most caregivers when it came to managing their LTCs. For example, when asked how she was managing her LTCs Karen referred to her dietary and sleep behaviours, albeit in a dismissive, joking manner:

I'm sleeping okay at night. Doing all what I've been doing to get you know relaxation and what have ya. And I still take me [sic] two kiwi fruits (laughs) before I go to bed and its working (laughs)! (Karen, Spousal Caregiver)

Anna responded in a similar way, emphasising the importance of respite to allow time for relaxation and exercise.

> **Researcher: How do you manage these long-term conditions?**
>
> Exercise and relaxation – we have a static caravan [in a different city], so when that's open during the summer season I go there and I get my respite break once a month (Anna, Filial Caregiver)
>
> **[When discussing the need for a knee replacement due to arthritis]**
>
> I'm getting to the stage now where it's [arthritic knee] going to need doing [operating] – but it's been a very, very slow progression – but I do umm – I try and keep up with exercise (Anna, Filial Caregiver)

Although Anna acknowledged that she required medical intervention for her LTC symptoms, as mentioned earlier she was reluctant to arrange an appointment for herself because of her caregiving responsibilities towards her mother. Here she reveals, somewhat dismissively once again, that her arthritic knee probably requires more medical attention. Other caregivers also indicated that they considered exercise a significant facilitator to their LTC management but were often unable to find time for it.

> I think doing more exercise might do me good [for arthritis]. You know because I don't get much chance to do exercise but I should be doing exercise you know. (Maya, Filial (in-law) Caregiver)

> I kind of think – if I could get myself back into my swimming and my chill out mode I kind of think <u>that's my best medicine</u> – bit of exercise and some sleep – positive mental attitude – which I do have – but sometimes gets a bit battered. (Janice, Filial Caregiver)

Daniel also acknowledged the benefits of exercise and healthy eating, although he stated that he was not currently able to accommodate these activities in his caregiving routine:

> For me – getting really what I don't do – but having quite a lot of exercise and eating properly – you know don't starve yourself – don't do that – yeah I don't eat sensibly though – I don't – I eat a lot of fast food – I keep saying "I'm going to try and buy a lot more of…[healthy food]" – but that *does* help – fantastic – you feel healthier – you lose weight, you feel fantastic – and also physically you think quicker – and when you're out on your bike its surprising how therapeutic it is – because you start sorting your life out and then you feel better within yourself – it's surprising how – what seems like a big problem and you're thinking about it and you're out on your bike. (Daniel, Filial Caregiver)

6.3 Facilitators to self-management

6.3.1 Prioritising person with dementia

Many caregivers expressed that they were aware of the significance of maintaining their health as it had implications for the care of the PWD. Thus, prioritising the person with dementia was a mechanism that served not only as a barrier to self-management but also a facilitator. Some examples have been provided below.

I knew I had to look after myself before I could look after him. (Emily, Spousal

Caregiver)

Janice's response revealed that although caregiving was all-consuming, caregivers were

aware of changes to their health, and in this case prioritising the PWD was an important

facilitator to self-management.

I think you know your own body and you know when something's not right – it might

be something trivial but as it is at the moment I can't afford to be poorly and I think

if I can't look after myself then it'll be a major problem won't it! (Janice, Filial

Caregiver)

Andrew's response contained both a facilitator and barrier to self-management. While on the

one hand prioritising the care of his wife forced him to look after himself, he mentioned that

he might not have been so adherent with his medication if he did not have this incentive. This

indicates the potential role of health-beliefs.

Basically, these tablets and the cholesterol ones just do – well just maintain my health

so I don't have a stroke or that sort of thing. I don't know that I'd be taking them all

quite frankly, if you know, I weren't doing this caring role. I feel like I'm taking these

tablets to make sure that I stay alright. I know it's a thing that people neglect

themselves for the other person but it's like – it's an inbuilt thing with women if they

don't look after themselves they can't look after the children if they can't look after

the children they'll [children] die (laughs). You know what I mean so that's the thing

you know. (Andrew, Spousal Caregiver)

6.3.2 Fear of dementia

Emily mentioned that she stopped smoking after she witnessed her husband's and friend's health deteriorate due to dementia.

> When he [PWD] were diagnosed with dementia – well <u>it's sort of a crutch</u> – also – a friend of mine was in hospital at the time and she had dementia – and when I saw the state she were in I thought "that's it – <u>I don't want to end up like her</u>!" (laughs) – so that gave me the incentive to quit smoking! (Emily, Spousal Caregiver)

6.3.3 Deterioration of health

Consistent with previous findings, some caregivers acknowledged that they only addressed their health needs when their health deteriorated significantly. In Maya's case her first prompt had been the deterioration of her diabetes. She stated however that despite that emergency incident she still only makes an appointment if she is unwell. This reveals that issues regarding health can extend beyond caregiving or potentially be conditioned by the caregiving role, in Robert's words the PWD "unlearns" and becomes more and more dependent as dementia progresses; it is perhaps this conditioning that causes the caregiver to also 'unlearn' how to prioritise themselves.

> It's only doctor's when I'm poorly or something then I go, I don't regular go [sic] (laughs). (Maya, Filial (in-law) Caregiver)

Maria mentioned that she usually made an appointment with the GP when she felt overwhelmed by her mental health conditions. She had depression and anxiety therefore a

deterioration in her mental long-term conditions prompted her to take self-management action more often than her physical long-term conditions.

> You know it's like when I go for a few months and don't see the GP – it kind of comes up as a <u>build-up of stress</u> over time and then something triggers it [anxiety] off and "right I better do something about this – I better just go!". (Maria, Spousal Caregiver)

Maria explained that with regards to her physical long-term conditions she only went to the GP if it seemed serious. She recalled an "incident" when she was suffering serious chest pains which she had initially dismissed as indigestion, but as the pain had not subsided overnight she visited the GP. Due to her existing long-term conditions, such as hypertension, the GP suspected that she may be experiencing a heart attack and called an ambulance to take her to the hospital. Although the symptoms later subsided and Maria was not diagnosed with a myocardial infarction she mentioned that even on this occasion, her primary concern had not been her own health, rather it had been the welfare of her husband.

> I thought I'd had indigestion during the night and usually if I take a Rennie it clears up and it didn't so I rang my GP and got an appointment immediately and she took my blood pressure in the doctors' surgery and she said "I'm sorry I'm sending for an ambulance" – and they took me to the hospital and again thinking I was having a heart attack because of my heart rate and my pulse – it were absolutely racing – you know I didn't sort of feel particularly anxious at the time – but she [GP] was very concerned – and I was concerned at that point because Matthew was sat outside in the car and she let me go just into the car park to get Matthew in – and by this time the ambulance

had turned up and I was in the hospital – but I was discharged the same day. (Maria, Spousal Caregiver)

Maria added that she knows that her health symptoms can inevitably indicate serious issues but often her own health does not take precedence:

I think I know when things aren't right – and sometimes you sit and think "oh well I'll deal with that later". (Maria, Spousal Caregiver)

6.3.4 Prompts & support from family

Many spousal caregivers revealed the benefits of receiving prompts for self-management from their family members such as adult children. Vanessa, who had the most (7) long-term conditions in the entire sample and physical frailty, which is considered a long-term condition of its own, explained that her daughter helped her with medication and appointments.

I would forget if my daughter weren't there because she takes me down to the doctor's if I have to go and get medications and stuff like that – I wouldn't be able to manage without her. (Vanessa, Spousal Caregiver)

She also stressed how important it is to involve a family member in such tasks as the caregiving role can be so consuming that the caregiver does not "bother" to take care of themselves.

> You need somebody, like someone in the family to prompt you [to take care of your health]. You don't bother until you are struck down and then you really can't get about. And that does it. Too poorly to do owt and then you learn of it – a bit of sense. (Vanessa, Spousal Caregiver)

Maria explained how her daughters encouraged and supported her to attend a caregiver self-management course that has really helped her become diligent with self-management tasks.

> There were courses we could do you know 'looking after me' – I said "I can't leave Matthew" – my daughter said "(firm tone) mum you're gonna do it – how it's gonna be done we'll work it out – you are gonna do it!". (Maria, Spousal Caregiver)

James explained how he was undermining his symptoms until he mentioned them to his daughter who told him to take prompt action as it could be a sign of a major flare up.

> I told my daughter and she says "get to the doctor! Get to the doctor!" so I went to the doctor! (James, Spousal Caregiver)

Anna, a filial caregiver, of a similar age range to the spousal caregivers explained that since her only son suffered with a mental health condition and did not live with or near her, she had only her husband to rely on for additional support. She explained that often when her mental health or arthritic symptoms deteriorate, her husband manages her caregiving tasks and other chores.

> Along with the hypertension and the osteoarthritis I do suffer with depression as well – so some days if I've got a bad day I just won't go out anywhere so that's when my husband has got to step you know if we get a crisis. (Anna, Filial Caregiver)

6.3.4.1　　Prioritising PWD

Maya, lived with her sister-in-law as well as her husband and mother-in-law (PWD). She explained that ever since she had to make an emergency appointment due to the deterioration of her diabetes resulting from poor medication adherence, her sister-in-law now made sure to prompt her to take her medicines on time. She stated with a laugh that the incident made her family realise how important it is to keep her well, as she is her mother-in-law's primary caregiver.

> Now I take it [medication] regular, I don't miss it one day I just take it regular – if I forget my sister [in-law] reminds me (laughs) because she knows if I get poorly (laughs) everyone's gonna suffer – so if I get poorly it affects everybody. (Maya, Filial (in-law) Caregiver)

6.3.5 Using memory aids and written strategies

When asked if they have devised ways to overcome the barriers to self-management, some caregivers stated using memory aids such as pill organisers (dosette box).

Janice and Vanessa mentioned using dosette boxes to organise their medication.

> I have a li'l [little] box now [for medicines] that's the easiest way of dealing with it (Janice, Filial Caregiver)

Karen and Janice also mentioned using written strategies to help remember their self-management and other tasks.

> Well I write everything on the calendar. If I thought I was going to be forgetful – for example, if its two tablets three times a day – I'd cut six tablets off and leave it at the top of the microwave. (Karen, Spousal Caregiver)

Janice explained that due to her morning routine of checking up on her mother whilst also getting ready for work she tends to use "cards" to remind her to take her lunch; Janice's diet was particularly important for the management of her LTC.

> I mean I've got cards at home that I leave behind my door for reminding me to take my lunch to work cos you forget when you're rushing don't ya (laughs). (Janice, Filial Caregiver)

6.3.6 Goal-oriented strategies/behaviours

Some quotes revealed that the strategies caregivers were using to cope with and manage the mental and physical impact of caregiving and their LTCs appeared in the form of goal-oriented if-then plans. For example, Anna explained how she dealt with her depression and anxiety:

> If I wake up tomorrow morning and think I've got a black mist over me then I just take that day as it comes – sometimes I won't get washed and dressed or brush my teeth – and I just let it take its course – because I think it's my body saying to me "slow down" it's a safe day trigger – "you've been doing too much" – so I manage it myself. It's down to self-management again – knowing what your limits are if you feel tired then don't push yourself, sit down, take a breath and rest. (Anna, Filial Caregiver)

Andrew also explained his coping strategy in the form of an if-then sentence.

> If I ever get fed up – which is mostly through being physically tired – then I read the
> paper. I sit down and read the paper for ten minutes. (Andrew, Spousal Caregiver).

6.4   Conclusion to Chapter 6:

This chapter showed how the context and mechanisms mentioned in Chapter 5 influenced various self-management outcomes in the dementia family caregiver. The next chapter presents the methods and findings of a second study (Study 2) that was conducted to build further on these mechanisms.

CHAPTER 7: STUDY 2

7.1 Introduction

The cornerstone of realist evaluation research is to adopt a distinct perspective on how interventions affect and bring (or fail to bring) about change in their subjects (Pawson & Tilley, 1997). Integral to developing this understanding of an intervention is the "teacher-learner relationship" (Pawson & Tilley, 1997, p. 217) or "assisted sense-making" (Mark & Henry, 1999, p. 179). The teacher-learner relationship/function refers to the realist idea of co-constructed knowledge (Pawson & Tilley, 1997). Initially research participants are responding to what they think represents the interest of the researcher; this process involves some form of 'teaching' the participants about the programme theories being explored in the research. This serves the purpose of ensuring that to some degree, the participants will provide responses relevant to the C-M-O configuration pertaining to the research question. The participants, having 'learned' the research aims and questions are now able to 'teach' the researcher with their responses. This ongoing process comes full circle when the researcher, now informed by the participants' responses further 'tests', or in other words, explores their theories to progress the evaluation (Pawson & Tilley, 1997). In keeping with the realist evaluation cycle a second qualitative study was conducted in 2017. This study involved interviewing both the service-user and service-provider to gain further insights on the findings of the first study. This chapter presents a summarised account of the rationale, background, aims, methods and findings of the second study. Information relating to the previous study has been referred to as Study 1 or the first/main study/findings/data-set throughout the remainder of the thesis.

7.2 Rationale for Study 2

This section explains how the focus of Study 2 was defined based on the first data-set, existing practice and literature. Table 35 summarises the key methodological, literary and practice-based aspects that informed the rationale for Study 2; key terms have been italicised and explained in more detail later in this section.

Table 35   Rationale for Study 2

Key Points of reference	Rationale	Relevance to second study
Chapter 2: Research Philosophy and Design (The realist evaluation cycle)	Methodology Must build on existing data-set by further testing/exploring theories/findings in a second phase of data collection.	Findings from first study will be used to inform the design of the second study. Both service-users and service-providers will contribute to the *'teacher-learner function'* of realist data construction.
Chapter 3: Realist Review (Realist Explanatory Statement 6)	Building on existing literature If caregivers are provided regular verbal and written behaviour change strategies then they are more likely to engage in positive health-related behaviour change (Connell & Janevic, 2009).	Evaluate the potential use of written strategies in implementing/changing LTC self-management behaviours.
Chapter 3: Realist Review (Informal discussions with third-sector service-providers section 3.5)	Building on existing practice: Service-providers are currently using written techniques to monitor behaviour change in dementia caregivers.	

Chapter 4: Methods (Quality appraisal in template analysis)	Quality appraisal used in Template Analysis: Member-checking recommended by King and Brooks (2017), Nowell et al. (2017) and Lincoln & Guba (1985, 2017) as a way to improve credibility, transferability and confirmability of data	Conduct a *synthesised member check* (Birt, Scott, Caver, Campbell & Walter, 2016) on main findings with a selection of original caregiver sample and also with new service-provider sample.
Chapter 6: Outcomes Other mechanisms and outcomes (goal-oriented strategies and behaviours)	Methodology & Methods (quality appraisal of realist evaluations) Teacher-learner relationship developed; service-users' own self-management strategies explored further. Thus, provides dementia family caregiver perspective on mechanisms that may work to enable self-management.	Evaluate the use of 'if-then' plans of action to bring about behaviour change – also known as 'implementations intentions' (Gollwitzer, 1993)

Explaining key terms

Teacher-Learner Function:

Pawson and Tilley (1997) state that the teacher-learner function involves the researcher/interviewer taking an "active role in teaching" (p. 167) the research aims to the participants through the use of detailed explanatory passages, linking narratives and repeated checking questions.

Synthesised Member Check:

Birt et al. (2016) developed this detailed member-checking technique to be used in realist research as it allows the co-construction of knowledge by allowing participants "to engage with, and add to, interview and interpreted data, several months after their semi-structured interview" (p. 1802). Table 36 summarises the five stages of a synthesised member check (SMC) as described by Birt et al. (2016).

Table 36   Stages of synthesised member check

1.	Summarise themes in non-scientific language and use quotes to illustrate the themes
2.	Consider ethical implications of participants eligible for member-check. Ask gatekeeper who would benefit from member-check, based on their current health status and prognosis.
3.	Conduct SMC using open questions such as: "Does this match your experience?" "Do you want to change anything?" "Do you want to add anything?" (Birt et al., 2016, p. 1806).
4.	Add responses to data-set (thematic) template/framework; conduct descriptive statistics on dichotomous yes/no responses to themes.
5.	Cross-reference and integrate findings new and old, report disconfirming data.

Birt et al. (2016) state that member-checking techniques should match the epistemological approach to the study. In order to ensure in-depth data collection from both samples a semi-structured interview approach to this synthesised check was adopted. Using the same approach for both caregivers and service-providers allowed the researcher to maintain consistency across both samples. This approach also ensured that in-depth data would be collected that would enrich the original data-set. As sample sizes were small this approach was viable.

7.3 Aims and Objectives

Aim

To continue 'theory-testing' (evaluating) and 'theory-building' (refining) findings by conducting a synthesised-member check on the first data-set in order in order to gain a deeper understanding of the mechanisms which may act as potential barriers and facilitators to self-management from both a service-user (dementia family caregiver) and third-sector service-provider perspective.

Objectives

1) Improve and add to the findings of the Study 1 by checking with original respondents.

2) Gain insight on the barriers to self-management from a service provider perspective.

3) Check from both caregivers and service-providers whether written, goal-oriented strategies would work to bring about positive self-management behaviour change in dementia caregivers with LTCs.

7.4 Background Literature

The goal-oriented strategies investigated in this second study were strategies of implementations intentions (Gollwitzer, 1993). The choice of strategy was informed by the Study 1; as seen in the facilitators theme some of the strategies stated by caregivers were in the form of if-then plans for example, when Anna stated that she 'if' she feels emotionally overwhelmed 'then' she tries to rest, or when Karen stated that 'if' she thinks she will forget 'then' she writes her medications down on a calendar; such strategies are similar to the theory of implementations intentions proposed by Gollwitzer (1993) to bring about behavioural

changes. Implementations intentions are 'if-then' plans that link a critical situation (if) to a planned behavioural response (then) (Gollwitzer, 1993). Gollwitzer (1993) developed implementations intentions based on the distinction between the motivational and volitional phases of the original four-stage Rubicon model of behaviour change proposed by Heckhausen in 1987 (Gollwitzer, 2012), he termed this the Mindset theory of action phases. The Mindset theory proposes that a number of distinct cognitive appraisals are carried out between the decision to choose a goal and the implementation of the goal (Gollwitzer, 2012).

According to Gollwitzer (1993) and Keller and Gollwitzer (2017) people fail to implement goals due to a gap between choosing a goal and implementing the goal. Gollwitzer (1993) argues that this gap may be the result of considering more than one goal at a time and therefore implementations intentions can 'protect' the individual from conflicting cognitive appraisals by favouring and prioritising one "goal-directed behaviour with an anticipated situational context" (p. 152). Implementations intentions have been successfully applied to various clinical contexts such as appointment attendance (Sheeran, Aubrey & Kellett, 2007); diet (Prestwich, Ayres, & Lawton, 2008), smoking (Armitage, 2008; Armitage & Arden, 2008), depression and anxiety (Varley, Webb, & Sheeran, 2011). Chenoweth et al. (2016) utilised Bandura's 'self-efficacy for caring' model to coach dementia family caregivers to carry out smaller, more manageable goal-oriented caregiving tasks. The purpose of the latter study was to use goal-directed strategies to develop caregiver confidence in the face of difficult BPSD, reduce "hassles" (p. 1) and enable the caregiver to focus on their health needs in order to improve their health and well-being. Caregivers worked with coaches to write and monitor short and long-term goals and help-seeking behaviours focusing on "resource acquisition" (Chenoweth et al., 2016, p. 4) in order to achieve those goals. The results indicated that

individual coaching sessions achieved greater non-significant improvements in caregivers'

help-seeking behaviours, respite use and health status (based on the Short-Form-12)

compared to the group coaching and noncoaching samples. A qualitative study was also

carried out to receive feedback from the caregivers through semi-structured interviews. The

following are excerpts from the interviews conducted by Chenoweth et al. (2016), they show

how goal-oriented strategies helped caregivers in various situations:

> I am able to create strategies to prevent him from becoming agitated.
>
> (Caregiver quote reproduced from Chenoweth et al., 2016, p. 10)

> By creating goals it has made me feel strong and confident as I am able to create
>
> ways of convincing my care partner to do what I want him to do.
>
> (Caregiver quote reproduced from Chenoweth et al., 2016, p. 11)

> It definitely has improved my health and well-being, being on my own for just a
>
> couple of hours while my husband goes to respite care make me feel free.
>
> (Caregiver quote reproduced from Chenoweth et al., 2016, p. 11)

Evident from the quotes these strategies were mainly aimed at behaviours related to

caregiving and the PWD; goal-oriented strategies, specifically implementations intentions

have not been applied to dementia caregivers with regards to their self-management

activities for their own long-term conditions. As this was not only an extensively researched

and recognised theory but also unwittingly alluded to by caregivers themselves it was

selected as an optimal strategy upon which to carry out further qualitative investigations.

7.5 Methods

The themes were summarised (Appendix 14) and presented to the participants using examples from specific cases (Appendix 15) to illustrate the themes. The participants were questioned regarding the themes identified in the first phase of the interview to elicit further barriers, solutions and potential support available to help dementia caregivers. The interview schedule can be found in Appendix 16.

The same ethical guidelines and principles outlined in Study 1 were applied and followed for Study 2. An additional ethical precaution was taken by consulting the caregiver recruiting organisations to ask which participants from the original sample would be suited for a second interview considering their existing circumstances. A list of participants was provided and the researcher contacted the caregivers directly for interview, participant information sheets can be found in Appendices 17-18. Managers of the recruiting bodies were emailed with participant information sheets (Appendix 19) for the service-providers and asked to circulate these to their colleagues and staff members from their own and other collaborating organisations in order to recruit service-providers for interview.

Four of the caregivers from the original caregiver sample were interviewed along with six service-providers from within the third-sector and NHS' dementia memory clinics (Table 37). Separate ethical approval was obtained from SREP and written consent forms were completed for all participants (Appendix 10).

Safety measures were considered as they were for Study 1. The caregivers were interviewed in their home and the service-providers were interviewed at their place of work. Interviews

lasted between 1-2 hours. The interviews were recorded and transcribed verbatim by the

researcher/interviewer.

