SUPPORTING THE MANAGEMENT OF LONG-TERM CONDITIONS IN DEMENTIA

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A thesis presented for the degree of Doctor of Philosophy (PhD)

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January 2022

NIHR Collaboration for Leadership in Applied Health Research and Care North Thames
ubel A LONDON DOCTORAL TRAINING PARTNERSHIP
UKRI Economic and Social Research Council

Declaration

I, Jessica Laura Rees confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Jessica Laura Rees Date

Acknowledgements

I would like to sincerely thank my supervisors, Claudia Cooper, Kate Walters and Alexandra Burton for their support and guidance throughout my PhD. Claudia, I will always be grateful for your prompt feedback and endless reassurances. Kate, your knowledge of primary care has been invaluable. Alex, you have always been there for advice, in the office and since the pandemic on Teams. I feel lucky to have learnt so much from each of you over the past three years. I would also like to thank everyone from the NIDUS team and Division of Psychiatry who have been part of my PhD journey. I specifically want to thank Remco Tuijt for his contribution to my systematic review.

Thank you to the ESRC and NIHR Collaboration for Leadership in Applied Health Research and Care (North Thames) for funding my PhD, and for the opportunity to be part of the University College London, Bloomsbury and East London Doctoral Training Partnership. As Socrates said: “One thing only I know, and that is that I know nothing.” This thesis would not have been possible without the contribution of participants, who kindly shared their experiences with me. Thank you for trusting me to know your stories.

Thank you to all my family and friends for your endless love, support and encouragement. To my mum, for teaching me to believe in myself. To my dad, for teaching me perseverance. To my sisters, for being my inspiration and motivation. To Auntie Angela, for sparking my interest in health psychology. To Greg, for everything. I may be first on the mail, but you will always be first to me.

This thesis is dedicated to Harriet, Emily and Bethan. As our school taught us, Ni Lwyddir Heb Lafur. I hope that becoming the first Dr Rees is an example that anything is possible.

Abstract

Background

Most people with dementia live with another long-term condition requiring additional support. There is little evidence about how long-term condition guidance is adapted by professionals to account for dementia, and how people with dementia and their carers manage long-term conditions in the community.

Aim

I aimed to understand how people living with dementia manage and are supported to manage co-occurring long-term conditions in the community, by family carers, homecare workers and primary care.

Methods

I systematically reviewed the literature on self-management and undertook a secondary thematic analysis exploring experiences of people living with dementia, and their carers, regarding the management of co-occurring long-term conditions. This informed a qualitative study where I developed eight in-depth case studies of dementia care networks. I thematically analysed data from remote qualitative interviews, event-based diaries and consultation notes to explore how this management occurred in the community.

Findings

From 13 studies, I found in my systematic review how dementia symptoms inhibited self-management of long-term conditions, while adaptations and routines enabled it. Family carers, supported by healthcare professionals, substituted self-management where and when necessary. My secondary analysis of 82 interviews identified how the process of substituting self-management evolved with advancement of dementia symptoms. Communication in the care network was critical to ensure care plans were adapted to consider the impact of dementia on long-term conditions and vice versa. In my qualitative study, I identified six themes across eight case studies: 1) Balancing support and independence, 2) Implementing and adapting advice for dementia context, 3) Balancing physical, cognitive and mental health needs, 4) Competing and entwined needs and priorities, 5) Curating supportive professional networks, 6) Family carer support and coping.

Conclusion

Based on an integrated summary of findings I conclude that support for managing long-term conditions in dementia should be holistic, flexible, and consider networks of care.

Impact statement

In my thesis, I aimed to understand how people with dementia can be supported to manage any co-occurring long-term conditions. Intended beneficiaries are academic researchers working in dementia and health and social care research, those interested in qualitative methodologies, non-academic beneficiaries working in healthcare and policy, and people with dementia and their care networks.

I have published the findings of my systematic review in The International Journal of Nursing Studies (Rees, Tuijt, et al., 2020). My findings on cognition and self-care have been cited by research informing dementia care in general practice (Gibson et al., 2021). My secondary analysis has been published in BMJ Open (Rees, Burton, et al., 2020). I have presented findings from my PhD at national conferences including the Qualitative Health Research Network Conference (March 2021, online), and the British Society of Gerontology Conference (July 2020, online). I have presented at the International Psychogeriatric Association Conference (September 2019, in Spain), European Conference of Family Doctors (December 2020, online), and the Alzheimer's Association International Conference (July 2021, online). I have co-authored five publications during my PhD where I have shared learning of qualitative methodology from my work (Hallam et al., 2021; Leverton et al., 2019; Sherian Rains et al., 2021; Sheridan Rains et al., 2021; Tuijt, Rees, et al., 2021). I am preparing my qualitative study findings for publication and have submitted an abstract to the Alzheimer's Association International Conference 2022.

I have disseminated my findings through teaching. In 2019 and 2020, I disseminated my findings to Masters research students in a UCL lecture on independence for people with dementia. As part of The Brilliant Club, I developed a six-session tutorial for secondary school pupils on my PhD research titled 'Dementia rarely travels alone: Managing your body and brain' which I delivered in November 2020.

Supporting people with dementia, and the management of multiple long-term conditions are both policy priorities which findings of my PhD can inform. I have engaged with non-academic beneficiaries such as the Alzheimer’s Society Policy Unit. In September 2021 I joined five other UCL PhD students working in dementia to present my PhD findings to inform their new research strategy. I was awarded a Beacon Bursary by UCL Culture in October 2020 where I facilitated dementia education workshops to physical health support groups that drew on my thesis findings. To organise these workshops, I collaborated with national third sector organisations such as the Stroke Association and Diabetes UK. I published a blog of shared learning in September 2021 to assimilate knowledge of remote methods from my PhD. Following this, in September 2021 I was invited by Diabetes UK to host a webinar with the Alzheimer’s Society on the topic of Dementia and Diabetes.

Since September 2021, I have worked in the Applied Research Collaboration East of England, as a Research Fellow in Ageing and Multimorbidity. As part of my role, I continue to share learning from my PhD.