Table 37   Study 2 Participant characteristics

Service-Provider pseudonym	Gender & Ethnicity	Role & sector
Alice (previously *DFC)	Female – Caucasian	Staff member third-sector
Molly (previously *DFC)	Female – Caucasian	Staff member third-sector
Paige	Female – African	Staff member third-sector
Rose	Female – Caucasian	Staff member third-sector
Hannah	Female – Caucasian	Staff member third-sector (manager)
Aron (Previously *DFC)	Male – Caucasian	Staff member third-sector and NHS memory clinic
*DFC – Dementia Family Caregiver; these staff members had previously also been a family caregiver for a parent with dementia.		
Caregiver Pseudonym	Gender & Ethnicity	Relationship to PWD
Karen	Female – Caucasian	Spousal Caregiver
Maria	Female – Caucasian	Spousal Caregiver
Vanessa	Female – Caucasian	Spousal Caregiver
Ethan	Male – Caucasian	Spousal Caregiver

A similar six-step procedure to coding and Template Analysis was carried out in Study 1. However, this Study relied heavily on a-priori themes generated from the first data-set. The three main themes were as follows:

1. Mechanisms/outcomes/themes from first data-set that were further elaborated on by caregivers and/or service-providers

2. Data related to implementations intentions/ goal-oriented strategies

3. Data related to written strategies

Three members of the supervision team independently reviewed the interviews and codes. A pilot interview was also reviewed by the team members in order to ensure that the quality and style of questioning matched the aims of the study.

7.6 Findings

Table 38 shows the template for the key findings of Study 2. Themes were generally divided into three areas: 1) input from participants on the mechanisms and outcomes from Study 1; 2) views of participants on implementations intentions type strategies for specific self-management behaviour change and 3) views of participants on written strategies for behaviour change. The findings have been presented thematically; individual sub-themes have not necessarily been discussed under individual sub-headings as most were inclusive in single quotations, however they have been separated into barriers and facilitators where possible. Quotations have again been left in their long, raw form in keeping with realist methods. Salient points for discussion have been underlined throughout.

Table 38   Final Template Study 2

Contexts, Mechanisms and Outcomes discussed by participants	

→ **The context of dementia caregiving an all-consuming role**
 	
 Medication-related
 → **behaviours**
 	
 Barriers
 • Routine & time
 • Health beliefs
 • Forgetfulness and confusion
 • Guilt
 	
 Facilitators
 • Memory aides
 • Combined routine with PWD
 	
 → **Appointment-related behaviours**
 • Alternative routes and system benefits
 • Routine and time
 	
 → **Sleep-related behaviours**
 • Sleep hygiene
 	
 → **Exercise-related behaviours**
 	
   -
	→ **Matters of Respite & external support:**
	
	 Barriers
	 • Support not tailored to dementia & caregiver needs
	   - Negative experiences of respite
	   - Information & knowledge
	   - Funding & cost
	   - Professional well-being
	 • Caregiver choice and agency
	   - Relationship & attachment
	   - Caregiver identity
	   - Gender/age/family barriers
	   - Fear of being watched
	   - Guilt
	
	 • Lack of consistent care pathways and guidelines
	
	 Facilitators
	 • Tailoring respite for better quality care
	 • Prioritising the PWD
	   - Appraisal of long-term capacity to care:
	 Improved quality of Caregiver-PWD relationship

Implementations intentions strategies	**Views on written strategies**

Diet
 Smoking
 Drinking
 Emotional management
	Barriers to written strategies
	    Extra work/hassle
	    Literacy
	    Confidence
	    Health beliefs
	
	 Benefits and facilitators to written strategies
	    Monitoring
	    Ease of implementation:
	    existing/common daily practice
	    amongst most caregivers

7.6.1 Context, Mechanisms and Outcomes discussed by participants

There was an overall consensus amongst all participants on the existing issues faced by dementia family caregivers as highlighted by Study 1. This theme includes contexts, mechanisms and outcomes that participants chose to speak more about, thus either providing validation for the findings and/or additional insights into new C-M-Os. The staff members who have previously also been a caregiver for a parent have been marked with an asterisk next to their name after their quotes.

The context of dementia caregiving: An all-consuming role

Staff members agreed that role consumption was one of the major reasons why family caregivers of people with dementia struggled with implementing self-management behaviours. Some examples have been provided below and others have been discussed under specific mechanisms.

> It doesn't matter how bad their condition is – the severity of it – there are some tasks, but the work involved in the caring is actually common across a range of different types and severities of dementia – like preparing their food. Unless somebody has cared for someone with dementia they don't realise what it can entail – even if someone's dementia is not as progressed as another person's – they probably need the same level of basic care at home. (*Molly, Staff Member)

Staff member Alice, gave a similar example to caregiver Emily from the first study, regarding the comparison of dementia caregiving with other LTC caregiving.

Every illness has its you know – negative points – like someone with cancer there's the worry of it the stress of it and you know that there's going to be an end – but I think in terms of dementia – it's confusing because sometimes the people seem fine and there doesn't ever seem to be an end to it. (*Alice, Staff Member)

Aron highlighted a number of significant sacrifices, evident from the first data-set, that a family caregiver has to make when providing care for dementia:

They have to give up everything you know they might want a part time job or to do something for themselves which everybody is entitled to – and they have to sacrifice their whole life to looking after this person (*Aron, Staff Member)

Medication-related behaviours

With regards to medication, participants generally discussed issues pertaining to lack of a regular routine; methods to overcome these hurdles were also discussed such as the use of memory aids. Additionally, health beliefs related to adherence, which had been briefly alluded to by some caregivers in Study 1, reappeared in caregiver responses in Study 2. For example, the following conversation with Ethan highlights that caregiver beliefs about medication will play an integral role in the implementation and success of self-management support interventions and strategies:

ETHAN (Spousal Caregiver)

(Sigh) I don't know [how to try and remember medicines] because they are there on the dressing table – right in front of me.

Researcher: How could you make it more apparent to you?

I don't know – put a big notice on the breakfast table or something? I could do that.

Researcher: Exactly it's little things like that.

(With more confidence) Yes, I would put a notice! I mean I put one on to put my wheelie-bin out.

Researcher: Oh! So, you do it for the wheelie-bin?

I do it for the wheelie-bin yes – well that's more important!

Ethan, like Karen had mentioned in Study 1 that he would have be more diligent with his medication had the condition been been 'life-threatening'. Maria's response also reflected this view, although she emphasised that the main mechanism that gives rise to the problem is the lack of a regular routine:

> I don't notice that it's [missed medication] impacted it [own health] – it's just that I see these tablets over the month and they've accumulated and I think I probably should have taken that – but for me – if it didn't happen that morning with my cup of coffee then it didn't happen! – Cos I'd moved on then – so it had to be a routine but if you're not able to keep that routine – it becomes very hard. (Maria, Spousal Caregiver)

Vanessa echoed this view as she explained that although the use of a dosette box has been a helpful reminder, her adherence to medication is still largely dependent on her routine.

> I tell you what I do – I have a little box now and I put them in – and even then you can forget! But it isn't that you forget – we went out to a party yesterday you see – granddaughter's party and I put mine and Adam's [PWD] in a little box – well by the time we got there – he's supposed to have one a half an hour before the meals and I

am – and I forgot – that's because you are in another routine! (Vanessa, Spousal Caregiver)

Disruption of routine was one of the major barriers to self-management as seen in Study 1. Vanessa's response demonstrates the significance of a routine in self-management practices. People with regular routines are more likely to adhere to medication regimes (Solomon et al., 2015, WHO, 2003).

Karen explained the advantage of using multiple memory aids along with merging one's own routine with the PWD's medication routine. Karen's response indicates how prioritising the PWD's tasks can be used as a tool to develop strategies for self-management in the caregiver.

I usually take it with me when I'm out and if I've got it in my purse – I usually remember because I open my purse more often – or I put it in my glasses case and then I don't forget – and then if I've forgotten to take it when I've gone out I've had to take it when I come back – that's the only thing I can do. I'm not too bad with my medication – I just think it's quite important. And it's probably cos I'm doing his as well that I remember mine you see – I haven't to forget his so I take mine at the same time on the night ones and the morning ones. So, it does prompt me. (Karen, Spousal Caregiver)

Staff members also emphasised the significance of clear reminders and organisation skills as strategies to improve adherence.

What I do is put these pills out in the morning – set them out four in a row – then I know I've got to take them – it's being more organised – if you leave them in the box and say I'll go back at two o'clock or go back at four o'clock, you forget – it's not just keeping it in front of you but also having them set out in a way so you know when to take what. (*Molly, Staff Member)

In Study 1, some caregivers had mentioned that their medication can get "mixed up" and confused with the PWDs' medication as they have multiple routines to manage. Staff member Aron acknowledged a similar issue but also highlighted that there are further underlying mechanisms such as guilt and/or generational perspectives on medication use that could also be at play amongst these barriers.

I think sometimes people forget what medicines are for – if they get out of the habit of using something they forget what it's about and what they are trying to achieve. If they have not been taking it they might feel guilty about stuff. They might get a prescription and then feel guilty about – carers think of themselves as if they are a burden on the state – "oh I'm taking medication therefore I'm running up a bill for the state!"! (*Aron, Staff Member)

Molly also stated that the interrelatedness of the underlying mechanisms involved in creating role consumption is so complex that perhaps caregivers do not require self-management strategies as much as they require respite.

It might not just be that they need a reminder to take their own medication – it might also be that the person they are caring for – somebody just needs to take them out for a day, one day a week – so that person can recharge their batteries. It might not

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be just those particular things – the underlying causes could be very complex and interconnected – so maybe once the stress is taken away – I mean once somebody has taken responsibility for the person with the dementia – they might just be able to organise themselves and the other issues will resolve. (*Molly, Staff Member)

<u>Appointment-related behaviours</u>

Staff members agreed to the issues involved with appointment attendance, however they were keen to highlight the system benefits and alternative routes in place to help such caregivers. Some caregivers also highlighted that they were now aware of and utilising these benefits.

Appointments for the doctors can be made in different ways these days. I think people always think "oh I couldn't get a hold of them on the phone" or "it's too far to travel" – there are other ways – a lot of GP practices have an email system now as well – so don't give up on just the basis of what you've experienced before. Some practices have changed their working hours – some of them have well-man clinics or well-woman clinics. Sometimes they will prioritise carers – because they realise there are two people or more than two people in that makeup maybe – so there are some different scenarios there. (Paige, Staff Member)

Caregiver Karen's response indicated that these measures were indeed helping caregivers in their appointment-management. Karen highlighted that it is the effort of these third-sector organisations that have helped create awareness for the specific needs and difficulties of dementia family caregivers.

You see I'm <u>down as a carer at the GP</u> – so we take priority – we are classed as emergency appointments if we ring. Carers Count advice people to do that – have a word with the doctors and they'll say "oh we haven't got an appointment till next week bla bla bla" – well you'll get one the same day if it's possible and I can't fault them on that. She [GP receptionist] rang me up last week when my blood test came back and she said "I'd like you to make an appointment" I said "it'll be two appointments" she said I'll make them on the same day to make it easier – so I was able to do it – the appointment after was to see the nurse. So, I didn't have to go twice – so that doesn't cause any problems really now. It used to cause problems at other one – but since Carers Count are going around to the doctors' surgeries with their information – it's obviously gone through and they've realised "if you're a carer – if you're ill – who's gonna care for him [PWD]? So we'll hit it before it happens!". (Karen, Spousal Caregiver)

However, overall staff responses indicate that service-providers expect a level of agency from caregivers with regards to self-management:

Contact the doctor and explain the problem! See if the health centre can arrange an alternative like a consultation over the phone or something like that? (Rose, Staff Member)

The assumption that caregivers are willing to take the initiative in the first place may itself be a barrier to providing adequate self-management support and this issue was addressed by some staff members who had previously also cared for a family member with dementia.

In my experience getting an appointment with the doctor is a difficult thing anyway to be honest. So, for a carer bottom line is that it's more work – it's more stuff to do. I think respite is the biggest thing because actually maybe even thinking about it – so thinking about going to an appointment – I can imagine might even create more stress cos you have to work out how you are going to do that – so actually if you don't do that then you don't have to worry about working out how! (*Aron, Staff Member)

Like Aron and Alice, Hannah also stated that for medical self-management, other than understanding the need for self-management, caregivers require adequate respite time, otherwise they will continue prioritising the needs of the PWD above their own.

I would say that the big one is that there's no one to look after the person that they care for. And maybe just generally forgetting about themselves – just forgetting that they need to have an appointment because they are so fixed on the person they care for – possibly not valuing their own health and thinking that they need an appointment. (Hannah, Staff Member)

Sleep-related behaviours

With regards to sleep, staff member Aron pointed out that this is an underrated aspect of good health and self-management and requires better monitoring and support.

We are sitting on a time bomb with sleep because it's linked to so many health problems. We are really sitting on a time bomb – I found it really helpful going to my GP to talk about sleep. And I still haven't found a solution to my sleep problems really – they're still there – I'm lucky if I get three hours a night. (*Aron, Staff Member)

Aron and Molly both discussed the significance of education and awareness around sleep hygiene:

> It's really difficult – really difficult – NHS is not really good at sleep stuff really – again it comes back to finding time to relax – if it's all wrapped up in the caring responsibilities. But sometimes there's a bigger story behind that. So, what are the sleep routines? What's the sleep hygiene? Looking into patterns of sleep – what is happening that's stopping you from sleep? What can you do about those individual bits and pieces? You see you can't sleep if you're a carer – it makes it so much more difficult to do this stuff – particularly if they've got someone who is wandering – it's the sun-downing thing. When I was a service-user I took medication to help me sleep. When I came off it – I couldn't sleep. They [doctors] think it's a really bad thing to make people dependent on something that helps them sleep; I think it's a really bad thing to be sleepless. I'd much rather be able to get [sleep] – I think my trade-off is: I'm dependent on something that makes me sleep. I don't want dementia myself!
> (*Aron, Staff Member)

Aron's response refers to a number of issues experienced by caregivers. It was seen in Study 1 that Maria was not able to take certain medications as she had to stay alert at night due to her husband's continuous attempts at escaping/wandering. However, Aron emphasised that a lack of sleep comes with its own long-term physical and mental health issues which will eventually impact the caregivers' ability to provide care anyway. Aron also highlighted the fear of dementia which some caregivers had previously alluded to and other staff members also highlighted in this study.

Molly emphasised the significance of lifestyle on sleep hygiene, particularly if caregivers need to avoid dependence on sleep-inducing drugs.

> I know some people just can't get back to sleep if they've been woken up. Relaxing like taking up something – see I do swimming and gym and that all helps to sleep. So, I think some of that comes down to lifestyle – so they need to take up hobbies or pastimes where they spend a certain amount of time doing something that relaxes their body – like swimming – I also do meditation and walking. So, I would talk to people and find something that helps them relax – doesn't have to be a big task if it's not possible for them but something – I mean the other alternative is to take sleeping tablets – but then you're back into the routine of dependence. I think another thing people have to realise is that sleep hygiene isn't just at the point of going to sleep – it's a whole lifestyle that dictates it – so bigger changes are necessary otherwise they won't bring about lasting change. (Molly, Staff Member)

Exercise-related behaviours:

Exercise was another self-management behaviour that participants discussed in further detail. Both staff members and caregivers highlighted that exercise advice needs to be specifically tailored to the needs and circumstances of the caregiver and the PWD in order to reduce barriers. Molly and Paige highlighted that many dementia family caregivers are themselves old with long-term conditions that cause pain and limit movement, this accompanied with a lack of time and energy due to caregiving results in further barriers to developing a regular exercise routine. Paige also highlighted the role of medical professionals in health promoting advice and behaviour change.

I think it's having time and it's having the ability as well, conditions like arthritis are painful so it's not enjoyable to them, so maybe having them think of exercise like physical ones will put them off. Maybe just encourage them to go for a walk with someone, especially the one they care for. (*Molly, Staff Member)

People think exercise and they automatically think something strenuous that they are not going to enjoy – I think doctors should encourage people to walk. (Paige, Staff Member)

Vanessa confirmed the issues raised by Molly when she explained that the exercises advised by her doctor have created more pain due to her multiple long-term conditions and this has prevented her from continuing with them.

Exercise is too strenuous so it puts me off altogether. Doctor gave me these exercises – and I thought (laughs) my back's not good again. It knocked my back because I had a right back pain when I came out of hospital. (Vanessa, Caregiver)

Matters of respite & external support:

It was highlighted in Study 1 that respite and external support may not necessarily enable self-management behaviours in the caregiver due to other mechanisms such as merging identities, guilt, previous negative experiences of respite and a perceived lack of understanding from professionals regarding the nature of dementia. However, as evident by Study 2, many staff members appeared to believe that respite was an integral mechanism in alleviating other barriers to self-management and so this aspect was discussed in considerable detail by the service-providers. Staff responses validated the caregivers'

reservations and barriers to accepting or accessing respite, however, they also offered deeper insight into the problems, particularly highlighting certain system issues that were out of the staff members' own control.

Barriers:

Karen reiterated her reservations about using permanent care services:

> And you can't shove them all in a home – and shoving them in a home is a death note – it really is. All the people that I've known that's gone in – they haven't lasted two minutes – I can see that through [named service] – how they've all – you know we're the only ones left of the originals! (Karen, Spousal Caregiver)

Staff members agreed that negative experiences of respite are a significant and justified contributor to preventing caregivers from accessing or accepting respite services.

> You go back to care homes and the things that happen in care homes that they tell me – I can't talk about it but – I just think when is – when is somebody going to take charge of this and make it easy and simple – for all of them?! (*Alice, Staff Member)

Like caregiver Daniel had stated in Study 1, Alice also mentioned that even professionals did not appear to understand the sensitive needs of a person with dementia:

> I know one doctor – somebody had had an accident with dementia – and the doctor said "oh well you'll be able to go home now" – so the doctor meant tomorrow because it's late – but this chap sat waiting all dressed from midnight onwards, waiting for someone to come and pick him – cos the doctor said you can go "now". You have to

deal with dementia differently, and I thought this is somebody who's educated – who's supposed to be trained and they don't know how to speak to people! (*Alice, Staff Member)

Staff member Aron who, like Alice, had also previously been a dementia family caregiver for his mother, echoed these views:

Having a bad experience in the past with respite – yes, I recognise that one – I had plenty – I could write a book about it – not a very pleasant book. (*Aron, Staff Member)

He further stated that some of the issues related to a lack of continuity of care for the PWD are in place to protect the professional, although this can be very disconcerting and distressing for the PWD and their caregiver:

Mum had dementia and we wanted to keep her at home for as long as possible – so the people coming in who she didn't know and every day they were different – and so apparently the reason for that is so they [professional caregivers] don't get attached – and I just think well so you have a stranger coming in your house taking your clothes off washing your body and a different one every day! (*Aron, Staff Member)

Alice highlighted that although safety measures in place for the well-being of the professional may appear to be a barrier for caregivers in accepting external support, however, for the professional this is an important and often overlooked aspect of dementia care.

Because it's such an emotionally draining job – to be around it all day – you're faced with your own mortality – I'm faced with my own mortality every day you know, I'm faced with the fear – is this going to happen to me?! (*Alice, Staff Member)

This fear was also shared by family caregivers in Study 1, and for some it provided an incentive to improve their own health and well-being.

Staff members also explained that a lack of funding means that dementia care and respite cannot be tailored to suit the needs of the caregivers and PWDs. For example, Rose mentioned that in order to enable caregivers to attend support sessions, services require adequate provisions in place for the care of the PWD.

I do think respite is the biggest issue – because I – we've just had to close a group that we did once a month – and uh they came at half past ten and – uh left at half past two and we got entertainers and lunch, and carers bought people with dementia with them there – and it was like (laughs) – cos they got to breath – and the people with dementia loved this group – but the costing of it – and we had to finish it – and they looked forward to that every month! That's all they got – some people are now living on their own and they're coming once a month – and so – it's about the funding, it's about you know, staffing – and so somebody with dementia who's not bad can come to the groups and they come for a long time and they get worse and worse and worse and we really shouldn't be having them then – because we're not – you know nursing or – that sort of thing – and we should say "you can't come anymore" – it's all kind of twisted – it's really twisted. Sometimes they are the services for the person who's being cared for and then there's the support services like us – for the carer – we don't

have any money in our contract to be able to say "carer you can come along to our group we will pay for somebody to sit with the person that you care for". (Rose, Staff Member)

Alice and Hannah further explained that many third-sector support sessions are managed by unpaid volunteers:

A lot of these places are run by volunteers so where would we be without volunteers?! (*Alice, Staff Member)

It was that carer-break service but it relied quite heavily on the volunteers to be able to go and sit with the person who was being cared for. (Hannah, Staff Member)

As mentioned before, some staff members placed a greater emphasis on caregiver choice and agency when it came to self-management behaviour change. They stated that accessing and accepting support was in fact a matter of choice that the caregivers would not make until they reached a critical stage in their journey.

They think they have a choice that it's either at home or in the care home and they just carry on and carry on and they'll fight till the bitter end until sometimes they're on their knees with despair. (*Alice, Staff Member)

Until something collapses you'll just keep plodding along – that's the easier option – just to keep going. (Paige, Staff Member)

Molly explained that the underlying mechanism behind this reluctance to accept support can be due to a number of reasons, primarily the costs versus the quality of care received as mentioned in Study 1, however she also stated that this choice can result in the caregiver and PWD requiring emergency care and support.

> I think what puts people off is the service you get from people coming in and the cost of it. And you think well you could be sitting there waiting for half an hour for them to turn up. But I think it gets to the point where you have to have somebody. People tend to leave it to a point where they can't manage at all then they get somebody to come in – I know a carer who has done that and she has ended up in hospital. I think a lot of it puts people off about letting go is 1) it could be the service and 2) it could be that people still think they can manage when actually they can't and 3) the cost. If somebody has only got so much money and they keep thinking "oh I have to keep paying for somebody to come and look after [PWD] – I won't have any savings" – and then a lot of it comes down to how much you're allowed to have in your savings before – if people get old, they don't like their savings to disappear because they feel like it's a safety net. (*Molly, Staff Member)

Drawing on his own experiences Aron acknowledged the guilt felt by family caregivers when using respite services:

> Feeling guilty about respite – ABSOLUTELY – it's a dreadful feeling – dreadful – mum didn't like going into respite care and I felt – many, many, many tears were shed. (*Aron, Staff Member)

Hannah also acknowledged this guilt, however, also pointed out that a lack of self-management can also eventually lead to more guilt for the caregiver:

It's about putting more value on themselves. If they don't keep themselves well, then, the person they care for can go downhill as well – without adding extra guilt on cos that could act extra guilt on – they could end up feeling even more guilty. Yeah, it's a really tricky one! (Hannah, Staff Member)

Aron did state that ultimately accepting support was still the caregivers' choice and merging one's identity with being a caregiver was an enormous barrier to enabling self-management support from a service-provider perspective.

Another thing is registering as a carer that people don't understand – there are certain kinds of help you are going to get if you register as a carer – if you aren't then you are kind of invisible to a system that you don't know yet. I have talked to hundreds of carers who knew they were carers – but I've also talked to carers who didn't see themselves as a carer they were just *caring*. Carer is a technical label really – but they didn't see themselves as unpaid carers. "I'm a son" or "a daughter" or "a wife" yeah and fair enough but there are advantages to it – and that's what I will point out that there are advantages to being a carer. In actual fact – carers as a movement is a big thing now – so in society – resource wise, people need to know: this is the amount of carers, this is what they're made up of, this is where they live, these are the people they are looking after, this is the amount of money they SAVE us! And that's for the people we know of – all the other folk!? There are people out there with services that

can help but if they don't know who you are how can they reach you? (*Aron, Staff Member)

Hannah highlighted that it was perhaps the role of the service-provider to make the caregiver aware of their new role and identity, as it can be difficult for a caregiver to dissociate from their familial roles even if they want to, she also stated that such discussions can initially upset caregivers:

> A lady came in the other day and I don't think she necessarily wanted to be a carer – but felt that she had to be and I think I might have been the first person – cos she got upset when I said it so I wonder if I was the first person to say that to her. But I said "you don't have to do it" – she was caring for her son and I said "just because he's your son doesn't mean you have to care for him – there are organisations that will help him get his tenancy" and so it's giving the carer some choice as well and letting them know that they've got some choice. (Hannah, Staff Member)

As in the case above, another example of the caregiver merging their identity with their caregiving role was evident from this second data-set through caregiver Maria's response:

> It's isolating really – although I have a lot of free time – I don't feel free – I'm not free and I don't want to be free! It sounds silly that, doesn't it? I'm still very much Matthew's wife. (Maria, Spousal Caregiver)

Aron and Paige highlighted that there are generational and gender barriers to accepting support from extended family and friends as well, which can further isolate and overburden the caregiver.

I think the problem is loads of people would like to go [out] but they don't leave because there's nobody to look after their [PWD] – it's kind of like they think "oh I've got to ask so and so again can you come please for two hours while I go and – oh ugh I won't bother". The thing is there's still an option – so don't dismiss the situation. I mean if sometimes you really have to do it – I used to hate doing it but sometimes I just had to you know phone my cousin or phone my neighbour – loads of people are reluctant in seeking help – and particularly men I think – we're terrible at it – so you just have to weigh things up (*Aron, Staff Member)

In Study 1 filial caregivers had highlighted the difficulty in providing care for an older parent with dementia due to the generational barriers involved with accepting help. Paige highlighted that these issues are not limited to the PWD and apply in particular to older spousal caregivers as well.

Some people have a lot of pride – and certain generations where they don't want to ask for help or it's seen as a weakness to ask. (Paige, Staff Member)

Karen had explained in Study 1 that she refused to contact the Admiral nurses after they gave her a "ticking off" for her behaviour towards her husband. Alice also alluded to this fear as being a barrier to caregivers accessing self-management support when needed:

I think sometimes people worry that if they highlight issues about themselves then the services kind of start to interfere – cos carers sometimes feel a bit watched – invigilated. So, there are some anxieties around that. (*Alice, Staff Member)

Additionally, many service-providers highlighted that a key system issue was due to a lack of specific and consistent guidelines and care pathways to support dementia family caregivers. Staff members discussed how a lack of coordination and timed delivery of information and support result in ineffective use of services. For example, Hannah explained that third-sector support service-providers are primarily responsible for the support and care of the dementia family caregiver, however her response reveals that the adherence to the care pathway relies mainly on "chance":

> We are the first port of call for carers – <u>we would hope</u> that if they didn't know about us – that they'd google something or they'd ring the council and that the council would then put them in our direction. We would hope that if the carer had to take the person that they care for to the doctors – that one or either of them would see the posters up, see the carers board. We then <u>would hope</u> that either the receptionist, the practice nurse or the GP would say "are you a carer? – I can refer you to this organisation" – that's the idea. (Hannah, Staff Member)

Aron's response also indicated a similar perspective on care pathways, although he highlighted the role of the caregiver in enabling this pathway by first identifying themselves as a caregiver.

> There are pathways in the sense that if you are caring for someone and there are services involved – that service should be asking you about yourself if you are a carer and they should be signposting you to other stuff. If you go to your GP and tell him then that should alert him to signpost you to other stuff. There are these pathways it's just that where it goes wrong is when people are not identifying themselves as

carers or are let down by people who are not doing that pathways work – so I think that's where the gap's been. Sometimes there's a mismatch between what needs to happen and what does happen. (*Aron, Staff Member)

Alice highlighted that a greater underlying problem is the point at which people receive information for support and self-management. She explained that the initial signposting usually occurs in a memory clinic after the PWD has been diagnosed. She explains, however, that this may not be the most appropriate time for the caregiver to be able to absorb or be concerned about this information, and therefore as mentioned by caregivers in Study 1 regular and routine monitoring of caregiver needs is required to optimise service-use.

It's all good in theory – I just think people need a lot of support and guidance – because if the doctor doesn't tell them to come and see us after they've had their diagnosis – they don't even know – so they think "what do we do now? Where do we go to?" – the only thing they can think of is go back to the doctor! It's kind of like – "this is what you've got – alright bye!" – let someone else in – I don't think there's enough support from GPs, I don't think there's enough support from doctors in hospitals or nurses – unless they are trained about it. Unless the doctor says do you want to go in here or – it needs organising differently – because really – after the diagnosis to say to them "have a quick word with them [support services] when you finish" – because you know, they might not want to see anyone after their diagnosis because they're too sad. (*Alice, Staff Member)

Aron also pointed out that the timing of information is dependent on the timing of the caregivers' needs. However due to a lack of clear guidance, communication and integration, the information circulating between services is not always the same or up-to-date:

> They [caregivers] might see dozens of different services and just not remember that they've been told about something or might not want to hear it at the time. So, you kind of go full circle and realise – but when you start on these journeys with someone with dementia – unless you are in our services and you know a lot about health, you are not necessarily gonna know any of this stuff – so I wouldn't expect it to be anything other than a bit chaotic at first – really, to be honest. And I don't think that will change necessarily really because people only need to know what they need to know and when they need to know it. I just think if there was wider knowledge out there of the support for carers and that they are recognised and respected – there would just be a bit more knowledge in the community. Nature of the beast is that um services – workers aren't able to keep everything current in their head so they struggle sometimes to give people the right information – and they [caregivers] will subsequently find out and say "why didn't anyone tell me about that?!" – they [service-providers] weren't doing it on purpose – didn't know – forgot – weren't confident the knowledge they were going to give was correct – didn't know whatever the service is and therefore weren't willing to trust it. A lot of things are based on trust and sound and first-hand knowledge or the knowledge of other people that they trust. It is a commonly heard thing. Don't know what else you can do? (*Aron, Staff Member)

Rose highlighted that services need to work together efficiently in order to provide seamless care and support for caregivers in a timely manner:

> A few people that I've met along the way – a big worry is – if something happens to them – and I can see that they really *really* suffer with this – if the persons got dementia and they're looking after them and they know they've got something themselves and they know they might have to go into hospital – "What do we do?! What's going to happen to this person?! Who's going to look after them and who's going to take care of them?!" and I have to help them with that and tell them where to go and who to talk to and then hopefully they'll tell me what – because that's somebody else's department that's not my department and people really, really worry – it causes a lot of anxiety, a lot of pressure. (Rose, Staff Member)

Molly mentioned that the existing care pathways and advice available needs to encompass providing and signposting to specific, holistic and realistic self-management activities and services, as these are often overlooked in the primary and secondary care of LTCs:

> People can get into a rut being ill. When people have been very ill for a period of time – it's about getting back into – or finding something less strenuous – if it's sports or dancing – so I think really it's about people needing to find out about what's available. GPs talk about PALS [Patient Advice and Liaison Service] and there's also some social networking they would recommend but maybe there needs to be more focus on that – we've always said when people go to the doctor, they are quick to hand out antidepressants and different medications rather than talking about the obvious self-care things like exercise, going out, hobbies, social – you know – rather than just saying

"here's some more antidepressants" they need to be saying to people "there's these groups available – you don't have to sit alone at home – there's all this available for you". (*Molly, Staff Member)

Vanessa, who in Study 1 had stated that there is insufficient support and information for caregivers, now mentioned that perhaps there is too much information and the problem, as highlighted by the staff members above, is about the timely distribution of this information:

I think there's too much information actually, it's [about] getting it, kind of so it comes across to people, so they don't just get stacks and leaflets – it needs to be recommended. I went to 'Looking After Yourself' [Looking After Me – self management course] but I didn't get through it – it were a long do it were. (Vanessa, Spousal Caregiver)

Facilitators:

Caregivers and staff members mentioned that there are ways in which PWD distress at respite services can be reduced and thus utility of these services increased. Staff members placed a significant focus on using 'prioritising the PWD' as a central mechanism to promote and encourage service use and alleviate some of the stresses of caregiving. Staff members explained the significance of providing adequate counselling to caregivers in order for them to overcome the underlying mechanisms acting as barriers to accepting and utilising services.

When it hits them and they actually realise that their health was suffering – their mental and physical health was suffering so badly – my experience from what people have said – that if it had gone on any longer they would not have been able to care for

that person because they then would become really ill – so I think when they realise it's the only way to go – um and I think it's a long process and I think they do need counselling for it. They need counselling and to be told that you're are okay and you are not a bad person – they don't have to feel guilty – I mean you can't tell someone don't feel guilty when they do but –! (*Alice, Staff Member)

Aron and Paige explained how they use 'prioritising the PWD' as a tool and incentive to help caregivers prioritise themselves:

The solution – is really to get in the frame of mind that if you aren't looking after yourself then you are not going to be able to look after your loved one. So, you need to get into that frame of mind 'fit and well to care'. I mean if you work for the council – that's the mantra for the council – 'fit and well to care' – so they want the staff to look after themselves – because if the staff doesn't look after themselves they won't be fit and well to 'care'. (*Aron, Staff Member)

I'd probably say that you need to look after yourself because if you aren't mentally and physically in good health then you would struggle to be able to look after that individual – so without being preachy or judgemental I would be thinking of their health and just like being a parent where, you know, you have to keep yourself well in order to keep your family well – so that's how I'd try to make them think of themselves. I understand because they don't want the focus to be taken away from the person that they are caring for but I would sort of say that they need to think about themselves first and ask what's stopping them and what they need – like getting a befriender – look at other options too maybe other family members – like family that's

nearby – it's giving them the peace of mind. Once they know that individual [PWD] is being cared for they might be encouraged take care of their own needs. (Paige, Staff Member)

Rose explained that it also helps to ask caregivers to view exploring external support options earlier in the caregiving journey as a safety-net, in case of emergencies. She stated that highlighting the significance of being well-informed can empower a caregiver and relieve some of their underlying concerns about the quality of external support provided.

Anxiety is very understandable – people are worried about their health condition – however a lot of health conditions can be treated if they are addressed early and so it's often about a solution even though it's scary at the time. Also, it will help with caring because if that's their priority then they need to be well in order to carry it out. I mean it was very often in a circumstance that the cared for person had suddenly become very poorly – so typically a couple who was quite elderly – both been in okay-ish health and then one of them would have had a stroke and there were severe consequences of that stroke so in this situation the carer suddenly has to increase the amount of care. So they then have to appraise that new situation and they realise that it would be better to put them in a home. It won't go away – you might as well do it now and not worry about it because that'll cause more stress – the fact that you're worrying about it. if you leave it too late you'll never forgive yourself – you might have been able to do something about it. that's the way I look at it now. It doesn't matter in any illness – the earlier you get it the better. Don't leave it – it could end up with something nasty you know what I mean. Worry can kill ya easier than other things. (Rose, Staff Member)

Other staff members also explained that the caregiver must see the benefits of respite and support services for the PWD in terms of building an improved caregiver-PWD relationship.

> Well usually (confidently as if common case), very often by the time this [respite advice] is happening – people are kind of at the end of their tether and so you know I would talk about the quality of the relationship with the person they are caring for – one of the benefits of having somebody else doing the kind of routine day to day care is that when the carer sees the cared for person – they are able to give them better quality time – in terms of being with them in a relationship, because they are not tired or worn out and haven't had an argument with them over getting their clothes on or whatever – somebody else has done all that – and they can just go and be with them or visit them and have a nice time – bring some treats in and watch a program on telly together and not be fretting about what else they should be doing at the same time. So, it actually helps people have a better quality time when they're with the cared for person – that's really important in terms of – especially if it's something that looks like it's going to last a long time – it's a better end in terms of last few years of life or whatever than if they're just running to the ground and they can't communicate well because they're just together all the time. Just sort of being aware of that and actually making that decision and when I talk to them about it – that's the sort of thing they come out with by themselves – "I'll be able to be nicer to him if I'm not spending all my time cleaning up after him and have my own life as well". (Rose, Staff Member)

The health and safety risks of the physical aspects of caregiving were evident in Study 1, particularly for female spousal caregivers with mobility issues and frailty concerns. Alice mentioned that caregivers don't realise that they risk not just their own safety but also the

safety of the PWD in cases where manual handling is concerned. In accordance with the findings of Study 1, Alice also stated that such acts of caregiving can create resentment, and therefore utilising external services can improve the caregivers' relationship with the PWD.

> I just say to them while you've got your time you can get your rest – you can do something for yourself – and when you go see your husband or wife you might be renewed to deal with what's going on because you've had your rest – someone else is doing all the heavy work – you know a lot of women are trying to you know – lift big men – getting washed and go to the toilet – and it's heavy work and they are struggling – so someone else is doing that hard work and they can go and feed them mentally and with love – because they can deal with it –and I think maybe even though a lot of people don't admit it, there is some resentment there and that can tend to go because the heartache has been taken off them. (*Alice, Staff Member)

Aron also highlighted that in addition to the benefits to the relationship, it is worth pointing out the benefits to the PWD's health as once again 'prioritising the PWD' may provide a stronger incentive for the caregiver to explore other options and services in order to reduce isolation and inactivity.

> So how can you make it fun and incorporate it into your routine without it feeling like just another thing to do? You could even try and do it with the person you love. There are people with dementia who go on walks with their loved ones – so it's about exploring what you can do together and with dementia – exercise can slow the disease down. So, it's definitely something to be explored. (*Aron, Staff Member)

Hannah explained that sometimes a changed perspective can help the caregiver see that perhaps others can provide care in ways that they can't. This resonates with the view some caregivers had in Study 1 of the PWD using manipulative and attention seeking behaviours specifically with them and not others.

> Like my little lad's in nursery while I'm here – and I know they won't do things the way I do things – but that's not necessarily a bad thing – they might do things different and better in some ways – I might do things better in other ways – but at the end of the day I pick him up – he's been fed, he's slept, he's fine! He looks happy, he's still here. And I'm getting my time – I'm doing work stuff which I enjoy. So, it's just being open to the possibility of somebody looking after them and seeing the positives to the person who's being cared for – allowing them to go off on their own and do something for themselves with another group of like-minded people so that you can go off as a carer and do something. (Hannah, Staff Member)

Caregiver Ethan highlighted that sometimes the PWD also needs a change of environment and people and can in fact return in a better mood.

> She doesn't come back in a worse mood. She probably, no – she, she's quite happy to go. Actually, whoever comes to pick her up – the girls or sometimes a man. She's always happy – she smiles at them and off she goes. When she comes back at night time, she has only me to look at so she doesn't seem as happy (laughs). I don't have any guilt. (Ethan, Spousal Caregiver)

Aron and Hannah explained that there are many tools and methods in place to alleviate some of the caregivers' concerns.

They don't use respite because they think they [respite services] won't take good care of their loved one. They never will take as good a care as you will and you have to accept that they won't. They might do it in a different way – they might do things that you can't do and that's all great. So that would be a reason to put them in – but if your standards are really high – you will have trouble because they just don't – you've got one or two or three people to care for – they've got loads and only a few staff – and they don't know your loved one like you know them – but you can give them some of the tools – so they will do an assessment – you can give them some tools to do the job as best as you can – you can put together a life-story book – you can have your conversations and care based around these things – you can get the help of and advice about other people – look at CQC [Care Quality Commissioning] reports about that home. You can vet the home in different ways to put your mind at rest – get other peoples' opinions about the home – so I understand it, but there are other things you can do and you've perhaps got to accept that it might not always match your standards. (*Aron, Staff Member)

So, if the person who's being cared for is going off to respite – that doesn't necessarily have to be a negative thing – there's all kinds of really great places that they can visit. [Respite name] have quite a lot of reminiscence stuff out so particularly with people who have dementia they can do the memory box work, they can do looking through the reminiscence boxes – so stuff that dates back to the 1950s, '40s, stuff that's quite sensory – like talcum powders and things that would have been around at the time so they can smell things – we would try and spin it that way – we would try and show the carer that it doesn't have to be a negative thing. (Hannah, Staff Member)

Caregiver Maria shared her experience of using these tools and explained how it had made service use more effective:

> I built up an album of his family with his mum and his dad and all his brothers and sisters at various ages and stages and a little bit of story – and then from us getting married and our story and our children and house – all about his work, what he did all that stuff. And now he takes it with him every time he goes to the home – it's the only thing they can settle him with from time to time – if he gets really distressed they'll sit him down with the memory book and he'll go through this – he's only interested in the first few pages which relate to his childhood – because from the time we were married he doesn't recognise his family – and I've put friends in and caravan in – holidays we've been on – we were invited down to Buckingham palace to the garden party – now he does look at that and he's obviously – I put the copy of the invitation from the queen in the book – and he does look at that and I can hear him from the kitchen when he's looking at this "not many people get to go – we've been invited down to Buckingham palace!" and he's so proud of it but he doesn't actually remember the event I think. Because he'll say to me "I've been invited to the palace – look the invitation's here – did you know about this?!". There are photographs of us there in all our finery but he doesn't recognise that's us there. (Maria, Spousal Caregiver)

The alternative perspective, tools and counselling methods discussed in this section could potentially also be used to help caregivers set intentions and goal-oriented strategies to overcome emotional hurdles and barriers to respite and support. The next theme discusses these strategies in more detail and offers specific examples.

7.6.2 Implementations intentions strategies

Caregivers and staff members offered examples of implementations intentions strategies that could be used for some of the common LTC self-management tasks. Staff members in particular also offered additional insight into what would work for whom and why.

> It's like replacing it with something else – like instead of reaching for the chocolate or the biscuit why don't you reach for the fruit instead – have a healthy alternative. (Rose, Staff Member)

However, staff members also highlighted that core beliefs and motivations behind negative self-management behaviours must be addressed for the long-term success of such strategies.

> It's just swapping things – looking at your behaviours – it's like CBT [Cognitive Behaviour Therapy] really. What are the circumstances in which you reach for a can of beer rather than read a book? Is it helping you to sleep? It's like looking at *why* you are doing it and *when*. (Paige, Staff Member)

Aron referred to caregiver Andrew's quotation "a drudgery of a life" to illustrate that it is primarily the emotion that needs to be changed before the habit can be addressed.

> It's the FEELING that they need to replace! And that could mean all sorts of things. So if you are a carer – and it feels like a massive weight on your shoulders – "drudgery" is good word – life just feels like this – but it's like what other things do you need to do? So, if you were an OT [Occupational Therapist] there's a whole stet of tick boxes that you could explore – if you were a worker that used a recovery star or something – you can look into things. They've got a chart of interventions and things that people

would enjoy – that's a starting point – but it's about having an initial conversation with someone about what do you mean by "drudgery" – what would get you out of that? (*Aron, Staff Member)

Hannah and Molly explained that the psychology behind detrimental health behaviours such as smoking and drinking can simply come from a need to have either some alone time or some social interaction. Hannah also referred to Andrew's example and suggested that since dementia caregiving is so consuming, smoking may be providing Andrew the ten minutes of 'respite' he is otherwise unable to attain.

> I think it's the habit and routine of that – so for him [Andrew] – he might be going outside it might be his only ten-minute break every couple of hours that he has to himself. (Hannah, Staff Member)

Molly referred to James' example of over-drinking when his wife was in respite to explain the underlying causes behind his habit:

> People often do that [smoke/drink] when they are sat down and bored. So, try socialising? It's a habit – drinking and smoking – so it's getting somebody out of that habit by suggesting alternative habits that are achievable so they can repeat them. (*Molly, Staff Member)

Karen offered a similar perspective on behavioural change by suggesting that behaviours be associated with the body part that carries out the act, while referring to Andrew's smoking example she stated:

Find something else to do with your hands! Do a jigsaw puzzle – do anything but don't smoke. Try to do something with your hands and your mind – anything – read the paper. Go and meet other people. (Karen, Spousal Caregiver)

7.6.3 Views on written strategies

This theme explains both caregiver and staff views on the barriers and facilitators to the act of writing intentions and goal-oriented strategies to promote self-management.