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List of abbreviations

AB	Alexandra Burton
CC	Claudia Cooper
COPD	Chronic Obstructive Pulmonary Disease
COVID-19	Coronavirus disease 2019
GP	General Practitioner
HbA1c	Glycated haemoglobin
HRA	Health Research Authority
JDR	Join Dementia Research
IPA	Interpretative Phenomenological Analysis
KW	Kate Walters
NHS	National Health Service
NICE	National Institute of Health and Care Excellence
NIDUS	New Interventions for Independence in Dementia Study
NIHR	National Institute for Health Research
PPI	Public and Patient Involvement
PR	Penny Rapaport
QOF	Quality Outcomes Framework
REC	Research Ethics Committee
RT	Remco Tuijt
TIA	Transient ischaemic attack
UCL	University College London

Statement of personal contribution

My contributions to this thesis were as follows:

- I developed the research questions and objectives, research design and methodology for each stream described in this thesis.
- I conducted all aspects of the systematic review in Chapter Four.
- The original data for the qualitative interviews presented in Chapter Five were collected by the NIDUS study (New Interventions for Independence in Dementia). I contributed to the development of the topic guide for these interviews. To meet my objectives for this thesis, I conducted a secondary analysis of the data focusing on the experiences of long-term condition management in dementia independently of the NIDUS study. This was not part of the original NIDUS study objectives.
- I developed the protocol and ethics application for the qualitative study presented in Chapter Six. I conducted all data collection, analysis and write up independently.
- I wrote all the thesis content.

Chapter 1 Introduction

"*Dementia rarely travels alone*"- All Party Parliamentary Group on Dementia (2016)

1.1 Living with long-term conditions in dementia

As people age, the risk of developing long-term conditions increases (Barnett et al., 2012). So too, does the risk of developing dementia (Corrada et al., 2010). The number of people living with dementia worldwide is predicted to double every twenty years (Prince et al., 2015). Long-term conditions are common in people with dementia (Poblador-Plou et al., 2014), with an estimated 8 in every 10 people with dementia living with another long-term condition (Public Health England, 2019). People living with certain long-term conditions, such as diabetes, hypertension or stroke, have an increased risk of developing dementia (Public Health England, 2019). With a healthcare system that is often designed around single condition services, improving the treatment and management of multiple long-term conditions is an important challenge for the National Health Service (NHS) (Coulter et al., 2013).

When living with a chronic disease, self-management is a daily task (Lorig & Holman, 2003). This task is severely impacted by the symptoms of dementia (Ibrahim et al., 2017). Self-management support from family carers, social care and primary care can facilitate the optimal management of long-term conditions to prevent hospitalisation, slow cognitive decline, and enable people with dementia to live independently at home for longer (Bordier et al., 2014; Doraiswamy et al., 2002; Fox et al., 2014).

The presence of dementia complicates healthcare delivery (Bunn, Burn, et al., 2017). The ideal of person-centred care lies at the centre of many models of care (Coulter et al., 2013; Wagner et al., 1996) and health and social care policies (Department of Health, 2016; NHS, 2014; NHS England, 2019a) which have been developed to manage complex care needs. Such care is proposed to be holistic, integrated and organised by need and not disease (World Health Organisation, 2015). However, healthcare professionals sometimes report lacking the skills and confidence to develop person-centred physical health care plans for people with dementia in collaboration with those who support their care (Bunn, Burn, et al., 2017). A greater understanding of the needs of people with dementia and long-term conditions is required to ensure condition-specific guidelines are relevant to people with dementia (Scrutton & Brancati, 2016).

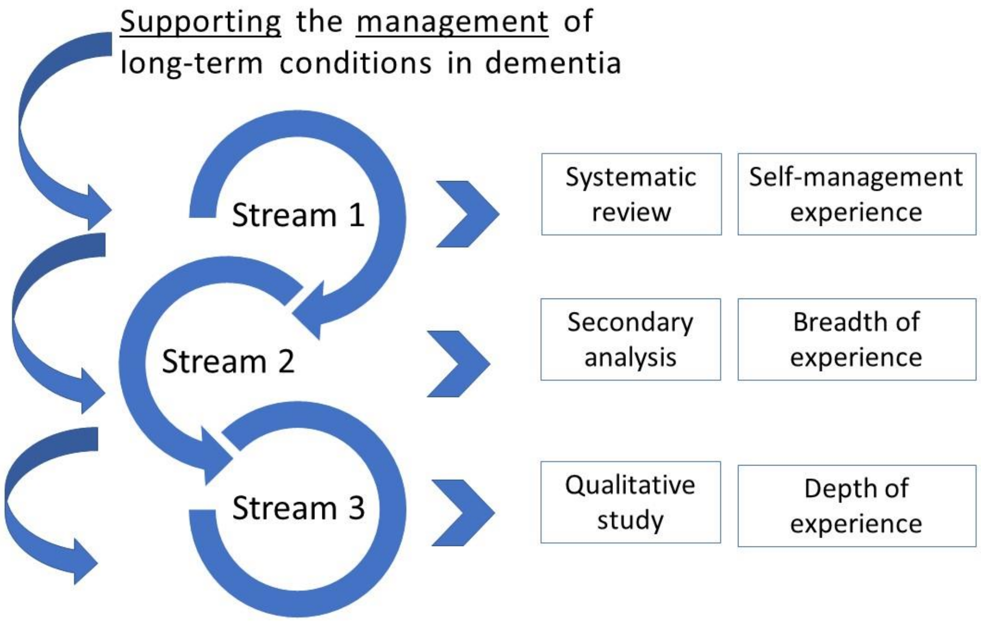
1.2 Research outline

In this PhD, I aim to understand how people with dementia manage, and can be supported to manage co-occurring long-term conditions, by family carers, homecare workers and primary care in the community. I explore the complex system involved in supporting the management of long-term conditions in dementia. I plan that this understanding will inform primary care approaches to supporting people living with dementia and other long-term conditions.

While researching adjustment to diagnoses of chronic conditions prior to my doctoral work, I saw how varied support can be, and the impact it has on clinical outcomes. My interest in health psychology motivated me to undertake this PhD, to explore the added complexities to managing health in the context of cognitive impairment.

First, in stream one, I reviewed the literature on strategies related to self-management in this context. Then in stream two, I analysed how stakeholders experience and negotiate the management of long-term conditions in dementia. In stream three, I used these findings to develop a study exploring how care for long-term conditions in dementia is provided and supported, from a primary care setting to implementation in the community. As visualised in Figure 1.1, each stream of my PhD informed the research objectives for the subsequent stream.

Figure 1.1. Research Overview



In Chapter Two, I summarise the background literature in the areas of dementia, long-term conditions, self-management, and how care for long-term conditions is currently being supported and delivered in the context of dementia.

In Chapter Three, I outline the aims and objectives for the three streams of my PhD.

In Chapter Four, I describe my systematic review of the factors that enable or inhibit people living with dementia to self-manage long-term conditions. I found limited evidence on how self-management activities broader than taking medication were managed which I aimed to explore further in my subsequent stream.