Barriers to written strategies

A number of potential barriers were suggested by both caregivers and staff members. Karen's immediate response was what most staff members alluded to when considering the barriers to writing self-management strategies:

Well I don't want to see any more paper actually because I hate filling forms! (Karen, Spousal Caregiver)

Much like Karen, caregivers in Study 1 had also mentioned the hassles associated with accessing support, including the amount of "red tape" they had to go through. For similar reasons, some staff members stated that dementia family caregivers are unlikely to be interested in written self-management strategies as they already avoid filling out important support forms such as those for financial support.

I think they need interaction with people rather than [written strategies]. I don't know I might be wrong – I think if I asked them questions and questions, I don't know if they would be bothered to write anything – it's like "oh I can't" – that's why I do Attendance

Allowance [financial support] forms because the amount of people that won't even claim it because they look at it and think "I can't be bothered!" (*Alice, Staff Member)

Similar to Alice, Molly stated that the issue requires a "social solution" and such strategies would probably be secondary to face-to-face, self-management support groups, as caregivers must first see the significance of self-management before they can be convinced or willing to attempt strategies with existing barriers to writing.

I think the course is to start with – because when we tell people what to do without these courses – they often don't listen they'll say "it's not very helpful" – but the ones that have attended these 'Looking After Me' eight-week courses – they not only get detailed explanations of the implications of some of their behaviours but they also get to meet other people who are in the same situation – so they get that additional support. So, it's a social solution – where everyone works together. A lot of it is about meeting people and understanding that others are facing a similar situation. So, I think that's the best way forward. But I know that there are many people who will say they haven't got time to go on an eight-week course – so perhaps for them doing the written strategies straight would be the most viable option or solution to their issues. I do know that sometimes it takes convincing, in order to highlight the purpose of the course – you know because it's all about priorities – if they don't know the course they will think it's useless – but there was one lady I spent ages convincing and she finally went – but she didn't complete it because she had a lot of health conditions and she fell ill during the eight weeks – so perhaps for her it would have been better to do some written strategies to get her health in shape so she could actually attend the course – because she did tell me she was enjoying it. (*Molly, Staff Member)

However, Rose highlighted that a significant barrier pertains to issues with caregiver literacy.

> They don't like forms, they are not good with literacy or you know they have so many paper things they sort of think it's a gimmick or whatever – I think to introduce it as an option is great – but for some people it's immediately like "oh no! not more paper-work!". Because I mean in all the years that I've worked I've been shocked by the level of illiteracy, or poor literacy, in this country – not complete illiteracy but lack of confidence about literacy. It's a given – and I'm talking about people who have been brought up and educated here – so we know they've gone through the school system – but as adults they would sort of look at that and think "ugh!" – so a complete turn off. So that's the issue with that – I mean obviously there are plenty of people who it would be good for – but I just think you've got to be cautious because it's not a solution for everybody. (Rose, Staff Member)

Similarly, Aron explained that confidence in one's own abilities also plays an important role in what caregivers are willing to attempt.

> And a lot of it is confidence – rather than [other barriers such as "red tape"] – and worried that they might make a mistake – and that'll say something worse – that to them feels worse than actually having to say to you "can you do it for me?" – all that can be historical and how they've been treated – some of it could be laziness there's a whole range of these things. (Aron, Staff Member)

Benefits and facilitators to written strategies

However, both staff and caregivers, particularly those who had previously attended self-management support sessions, also offered a positive perspective on written strategies.

It was evident that all staff members saw writing as an indispensable monitoring tool, integral to successful self-management support and continuity of care. For example, Aron concluded that despite all issues and barriers to written strategies, it is imperative to write things down in order to allow adequate monitoring of the caregivers' needs and progress.

> If that's the way people feel [too much paper work] – keep it simple – how are you going to remember it otherwise and how will it be tracked? It has to be written. If another worker comes along how are they going to see what your plans are? If you've got medical records that other workers can see – they all see the same thing – so it's gotta be written down! There's no getting around it. However, people want to think – 'paper work paper work paper work' – it's a tool! And it's been designed for a reason – it can always be better – it's not perfect – but it makes sense! (*Aron, Staff Member)

Paige suggested that although a lot of writing can be overwhelming to a caregiver, something as simple as a short, written intention may work, as it would also provide a tangible memory aid for the caregiver to look back on. She also stated that it would in fact be necessary for these to be in some written format in order to allow adequate monitoring of the behaviour:

> I hate presentations where you've got reams and reams and reams – I just switch off – I just like bullet sentences and a bullet point and again it's the same thing. I find it really helpful to write things down – then you've always got something to refer back

to. So, like if you weren't recording this [interview] you would leave out of here and forget half the things I would say and the discussions that we have. But if it's there and it's written down in the simplest form – and it has to be workable for that individual as well, in a simple format they can always look back and remember that they discussed that. And then also monitor it – so if it's not working then why? And what worked? And what didn't? And write down why it didn't and what could be done differently – because that's the thing with strategies they have to be reviewed and have to be evaluated and monitored and changed as well if it's not working. (Paige, Staff Member)

Paige added that if there are substantial barriers to writing things down then there are other paperless forms of text that may be explored as viable options as well:

Not everyone uses a mobile phone effectively – so it might not be on a piece of paper – it might be something that you send someone on an email or something – people use technology for a lot of different things now – you know, your doctor's surgery – everything can be done online – so maybe we can set up some technology where we don't have to use any paper. (Paige, Staff Member)

Rose stated that written strategies would be beneficial if carried out with a professional such as third-sector service-providers, as they could offer to write things down if the caregiver was reluctant.

Well I think you can say "well is it alright if I just make some notes about what we've agreed?". Then we can check it against them next week – not give them the paper-work – because they may not want to deal with the paper-work – they may not mind,

however, me doing the paper-work. It's more them having to do the work that they think is a problem. (Rose, Staff Member)

Hannah also highlighted that writing things down could be tailored to appeal to and engage the various creative sensibilities of caregivers:

I get that point that you can have too much paper. But I think the flip side of that is that if you write it down – it's a plan. If that carer wants to work towards something and wants to put a plan in place – having key points written down and have it stuck somewhere with different colours or whatever – probably would – it would remind and help to prompt. If it was just reams and reams of paper, I guess that probably wouldn't be very helpful. But we could sit down and do it in different colours, we could laminate it, we could stick it up – they could make notes on it themselves. You know if you make it more of a document where both organisation and carer are working together then yeah, I think it would work. (Hannah, Staff Member)

Upon probing it was evident that caregivers previously had a positive experience of and/or were currently using some form of written aid to help them remember important tasks for themselves. Where staff member Molly had emphasised the significance of a course in highlighting the benefits of self-management, Vanessa highlighted that it was the written and monitoring strategies of the course that were increasingly beneficial in encouraging behaviour change:

I think the useful thing with the course was that you were writing it down but then you were going back every week and telling them what you'd done – so you were

motivated to write it down and do it and you were interested in seeing what everybody else had done. (Vanessa, Spousal Caregiver)

Ethan reflected on how making written lists had helped him accomplish his tasks in both his personal and professional life:

Well (laughs) you get the job done – writing things make it happen. I do make lists! I just get a piece of paper and write down all the things. I have long lists of stuff to do – ring so and so – do this, do that and do the other. They are daily written reminders – I mean you keep a diary and that's the same thing. I have a shopping list – I still don't always get everything on it – but I think it works – no, it is very good – in fact, I don't know how folks can do without making lists really?! I think it's very satisfying when you cross it off – "oh that's something else done!" – it gives you motivation to continue – I've always made lists, I've always made lists at my job at work – I always have lists. Lists are good – I never thought of doing – writing it down for the things that you mentioned though. (Ethan, Spousal Caregiver)

As mentioned earlier, both Study 1 and 2 have shown that Ethan did not consider writing reminders for his LTC self-management tasks mainly due to his beliefs about 1) a lack of serious consequences of poor management (e.g. missing medication) and 2) placing little value on his own health needs due to the overwhelming needs of the PWD.

Although Karen's initial response to the usefulness of written strategies had been negative, after a detailed discussion she revealed that she is already taking the initiative and using such strategies to help her in the self-management of her LTCs.

I did put it on the tablet (iPad) – finding out ten things that are good for type two [diabetes] – and I've written it out – I bought myself a little book and I've written down these ten things and I'm doing things like that stuff you should and shouldn't do. I do think some things are a lot easier because I write it down – I have a pin-board in the kitchen and when I have a doctor's appointment – I put it up on the pin-board – then nearer the time I put it in the calendar – so I am doing it in a way I suppose – the fact that I write it all in the calendar. So, I suppose really, I am doing that without thinking – you don't think about these things. (Karen, Spousal Caregiver)

Both caregivers and staff members highlighted that written strategies, although not specifically tailored for LTC self-management, were taught and used in other areas of self-management. For example, emotional self-management was one area where both caregivers and staff members highlighted the usefulness of written strategies:

Journaling and writing things down is meant to be very therapeutic – a lot of carers do, do that – you know writing everything down at the end of the day – getting it out of their head. I do know people that will keep a pad next to their bed and just write some things down and try and get back to sleep. (Hannah, Staff Member)

Try to remember that you might have felt like this before and you got through it – so again have an event or thought from the past where you overcame it and write it down and then associate it – try not to catastrophise about it. Cos you unconsciously and consciously listen to them [negative thoughts] – so if you wrote them out you'd think "who is that!?" you know what I mean? If you listen to all the negative stuff in your head – you'd never leave the house (laughs)! (*Aron, Staff Member)

Paige highlighted that written strategies are the first step in externalising the caregivers' problems and once these problems are "out of their head" as Hannah suggested, then it provides the motivation required to progress by tackling the individual issues one at a time.

> Maybe write down the things that are really bothering you – put it in order – if it's finances that's worrying them – we would put them in touch with support groups to help manage debt in particular, or citizen's advice and look at what specific support or specialised support they have – looking at what agencies and services can support them. A lot of people and colleagues have said to me that the first step is just getting that information out. Getting that contact number and name to call the person – it's almost like once you get it all out – it's shared with somebody else and that person starts feeling that they are doing something about the problem rather than the problem just being there constantly – once they get some direction then they can ease some of the worries. (Paige, Staff Member)

Like other caregivers, Maria also highlighted the benefits of written (emotional) self-management strategies as it provides a monitoring tool that allows her to see all that she has accomplished as a dementia caregiver:

> I do write my feelings down which does help sometimes when I do these talks [at conferences or support groups] and then for me to read them back sometimes – it makes me think what my life was like a year ago and what it is now – I think again it's cathartic to talk about it and write it down. (Maria, Spousal Caregiver)

7.7 Conclusion to Study 2

The service-provider interviews provided valuable insight into both system issues and caregiver issues. Service-providers deal with many and different types of caregivers, therefore their agreement to the themes of Study 1 adds weight to the original findings. Re-interviewing original participants was particularly useful for a realist approach to evaluation as it allowed both the researcher and participant to switch roles in the 'teacher-learner' function, thus enriching the entire data-set. Viewing caregiver and staff views together has helped reveal some of the conflicting ideas between these two groups, specifically with regards to caregiver agency, which may act as an additional barrier to adequate support-seeking and subsequent self-management behaviours. However, most staff members, particularly those who have previously also been dementia family caregivers appear to be sensitive to the needs of the caregivers but are limited by wider contextual issues such as policy and funding. The next chapter will discuss the contribution of the findings from Study 1 and 2 with existing literature, policy and practice.

CHAPTER 8: DISCUSSION

8.1 Overview of Chapter 8

This chapter discusses the findings presented in Chapters 5-7 and the researchers' reflections on the research methodology and methods. The key mechanisms and outcomes from the main study (Study 1) have been depicted in a mind-map and this is used to guide the discussion of the key findings with existing literature, policy and practice. The complexity checklist (described in Chapter 2 and 3) is revisited and used to synthesise and summarise the findings of the whole research from a realist perspective. This is followed by a reflexive account of the research process, outcomes and strengths and limitations from the researcher's point of view. Future recommendations for policy, practice and research are made and the unique contribution of this study is considered; this is followed by a conclusion to the thesis.

8.2 C-M-O mind-map

The purpose of Final Template 1 and 2 (Study 1) was to organise the data in such a way as to be able to thematically present in-depth accounts of the various mechanisms at play in the dementia family caregivers' life as they live with their own long-term conditions. The multiple mechanisms and outcomes are linked intricately and indefinitely; in Pawson's own words:

> Any formulaic representation of a method is liable to provoke a mechanical following....I opted deliberately for the simplicity of the original C-M-O formula as an agile aide memoire for researchers on how they should begin to construct causal explanations. It is intended as a signpost and not an instruction manual....The

evaluators task is thus to delve into a kaleidoscope of potential configurations and

uncover the pertinent and active causal mechanisms. (Pawson, 2016a, p. 137).

As recommended by King and Brooks (2017) and reflective of the embeddedness of C-M-Os,

the key mechanisms have been depicted in a mind-map form (Figure 14), showing all possible

links between these mechanisms. The arrows and boxes in bold show how the trust-doubt

ratio and organised scepticism were used to make an 'informed guess' based on the data and

existing evidence from LTC policies, theoretical frameworks and the stress process.

Figure 14   Mechanisms influencing dementia caregiver self-management behaviours
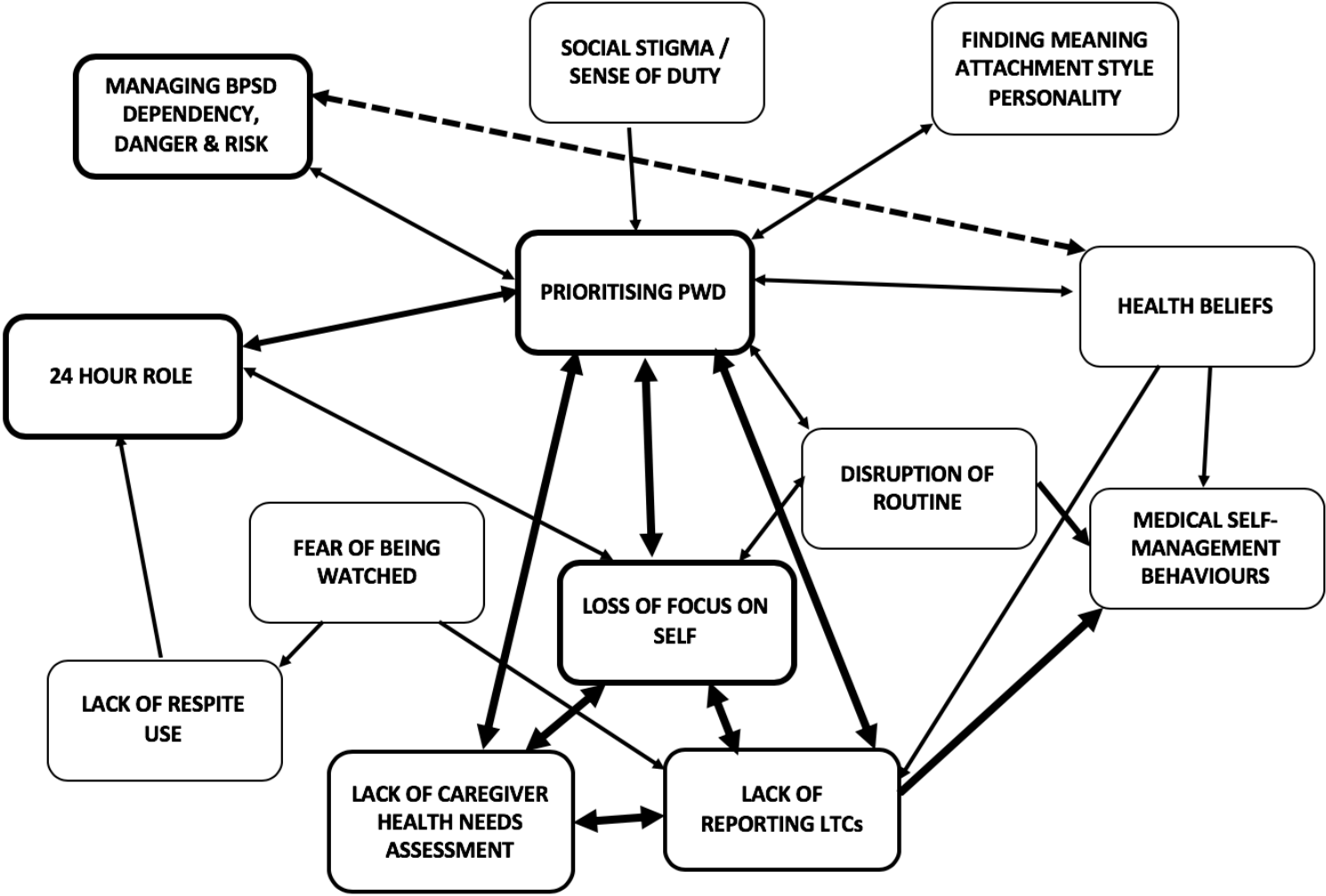
8.3   Discussion of key findings

The main context of dementia caregiving under which most negative self-management mechanisms operate is its 24-hour, all-consuming nature. Dementia caregiving has previously been described as a '36-hour day' as the caregiving is perceived to be so demanding that a regular day feels longer than it is (Mace & Rabins, 2012). The key mechanisms identified as barriers to LTC self-management behaviours were related to BPSD, such as prioritising the care needs and tasks of the PWD. Other mechanisms involved the caregivers' changing self-perceptions and health philosophy or potential health beliefs such as perceptions of self-management behaviours and needs. All mechanisms can be embedded within each other, for example, although BPSD and related dependence is one of the key mechanisms through which the caregiver becomes accustomed to always prioritising the PWD; individual personalities, attachment styles and health philosophy may also be affected by assuming the role of dementia caregiving.

A recent qualitative study exploring caregiver perspectives on health services for people with dementia, labelled one of their key themes as "caregivers' role is all-consuming" (Granbo, Boulton, Saltvedt, Helbostad & Taraldsen, 2019, p. 3). One of the sub-themes giving rise to this contextual condition was called "the sole caregiver" (Granbo et al., 2019, p. 4), here participants expressed that the main reason why dementia caregiving felt like an 'all-consuming' role was because they were the 'sole' person responsible for all of the caregiving tasks. However, sample responses from the participants hinted that this in fact may be due to the behavioural changes occurring in the person with dementia, for example:

He [PWD] does not allow others to come into our home. He trusts me and that I will look after him, for the rest of the life" (Caregiver quote reproduced from Granbo et al., 2019, p. 4).

In the present study, PWD distress at care homes was one of the barriers to accessing external support, however, Study 1 also showed that although a person with dementia may trust their family caregiver they may not necessarily recognise them as a result of memory loss or other BPSD. Additionally, this could be a reflection of the stage of dementia and memory loss in the PWD, for example in many cases it was also evident that the PWD no longer trusted, recognised and/or allowed their caregivers to provide certain types of care, which increased feelings of anxiety and responsibility in the caregiver and thus contributed to them prioritising the PWD even more. Both the present study and Granbo et al. (2019) did not assess severity of dementia, however the present study differs in its contribution to the knowledge-base as it explored caregiver perspectives on service-use for the caregiver and not the care-recipient; it also looked at caregivers with long-term conditions whereas Granbo et al. (2019) looked at overall mental well-being.

In a phenomenological study Ali and Bokharey (2015) revealed that BPSD and related maladaptive cognitions can lead to multiple losses, such as the loss of time, control which impact the physical health of the caregiver in domains of fatigue and sleep, all of which were observed in this study, however, the present study was the first to explore the impact of these losses on specific policy-oriented self-management behaviours in caregivers with long-term conditions. Study 1 showed that BPSD was the main mechanism through which these losses were eventually incurred, for example, even the loss of the caregivers' sense of self was due to merging identities, which itself was heavily influenced by the unique care demands of

dementia. Skaff and Pearlin (1992) have provided many insights into the loss of the 'self'. They introduce the concept of 'role engulfment' as a situation where "the very being of the caregiver may become engulfed by caregiving activities" (Skaff & Pearlin, 1992, p. 657) which subsequently contributes to a loss of the 'self'. The 'being' of the caregiver is described through measures of the self-concept, in particular the various roles the caregiver has in their life which have to be sacrificed for the caregiving role. Unlike Skaff and Pearlin (1992) who performed a correlational quantitative analysis on various self-concepts such as mastery and self-esteem in relation to social engagement and outside roles, the present study indirectly addresses these self-concepts by highlighting how personal losses impact a caregivers' perceived ability and agency to attend to their own health-needs and result in poor self-management behaviours related to LTCs.

It was also evident across some cases, that caregiving seems to erode the caregivers' self-worth, resulting in depressive symptoms and acting as a barrier to self-management. This is contrary to previous quantitative findings such as Zhu et al. (2015) who suggested that increase in depressive symptoms resulted in an increase in service-use for the caregiver. Findings of Study 1 where participants linked depressive symptoms to lowered self-esteem and the feeling of "carrying someone else's misery" and thus not feeling motivated to care for oneself are more in line with the findings of Gallant and Connell (1998), where an association between depressive symptoms and engagement in negative health behaviours was observed. However, as evident from Figure 14, such issues are also connected to other interrelated mechanisms such as potential health beliefs and a loss of focus on the self.

The concept of 'self', social cognition and their consequences for behaviour change have been studied for many years. One of the earliest pioneers in the psychology of 'self' was William

James (NICE, 2006). James (1890) defines the 'self' of an individual as "the sum total of all that he can call his" (p. 651). James refers to his conceptualisation of the self as 'me' in an attempt to distinguish it from the concept of 'pure Ego' and 'I' as described by his predecessors like Kant, Fichte and Hegel; though James acknowledges that it is difficult to draw the line between the terms 'me' and 'mine'. He explains three aspects of the 'self': the constituents of self; the feelings that result from the constituents of self which he terms 'self-feelings' and finally the actions that result from these feelings. The constituents of self are further divided into three parts: the material self, the social self and the spiritual self. These aspects of self will be discussed with regards to dementia caregivers' sense of self in relation to their long-term health conditions.

The material self, refers to the physical body, material gains, and the extension of the self which includes immediate family members, the loss of whom reflects a loss in the 'self' (James, 1890). In dementia caregiving this aspect of the 'self' can suffer losses in many ways throughout the disease trajectory. According to Blandin and Pepin (2017) the most significant grief experienced by dementia caregivers is pre-death grief which increases as caregiver health deteriorates and burden increase. These pre-death grievances can be due to a number of factors. Loss of memories, communication and activities shared with the family member with dementia are termed 'compounded losses' which result from the accumulation of many large or small losses (Santulli, 2011). There is also the loss of hope and future plans as a result of changing cognition and consciousness in the person with dementia, these are termed 'ambiguous' losses (Blandin & Pepin, 2017). The third and final type of loss described by Blandin and Pepin (2017) is the 'receding of the known self'. This is a distinct form of grief experienced specifically by caregivers of dementia and reflects their psychological loss. This

psychological loss contributes significantly to caregivers' health (Lindauer & Harvath, 2014; Meichsner, Köhler & Wilz, 2017).

The second constituent of self is key to understanding many of the contemporary theories of behaviour change as it refers to the 'social self' (James, 1980). This includes human roles within society and the need for recognition and appreciation from others (James, 1980). James (1890) states that a lack of this appreciation would result in feelings of unworthiness and despair giving rise to health issues. He further states that "a man has as many social selves as there are individuals who recognise him" (James, 1890, p. 656). Of these individual relationships James considers the spousal relationship to be the most influential on the intensity of positive and negative feelings for the social self. For dementia family caregivers, a loss of recognition and appreciation from their spouses and marital relationships can adversely affect their physical health (Fauth et al., 2012). In this study and consistent with previous studies (Furlong & Weust, 2008) the PWD loses recognition of their family caregivers' self-management needs, health status and in many cases the family member themselves. The third self is the 'spiritual self' which encompasses human cognition, psychology, subjective being, capabilities, values and habits (James, 1890). For dementia family caregivers this aspect of self is important in their cognitive appraisals, coping mechanisms, problem-solving skills, self-efficacy and their ability to find meaning for the 'self' in the caregiving role (Parkinson, Carr & Abley, 2017). According to James (1890) these are the aspects of self that create feelings in the 'self' which then mediate the actions one takes.

Models of 'self' and attachment have previously been studied with regards to caregiving behaviours. This issue is of particular relevance to dementia caregivers as their choices are often shaped primarily by their role as a family member; as noted in a multi-ethnic qualitative

study "prioritizing the person with dementia was viewed as a virtuous behaviour" (Lawrence, Murray, Samsi & Banerjee, 2008, p. 243). Carpenter (2001) stated that caregiving stress can influence a stronger attachment bond, this is consistent with the findings of this study as the mechanisms related to merging identities and prioritising the PWD were related to increase in stress due to various manifestations of BPSD in the PWD.

Carpenter (2001) studied the dimensions of attachment related to security and anxiety in adult daughters who provide care for their mother for various different health conditions. They found that the secure attachment styles associated with a need for emotional security resulted in providing more emotional acts of caregiving and reduced caregiver burden, whereas insecure attachment styles and associated anxiety with regards to the care-recipient was related to less caregiving acts. Both security and anxiety were unrelated to instrumental acts of caregiving. Carpenter (2001) concluded that instrumental and practical caregiving was independent of attachment patterns between child-parent; and other types of caregiving, such as emotional support were better predicted by attachment patterns. Carnelley, Pietromonaco and Jaffe (1996) emphasised the significance of studying attachment styles in caregiving relationships with childhood relationships. Their own findings suggested that men and women express similar caregiving characteristics as their same-sex parent; those that were less anxious and fearful in childhood offer more support through acts of caregiving to their partners.

In a systematic review Nelis et al. (2014) concluded that secure attachment styles are important for the psychological well-being of the dementia family caregiver and provides them incentive to continue caring. Contrary to Carpenter (2001), Lee et al. (2018) found that in Korean dementia family caregivers a high sense of obligation to provide care along with

avoidance-attachment was associated with lowered burden. In the present study, a duty of care towards the PWD, as a result of, or due to a combination of religious beliefs, marriage vows, filial piety and/or BPSD-related stressors, was a prominent feature in the caregiver either prioritising themselves or prioritising the PWD. In Study 1, Robert's case was an exception amongst the rest; his emotional detachment led him to feel captive in the caregiving role as a "prisoner" and therefore he sought outside help. Based on the concepts derived from Carnelley et al. (1996) Robert's background characteristics may hold relevance to his attachment style, for example when Robert mentioned that he had previously been divorced twice and his ex-wives had been unfaithful to him, he stated with a laugh that it may seem that he was doing the same to his current wife; however, he then pointed out that it was not the same as he has already lost her to the dementia. Robert was also the only caregiver from a lower socioeconomic background as he was the only one who received Carer's Allowance, which is given to caregivers who earn less than £120 a week (DWP, 2018). Robert stated that he had been working from a very young age and been unable to complete his education, this was why permanent respite was not the preferred option of support for Robert as his current caregiving situation combined with a lack of attachment to his wife allowed him to lead an independent and financially secure life. The impact of this on his health behaviours however was that it resulted in him engaging in risky sexual health behaviours.

Previously Snyder et al. (2015) identified that caregivers with positive coping strategies reported fewer long-term health conditions whereas those with negative coping strategies such as 'blaming others' correlated with an increase in reporting long-term conditions. The present study shows conflicting views on this, while in some cases negative coping mechanisms such as feeling captive in the new role could result in greater acknowledgement

of the caregivers' own needs and thus positively influence self-management, it was also evident that it could result in additional negative self-management behaviours such as increase in smoking, drinking and risky sexual health behaviours. This study, however was not a correlational study and therefore greater exploration of beliefs with regards to self-management and with regards to what is considered significant to one's health and well-being must be further explored. Snyder et al. (2015) also based their study on the conceptual model of Pearlin et al. (1990) and the coping strategies identified by Lazarus and Folkman (1984), therefore future studies could focus on integrating models of behaviour change into dementia caregiver research such as the 'health belief model'.

The health belief model (Becker & Maiman, 1975; Hochbaum, Rosenstock & Kegels, 1952; Rosenstock, 1966) explains health behaviours both before an illness has occurred, and the compliance with self-management after an illness has been diagnosed. According to this model, for an individual to take self-management actions against an existing illness, they first have to perceive the severity of the consequences of a lack of self-management and the potential benefits of positive self-management. It also states that barriers such as cost or time should not outweigh the perceived benefits otherwise behavioural change will be unlikely. The theory also offers strategies that may support or promote this change such as verbal or visual reminders. This model is relevant to the findings of the present study as although some caregivers improved their behaviours using both positive and negative coping strategies, it became increasingly apparent, particularly from the second data-set that health beliefs, both dependent and independent of being a caregiver, played an integral role in bringing forth these behavioural changes. In terms of beliefs dependent on being a caregiver, cost and time are two factors that weigh in negatively on a dementia family caregivers' daily routine.

However, personal beliefs regarding the severity of the condition based on the number of evident symptoms or the perceived benefits of taking medication or visiting the doctor were also issues that are exacerbated by objective stressors related to the PWD. The emphasis on health beliefs was strengthened in Study 2 by staff members when explaining the potential barriers to written strategies. Staff members stated that before such strategies can be implemented the caregiver must attend self-management courses where their health beliefs may be brought into alignment with the necessary self-management tasks required from them.

Previously Furlong and Wuest (2008) and Zhu et al. (2015) suggested that mental and/or physical health decline would increase the likelihood of self-management behaviours in dementia family caregivers. Consistent with these findings many dementia caregivers in the present study did not report attending to their health conditions until their health deteriorated and then quite often through prioritising the long-term welfare of the PWD and/or through prompts from other family members (often due to the former incentivising mechanism) they are encouraged to attend to their own health. Previous studies also offered suggestions that would improve caregiver self-management behaviours. For example, Shelton et al. (2001) recommended that effective case management such as frequent assessments and health promotion could improve the management of LTCs. The present study also shows that caregivers desire more support from GPs and require frequent health and personal needs assessments.

Connell & Janevic (2009) proposed that caregivers would be more likely to engage in positive health-related behaviours if regular verbal and written behaviour change strategies are provided. This aspect was touched upon by some caregivers in the memory aids and coping

strategies theme of the facilitators to self-management. This theme was further explored through the concept of implementations intentions in the second phase of data collection where it became apparent that many caregivers were already using such strategies in their daily life. The issues surrounding the implementation of such strategies in practice by third-sector professionals is required. More recently, a feasibility study on the usefulness of implementations intentions to prevent remission of depressive symptoms in people receiving psychological therapy revealed positive results (Lucock et al., 2018). The latter study found that out of 54 implementations intentions strategies the majority were plans involving overt behaviours, and only a small portion involved cognitive strategies, or a mixture of both. Similar to the present study, Lucock et al. (2018) also received some negative qualitative feedback on the use of written strategies as requiring "too much paperwork" (p. 630). Also consistent with the findings of the present study and existing literature, Lucock et al. (2018) report that participants found it helpful to share their plans with family and friends.

Previously, O'Reilly et al. (2008) demonstrated that caregivers as compared to non-caregivers reported fewer long-term conditions yet poorer general health. The latter findings were based on the 2001 Census, which included a question regarding the presence of a long-term condition with a dichotomous yes/no response and a three-point Likert response to general health to include 'good', 'fairly good' and 'not good'. Based on these preference-based measures, O'Reilly et al. (2008) concluded that caregivers probably reported fewer long-term conditions due to the 'healthy worker effect' or the 'healthy caregiver hypothesis' whereby those who are healthy will naturally select and appear in caregiving roles compared to those who are unhealthy (Fredman, Lyons, Cauley, Hochberg & Applebaum, 2015); although, they did acknowledge that this finding may vary across regions as it may inevitably be influenced

by alternative forms of available statutory and private support. O'Reilly et al (2008) attributed the self-reporting of poor general health to the fact that general health is understood as a multi-dimensional construct consisting of physical health, mental health and other health-related behaviours and therefore is more representative of overall health status than the presence of a long-term condition. The lower self-reporting of long-term conditions was further compounded by the fact that their study revealed significantly lower mortality rates for caregivers compared to non-caregivers even after adjusting for health status and hours of care provided. While O'Reilly et al. (2008) acknowledge that census-based studies are criticised for "naïve self-reported measures of health" (p. 1288) they argued that based on existing empirical evidence self-reported measures are strong and valid predictors of mortality. As evident by the present study the main limitation/point of contention with these previous studies lie in their methodology and subsequent lack of explanatory focus. While quantitative studies are able to highlight associations, qualitative findings are better able to highlight the deeper underlying causes behind the findings.

In a recent qualitative study Tatangelo, McCabe, Macleod, and You (2018) conducted semi-structured interviews and identified five key themes related to the unmet needs of a total of twenty-four filial and spousal caregivers of people with dementia. The first theme holds resonance with a few key findings of the present study such as lack of reporting long-term conditions and a lack of focus on the self as evident from their inability to maintain the focus of the interview on themselves. Tatangelo et al. (2018) named the theme "caregivers' overall assessment of their general health needs" (p. 10). This theme details how caregivers rated their health on a five-point Likert scale ranging from poor to excellent and how this contrasted with what they eventually revealed about their health-needs during the interview. They found

that the majority of the caregivers rated their health positively, and stated that prioritising the long-term care of the person with dementia was a key incentive behind ensuring their health needs were being met. However, after further probing, Tatangelo et al. (2018) also found that caregivers in fact found it "difficult to identify and discuss their unmet needs" (p. 10). Tatangelo et al. (2018) stated that partner caregivers in particular found that the "caregiving role consumed their lives entirely and therefore they did not spend time thinking about their own health needs" (p.10). A quote from a female spousal caregiver within their study has been presented below to show how their findings support the C-M-O configurations developed within the present research:

> It's a funny thing you don't think about your own needs... I don't concentrate on my needs at all... Well it's pretty consuming, apart from when [PWD] is out like now which is great, you're constantly watching him, you're constantly doing things and he's constantly asking you questions. So I think I just don't focus on my needs. (Tatangelo et al., 2018, p. 10)

Unlike the present study Tatangelo et al. (2018) did not focus on identifying caregivers with existing long-term health conditions, nor did they investigate specific self-management behaviours as routinely measured in practice. Instead, their study focused on identifying general health needs as reported by the caregiver. Their remaining four themes consisted of the domains of unmet need as stated by caregivers to include: mental health needs, emotional and social needs, diet and exercise needs and personal time. The present study revealed that BPSD and its relationship to the loss of self as two prime mechanisms operating in the all-consuming context of dementia caregiving subsequently influencing self-management outcomes in the caregiver. Therefore, future research could focus on what

caregivers understand by the terms 'self' and 'self-management' and whether they consider this understanding to evolve during their role as a caregiver. This could be further developed by comparisons between gender, ethnicity and the caregiver-PWD relationship. Relational differences need to be assessed from the perspective of cultural differences as well; co-residence in South Asian families could reflect a cultural norm (Jethwa, 2017), the impact of this was evident only in one filial (in-law) case, therefore this area remains under-researched with regards to its implications for caregiving and the impact on the caregiver as the caregiving and dementia trajectory evolve together (Jethwa, 2017; Schulz & Eden, 2016).

8.4   Healthcare Policy and Practice within the UK

The following section discuss models of care for long-term conditions and self-management in the UK to suggest that a separate pathway, sensitive to the needs of dementia family caregivers is required.

Over the years a number of different conceptual models have been proposed for the management and care of long-term conditions of which the most frequently used theoretical mode is the Chronic Care Model (Davy et al., 2015; Grover & Joshi, 2015).

NHS England (2014, 2018b) proposed a new patient-centred model of care for long-term conditions in 2014: The House of Care. The latter was built on existing models of chronic care, in particular the Chronic Care Model and the UK's Year of Care Programmes.

Wagner et al. (2001) developed the Chronic Care Model to restructure the healthcare system to address the growing, long-term needs of people with long-term/'chronic' conditions. This was described as an 'evidence-based' model, which characterised high-quality care by

effective and productive interactions between primary care practices and patients with LTCs. Wagner et al. (2001) stated that support for self-management, continuous assessments and follow-ups and optimal medical therapy are associated with positive outcomes for people with LTCs. They concluded that the essence of a productive interaction depends both on the service-user and the service-provider.

According to the Chronic Care Model patients must be informed and active in the decision-making towards the care of their LTCs in order to ensure effective clinical management and self-management. Wagner et al. (2001) stated that healthcare providers must be well-equipped with time, resources and evidence-based clinical expertise in order to support this management and become a proactive service rather than an acute-care based reactive service. Based on empirical and theoretical evidence Wagner et al. (2001) placed a heavy emphasis on the significance of self-management as a cornerstone for effective long-term management of LTCs. They concluded that existing patient education and counselling remained unsuccessful in achieving behavioural changes required for optimal self-management because they were aimed at increasing the patients' knowledge of the LTCs rather than the patients' skills and confidence in holistically managing the clinical and social impact of the LTCs. In essence, the Chronic Care Model conceptualised self-management as the most important requirement for the care of LTCs. Wagner et al. (2001) stated that interventions for chronic care should be based on improving and encouraging patients' self-management skills and confidence to care for their own LTCs. Their conceptualisation of self-management as dependent on confidence and skill became known as the patient activation theory as used in the House of Care (HOC).

In 2004, following a rise in poor health behaviours, long-term conditions and health inequalities, the Department of Health issued a White Paper to promote health through support for self-management behaviours (DH, 2004). In light of this report the Year of Care (YOC) 2008-2011 initiative was designed based on the Chronic Care Model, to address both care and commissioning in order to provide patient-centred care for people with long-term conditions in partnership with both the patient and healthcare professionals (YOC, 2008). The YOC initially started with diabetes as it was becoming increasingly difficult to manage by the available health resources due to its prevalence, complexity, and the overriding importance of continuous and diligent self-management behaviours in its successful management (YOC, 2008, 2011a). The patient-centred initiatives included collaborative consultations to elicit patient needs and priorities, and develop goals and plans for the achievement of behaviour change (Coulter et al., 2013; YOC, 2011a). The YOC included programmes such as health promotion for risky health behaviours, the expert patient programme, education programmes, telephone reviews, buddying groups and information services (YOC, 2008). Reports from the YOC revealed improvements in self-management behaviours of people with LTCs and demonstrated a need to adopt such a whole-systems approach to care for people with LTCs (YOC, 2011b). Subsequently the approach was adopted by the NHS as a new model of care for LTCs diagrammatically depicted as a house (Figure 15). The house was used both as a framework and a metaphor to highlight the interdependence of the elements forming the foundations of this house which placed the patient at the centre (YOC, 2011a). The House of Care (HOC) is the current approach used in the NHS to manage long-term conditions (Coulter et al., 2014; NHS England, 2018b).

Figure 15   The House of Care reproduced from Coulter et al. (2013, p. 20)
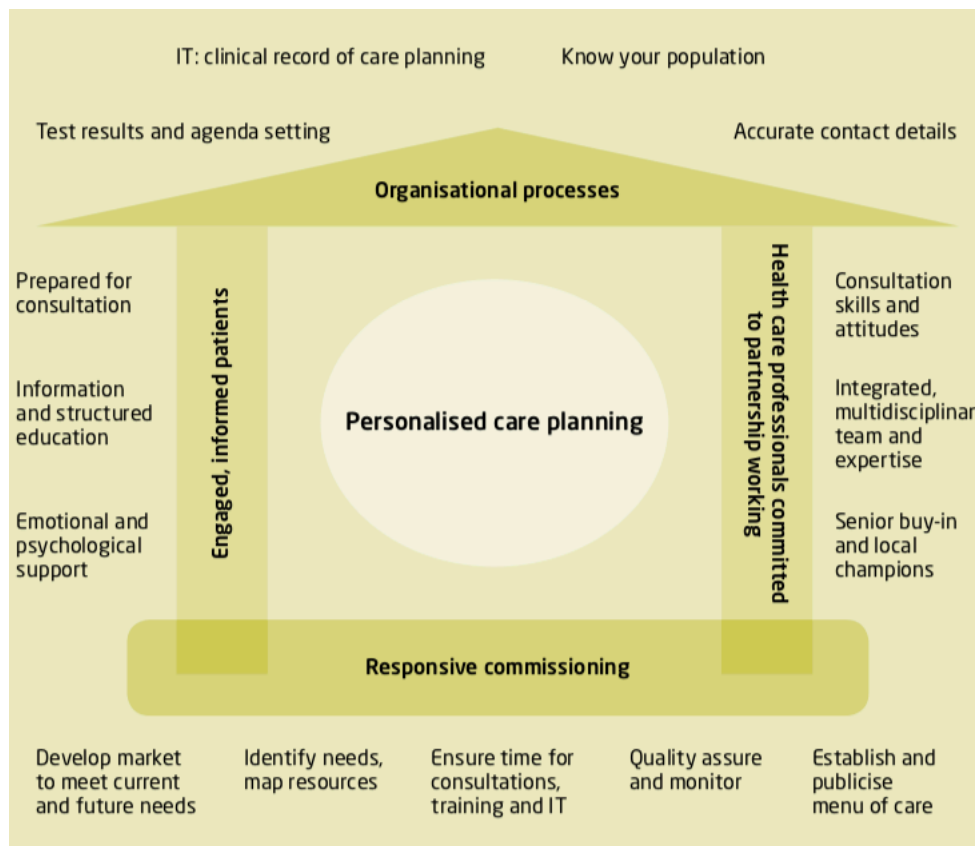
The HOC framework aims to coordinate organisational healthcare processes and healthcare commissioning with the needs of service users and providers in order to achieve person-centred care (NHS England, 2018b). Its key aim for the management of long-term conditions is to promote self-management behaviours. The HOC aims to address several issues within current healthcare policy and practice, these will now be discussed in light of the findings of this research.

The HOC (NHS England, 2018b) states that care is still fragmented as individuals are unaware of the available services and whom to approach with regards to their issues. Caregivers and patients should be informed of the services, and organisational structure should be

codesigned with the service-user where possible, in order to address their needs. Relational continuity is also vital to adequate care-coordination, individuals should be able to have a consistent relationship with care providers to enable seamless, efficient and high-quality care provision. Additionally, informational continuity is also lacking as care records are not shared between settings or with patients, this results in fragmented care, and a poor quality of care experience for the patient and caregiver. Individuals and their family members and caregivers should be able to access information about themselves and be able to share this easily with other services (NHS England, 2018b).

Fragmentation of services was identified as a barrier to accessing support in the present study. However, policy statements can be misleading as there is a distinction made between the caregiver and the patient with long-term conditions. It must first be acknowledged (both by service-user and provider) that caregivers themselves are also patients with long-term conditions and with a 24-hour caregiving role and irregular and unpredictable routine, dementia family caregivers are in particular need of a seamless and coordinated care pathway. Lack of continuity of care was also identified as a barrier to quality support and impinged on the caregivers' time as they had to re-state their needs and situation with each new service-provider. The wider system issues associated with data-sharing and patient confidentiality are still an ongoing discussion in the UK (NHS England, 2018c) and this was acknowledged by participants as a barrier to good quality care and accessing support. Study 2 highlighted that a reason for fragmentation is also a lack of communication and knowledge between service-providers of what is available and when, which translates into a lack of 'confidence' in informing the service-user.

With regards to fragmentation HOC also points out that the economic drive behind the healthcare system does not allow a whole-systems approach to care, there is a need to move away from the medical model and support people with "more than medicine" (NHS, England, 2018b, para. 10) which would include liaising with social services and other voluntary and third-sector services. This point is crucial for dementia family caregivers in the UK as their first port of call are third-sector support services. As evident from the data, caregivers are prone to a lack of reporting LTCs for many reasons and focus primarily on the needs of the PWD; therefore, services may miss the self-management needs of caregivers with LTCs. As mentioned by the caregivers, they would like more support and involvement from GPs and individualised care plans for themselves. However, moving away from the medical model can give rise to some issues related to medical self-management in primary care. For example, it was evident from this study that both service-users and service-providers spoke more about non-medical self-management activities, such as exercise and relaxation, which they commonly refer to as 'self-care', rather than medical self-management activities such as medication and appointment management. Here clarity and consistency in defining terms used in policy and practice across primary, secondary and third-sector services is important.