In Chapter Five, I describe the methods and results for my secondary analysis of 82 qualitative interviews with people with dementia, family carers, health and social care professionals and homecare staff, which aimed to explore how the management of long-term conditions is experienced and negotiated. I expanded on the existing evidence base identified in stream one by including the perspectives of a diverse range of stakeholders.

In Chapter Six, I outline the methods for the primary data collection for my PhD, a multi-data qualitative study. As I collected stream three data remotely during the COVID-19 pandemic, I explored how this context influenced care I observed.

In Chapter Seven, I acknowledge how my positionality impacted the research process and reflect on the experiences of my PhD including conducting research during a pandemic, and the adaptation of methods to a remote context.

In Chapter Eight I present six over-arching themes and how they resonated across case studies. I then consider the strengths and limitations of my multi-data qualitative study.

In Chapter Nine, I present an overall discussion on the findings of my PhD in relation to the literature, and outline future directions for research, practice and policy.

Finally, in Chapter Ten I summarise the conclusions of all three streams of my thesis.

Chapter 2 Background

In this Chapter, I introduce the topics of dementia, long-term conditions and self-management. I next focus on self-management in people with dementia and explore how this can be enabled by family carers and social care professionals. I then introduce the primary care context of long-term condition management in people living with dementia. I review current clinical guidelines for long-term conditions and consider their relevance to this topic. I present some guiding principles to primary care management of long-term conditions and dementia, then provide an overview of relevant theoretical models and policies of care. Finally, I outline the impact of coronavirus disease on people with dementia.

2.1 Dementia

2.1.1 Definition

The International Classification of Diseases (ICD-11) defines dementia as "an acquired brain syndrome characterised by a decline from a previous level of cognitive functioning with impairment in two or more cognitive domains. The cognitive impairment is not entirely attributable to normal aging and significantly interferes with independence in the person's performance of activities of daily living" (World Health Organisation, 2018). As dementia is a progressive condition, symptoms worsen over time (NICE, 2018c). All cognitive domains can be affected, including memory, executive function, attention, language, social cognition and judgement, psychomotor speed, and visuoperceptual or visuospatial abilities (World Health Organisation, 2018).

People living with dementia experience decline in daily functioning (Melis et al., 2013), lower quality of life (Black et al., 2012; Nelis et al., 2019), greater disability and increased healthcare utilisation (Brettschneider et al., 2013; Marengoni et al., 2011). Even moderate cognitive impairment can significantly decrease functioning, leading to an increase in mortality and length of stay in institutional settings (Snowden et al., 2017).

2.1.2 Epidemiology

Globally, the number of people living with dementia is predicted to rise to 152.8 million by 2050 compared to 57.4 million in 2019 (Dementia Forcasting Collaborators, 2022). In 2021, over 440,000 people on general practice registers in England have a formal diagnosis of dementia (NHS Digital, 2021).

The most common form of dementia is Alzheimer’s Disease (50-75% of cases), with 95% of cases developing at age 65 or over (World Health Organisation, 2018). Alzheimer’s disease is often associated with mental and behavioural symptoms such as depressed mood and apathy. Vascular dementia (20% of cases) is a sequelae of cerebrovascular disease with cognitive deficits related to ischaemic or haemorrhagic events (World Health Organisation, 2018). Other types of dementia include dementia with Lewy bodies (10-15%), which cause symptoms that include movement disorders similar to Parkinson’s disease through the same underlying abnormalities (Alzheimer’s Association, 2021), and Frontotemporal dementia subtypes (2% of cases), which cause language, personality and behaviour changes due to the area of the brain affected by disease (NHS, 2021a; NICE, 2019a). Mixed dementia, with features of more than one of the above types, usually Alzheimer’s and vascular dementia, is increasingly considered to be the most common type of dementia in older adults (Public Health England, 2019).

2.1.3 Impact

Worldwide, dementia accounts for one of the major causes of dependence and disability amongst older adults (World Health Organisation, 2019) and is one of the top ten most burdensome conditions for older adults (Prince et al., 2015). The measurement of disease burden is a combination of two indicators: years of life lost and years of life lived with disability as a result of a disease (Public Health England, 2015).

In addition to the individual, interpersonal and societal impact of dementia (Prince et al., 2015; World Health Organisation, 2019), there is also a substantial economic impact amounting to £34.7 billion in 2019 for the United Kingdom (UK). The care costs for a person with dementia in the UK are estimated to be £32,250 per year (Prince et al., 2014). Health and social care costs increase with the severity of dementia (Scrutton & Brancati, 2016). Social care including homecare and residential care account for 45% (£15.7 billion) of total UK dementia costs (Wittenberg et al., 2019). An estimated 40% (£13.9 billion) of care costs are for unpaid care contributions by family members (Wittenberg et al., 2019).

2.1.4 Management

In the UK, dementia diagnosis is usually made in secondary care (Prince et al., 2016). After initial presentation in primary care with memory complaints, individuals can be referred to memory services who then support with the dementia diagnosis (Dodd et al., 2014).

There are currently no disease modifying therapies which can prevent or delay the onset or slow the decline of dementia (Cummings & Fox, 2017). Acetylcholinesterase inhibitors or Memantine can be used to treat symptoms dependent on the stage of dementia (NHS, 2020a), while other medication can be used to manage non-cognitive symptoms such as agitation, aggression and psychosis (NICE, 2018c). Availability of non-pharmacological treatments for dementia vary between services but generally include cognitive stimulation therapy as well as signposting to carer groups and other community sources of support (Alzheimer’s Society, 2021b).

2.2 Dementia and long-term conditions

2.2.1 Terminology of long-term conditions

Before I present an overview of the current literature on long-term conditions in dementia, I will briefly summarise the different definitions and conceptualisations which describe an individual living with concurrent chronic conditions.

Within the literature, a variety of terms mirror the different ways of thinking about co-occurrence of long-term conditions (Almirall & Fortin, 2013). The terms ‘multimorbidity’ and ‘comorbidity’ are used most commonly and often inter-changeably despite their different meanings (Yancik et al., 2007).

Although there are different conceptualisations within the literature, in general ‘comorbidity’ refers to multiple diseases or conditions which co-exist with the ‘index condition’ (Almirall & Fortin, 2013). It is commonly used when considering the possible effects of other diseases on the index condition (Marengoni et al., 2011; Valderas et al., 2009).

By contrast, ‘multimorbidity’ indicates that the focus of interest is the individual living with multiple long-term conditions, both mental and physical, which are considered in parallel (Almirall & Fortin, 2013). Since 2020, the National Institute for Health Research (NIHR) have adopted the terminology ‘multiple long-term conditions’ after recognising the lack of understanding and identification with the term ‘morbidity’ (NIHR, 2020).