HOC states that a holistic approach, including emotional and psychological support is required to deal with the rising issue of multimorbidity "as the primary care QOF, most clinical guidelines, and the most common IT [information technology] systems and data-sets are all structured around single conditions" (Coulter et al., 2013, p. 21) and there is a lack of attention towards the physical health of caregivers, particularly those with pre-existing mental health conditions as well.

All participants in the sample had multiple long-term conditions. The people they were providing care for also had multiple other long-term conditions along with dementia, although this was not specifically accounted for in the present study as the primary focus was on their care needs as a person with dementia. The issue of managing multiple multimorbidity was identified as a barrier to the caregivers' own self-management. This is an added concern for filial caregivers who do not co-reside with the PWD and have other members within their family such as spouses, in-laws or children with long-term conditions as well.

Although psychological and emotional support is available from third-sector support organisations, the lack of identification and specific care pathways for dementia caregivers with LTCs can keep their physical health needs hidden from services. This was evident during participant recruitment when some service-providers who had been working with the caregivers for years stated that they were not aware that some of these participants had LTCs. This could be due to a lack of LTC-assessment procedures in place for the third-sector service-user, but also because of a lack of acknowledgment and reporting of LTCs by the caregiver due to the many reasons evident in Study 1 such as fear of being watched, merging identities, prioritising the PWD and health beliefs. Unless these underlying mechanisms and aspects of caregiver burden, particularly the psychosocial and physical (fatigue) consequences of caregiving on the caregivers' existing compromised health is considered, alongside the mechanisms which give rise to a lack of accessing or accepting external support (including caregiver self-management education programmes), signposting will come to no avail. Here, along with the objective stressors that act as barriers to self-management, the health belief model should also be considered in relation to the caregivers' decision-making agency.

From a methodological perspective an additional and unique finding of this study was the usefulness of designing the qualitative interview schedule using QOF indicators, which, in primary care is a tick-box exercise. The questions regarding medication, appointments and monitoring often led to caregivers finally acknowledging more LTCs than they had initially disclosed. This is of utmost relevance to the ongoing debate on the usefulness of QOF in primary care (Forbes, Marchand, Doran & Peckam, 2017). In April 2016, NHS England and the RCGP issued a review stating that the that despite its usefulness to population-based healthcare, QOF may be a "barrier to holistic management of health conditions" (NHS England, 2016b, p. 31; 2018e, p. 9) given the rise of LTCs and life expectancy. NHS England agreed to undertake a joint review of QOF with the General Practitioners Committee (GPC). In 2017 the GPC urged NHS England for a national suspension of QOF in order to "reduce unnecessary bureaucratic burden" (Bostock, 2017, para. 7) and intense GP workload.

However, in 2018 NHS England issued another report reviewing QOF in England and stated that with regards to QOF "the baby shouldn't be thrown out with the bath water" (NHS England, 2018e, p. 9). Additionally, a report produced for NHS England revealed that removing indicators from QOF can translate into removing incentivisation for good quality care for patients (Wilding, Kontopantelis, Munford & Sutton, 2018). The findings of the present study offer an additional perspective on this situation. Perhaps it is the setting and method in which the tool is used that is preventing the identification of unmet needs in vulnerable populations. For example, in line with the methods of Study 1, QOF indicators could be used as a general guide in third-sector settings during caregiver and service-provider discussions and assessments of caregiver needs. Such settings offer professionals more time with the caregiver than primary and secondary care settings. This offers a potential solution

to the workload issue in primary care and the existing care pathway for dementia caregivers with long-term conditions. Since caregivers often do not find time to make or attend their own ten-minute GP appointments, these questions are better placed in a third-sector setting where the caregiver attends more regularly and for longer durations of time.

Table 39 refers back to the reasons for exclusion from QOF mentioned in Chapter 1. The findings of both studies have been used to explain how the exceptions reporting system would affect dementia family caregivers.

Table 39   Implications of primary care exceptions categories for dementia family caregivers

Non-discretionary reasons for excluding patients from QOF calculations	Impact of non-discretionary exceptions on dementia family caregivers	Discretionary reasons for excluding patients from QOF calculations	Impact of discretionary exceptions on dementia family caregivers
Patients' refusal to attend appointments after being invited three times in the last 12 months.	Due to prioritisation of PWD primarily as a result of BPSD. If traveling with the PWD and/or arranging external care for the PWD are not guaranteed then caregiver is unlikely to attend. Home visits and priority to such caregivers would be advised.	Patients for whom it is not safely appropriate to carry out LTC reviews (for example taking the blood pressure of an extremely frail patient).	Frailty is an LTC in its own right, spousal caregivers in particular are prone to frailty, particularly female spousal caregivers carrying out heavy manual handling tasks in the care of the PWD. If patient is deemed too frail for adequate health monitoring they must also be considered for an assessment of caregiving competency based on the physical and emotional acts of care they provide.

Newly diagnosed or recently registered patients.	Caregivers may change residence in order to care for the PWD. Newly registered caregivers require effective communication and transfer of details between health services in order to ensure continuity of care.	Patients who are already on the maximum approved dose of a medication and treatment cannot be adjusted any further despite a lack of improvement.	Additional/alternative measures are required to support caregivers who are unable to take certain medications due to their caregiving responsibilities, particularly in the care of mental health conditions.
Patient's informed dissent – disagreeing to treatment.	Caregivers may have to disagree to treatment due to adverse effects while being a caregiver, such as feeling drowsy as a side effect of medication when needing to be alert during the night for the PWD. In such instances all possible alternatives should be considered. Caregivers may also be at a stage where they require counselling for a shift to permanent care or increased use of external care services.	Patients for whom medication cannot be prescribed due to allergies, adverse effects or complete lack of tolerance.	Same as informed dissent to treatment. Additional psychosocial support measures should be considered in depth when reviewing such patients.

Lack of access and availability of a secondary care or investigative service.	This can be problematic for both caregiver and care-recipient in the case of an emergency, therefore primary care and third-sector services need to be more vigilant in such cases in order to minimise the risks of ambulatory care sensitive conditions.	Patients with illnesses that intervene with the treatment of other LTCs (for example cholesterol medication in the presence of liver disease).	Unless routine monitoring of caregiver health is conducted, these exceptions may be missed. Additionally any side-effects observed by the caregiver between intervening treatments may negatively impact their health and self-management beliefs and lead to rapidly changed health behaviours due to a prioritisation of caregiving responsibilities. These changes may not be documented if visits to a professional are already limited and/or the caregiver fears being 'watched' or 'invigilated'.

The HOC states that services are reactive and not 'predictive'; services need to be able to predict risks for vulnerable populations in order to identify and address their needs to prevent a deterioration in their LTCs, which would reduce their quality of life and require emergency admissions and hospitalisations (NHS England, 2018b). As evident from the data and from previous literature, dementia family caregivers tend to use services once a health crisis emerges. Third-sector services offering courses that promote self-management and a focus on the caregivers' sense of 'self' were found to be useful to many caregivers, however, it was also mentioned in both studies that time constraints can prevent the caregiver from completing or attending such courses. Policy and research must focus not only on vulnerable populations but also on the mechanisms that were identified as barriers to self-management in both studies.

HOC also states that services need to consider individuals as experts in their own LTC and the impact this has on their life (NHS England, 2018b). Individuals should be actively involved in their own care by encouraging self-management behaviours and working in partnership with the patient. As evident from this study services must first consider the caregiver as the 'individual' or 'patient'. As mentioned by participants, it is a "generational thing" to consider the caregiving role as a natural filial or marital duty. Therefore, perhaps policy should focus on normalising the role of the caregiver to the caregiver. This moves the discussion towards issues of definition within policy.

8.4.1 Issues of definition: What's in a name?

This section discusses the implications of the various terminology and their definitions used in healthcare policy and practice to refer to caregivers, long-term conditions and self-management.

8.4.1.1   Caregiver

Initially the term 'caregiver' had been selected for use in this thesis due to its global recognition and prevalence across multiple professional domains such as literature, policy and practice. However, after reflecting on the findings of the research and existing literature it is evident that these labels, can consciously or subconsciously, hold serious implications for the 'self' in self-management.

The risk of remaining in the familial role of a husband/wife or son/daughter/-in-law can undermine and challenge the changes that occur in the self-concept of the caregiver. Thus, being labelled a 'family member' who provides 'informal' care can validate the caregivers' feelings of obligation towards the PWD and encourage them to keep providing care even when their physical health demands otherwise. For this reason, the caregiver may also be unlikely to approach or even be aware of the support and benefits available to them as recognised caregivers. The covert and overt stigma associated with losing one's relationship identity might explain why caregivers are reluctant to acknowledge their caregiving role or adopt technical labels, for example when Anna mentioned "in years gone by daughters used to look after the parents" and Emily expressed her shock at considering respite by stating that after a long marriage she "can't just dump him". However, the terms 'family member', 'informal' and official role titles such as husband/wife may undermine the amount of work

that is carried out by a family caregiver for someone with dementia. The term 'informal' is synonymous with terms such as 'casual' or 'relaxed' that are in fact direct antonyms to the intensity and amount of time, work and energy contributed by the dementia family caregiver.

This is not to say that technical terminology should be avoided altogether, rather, researchers, policy-makers and service-providers should adopt uniformity and sensitivity with regards to these labels in order to normalise them. Normalisation of these technical terms may be the first step towards encouraging caregivers to perceive themselves in a new role and therefore acknowledge the new demands being placed on them as separate from the existing role-demands of a spouse or adult-child. A case is made to encourage the use of the word caregiver, not only due to its global appeal, but also due to its grammatical connotations. 'Caregiver' is a coining of two nouns 'care' and 'giver'. However, both these nouns carry a verb form 'to care' and 'to give' which when coined together gives the implication of an action supplementary to regular actions in regular familial roles. The hidden verb forms in the terms 'caregiver' and 'caregiving' allow room for consideration of the caregivers' personal agency and choice to provide care. In contrast the term 'carer' can be perceived as restrictive as it carries a sense of self-stigma associated with the merging of existing familial roles with caregiving roles.

Lai (2003) states that the use of the term 'formal' for paid professional caregivers carries a sense of expectation with it, which she argues is equally applicable to a family member "do we not expect families to care about each other?" (para. 2). She mentions that in countries such as Denmark, it is the State rather than the family that is primarily responsible for the provision of care for the ill and elderly. She also argues against the use of British technical terminology such as 'carers' and 'significant others'. Lai (2003) states that 'care' can have

multiple meanings such as 1) providing the care and 2) caring about the person requiring the care; she therefore challenges an important presumption about caregivers: "is it not asking too much of a carer that he or she should care about someone?" (para. 4). For this reason, terms such as 'loved-one' and 'significant other' have been avoided in this thesis and instead 'person/people with dementia' has been used instead. In practice however, it would be unlikely for a professional to speak to a caregiver and refer to the person they care for as the 'person with dementia'. In fact, a recent study shows that some caregivers do not really consider dementia an illness: "my husband is not ill – he has short term memory loss" (Granbo et al., 2019, p. 1). However, Lai (2003) concludes that it would not be prudent to distinguish between terms and labels due to individual and cultural differences in defining family and professional roles and therefore they should be kept "ambiguous, leaving room for imagination" (para 7).

Unfortunately, as evident from the findings of the present study, embracing the ambiguity and blurring of boundaries in family and caregiving roles not only acts as a barrier to accepting or accessing respite and external support services but it can also translate into ambiguous and unclear guidance and policy for the provision of support, interventions and care for the dementia family caregiver. As evident from Study 2, while some caregivers may initially be upset at the use of terms such as 'carer' or 'caregiver', this may not necessarily reflect a desire to continue upholding the responsibilities they perceive necessary as a part of their familial role. In such cases, sensitive and timely counselling proved beneficial and enabled the caregiver to consider other options which would not have been considered had they continued referring to themselves as a mother or husband and so on. Therefore, the

recommendation would be to remain persistent with normalising specific technical terminology as it may in fact help overcome cultural barriers.

8.4.1.2   Long-term conditions

The NHS (NHS Employers, 2018) and the Department of Health and Social Care (DH, 2012a) in the UK, provide a comprehensive list of examples for long-term conditions, yet their definitions do not reflect the sensitivity required in understanding LTC self-management behaviours and needs. The role of health behaviours should be incorporated into LTC definitions in order to synchronise them with LTC policy and targets. Long-term or chronic conditions, diseases and illnesses are defined in the UK as health conditions for which there is at present no cure and therefore must be managed with ongoing medication and therapies (DH, 2015a). Internationally, there is however considerable and ever-increasing variation in the usage and understanding of LTCs due to its broad definitions (Bernell & Howard, 2016). For example, the Centers for Disease Control and Prevention ([CDC], 2018) in the United States of America (USA) offer a similar but more specific definition of chronic diseases as being those conditions that last a year or longer, limiting activities of daily living and/or requiring continuous medical support. The CDC (2018) also state that most chronic diseases are caused by risky health behaviours such as a poor diet and sedentary lifestyle and/or substance abuse, including tobacco, alcohol and drugs. The Department of Chronic Disease and Health Promotion at the World Health Organization acknowledge that chronic diseases are of a long duration but they include a more diverse list of health determinants and risk factors as causes of chronic illnesses to include genetic, physiological, behavioural and environmental factors (WHO, 2018a).

WHO use the terms chronic disease and noncommunicable disease synonymously; they include cardiovascular disease (heart disease and stroke), diabetes, chronic respiratory diseases and cancers as primary examples of chronic illnesses causing the majority of premature deaths worldwide (WHO, 2005, 2007, 2017c, 2018a). A more comprehensive understanding that closely resonates with the characteristics of the chronic illnesses identified in this study is reflected in the definition provided by the Australian Institute for Health and Welfare (AIHW). They state that chronic conditions are those conditions that: have multiple and complex causes; develop over a long period of time and may therefore initially be asymptomatic; lead to other illnesses and complications and may cause disability or functional impairment (AIHW, 2018).

8.4.1.3   Self-management

The concept of self-management emerged in the literature in 1976 as a concept defining the active involvement of the patient in the care of their own long-term conditions (Creer, Renne & Christian, 1976). Self-management and self-care form the cornerstone of many global long-term conditions care and management models (Grover & Joshi, 2015). However, these terms lend themselves to considerable debate as definitions are often ambiguous and inconsistently applied within the literature (Grady & Gough, 2014). Richard and Shea (2011) state that self-care is a broad concept; in a healthy individual it can be understood as their ability to engage in protective health behaviours necessary for the maintenance and promotion of optimal health. In individuals with chronic illnesses, self-care can refer to management behaviours that prevent deterioration of the chronic illnesses.

It has been noted that 'self-care' can be subsumed in the concept of 'self-management', a term which is more prevalent in chronic disease literature (Grady & Gough, 2014; Grover & Joshi, 2015; Kamradt et al., 2014 Lorig & Holman, 2003; Richard & Shea 2011; Wilde & Garvin, 2007). In the UK, the terms self-care and self-management are used interchangeably (BMA, 2015; DH, 2005, 2011; NHS England, 2018f). The current definition of self-management/self-care by NHS England (2018f) is "all the actions taken by people to recognise, treat and manage their own health" (para. 1). One of the most frequently used definitions of self-management for chronic disease, found in current books and guidance (Eldredge et al., 2016; Haslam, et al., 2018); policy and standards (BMA, 2015; NICE, 2013; Haas et al., 2012; Coster & Norman, 2009) and published literature (Bielsten, Lasrado, Keady, Kullberg & Hellström, 2018; Hudon et al., 2018; Huis in het Veld, Verkaik, van Meijel & Francke, 2018; Hughes et al., 2018; Schulman-Green et al., 2012) is the one proposed by Barlow, Wright, Sheasby, Turner & Hainsworth (2002). They define self-management as an individual's ability to manage the symptoms, treatment, physical and psychosocial consequences of their long-term condition whilst maintaining a reasonable quality of life though appropriate behavioural, emotional and cognitive responses.

Similar to the conceptualization of self-management by Barlow et al. (2002), the Department of Health in the UK define self-care as the actions people take for themselves and their families to 1) maintain fitness, 2) maintain physical health and mental health especially after an acute illness or hospitalisation 3) prevent illness and accidents 4) care for minor ailments and long-term conditions, and 5) ensure psychological and social needs are being met (DH, 2005).

The NHS England (2018f, para. 1) definition of self-management is underpinned by a behavioural concept known as 'patient activation' which bases a person's ability and capacity to manage their illness, on their "self-reported knowledge, skill and confidence" (Hibbard, Mahoney, Stockard & Tusler, 2005, p. 1918), a concept similar to Albert Bandura's 'self-efficacy' (Bandura, 1977a). There are four levels of patient activation which highlight factors that may impact the patients' ability to engage in self-management. The two factors most relevant to dementia caregivers include feeling overwhelmed, and being unable to maintain health promoting behavioural changes "in the face of life stressors" (Hibbard & Gilburt, 2014, p. 9). The definitions applied across UK health policy are not consistent and do not highlight the significance of specific self-management behaviours as measured in primary care. Both self-care and self-management are thus professional and medical terms, not frequently used or universally understood by patients or professionals (BMA, 2015; Corben & Rosen, 2005; Omisakin & Ncama, 2011). According to Ehrlich, Kendall, Parekh and Walters (2016) self-management is a western construct and may not be applicable across different cultures and ethnicities.

Thirsk and Clarke (2014) argue that language is not a semantic construct and reflects underlying assumptions and world-views and therefore the use of the word 'self' in relation to long-term conditions' management reflects the assumptions made about human behaviour and support interventions. They state that the word 'self' implies that LTC management is an independent activity and thus interventions largely target changes at an individual level. According to Thirsk and Clarke (2014) this approach neglects the psychological and anthropological evidence of the impact of cultural and other influences on independence, motivation and behaviour change. Kendall (2010) argues that long-term

conditions are "embedded in family, community and societal conditions" (p. 15) which subsequently influences the health and care behaviours and choices made by an individual.

Consideration should also be given to whether the terms can be used interchangeably or not, self-care appeared to be more common in both service-user and service-provider vernacular. However, both terms are technical terms and have different meanings for different people. As evident from this research, caregivers consider behaviours such as relaxation and hobbies involving exercise as the "best medicine" to their LTCs and not only refer to this as 'self-care' but also consider it a substitute for the specific medical self-management behaviours.

Consistency and attention to detail when defining these terms in policy guidelines could offer a good starting point for service-users in the first instance to become clear and consistent with their understanding of the terms. The definitions would then need to be frequently used in practice and explained to caregivers, particularly those with medical self-management needs. Perhaps it would also be useful to separate self-management behaviours related to medical self-management in those with long-term conditions from self-management/care behaviours regarding general health and well-being.

8.4.2 Completing the Complexity Checklist

1) Volitions: What choices do caregivers have to make to achieve self-management?

Consistent with previous knowledge on volitions, the present data-set shows that caregivers show a lack of acknowledgement of their own long-term conditions and subsequently its needs. As evident from the mind-map of mechanisms (Figure 14), this can be due to numerous mechanisms that mainly stem from prioritising the care and needs of the PWD. For example, caregivers can underreport LTCs as a result of not realising the magnitude of their own needs

relative to the needs of the PWD, they may also be reluctant or hesitant to report their conditions due to a fear of being stigmatised and considered incompetent to continue providing care. However, the data revealed other factors such as beliefs about the impact and side effects of medications can also act as barriers to self-management. Additionally, those caregivers who fall into the exceptions categories of QOF, can do so due to the prioritisation of the PWD. For example, as long as the caregiver maintains their role as the primary caregiver they may be unable to consume certain medications and thus form a part of the QOF exceptions report. However, the primary factor affecting the decision-making behaviour of the caregiver with regards to self-management needs and behaviours is the prioritisation of the PWD, which in turn appears mainly to be operating under emotional mechanisms.

2) Implementation: What would be the chain of implementation between existing policy and practice in the care of dementia caregivers with LTCs?

A more specific and explicit pathway is required for practitioners to follow in the care and management of caregivers with LTCs. Currently, caregivers go to the third-sector in order to address their needs. However, caregivers often address caregiving related needs and not their own personal and health needs. Health needs, when finally acknowledged, often in a state of extreme distress and emergency are with a GP, however, here the implications of being a dementia family caregiver are not always discussed in as much depth as is required. This is also influenced by the short appointment times available with GPs, whereas caregivers have longer and more frequent access with third-sector service-providers, who can then signpost to the GP. The main gap in this sequence is of communication and awareness. Third-sector services should focus more on caregiver health needs, tools can be tailored, or indeed existing

primary care tools can be used in different settings and different approaches to reveal these hidden needs.

3) Contexts: What situations and circumstances are dementia caregivers immersed in on a daily basis? How could these impact their self-management behaviours?

The primary context which dementia caregivers appear to operate under, and which makes dementia caregiving different to caregiving for other conditions is the all-consuming and unpredictive nature of dementia. Dementia demands continuous damage control, and is unpredictable and unique to different individuals both in its trajectory and manifestation of symptoms. This makes daily life and routine difficult to manage for a family caregiver. Self-management is a way of living routine life that caters to the care of an LTC, dementia family caregivers are unable to implement this routine and regularity in their daily lives and are thus unable to implement self-management behaviours effectively.

4) Time: How have these issues been dealt with previously – for example how effective have self-management programmes been in the past and what are the implications of this for policy-making and practice?

Existing literature shows benefits in monitoring practices and prompting and documenting behaviour change. The data also points towards these as potentially successful strategies for behaviour change, however they will need to be assessed in conjunction with non-dementia related factors such as an individuals' pre-existing health beliefs, how theses shape their views on self-management and whether these beliefs have been strengthened or weakened after becoming a caregiver. This would require policy to be more explicit in its definition of 'supporting' the caregiver. Specific policy targets can refer to the use of implementations

intentions strategies to promote behaviour change, alongside plans for continuous and frequent monitoring, both professionally and within the caregivers' own personal network of family and friends where possible.