In this chapter, I use the terminology ‘comorbidity’ to describe how dementia interacts with concurrent long-term conditions. For the remaining chapters, I recognise the NIHR positioning on the terminology ‘morbidity’ and refer to my study population as people with dementia and long-term conditions.

I will now outline which long-term conditions are most common in people with dementia, and how health service receipt differs between people with and without dementia.

2.2.2 Epidemiology of long-term conditions in dementia

Over two-thirds of people in the UK aged over 85 live with two or more diseases, and this is predicted to rise to over 90% in the next twenty years (Kingston et al., 2018). The management of long-term conditions accounts for around 70% of health and social care expenditure (Department of Health, 2012). Age is associated with an increased risk of developing both dementia and long-term conditions (Barnett et al., 2012; Prince et al., 2014). People with cognitive impairment account for a third of people with four or more diseases, termed complex multimorbidity (Kingston et al., 2018).

For people living with dementia, the management of cognitive symptoms rarely happens in isolation. The Health Improvement Network (THIN) dataset covers 2% of GP surgeries in England. The prevalence rate for dementia on THIN is comparable to England’s population (4.1% verses 4.3%). Public Health England used this data to look at the primary care records of people over 65 with and without a dementia diagnosis for ten specified health conditions[1]. They found that 77% of people with dementia were living with at least one additional health condition compared to 68% the all patient group (Public Health England, 2019). Prevalence rates for health conditions were generally higher among people with dementia compared to all patients, with rates for depression (17% versus 8%) and stroke or transient ischaemic attack (18% versus 8%) more than double in people with dementia than in the comparison group. This is consistent with previous literature which cites prevalent conditions in people with dementia as including hypertension (41-53%), painful conditions e.g. arthritis (34%), depression (24-32%), heart disease (22-27%), stroke (16-29%) and diabetes (13-20%) (All-Party Parliamentary Group on Dementia, 2016; Barnett et al., 2012; Browne et al., 2017; Bunn et al., 2014).

2.2.1 Receipt of care for long-term conditions in dementia

The National Institute for Health and Care Excellence (NICE) recommends “that people living with dementia have equivalent access to diagnosis, treatment and care services for comorbidities to people who do not have dementia” (*Recommendation 1.8.1*) (NICE, 2018c). However, research has indicated that people with dementia receive worse care for the same comorbidities than people without dementia (Scrutton & Brancati, 2016).

People with dementia and long-term conditions are less likely to receive equivalent care due to delays in recognising symptoms (Fox et al., 2014). Hypertension, joint arthritis and sensory impairments are more likely to remain undiagnosed in people with dementia (Bauer et al., 2014). In a large UK national sample of primary care recipients, people with dementia received fewer physical health checks (including annual blood pressure monitoring) and primary care contacts than people without dementia (Cooper, Lodwick, et al.,

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[1] Hypertension, Coronary heart disease, Diabetes, Stroke or Transient ischaemic attack, Depression, Parkinsonism, Epilepsy, Severe mental illness or psychosis, Asthma, Chronic Obstructive Pulmonary Disease.

2017). People with dementia are also less likely to receive annual diabetes monitoring (Thorpe et al., 2013), and age-related macular degeneration treatment to prevent loss of vision (Keenan et al., 2014).

Despite receiving lower quality care, healthcare costs for long-term conditions in people with dementia are estimated to be 34% higher than age-matched, non-dementia cases (Kuo et al., 2008; Zhao et al., 2008). This can be explained by higher rates of hospital admissions and prescriptions in people with dementia with higher numbers of comorbidities (Browne et al., 2017).

Data analysed from the Cognitive Function and Ageing Studies suggested that people with dementia who experience either stroke, diabetes or visual impairment have increased visits to inpatient services and receive more paid care from homecare workers and unpaid care from friends and family compared to people without dementia experiencing the same health conditions (Bennett et al., 2018). This increased need for unpaid care is common in the context of dementia, with the involvement of others in self-management crucial as cognition declines. I will explore this further in section 2.6 but first I will explore why certain long-term conditions are associated with increased dementia risk.

2.3 Relationships between long-term conditions and dementia

A central component of my thesis is the complex relationships between physical, mental and cognitive health. In this section, I will briefly explain some of the mechanisms behind these associations. Firstly, I describe where long-term conditions arise from shared pathologies with dementia. Secondly, I describe how certain long-term conditions are risk factors for dementia.

2.3.1 Shared cardiovascular pathologies

The links between dementia and type 2 diabetes, heart disease, and stroke can be explained by the ‘Brain-Heart connection’ (Global Council on Brain Health, 2020). Evidence shows ‘what is good for the heart is good for the brain’ as a healthy blood flow provides the brain with oxygen and energy. Changes in blood flow impair cognition. Thus, conditions such as diabetes and stroke can result in neuropathological changes that increase the risk of dementia (All-Party Parliamentary Group on Dementia, 2016). In the example of diabetes, high blood glucose impairs cognition, due to the immediate effects of hyperglycaemia (Kerti et al., 2013) and longer term due to the effect of insulin on amyloid metabolism (Biessels et al., 2006).

People with vascular dementia are twice as likely to have a diagnosis of stroke compared to other forms of dementia (Public Health England, 2019). Vascular dementia has a ‘unique pattern of comorbidity’ related to certain risk factors, including hypertension and diabetes (Public Health England, 2019). These are associated with poorer brain health across grey and white matter macro and micro structures (Cox et al., 2019). Vascular risk factors can also influence Alzheimer’s disease, according to the ‘two-hit vascular hypothesis’ which posits that tau pathologies develop secondary to vascular injury, reducing blood flow within the brain (Kisler et al., 2017; Zlokovic, 2011).

2.3.2 Long-term conditions as risk factors for dementia

A number of long-term conditions are risk factors for dementia including hearing loss (Livingston et al., 2017). As sensory impairments are thought to reduce cognitive stimulation, researchers have found this risk can be mitigated by the use of hearing aids (Maharani et al., 2018).

Researchers have estimated that if depression in later life were to be eliminated dementia prevalence would reduce by 4% (Livingston et al., 2020). Depression can increase dementia risk with reduced cognitive reserve being one hypothesised mechanism (Livingston et al., 2020). The relationship between depression and dementia is complex. It is bi-directional due to a variety of psychological and physiological mechanisms. Depressive symptoms are a prodromal feature of dementia and share common causes (Singh-Manoux et al., 2017). Rates of anxiety are also common in dementia (Seignourel et al., 2008).The Cognitive Debt hypothesis explains this relationship in term of repetitive negative thinking being a risk factor for Alzheimer’s Disease (Marchant et al., 2020). In relation to physical health, anxiety can cause high blood pressure, which may explain increased prevalence in vascular dementia in people with anxiety compared with Alzheimer’s disease (Alzheimer’s Society, 2021a).

2.4 Self-management of long-term conditions

Self-management is an integral part of long-term condition management, with time spent self-managing almost always outweighing the time spent interacting with healthcare services (Eaton et al., 2015). It has been defined as “an individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition” (Barlow et al., 2002). In the case of chronic diseases, self-management is a daily task (Lorig & Holman, 2003).

In this section, I introduce the concept of self-management of long-term conditions by describing underlying theories and how they have been applied in the context of dementia. Then, in section 2.5 I describe how taxonomies of self-management are impacted by the symptoms of dementia.

2.4.1 Self-efficacy theory

Self-management programmes aim to improve an individual’s ability to manage their health through increasing their sense of control over their treatment and health outcomes (Newman et al., 2004). Theoretical underpinnings of such interventions include Self-efficacy Theory (Bandura, 1997; Bandura, 1977). This posits that an individual’s belief in their capacity to perform actions and achieve outcomes can influence behaviour change. Based on Social Learning Theory, perceived self-efficacy supposes that a behaviour (e.g. proactive pain management) is more likely to be performed if individuals have confidence in their own ability to use it to achieve desired outcomes (e.g. reduced pain). Bandura extended this hypothesis in Social Cognitive Theory (Bandura, 1977b, 1986) which proposes that behaviour change is determined by an individual (self-efficacy and outcome expectancy) and their environment (incentives or reinforcements e.g. greater mobility). This can be useful for considering health promotion, as it considers an individual’s social system (e.g. prompts from family members) (Bandura, 2004). Self-efficacy has been associated with health-related quality of life for family carers of people with dementia (Crellin et al., 2014). For people living with dementia, the relationship between self-efficacy and quality of life is suggested to be mediated by the reduction of depression and anxiety (Tonga et al., 2020).

2.4.2 Theories of behaviour change

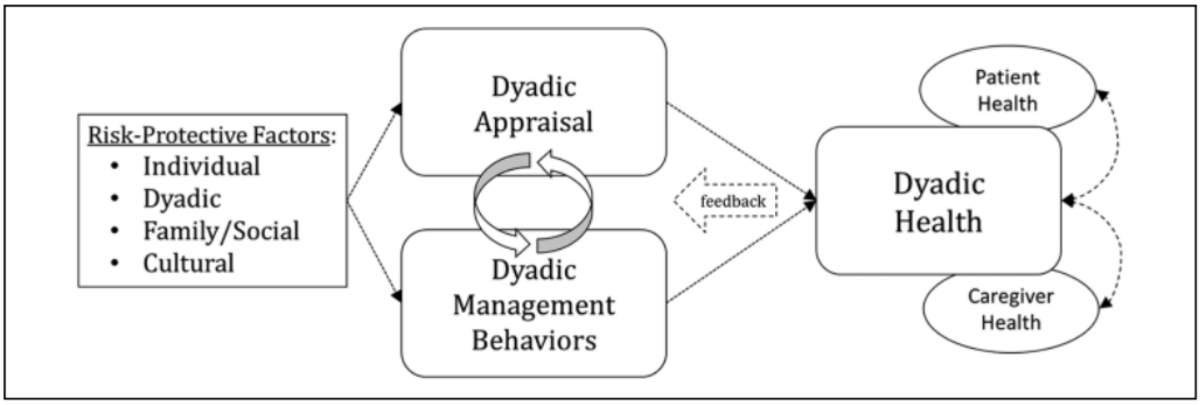
Another useful concept for self-management, as introduced by the Theory of Planned Behaviour (Ajzen, 1991) is intention. This theory links a person’s beliefs (subjective norms) and behaviour (perceived control). In one study, perceived behavioural control of hypertension self-management (e.g. antihypertensive use, home blood pressure control, weight loss, low-salt intake) was found to determine self-care behaviours (Pourmand et al., 2020). However, this theory has been criticised for focusing on cognitive models of behaviour which may overlook other factors influencing motivation (Webster et al., 2016). Theories of behaviour change propose how capabilities (e.g. physical and psychological capacity), opportunity (e.g. social context) and motivation (e.g. decision making, goal setting) interact to generate behaviour (COM-B model) (Michie et al., 2011). The COM-B model is commonly used as a theoretical framework for intervention development. For example, the development of a technological device to improve medication adherence in people with dementia (El-Saifi et al., 2019). A recent scoping review identified the aforementioned behaviour change theories in populations without dementia, and used these theories to develop a model for physical activity in dementia (Lorito et al., 2019).

2.4.3 Theories of illness management

Theoretical descriptions of self-management have evolved over time based on the perspectives of individuals living with chronic conditions (Grady & Gough, 2018). Family-centred theories have sought to recognise the role that relationships with others, including family networks, play in influencing self-management. Ryan and Sawin (2009) considered self-management to exist within a family unit, and that positive outcomes may be achieved by enhancing both the individual and families self-management processes. They proposed the Individual and Family Self-Management Theory which has three dimensions: context, process, and outcomes. Contextual factors influence engagement of an individual and family in self-management processes which in turn influences outcomes. Context includes risk and protective factors to self-management, such as complexity of the condition or treatment and a family's physical and social environment or capabilities. The process dimension is based on theories of behaviour change and includes knowledge and beliefs (i.e. self-efficacy), self-regulation (i.e. goal setting, self-monitoring) and social facilitation (i.e. support). These dimensions are thought to impact outcomes, which can be proximal (i.e. self-management behaviours) and distal (i.e. quality of life). Similarly, The Self and Family Management Framework incorporates the complexities of families, communities and the environment with a focus on risk and protective factors, processes, proximal and distal outcomes (Grey et al., 2015). The latter theory has been used as a theoretical framework for an intervention for family carers of people with cancer to increase self-efficacy (i.e. proximal outcomes) (Mazanec et al., 2021).

Recent theories have sought to expand on family approaches of self-management by adopting a dyadic perspective. The Theory of Dyadic Illness Management has three central concepts: dyadic appraisal, dyadic management and dyadic health (Lyons & Lee, 2018). As represented in Figure 2.1, dyadic appraisal of illness influences engagement with self-management behaviours. Both factors impact the health of a dyad which, over time, feedback to influence how illness is jointly appraised and managed. A key aspect of this theory of relevance to people with dementia is appraisal. The authors acknowledge the frequent disconnect between the values of the people with dementia and their family carer, who communicates and represents these values during care planning, especially in advance dementia (Orsulic-Jeras et al., 2016). Addressing this incongruence is a key aspect of this theory as shared appraisal is hypothesised to lead to better health management. Stage of illness, type of dyad and available support has been identified as risk and protective factors impacting appraisal and collaborative management.