5) Outcomes: What monitoring systems would be relevant to self-management in dementia family caregivers? Would changed behaviour be a result of being monitored or a result of the intervention or programme?

Consistent with the literature, the data also indicates that monitoring systems both personal and professional would benefit caregivers in initiating and maintaining behaviour change. The professional monitoring systems would involve third-sector services in the first instance to be more aware and attuned to the needs of caregivers with one or more LTCs. This would need to be communicated to primary care practices and provisions for the monitoring of patients who may easily fall under the exception's category should be made.

6) Rivalry: What is the current policy landscape within which self-management programmes are embedded, how would these override the actions of stakeholders or service-users?

Current policy is focused on economic evaluations and current practice is focused on validated quantitative tools to assess patient outcomes, both operating under small time frames. A single study is unlikely to change national policy, which already does not give considerable weight to qualitative evaluations in its evidence appraisal. A wider shift in healthcare paradigms would be required to bring about change within policy.

7) Emergence: How might an improvement in self-management of LTCs change the original context of the situation? What are the chances of the outcome being no change, change or unintended change?

The impact of no change has been discussed in the realist review as it would eventually impact the economic valuation and contribution by dementia family caregivers, thus economically burdening health services and negatively impacting the quality of life of both the caregiver and the care-recipient. The impact of changed behaviour would have some positive consequences for health services as improved self-management at home, in the community and in primary care would reduce strain on secondary care services and resources in times of austerity. However, the data indicates that as the primary context of dementia caregiving is an overall consumption of the caregivers' time, energy and sense of self, they would therefore need additional services in order to change this context. For example, an increase in respite, or permanent care would be required to pull caregivers out of a chain of guilt, role consumption and inevitable prioritisation of the PWD so that they can begin to acknowledge and address their own needs. This would require increased involvement of and integration of primary and secondary care services with third-sector, counselling and respite services.

8.5 Reflections on methodology and methods

At the heart of all these interwoven research activities are endless processes of selection; and in constantly justifying this selection, a 'good methodology' is more a critical design attitude to be found always at work throughout a study, rather than confined within a brief chapter called 'Methodology'. (Clough & Nutbrown, 2012, p. 39)

This section reflects reflexively on the methodology and methods employed within this study. It also considers the strengths and limitations of this research.

Pawson (2013) states that methodology "enables yet constrains research" (p. x). Through my experience, I have found that the lack of rigidity in Pawson's methodology, the importance given to judgement and inference, and the acceptance and viability of the researcher's discretion in making these analytic decisions 'enable' and do not 'constrain' the research design. The next few sections reflect reflexively on my experiences of each stage of this research process, including the impact of my role as a new researcher.

Prior to commencing this research my experiences within healthcare practice had made me aware of 1) a need to understand the patients' perspectives and values when formulating care plans, and 2) the lack of integration within services and policy guidelines. Therefore, I was aware that a qualitative component would be required in this research in order to understand the details of the lived-experience of the caregivers. However, coming from a medical model of practice my initial aim had been to use this qualitative data to inform the design and development of a quantitative tool similar to QOF, but tailored specifically for dementia caregivers with long-term health conditions. At this point my theoretical knowledge and understanding was heavily influenced by primary care tools around the globe that carried out risk and cost assessments to identify 'at risk', vulnerable populations. While I felt I had sufficient knowledge of what does not work in practice, I lacked experience and knowledge about what does or would work within the context of the existing policy landscape.

I had attended numerous workshops for research methods both qualitative and quantitative, however, I had not fully grasped the significance of clearly aligning one's chosen research

methodology with one's own beliefs and the requirements of the research topic from the onset of the research. This often resulted in cognitive dissonance whereby I sometimes struggled to see the validity and reliability of my own methods and findings due to my conflicting beliefs and limited knowledge-base. While textbooks and workshops were rife with information about critical realism, there was little mention of Pawson's realist evaluation, and in fact, his methods were often frowned upon by contemporary and renowned critical realists during conferences and within the literature-base, as he was often regarded as a 'positivist in disguise'. After reading his body of work and conducting this research, I can say that this is far from the truth. Pawson is a mixed-methods, pluralistic researcher and both of his own methods of evaluation (realist review and realist interviews) are far more constructivist in nature than positivistic. It wasn't until I started considering which literature review method would be most appropriate for my study that I came across Pawson's holistic method of reviewing the evidence-base and subsequently his philosophy of evaluation science.

My previous experience with literature reviews was restricted to systematic reviews and statistical syntheses. Taking a more holistic approach to reviewing the literature and focusing on areas of policy discord helped formulate an in-depth understanding of the multiple dimensions to this issue and enabled me to proceed with my chosen method of data collection and analysis with confidence. In particular Pawson's complexity checklist was useful in helping identify the degree of complexity that this study would entail and synthesising the findings in a pragmatic and focused way. The realist review evidence selection and appraisal may appear unstructured and irreproducible to a researcher coming from the structured paradigm of systematic reviews, however as Wong et al. (2013a) state:

While the description of the processes followed will not allow the reader to draw firm conclusions about judgements made, it will give an indication of the coherence, plausibility and appropriateness of the processes used to inform those judgements. (p. 9).

The main strength of the realist review was in helping identify an epistemological gap in this area of research which in turn supported the aims of the study throughout. Although Wong et al. (2013a) state that the "guiding principle is that transparency is important" (p. 13), as a new researcher, the lack of specific guidance in literature appraisal was initially difficult to tackle. The use of the checklist provided by Hawker et al. (2002) offered little insight on the quality or 'rigour' of the studies as a whole, although, this may be a general limitation of conducting reviews on a mixed evidence-base. There were also slight inconsistencies in guidelines and papers published by Pawson and his team on realist reviews, where some strongly advised against checklists of any kind (Wong et al., 2013b), while others stated that they could be used (Wong et al., 2013a). Wong et al. (2013a) however state that "it is impossible to be prescriptive" (p. 9) about data extraction and appraisal; therefore, syntheses should be focused on descriptive explanations of what was done in the study.

Based on my overall experience, and the guidance and publications by Pawson and his colleagues, rigour should be sought by in-depth thematic annotations, deriving themes that are relevant to answering the review question. An advantage of not excluding studies based on methodological hierarchies or critical appraisal checklists was that it provided insight into the epistemological approaches taken to research within this field of study, thus reinforcing the appropriateness of the chosen methodology and methods. With this in mind, perhaps the synthesis and critique of the literature was more a reflection of my own perspectives on

health philosophy, research and practice, and perhaps this is the intention and wisdom behind allowing researcher discretion and authority in determining the relevance and rigour of the studies. Instead of considering this method flawed I now believe that it perhaps offers novel pragmatic insights based on each individual researchers' or research teams' experiences and research objectives. For example, my experience and understanding of self-management behaviours in patients with multiple LTCs, and using NICE guidance to deal with it, already made me aware of the need for clarity in care pathways and additional support services prior to the review. This most likely tinted my analytic lens, and I have learned that this should be embraced as a strength rather than a limitation of realist philosophy, as the involvement of the researcher as an intentional agent in the research process is a strength and not a limitation of this methodology.

Here, it is crucial to reflect on my experience in "studying the unfamiliar" (Berger, 2015, p. 227). Researching a topic where the researcher has little practical or theoretical knowledge of the subject comes with both advantages and disadvantages. While I was familiar with the theories, practice and policy around self-management behaviours and psychology, and long-term health conditions and their management in primary care, my lack of familiarity with people with dementia, the manifestation of the illness and the lived experience of dementia caregivers, was an enlightening experience. Firstly, a lack of familiarity with the topic encouraged me to be an attentive interviewer. Having presented this research at various conferences I am often asked how I managed to derive such in-depth information form the participants. I believe this is partly due to the fact that I did not interrupt the participants and partly because they were comfortable with me, as a 'young student', and were unafraid to reveal details about their lived-experiences. This is an experience I have had during healthcare

placements and voluntary work as an undergraduate student as well. Patients would often talk to me in great detail about their conditions when the healthcare professionals left the room. However, not interrupting the participants' stream of thought sometimes resulted in long discussions, largely unrelated to the interview schedule. This meant that I had large amounts of data to first transcribe and then sift through for relevant information. I however consider this an important finding that highlights the levels of loneliness felt by the caregivers, as all participants were eager to talk and many even stated that it was cathartic and that "it's good to have a chat".

Secondly, a lack of familiarity with the topic allowed me to be relatively objective and open to emerging themes when coding for my analysis. However, at the same time it also meant that I perhaps introduced limitations from my existing knowledge of psychosocial theories in behaviour change, health beliefs and self-management in order to compensate for the lack of knowledge and understanding about dementia and family caregivers. It also meant that I found it difficult to stay focused during the coding process as in Pawson's 'teacher-learner' cycle I would often find myself drifting back into the learner's seat. Having a supervision team involving input from experts from different fields was a major contributor to quality-control in this process, as it allowed me to then consider all views and 'adjudicate' between them using the realist principles of 'trust' and 'organised scepticism'.

Additionally, the conceptual framework proved a very useful guide when trying to make sense of the information present in the data-sets. However, I would recommend that these conceptual frameworks be used for sense-making and aiding the understanding of a concept rather than simply trying to find the relevant associations and correlations between stressors in the linear fashion in which they are presented. For example, the conceptual framework

used in this study divides primary (objective) stressors and secondary (subjective) stressors into separate categories connected in a linear fashion, however, as evident from this research they are interrelated and overlapping in a very complex manner. This is a key point to consider as studies using these conceptual models, particularly in quantitative research determine the type of evidence-based interventions and support strategies provided to dementia caregivers. For example, if interventions are based on objective burden correlates then they will be designed to ease the objective load by providing primary support to the dementia patient such as drug therapy for sleep or behavioural problems (Campbell et al., 2008; Etters, Goodall & Harrison, 2007; Wolfs et al., 2012). If interventions are based on subjective burden correlates of dementia caregiving they will most likely be tailored towards the caregivers' unmet self-management and healthcare needs (Campbell et al., 2008; Flyckt, Fatouros-Bergman & Koernig, 2015; Mittelman, Roth, Haley & Zarit, 2004; Snyder et al., 2015).

I found that the most difficult aspect of analysis, when studying a complex issue through in-depth interview data, was to stay focused on the research question, which in this case was self-management behaviours. Many emerging themes, concepts and underlying nuances within interview data are all relevant potential mechanisms influencing each other but perhaps not rigorous enough within the entirety of the data-set to draw definitive conclusions. Here the flexibility offered by Pawson's methodology described as "informed guess-work" (Pawson, 2013, p. 80) and Template Analysis by King and Brooks (2017) helped, as they consider the validity of single case themes not as an anomaly, bias or discrepancy of the research process, but something which should be acknowledged as a finding and further explored.

Template Analysis was a crucial guiding force in structuring the coding process of the interviews and later in structuring the presentation of the findings. Pawson's own methodology offers little insight into specific analytic methods and relies on C-M-O configurations when constructing realist data. While C-M-O configurations were very helpful in the initial framing and development of an argument, the addition of the hierarchical coding strategies of Template Analysis really helped structure and identify the interrelations and embeddedness of the mechanisms with the contexts and outcomes. The hierarchical coding method of Template Analysis forces the researcher to consider the order and structure of their argument.

Hierarchical coding encouraged me to focus on the relationship between mechanisms within the hierarchy and use Pawson's 'trust-doubt ratio' to determine how mechanisms interact with each other. This hierarchical organisation of themes also offers a strong foundation for future quantitative enquiry seeking to identify associations between these mechanisms and variables using techniques such as factor analysis. King and Brooks (2017) also emphasise that, in Template Analysis, although themes are generally identified through repetition, isolated cases of relevance should not be ignored, this helped with the relevance and rigour underpinnings of realist evaluation as single case C-M-O's could be constructed. Overall Template Analysis proved to be a valuable and indispensable addition to the broad "organising principles" (Pawson, 2013, p. 86) of TARMATO offered by Pawson (2013). The addition of elements of discourse analysis, such as commenting on tone, verbal and non-verbal cues enriched the quality of analysis and highlighted the benefits of qualitative pluralism. I believe that conducting the interview myself and then transcribing it at the earliest opportunity (often the same day) contributed significantly to me becoming 'familiar

with the data', which is the first and one of the most crucial steps of most qualitative analytic frameworks.

The most significant turning point for me was to appreciate the value and validity of qualitative research methods, initially despite and later in spite, of my biomedical, positivist background. While the positivist's paradigm dictated that large sample sizes, controlled and consistent research environments and methods are the benchmark for quality-control, the methods employed and demanded by this study appeared in comparison rather too flexible for me to feel safe in my approach at the beginning. However, what helped me overcome my inhibitions with this new research methodology was to become an avid reader of qualitative research methods and publications, this helped me unpick the current methods that are considered the gold standard of applied evaluation research. More importantly the large volumes of insightful data that I had collected from 'just' twelve interviews was what finally convinced me that a change in paradigm is required, not just personally but also globally.

One of the most relevant findings to policy have been mentioned earlier in this chapter with regards to the current debate around QOF and its effectiveness. The idea that QOF itself is not ineffective, rather the setting within which the tool is used is perhaps ineffective is a finding that owes full credit to this realist, policy-driven approach to the study design and particularly the interview design. Had the interview schedule been based solely on preference-based outcome measures popularly used in research then the findings would not have been able to fill the gap between policy and practice. Thus, the realist premise that inquiry should not begin from scratch and should be based on and build on existing findings, holds the potential for economic valuation to researchers and practitioners involved in such policy and practice debates.

Another strength of the realist approach to evaluation is the acceptance of diversity. In a positivistic paradigm diversity and small sample sizes within a population may be seen as a red flag which introduce 'bias' in the study results. However, as Manzano (2016) argues in realist inquiry, numbers such as sample size are not as significant as the volume of data collected.

> Since the unit of analysis is not the person, but the events and processes around them, every unique programme participant uncovers a collection of micro events and processes, each of which can be explored in multiple ways to test theories" (Manzano, 2016, p. 8).

In this respect the sample size was adequate as the data was able to show demi-regularities between a moderately diverse set of participants. The male to female ratio was relatively fair for the sample of twelve participants in the first study. Where the study falls short on diversity is in exploring diversity within different socio-economic and cultural groups. Nonetheless, a major strength of realist interviewing techniques is that even the addition of single cases of socioeconomic and cultural diversity in the sample offered in-depth data that can direct future research questions. However, this strength also gives rise to the question of what additional perspectives, such as the perspectives of the person with dementia or GPs would offer in terms of a whole-systems approach to research. The study was also limited in terms of achieving diversity of the different sub-types of dementia being cared for, although perhaps this is also reflection of dementia statistics where Alzheimer's is still the most common type of dementia. Another limitation was that the additional long-term conditions in the care-recipient were not discussed in relation to the caregiving role. This was primarily because the caregivers identified themselves as primarily caring for dementia and not other

conditions. However, this naturally has implications on the workload of a caregiver, for example more LTCs in the PWD would likely imply that the caregiver has to manage more medications for the PWD. Table 40 summarises the strengths and limitations of this study.

Table 40   Summary of strengths and limitations of the research

Strengths	Limitations
Policy-driven realist approached allowed a bottom up critique and analysis of existing systems and practices.	Lack of service-user perspective from policy-makers and primary care practitioners hides an important dimension to a whole-systems approach.
Flexibility offered from a realist research paradigm offers a holistic approach to dissecting and evaluating healthcare practices from a patient-centred perspective.	Lack of clarity on realist analytic techniques in realist reviews makes the research process difficult for a novice in this research design.
Male to female ratio in sample was roughly equal and provided substantial in-depth data for the identification of demi-regularities and for comparisons to be made.	Sample size did not allow for the exploration of emergent themes and findings such as diversity within each sample. For example, differences within groups and influences of social factors within groups.
Purposive sampling allowed inclusion of diversity such as different socioeconomic status or ethnicity.	People not using third-sector organisations are unaccounted for in this study and could perhaps be those who are more vulnerable and more in need of support.
In-depth data collection allowed for multiple factors relating to the caregivers' lives to be considered in each case. For example, data related to caregivers' previous life experiences and previous caregiving experiences helped make more sense of their current situation.	Although tentative explorations have been made which can guide future research, an in-depth exploration of diversity both in the caregiver sample and the PWD sample was not conducted. For example, most PWD's had Alzheimer's Dementia this therefore does not account for variations in BPSD in different sub-types of dementia; most PWDs also had other LTCs, the potential of increased burden when caregiving for multiple morbidity was not considered in detail.

8.6 Key recommendations for policy, practice and research

8.6.1 Policy

- Globally, and particularly in the UK policy should focus on uniformity and clarity in definitions and integrate definitions within policy targets aimed at behaviour change.

- Dementia caregiver self-management behaviours as reported in this study reveal the need for a consistent and formal care pathway, designed in accordance with their needs.

- The development of formal guidelines such as NICE should incorporate more qualitative research evidence.

8.6.2 Practice

Professionals, particularly those who have longer and more frequent periods of contact with caregivers such as third-sector service providers should ask probing questions related to specific self-management behaviours in order to elicit the dementia family caregivers' hidden needs.

8.6.3 Research

A growing need for qualitative pluralism has been highlighted in existing research (Frost & Nolas, 2011; Hood, 2015). The role of the self and changing self-concept in dementia requires more research from mixed-methods research, for example, combining realist interviewing techniques with phenomenological analytic frameworks, close to the tenets of Heidegger's phenomenology otherwise known as hermeneutic phenomenology (Laverty, 2003).

Heidegger built on the principles of Husserl, however differed in that he focused not on the epistemology of phenomenology but rather on the ontology of phenomenology (Laverty, 2003). A focus on Heidegger is recommended as his questions were aimed at gaining an understanding of the 'Dasein' way of Being which Heidegger explains as "Being-in-the-World" (Heidegger, 1962, p. 234). This addition to the collection and thematic analysis of realist data could potentially help make sense of the caregivers' changing ideas of being in the world as a dementia caregiver.

Dasein has been interpreted by Brandom (1983) as a 'mode' of Being as understood by people. However, Heidegger was concerned with explaining lived experiences through factors that defined the existential state of Being in terms of ontology and not just the ontical causative factors (Heidegger, 1962). In addressing this concern Haugeland provides a pragmatic explanation of Heidegger's Dasein as a "way of life" (Rouse, 2013, p. 82) that is understood through the patterns of shared experiences of people and communities and not based simply on an ontical understand of individual factors. Heidegger (1962) emphasised that every interaction is influenced by the background and 'historicality' of an individual. He explains that historicality does not refer to history in terms of constituting a "sequence of experiences" (Heidegger, 1962, p. 440), rather he redefines the term historical as "the entity that exists as Being-in-the-World" (Heidegger, 1962, p. 440). This has been interpreted by Koch (1995) as the unbreakable bond between the world and the person through which interpretations should be perceived. Polkinghorne (1983) and Laverty (2003) described this process as bringing attention to the historical context of an individual such as their culture, language and background in order to understand the effects of their 'historicality' on their

lived-experience. Such methods would allow a deeper understanding of what policy intentions mean to the subjects for whom they are designed.

8.7   Unique contribution of study

- Realist methodology and the realist Science of Evaluation in dementia caregiver research shows the value of qualitative evaluations in a field dominated by quantitative and economic evaluations.

- Realist evaluation applied to UK policy for LTCs and dementia caregivers is the first of its kind for this complex patient group.

- Addressing specific LTC medical self-management behaviours in dementia caregivers shows the value of existing outcome measures and assessment methods, and can inform current debate on changing primary care policy for LTCs.

- A new model of viewing the caregiver stress process; previously stressors were categorised and depicted with linear connections; with the underpinnings of realist philosophy this study has shown the 'embeddedness' and interrelatedness of these stressors as non-linear constructs.

8.8   Conclusion to thesis

This study reinforces the significance of incorporating dualistic paradigms in the accumulation of knowledge pertaining to complex health issues and public health concerns. The findings of this study highlight that the plight of dementia family caregivers with long-term conditions is under-recognised by current research, healthcare policy, practice and by caregivers themselves. The findings have also uncovered potential new areas of research and emphasised the role and value of the researcher as an intentional agent in the research process, particularly in the field of healthcare.

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APPENDICES 1-19

Appendix 1   Data Extraction form for realist review

DATE EXTRACTION FORM:					
Reference			Peer Review		
Study design				Location of study	
Ethics					
Sample					
Aim/ Research question/ Hypotheses					
Outcomes & intervention					
Long-term conditions' measures Physical health measures & others relevant to health outcomes					
Analysis					
Results					
Conclusion, comments, issues					
RELEVANCE					
METHODOLOGICAL RIGOUR					

	Good [40]	Fair [30]	Poor [20]	V Poor [10]
1. Abstract				
2. Introduction / aims				
3. Method & data				
4. Sampling				
5. Data analysis				
6. Ethics and bias				
7. Findings/results				
8. Transferability/generalisability				
9. Implications/usefulness				
Total per column				
Total overall score	/360	Percentage		

1. Abstract and title: Did they provide a clear description of the study?
   Good   Structured abstract with full information and clear title.
   Fair   Abstract with most of the information.
   Poor   Inadequate abstract.
   Very Poor   No abstract.

2. Introduction and aims: Was there a good background and clear statement of the aims of the research?
   Good   Full but concise background to discussion/study containing up-to-date literature review and highlighting gaps in knowledge.
                 Clear statement of aim AND objectives including research questions.
   Fair   Some background and literature review.
                 Research questions outlined.
   Poor   Some background but no aim/objectives/questions, OR Aims/objectives but inadequate background.
   Very Poor   No mention of aims/objectives.
                 No background or literature review.

3. Method and data: Is the method appropriate and clearly explained?
   Good   Method is appropriate and described clearly (e.g., questionnaires included).
                 Clear details of the data collection and recording.
   Fair   Method appropriate, description could be better.
                 Data described.
   Poor   Questionable whether method is appropriate.
                 Method described inadequately.
                 Little description of data.
   Very Poor   No mention of method, AND/OR
                 Method inappropriate, AND/OR
                 No details of data.