Figure 2.1. Theory of Dyadic Illness Management with predictors



2.5 Self-management in dementia

2.5.1 Taxonomies of self-management

Seminal work into self-management conceptualises the process into three elements: medical management such as medication and attending appointments, behavioural management such as changing lifestyle or responsibilities, and emotional management in response to the emotions associated with health conditions (Corbin & Strauss, 1985, 1988). Researchers have expanded on these self-management tasks to define five core self-management skills. These are: problem solving, decision making, resource utilisation, interacting with healthcare providers and taking action (Lorig & Holman, 2003). As described in Figure 2.2, *problem solving* refers to the need to define problems as they arise and generate possible solutions, independently or with support from others, before evaluating if the solution worked to resolve the problem. *Decision making* can be conceptualised as part of problem solving, as daily decisions are required in response to changes in symptoms. *Resource utilisation* involves identifying and using appropriate resources used by people living with long-term conditions to acquire knowledge and accurate information to decide how to respond to changes. *Healthcare relationship* relates to the formation of partnerships with healthcare providers which supports the navigation of roles for professional (teacher, partner, supervisor) and patient (report symptoms, making informed choices through discussion). Finally, *taking action* is similar to decision making with a focus on action planning and solution implementation.

The aforementioned self-management processes require physical, emotional and cognitive abilities so may need to be reconsidered in the context of dementia (Fox & Kilvert, 2019). In the next section, I outline the perspectives of previous authors on the impact of dementia on self-management processes.

2.5.2 Impact of dementia on self-management

The impact of dementia upon self-management will vary according to the cognitive domains affected. Ibrahim and Colleagues (2017) developed a framework to describe the challenges to self-management in dementia and suggest how clinicians can address these issues to improve overall health. In Figure 2.2, I highlight how this was developed in the context of Lorig and Holman's (2003) framework. I now provide an overview of specific examples of how impairment in cognitive domains impact the ability of people with dementia to perform self-management tasks.

As problem solving is a cognitively demanding process, poor *executive function* (including insight, planning and response regulation) can impact a person's ability to shift thinking, conceptualise health issues and comprehend alternative management options. It can lead to difficulty recalling appointments or treatment regimens (Rosen et al., 2003) and judging what treatment is appropriate (Ibrahim et al., 2017). It may also impair recognition or response to previously familiar symptoms creating an increased risk of hypoglycaemia (Fox & Kilvert, 2019). This might explain the lower adherence to diet and exercise recommendations reported in people with dementia diagnosed with heart failure (Currie et al., 2015; Lovell et al., 2019).

Decision making relies on learning and *memory function* to choose appropriate solutions based on changes in health. Medication management is one of the main self-management tasks and often the first to be impacted by dementia (Corbin & Strauss, 1988). Being unable to remember information about conditions reduces an individual's ability to make informed decisions about management. *Memory function* has important implications for medication adherence (Brauner, 2009). Prevalence rates for non-adherence to medication in people with dementia range from 17% to 100% compared to 11% to 38% for people without cognitive impairment (Smith et al., 2017). People with dementia and long-term conditions often have complex medication regimes (Schubert et al., 2006), and as dementia progresses, the ability to plan, organise and administer medication safely diminishes (Elliott et al., 2015; Kaasalainen et al., 2011).

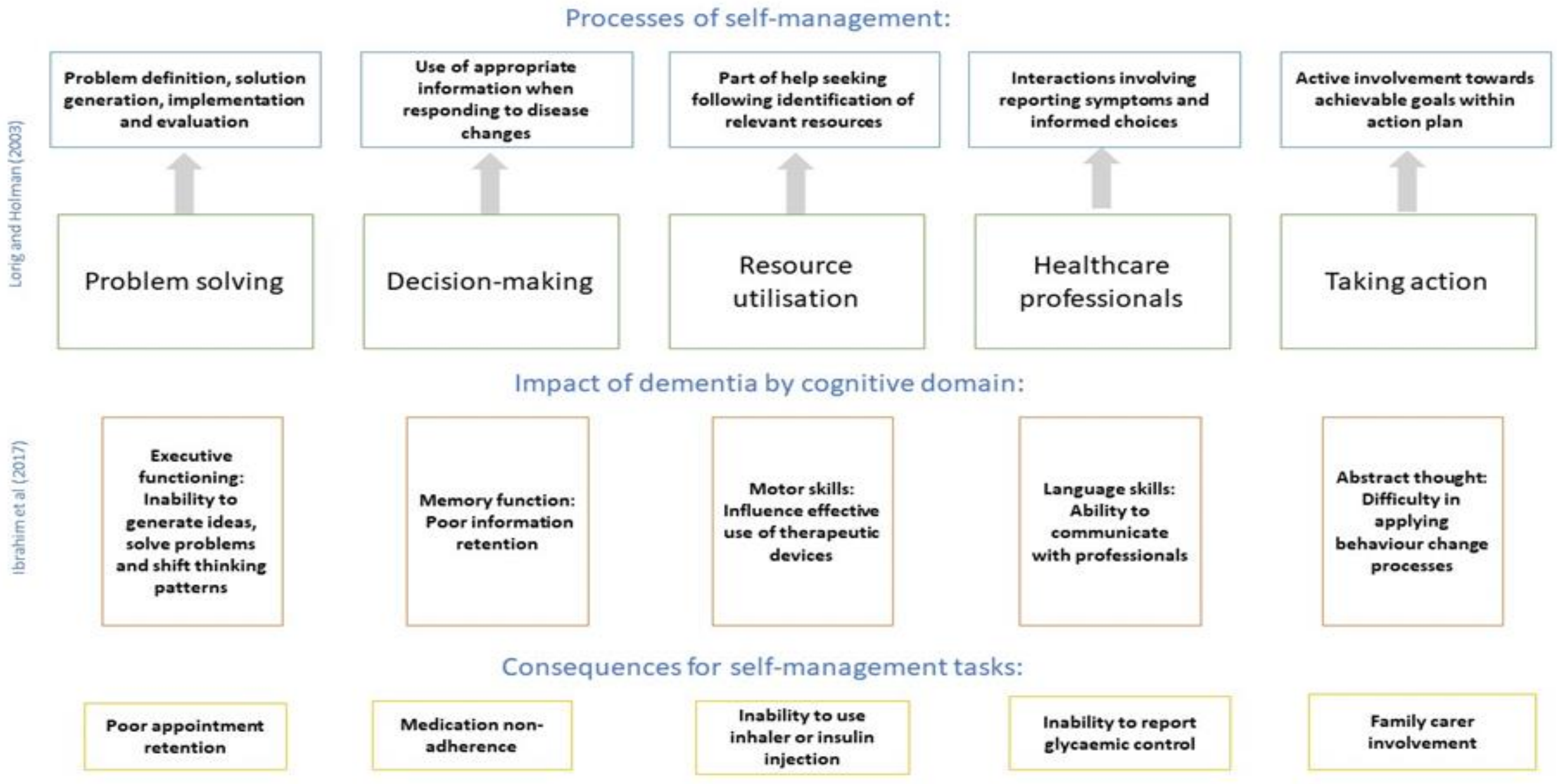
The process of self-management in dementia is influenced by the nature of the tasks required, which may be long-term condition specific. The use of therapeutic devices involves the coordination of complex movements requiring *motor skills* and visuospatial memory which is impacted when a person has apraxia. Specific medical tasks are impacted by impaired *motor skills,* for example performing insulin injections (Santos et al., 2018; Tomlin & Sinclair, 2016). For people with Chronic Obstructive Pulmonary Disease (COPD) reduced cognition is associated with challenges in self-administering inhaler devices (Allen et al., 2009; Baird et al., 2017; Board & Allen, 2006).

Another important context, which I expand on in section 2.6, is support from stakeholders. Healthcare relationship development and maintenance requires *language skills* and the ability to communicate. Impairments in these areas impact a person's ability to agree on goals, negotiate management strategies and report symptoms. The loss of *language skills* and abstract thinking as dementia progresses limits a person's ability to accurately identify and communicate symptoms. This has been demonstrated in the reporting of pain (Achterberg et al., 2020; Corbett et al., 2014; Malotte & McPherson, 2016), resulting in inconsistent and sub-optimal pain management (Lichtner et al., 2016).

Taking action is dependent on the successful implementation of the above processes and skills. Problems with *abstract thought* can be an additional barrier to implementing an agreed course of action. In reality these processes are inter-related and complex. For example, when booking a GP appointment, all self-management processes may be employed at various stages and consequently impacted by impairment in the associated cognitive domain.

In the next section, I will provide an overview of the literature on how the management of long-term conditions is supported by family and professional carers of people living with dementia.

Figure 2.2. Impact of dementia on self-management processes[2]



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[2] I developed this figure based on the work on Lorig and Homan (2003), Ibrahim et al (2017), and concepts identified from the literature relating to the impact of dementia on self-management tasks

2.6 Supporting self-management in dementia

The term ‘self-management’ suggests the active participation of an individual in their treatment (Lorig & Holman, 2003). However, most people with dementia require support in their daily lives to manage cognitive symptoms, usually from a family carer or homecare worker, or both (Allen, 2014; Health Education England, 2018). Similar support is required for long-term condition management (Fields et al., 2020; Goldberg & Rickler, 2011). In this section, I describe how family carers and homecare workers support people living with dementia in the community.

2.6.1 Support from family carers

From housekeeping to personal care, organising medical procedures and administering medication, the family carer role in supporting self-management of long-term conditions is multidimensional and challenging, especially in the context of multiple chronic conditions (Williams et al., 2016). Role responsibilities may also include management of appointments and finances for care and treatment (Carers UK, 2019). Such responsibilities may lead to physical, emotional and financial stress for family carers, although positive aspects of the role are also recognised, including a sense of personal accomplishment and strengthened relationships (Lindeza et al., 2020). Within primary care, the role of companions in medical appointments can include advocating for patients, ensuring accuracy of information and preserving rapport (Vick et al., 2018).

Family carers, especially in dementia, have higher levels of stress (Mohebi et al., 2018), depression (Omranifard et al., 2018), lower levels of physical health and self-efficacy compared to non-carers (Pinquart & Sörensen, 2003). Levels of carer burden and depression have been associated with behavioural problems in care recipients, while increased confidence and self-efficacy can promote carer mental health (Van der Lee et al., 2014). Deteriorating health is a particular issue with older carers (Williams et al., 2016).

Most of the care received by people with dementia and an additional health condition is unpaid help provided by family and friends (Bunn et al., 2016).

Family carer support has consistently been described as integral to effective self-management in this context (Baird et al., 2019). In a realist review which synthesised the mechanisms by which diabetes can be managed in people with dementia, the need to engage and support family carers was an overarching theme. One programme theory posited that effective self-management can be developed when family carer involvement in care planning and information sharing is supported and recognised. Thus, conceptualising self-management as a family-centred approach is integral to the self-management of diabetes in dementia, specifically to address carer anxieties around managing adverse health events, such as hypoglycaemia (Bunn, Goodman, et al., 2017; Wong et al., 2013).

2.6.2 Transition Theory

The caregiving role is not static, and involves multiple transitions related to changes in health status (Schulman-Green et al., 2021). Authors have described transition as when individuals move from “one life phase, situation, or status to another” (Schumacher et al., 1999) (p.2). Transitions are precipitated by changes that prompt the initiation of new strategies to cope with daily life experiences (Meleis, 2010). Identifying points of transition to provide support for individuals and families is a central concept within nursing (Schumacher & Meleis, 1994). Meleis and colleague’s (2000) consolidated research on the use of transition as a perspective and framework to develop a middle-range theory. According to this extended theoretical framework, types of transition can relate to health and illness (e.g. diagnosis), developmental (e.g. menopause), situational (e.g. caregiving), or organisational. Patterns of transition can be multiple, sequential, related. Properties of transition experiences include awareness, engagement, time span and critical points. Transition conditions can include facilitators (e.g. personal meaning) or inhibitors (e.g. socioeconomic status). Finally, responses to transitions can be process indictors (e.g. feeling connected) or outcome indictors (e.g. skill mastery).

Previous research has described transition points in dementia to include diagnosis, driving cessation, advanced planning for health considerations, and preparing for end-of-life (Rose & Lopez, 2012). The experiences of people with dementia have largely been excluded from studies investigating adjustment to residential care settings (Wareing et al., 2021). Research has therefore sought to understand the personality, social, cultural and institutional factors affecting transitions of people with dementia in this context (Wareing & Sethares, 2021).