4. Sampling: Was the sampling strategy appropriate to address the aims?
   Good   Details (age/gender/race/context) of who was studied and how they were recruited.
                 Why this group was targeted.
                 The sample size was justified for the study.
                 Response rates shown and explained.
   Fair   Sample size justified.
                 Most information given, but some missing.
   Poor   Sampling mentioned but few descriptive details.
   Very Poor   No details of sample.

5. Data analysis: Was the description of the data analysis sufficiently rigorous?
   Good   Clear description of how analysis was done.
                 Qualitative studies: Description of how themes derived/ respondent validation or triangulation.
                 Quantitative studies: Reasons for tests selected hypothesis driven/ numbers add up/statistical significance discussed.
   Fair   Qualitative: Descriptive discussion of analysis.
                 Quantitative.
   Poor   Minimal details about analysis.
   Very Poor   No discussion of analysis.

Appendix 3   Quality Checklist reproduced from Hawker et al. (2002, p. 1297) (Page 2/2)

6. Ethics and bias: Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?

Good	Ethics: Where necessary issues of confidentiality, sensitivity, and consent were addressed.
	Bias: Researcher was reflexive and/or aware of own bias.
Fair	Lip service was paid to above (i.e., these issues were acknowledged).
Poor	Brief mention of issues.
Very Poor	No mention of issues.

7. Results: Is there a clear statement of the findings?

Good	Findings explicit, easy to understand, and in logical progression.
	Tables, if present, are explained in text.
	Results relate directly to aims.
	Sufficient data are presented to support findings.
Fair	Findings mentioned but more explanation could be given.
	Data presented relate directly to results.
Poor	Findings presented haphazardly, not explained, and do not progress logically from results.
Very Poor	Findings not mentioned or do not relate to aims.

8. Transferability or generalizability: Are the findings of this study transferable (generalizable) to a wider population?

Good	Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling).
Fair	Some context and setting described, but more needed to replicate or compare the study with others, PLUS fair score or higher in Question 4.
Poor	Minimal description of context/setting.
Very Poor	No description of context/setting.

9. Implications and usefulness: How important are these findings to policy and practice?

Good	Contributes something new and/or different in terms of understanding/insight or perspective.
	Suggests ideas for further research.
	Suggests implications for policy and/or practice.
Fair	Two of the above (state what is missing in comments).
Poor	Only one of the above.
Very Poor	None of the above.

Appendix 4   Participant information sheet for dementia caregivers (Page 1/2)

We would like to invite you to take part in our study which will involve asking you questions about your health in relation to your experience as a dementia caregiver. We value your participation and would like to provide you with the following information on why we are doing the study and what it involves.
Purpose of the study
The aim of this study is to gain an understanding of how those who care for family members with dementia manage their own health and long-term conditions. We would like to understand whether any aspect of providing care such as emotional, financial, physical, social etc. has affected your own health and management of your health needs. With the rising number of dementia caregivers there needs to be better assessment of caregiver health and wellbeing that will enable them to care for themselves as well as their family member with dementia.
Who has approved this study?
This study has been approved by the University of Huddersfield Research Ethics Committee.
Why have I been invited?
You have been invited because you have one or more of the long-term conditions mentioned in this information sheet (page 2) and you are currently caring for a family member with dementia (such as a spouse, parent or parent-in-law). We are hoping to interview 12 dementia caregivers.
Do I have to take part?
No, you do not have to take part if you do not want to. You will be given a week to read, understand and discuss this information sheet with a family/friend/professional before you make your decision. If you decide to take part, you may keep the information sheet and the researcher will go over it with you before the interview. You will be given time to ask any questions related to the information sheet or the study in general. If you would like to take part please provide a contact number/ email to your organisation to be passed on to the researcher. Please note your contact details or name will not be used in the research. Alternatively, if you do not wish to provide contact details you may ask your organisation to arrange a meeting at a time that is convenient to you and the researcher.
What will I have to do?
You will be asked to answer a few questions regarding how you maintain/manage your health while caring for a family member with dementia. The interview is not expected to last longer than an hour, though it can last longer if you wish.

Appendix 5   Participant information sheet for dementia caregivers (Page 2/2)

Will my information be kept confidential?
Yes, all information from the interviews will be kept confidential. Recordings will be carried out using University of Huddersfield equipment and all your data will be kept securely at the University and will only be available to the research team. Direct quotes will be used in the publication of results, but a pseudonym will be used to protect your identity and the identity of anyone you mention in the interview. Any information that may lead to your identification will not be used. Age, ethnicity and gender will be required and used in the research. Following completion of the study, data will be stored safely at the University of Huddersfield and then destroyed in accordance with University policy.
What will happen if I don't want to carry on with the study?
You may at any point decide to pause, stop or withdraw from the study and your information will not be used without your consent and it will be destroyed immediately and securely at the University of Huddersfield. You will not be asked for a reason for your decision and this will not affect your ability to use or be a member of the organisation to which you belong.
What happens if there is a problem?
If you have a concern about any aspect of this study, or have a complaint about the way you have been dealt with during this study or any possible distress you might experience, you should consult Kirklees Council for services offering support for caregiver.   You may also contact the researcher or the principal supervisor at the University of Huddersfield (contact details provided below).
Indemnity statement
If you have a concern about negligence then you may have grounds for a legal action for compensation against The University of Huddersfield, but you may have to pay your legal costs.   Thank you for taking the time to read this information sheet and consider this study.   If at any point you have questions or concerns regarding this study, please contact Nafisa Zaman ▮▮▮▮▮▮▮▮▮▮ or phone: ▮▮▮▮▮▮▮ or Dr Serena Bartys (▮▮▮▮▮▮▮▮▮)
Appendix: Have you been diagnosed with any of these conditions?

1. Atrial fibrillation	8. Chronic heart disease	14. Depression
2. Heart failure	9. Hypertension	15. Mental Health
3. Peripheral arterial disease	10. Diabetes mellitus	16. Cancer
4. Chronic obstructive pulmonary disease		17. Chronic Kidney Diseas
5. Transient ischaemic attack	11. Asthma	18. Rheumatoid arthritis
6. Epilepsy	12. Osteoporosis	19. Palliative care
7. Learning Disabilities	13. Dementia	20. Stroke
21. Irritable Bowel Syndrome	22. Gastric Conditions	Anything else?

University of HUDDERSFIELD
Inspiring tomorrow's professionals

IF YOU CARE ABOUT DEMENTIA WE CARE ABOUT YOU!

CARING FOR DEMENTIA

We would like to know how you manage your health while caring for a loved one with dementia. If you would be interested in answering a few questions to support Dementia research within the University of Huddersfield please contact us:

nafisa.zaman@hud.ac.uk

Phone: 01484 472526

Appendix 7   University of Huddersfield (2015) SREP form (Page 1/3)

Researcher(s) details	
Supervisor(s) details	
All documentation has been read by supervisor (where applicable)	YES / NO / NOT APPLICABLE This proposal will not be considered unless the supervisor has submitted a report confirming that (s)he has read all documents and supports their submission to SREP
Aim / objectives	
Brief overview of research methods	
Project start date	
Project completion date	
Permissions for study	
Access to participants	
Confidentiality	
Anonymity	
Right to withdraw	
Data Storage	
Psychological support for participants	
Researcher safety / support (attach completed University Risk Analysis and Management form)	
Information sheet	
Consent form	
Letters / posters / flyers	
Questionnaire / Interview guide	
Debrief (if appropriate)	
Dissemination of results	
Identify any potential conflicts of interest	

Appendix 8   University of Huddersfield (2015) SREP Form (Page 2/3)

Does the research involve accessing data or visiting websites that could constitute a legal and/or reputational risk to yourself or the University if misconstrued? Please state Yes/No If Yes, please explain how you will minimise this risk	
The next four questions in the grey boxes relate to Security Sensitive Information – please read the following guidance before completing these questions: http://www.universitiesuk.ac.uk/policy-and-analysis/reports/Documents/2012/oversight-of-security-sensitive-research-material.pdf	
Is the research commissioned by, or on behalf of the military or the intelligence services? Please state Yes/No If Yes, please outline the requirements from the funding body regarding the collection and storage of Security Sensitive Data	
Is the research commissioned under an EU security call Please state Yes/No If Yes, please outline the requirements from the funding body regarding the collection and storage of Security Sensitive Data	
Does the research involve the acquisition of security clearances? Please state Yes/No If Yes, please outline how your data collection and storages complies with the requirements of these clearances	
Does the research concern terrorist or extreme groups? Please state Yes/No If Yes, please complete a Security Sensitive Information Declaration Form	

Appendix 9   University of Huddersfield (2015) SREP Form (Page 3/3)

Does the research involve covert information gathering or active deception? Please state Yes/No	
Does the research involve children under 18 or participants who may be unable to give fully informed consent? Please state Yes/No	
Does the research involve prisoners or others in custodial care (e.g. young offenders)? Please state Yes/No	
Does the research involve significantly increased danger of physical or psychological harm or risk of significant discomfort for the researcher(s) and/or the participant(s), either from the research process or from the publication of findings? Please state Yes/No	
Does the research involve risk of unplanned disclosure of information you would be obliged to act on? Please state Yes/No	
Other issues	
Where application is to be made to NHS Research Ethics Committee / External Agencies	
Please supply copies of all relevant supporting documentation electronically. If this is not available electronically, please provide explanation and supply hard copy	

PARTICIPANT CONSENT FORM (ADULT)

Title: Management of long-term conditions among informal family caregivers of people with dementia

Researcher: Nafisa Zaman

Participant Identifier number:

If you agree with the following terms please tick the boxes and complete the form with your name, signature and today's date.

I confirm that I have read and understood the participant Information sheet related to this research, and have had the opportunity to ask questions.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.	
I understand that all my responses will be anonymised.	
I give permission for members of the research team to have access to my anonymised responses.	
I agree to take part in the above study	

Appendix 11   Development of Template using Vanessa's interview

	Vanessa's interview	
	Themes/Modifications	Explanation
BARRIERS	Reporting symptoms	This sub-theme was added to the theme of Symptoms as Vanessa was initially dismissive towards acknowledging any major symptoms of her health

	Self-care
	
	      Sleep
	
	      Exercise
		Self-care behaviours that impacted overall health and well-being were also negatively influenced by dementia caregiving. Vanessa reported trouble getting back to sleep due to future health and financial worries related to caregiving. Vanessa also reported being unable to find time for exercises that were recommended by her doctor

	Forgetfulness	Vanessa reported forgetting aspects of her medical self-management, the impact on memory was merged with forgetfulness and included under the heading of medical management.
	Lack of validation from person with dementia (PWD)	Lack of validation for self and self-management behaviours from the person with dementia was also identified as a barrier. This was specific to dementia as the PWD no longer understands the situation.
	Admiral nurse	Issues with lack of support from admiral nurses, who are designed specifically for caregivers was a key barrier to accessing support for themselves
FACILITATORS	Family support	The benefits of prompts and respite support from close family members was identified by Vanessa's as a facilitator to self-management of her long-term conditions. This aspect had not been identified by Karen as she did not have close family to support her.

Appendix 12   Development of Template using Maria's interview

	Maria's Interview	
	Themes/Modifications	Explanation
BARRIERS	System hassles	Fragmentation of services/lack of information & communication were identified as barriers to accessing support for caregiving.
	Unfairness	This was highlighted as a key feeling throughout the caregiving process and was linked to a number of other issues such as financial impact, quality of care received, loss of the person.
	Finances	Although the financial impact had been mentioned by Karen and Vanessa, it did not directly relate to many aspects of self-management. However, it was being highlighted consistently as a growing concern amongst the caregivers. It was also highlighted by Karen and Maria that the unfairness of having to pay for dementia care was a barrier to accessing respite as the quality of care did not reflect the cost
	Impact on routine	Maria had a particularly difficult time managing the behavioural and psychological symptoms in her husband, her daily routine was unpredictable and this impacted her ability to incorporate regular self-management behaviours such as taking medications.
FACILITATORS	Strategies to overcome self-management issues	Maria mentioned a number of cognitive strategies that she used to appraise her own health in relation to her ability to continue caring. She stated this helped encourage self-management behaviours in her.

Appendix 13　Template development from remaining 9 interviews after Karen, Vanessa and Maria

	Remaining interviews	Themes/Modifications & Explanation
BARRIERS	Emily	This was added under barriers to self-care. Emily reported losing a considerable amount of weight due to the stress of caregiving.
	Andrew	Smoking was added in barriers to self-care. Andrew started smoking as a result of the dementia caregiving stress.
	Robert	Loss of intimacy was added to emotional stressors
	James	James reported drinking as a way of coping with loneliness; this was added to risky health behaviours
	Daniel	Professional's & support not sensitive to dementia care needs was added as a sub-theme in barrier to respite. Issues with diet and healthy eating were added to risky health behaviours.
	Ethan, Anna, Janice, Maya	No changes to template

Appendix 14   Visual aid, summary of themes

forget because busy caring	dont think its necessary	delay making it because caring	dont think its necessary
Medication management		**Appointments**	
cant because if side effects (interfere with caring responsibilities)		dont attend because can't take loved one with me (no one to care for them)	makes me anxious thinking about it so avoid it
Diet	Exercise	get up many times during the night to care	up at night thinking/worrying about future
Lifestyle changes:		**Sleep management**	
Smoking	Drinking	can't sleep properly because loved needs supervision (escape)	sleep has taken a toll on my health
doesn't interfere with daily activities	gets me down but i know how to cope & where to get help	as a child	as a relative
Mood		**Previously cared**	
have previously taken antidepressants	days when i struggle to cope (caring + self-care)	as a friend	caring for more than one person at a time currently
gave up job/career to care	retired earlier than plamnned	Financial	Emotional
Employment History		**Dementia patient related stress**	
finances affected as a result	Miss work	Physical	
Resentment	Anger	Religion/Meditation	outside help: family, carers, neighbours, respite
Feelings		**current coping mechanisms**	
Reward	Despondant	Poor health behaviours e.g. smoking, drinking	

Appendix 15   Cases from Study 1 used as key examples in Study 2

Andrew	Breaking glasses & BPSD Smoking after being a caregiver "drudgery" quote
Maya	Waking up early Taking care of medication for whole family except herself
James	Drinking when PWD at respite
Robert	Risky sexual behaviours, emotional detachment

Appendix 15   Study 2 Interview schedule

Open Questions/general topics	Sample close ended questions	
	Caregiver	Staff
Validity/ Acceptability of themes	We picked out these areas that we think are important to your self-management (visual aid). Do you agree with them? Is there anything you would like to add or remove?	We picked out these areas that we think are important to a dementia caregiver's LTC self-management. Do you agree with them? Is there anything you would like to add or remove?
	Do you think the themes we have identified are focused on your needs – specifically your health needs?	Do you think the themes are focused on the caregivers' needs – specifically their health needs?
Long-term conditions self-management awareness	Have you been asked questions around these themes before by any healthcare professional?	Have you addressed these needs before in an assessment tool etc?
	Do you think you would you be able to talk about each of these themes with a professional during one of the support meetings or coffee sessions?	Do you think you could use these QOF themes to elicit a conversation about the caregivers' own needs?
Self-management behaviour change	Can you see a clear link between these themes (obstacles to self-management) and your self-management habits? Do you think it's important to change this?	Is there a clear link between these themes and the issues/obstacles a caregiver might face during self-management?
Use of implementations intentions strategies	How do you feel about using written strategies such as 'if...then' statements to encourage you to improve self-management habits – do you think it would be helpful (work an example with them).	How do you feel about using written strategies such as 'if...then' statements to encourage carers to improve self-care habits – what do you think would help (work an example with them).
What needs amending?	Do you have any more comments/recommendations/ideas you would like to share to help develop this tool?	Do you have any more comments/recommendations/ideas you would like to share to help this cause? How might we implement this in your practice?

You may remember doing an interview with us a few months ago in which you were asked questions about how you manage your health whilst being a family carer for a loved-one with dementia. We have used the information you provided to develop some strategies to help you keep up with your self-care behaviours and we would value your feedback on it. We appreciate your participation and would like to provide you with the following information on why we are doing the study and what it involves so you can make an informed decision.
Purpose of the study
To help those who are caring for loved-ones with dementia be able to care for themselves as well.
Who has approved this study?
This study has been approved by the University of Huddersfield Research Ethics Committee.
Why have I been invited?
You have been invited because you have one or more of the long-term conditions mentioned in this information sheet (page 2) and you are currently or have in the past cared for a family member with dementia. We are hoping to interview around 3-5 dementia carers.
Do I have to take part?
No, you do not have to take part if you do not want to. You will be given a week to read, understand and discuss this information sheet with a family/friend/professional before you make your decision. If you decide to take part, you may keep the information sheet and the researcher will go over it with you before the interview. You will be given time to ask any questions related to the information sheet or the study in general. If you would like to take part please provide a contact number/ email to your organisation to be passed on to the researcher. Please note your contact details or name will not be used in the research. Alternatively, if you do not wish to provide contact details you may ask your organisation to arrange a meeting at a time that is convenient to you and the researcher.
What will I have to do?
You will be asked to read the questionnaire and provide your feedback on each of the domains.
Will my information be kept confidential?
Yes, all information from the interviews will be kept confidential. Recordings will be carried out using University of Huddersfield equipment and all your data will be kept securely at the University and will only be available to the research team. Direct quotes may be used in the publication of results, but a pseudonym will be used to protect your identity. Any information that may lead to your identification will not be used. Following completion of the study, data will be stored safely at the University of Huddersfield and then destroyed in accordance with University policy.
What will happen if I don't want to carry on with the study?
You may decide to pause, stop or withdraw from the study and your information will not be used without your consent and it will be destroyed immediately and securely at the University of Huddersfield. You will not be asked for a reason for your decision and this will not affect your ability to use or be a member of the organisation to which you belong. If you wish to withdraw from the study you must do so by the 31st of May 2017.
What happens if there is a problem?

Appendix 17   Caregiver participant information sheet Study 2 (Page 2/2)

Participant information sheet (CAREGIVER Page 2 of 2)

If you have a concern about any aspect of this study, or have a complaint about the way you have been dealt with during this study or any possible distress you might experience, you should consult Kirklees Council for services offering support for carers.

You may also contact the researcher or the principal supervisor at the University of Huddersfield (contact details provided below).

Indemnity statement

If you have a concern about negligence then you may have grounds for a legal action for compensation against The University of Huddersfield, but you may have to pay your legal costs.

Thank you for taking the time to read this information sheet and consider this study.

If at any point you have questions or concerns regarding this study, please contact Nafisa Zaman (████████████████), or Dr Serena Bartys (██████████████)

Appendix: list of long-term conditions – Have you been diagnosed with any of these conditions?

1. Atrial fibrillation	8. Chronic heart disease	14. Depression
2. Heart failure	9. Hypertension	15. Mental Health
3. Peripheral arterial disease	10. Diabetes mellitus	16. Cancer
4. Chronic obstructive pulmonary disease		17. Chronic Kidney Disease
5. Transient ischaemic attack	11. Asthma	18. Rheumatoid arthritis
6. Epilepsy	12. Osteoporosis	19. Palliative care
7. Learning Disabilities	13. Dementia	20. Stroke

Appendix 18   Staff participant information sheet Study 2

Participant Information Sheet (Support service Staff)

We appreciate you helping us to identify participants for the first part of our study. We have used the interview data to design a strategy to promote self-care behaviours those for family caregivers who have long-term conditions. We would now like to gain your professional feedback on this strategy and how we can implement it within your organisation. With the rising number of dementia carers there needs to be better assessment of carer health and wellbeing that will enable them to care for themselves as well as their loved one.
Purpose of the study
Develop written strategies to encourage health related self-care behaviours in family caregivers of dementia patients.
Who has approved this study?
This study has been approved by the University of Huddersfield Research Ethics Committee.
Why have I been invited?
You have been invited because you are an experienced professional who works closely with dementia caregivers and would be able to put this self-care tool in practice. We are hoping to interview around 3-5 professionals.
Do I have to take part?
No, you do not have to take part if you do not want to. You will be given a week to read, understand and discuss this information sheet with a family/friend/professional before you make your decision. If you decide to take part, you may keep the information sheet and the researcher will go over it with you before the interview. You will be given time to ask any questions related to the information sheet or the study in general. If you would like to take part please provide a contact number/ email to your organisation to be passed on to the researcher. Please note your contact details or name will not be used in the research. Alternatively, if you do not wish to provide contact details you may ask your organisation to arrange a meeting at a time that is convenient to you and the researcher.
What will I have to do?
You will be shown some themes and strategies that have previously helped people change their health-related behaviours. You will be asked to provide feedback on this through some questions. Interviews are expected to last between 20-30 minutes
Will my information be kept confidential?
Yes, all information from the interviews will be kept confidential. Audio recordings will be carried out using University of Huddersfield equipment and all your data will be kept securely at the University and will only be available to the research team. Direct quotes may be used in the publication of results, but a pseudonym will be used to protect your identity. Any information that may lead to your identification will not be used. Following completion of the study, data will be stored safely at the University of Huddersfield and then destroyed in accordance with University policy.
What will happen if I don't want to carry on with the study?
You may decide to pause, stop or withdraw from the study and your information will not be used without your consent and it will be destroyed immediately and securely at the University of Huddersfield. You will not be asked for a reason for your decision and this will not affect your ability to use or be a member of the organisation to which you belong. If you wish to withdraw from the study you must do so by the 31st of May 2017.
What happens if there is a problem?
If you have a concern about any aspect of this study, or have a complaint about the way you have been dealt with during this study you may contact the researcher or the principal supervisor at the University of Huddersfield (contact details provided below).

Indemnity statement
If you have a concern about negligence then you may have grounds for a legal action for compensation against The University of Huddersfield, but you may have to pay your legal costs.
Thank you for taking the time to read this information sheet and consider this study. If at any point you have questions or concerns regarding this study, please contact Nafisa Zaman ( ), or Dr Serena Bartys ( )