Based on transition theory, researchers developed a self-directed web-based intervention for family carers of people with Alzheimer's Disease and at least two additional long-term conditions (Duggleby et al., 2018). A randomised control trial sought to test the efficacy of this intervention at improving self-efficacy, hope and quality of life. The study did not find any significant differences between the intervention and control group, although noted higher hope scores ('positive readiness and expectancy') relating to aspects of the intervention that focused on adjusting to transitions ('common changes to expect'). As part of this trial, 72 qualitative interviews were conducted with family carers of people with dementia and multiple long-term conditions. Participants described changes related to increased responsibility for personal and nursing support and lack of personal time, which impacted carer health and wellbeing (Ploeg, Northwood, et al., 2020). Similar themes were identified in a recent study investigating the transition experiences of family carers and healthcare professionals in the context of multiple long-term condition (Lam et al., 2020). Less is known about the transition experiences of people with dementia, which is a gap I aim to address in the remainder of this thesis.

2.6.3 Support from social care

The collaboration between people with dementia, their family carers and healthcare professionals has previously been described as a triangle of care (Fortinsky, 2001). In the remainder of this chapter, I will describe the support provided by healthcare professionals and consider the organisational context of primary care service delivery. In this section I first discuss support from social care, including homecare workers, that enable people with dementia, and people with long-term conditions to remain living in the community (Cunningham et al., 2020; Stone, 2004).

As well as providing care for those without regular family support, homecare workers often work collaboratively with families (Leverton et al., 2021; Pollock et al., 2020). It has been reported that 60% of people receiving homecare have some form of dementia (Carter, 2016). Standard models of homecare are task-oriented including personal care, meal preparation, shopping and medication management (Carter, 2016). Previous research promotes the value of needs-based rather than task-based models to achieve person-centred care (Cooper, Cenko, et al., 2017). This is reflected in relatives of people with dementia prioritising emotion and social support over practical tasks when receiving homecare in the community (Pollock et al., 2020). Time constraints, organisational support and training impact the provision of good quality home care (Leverton et al., 2019). Failing to consider multiple chronic conditions presents a barrier to homecare services when supporting people to live independently at home (Northwood et al., 2021).

Homecare workers provide medication support, through prompting, helping remove tablets from packaging, and administering medication if it is documented in the care plan, following clear prescriber directions (Care Quality Commission, 2021b). However, not all medicines, for example insulin injections can be routinely administered by care workers unless delegated by a registered nurse (Care Quality Commission, 2021a).

In the next sections I will discuss healthcare support for long-term conditions in dementia. I explore how clinical guidelines, guiding principles, models of care, and policies influence and inform how primary care services are delivered to people with dementia and long-term conditions. This is to set out the overall context of my research which has been conducted in England.

2.7 Current clinical guidelines in England

National Institute for Health and Care Excellent (NICE) guidelines were established in 1999 in England. They aim to ensure the delivery of consistent, good quality care by providing evidence-based recommendations. Guidelines recommend how healthcare professionals should “set out the care and services suitable for most people with a specific condition or need, and people in particular circumstances or settings” to promote individualised and integrated care (NICE, 2020). I reviewed the NICE guidelines for a range of long-term conditions most common in dementia, to identify the current advice most relevant to people living with dementia and other long-term conditions.

2.7.1 NICE guidelines for long-term conditions

I investigated how dementia was considered within clinical guidelines for the following 13 long-term conditions, identified from literature as prevalence in dementia (Browne et al., 2017; Public Health England, 2019): Type 2 Diabetes (NICE, 2015b), Hypertension (NICE, 2019c), Chronic Heart Failure (NICE, 2018a), Cardiovascular Disease (NICE, 2014a), Stroke (NICE, 2019e), Parkinson’s Disease (NICE, 2019d), Epilepsy (NICE, 2012a), Depression (NICE, 2009), Asthma (NICE, 2017), Chronic Obstructive Pulmonary Disease (COPD; NICE, 2018b), Osteoarthritis (NICE, 2014b), Osteoporosis (NICE, 2012b) and Thyroid Disease (NICE, 2019f). A summary of recommendations reviewed can be seen in Appendix 1.

A number of these guidelines acknowledged the greater risks of dementia and cognitive impairment in relation to the index condition. Parkinson’s Disease guidelines (NICE, 2019d) highlight how dementia and cognitive impairment are recognised as symptoms of Parkinson’s disease. NICE guidelines for Thyroid disease describe the link between sub-clinical hyperthyroidism and risk of dementia (NICE, 2019f), while NICE guidelines describe Hypertension as a risk factor for cognitive decline (NICE, 2019c). For Chronic Heart Failure, clinical assessments are recommended to include an assessment of cognitive status (NICE, 2018a), while NICE guidelines for Epilepsy recommend neuropsychiatric assessment when a person experiences cognitive decline (NICE, 2012a).

However, only the NICE guidelines for COPD recognised the impact of dementia on self-management of the index condition. They acknowledge the inability of people with significant cognitive impairment to develop adequate inhaler competencies or use an inhaler device. They suggest a pragmatic approach guided by individual patient assessment when choosing a device (NICE, 2018b).

Using a single disease framework to organise healthcare has been criticised as being outdated (Coulter et al., 2015). Organising primary care around dementia, rather than long-term conditions, has been proposed to account for the profound effect of cognitive impairment on a person's ability to manage healthcare when planning care (Lazaroff et al., 2013). By focusing on single conditions, clinical guidelines may not reflect difficulties in managing multiple long-term conditions and thus require significant adaptation to address the needs of people with dementia (Bunn et al., 2016; Guthrie et al., 2012; Mutasingwa et al., 2011; NICE, 2016; Subramaniam, 2019). For example, treatment for one condition (e.g. type 2 diabetes) can worsen another condition (e.g. urinary infections) (Northwood et al., 2021).

2.7.2 NICE guidelines for dementia

Next, I investigated NICE guidance for 'Dementia: assessment, management and support for people living with dementia and their carers' for the aforementioned long-term conditions.

In terms of treatment, NICE guidance for Parkinson's Disease provides anti-dementia drug recommendations depending on the severity of Parkinson's Disease Dementia (NICE, 2019d). To advise on effective treatment for conditions that can exacerbate cognitive impairment if untreated, NICE guidelines for hearing loss in adults is cited for recommendations on managing sensory impairment (NICE, 2018d).

To advise on effective treatments for conditions where management is different in the context of dementia, in cases of severe dementia, it is recommended to follow NICE guidelines on type 2 diabetes in adults to set appropriate HbA1c targets (*Recommendation 1.8.7*) (NICE, 2018c). These guidelines do not explicitly mention dementia, rather they recommend relaxing HbA1c target levels on a case-by-case basis with particular consideration for people who are older or frail (*Recommendation 1.6.9*) (NICE, 2015b).

The NICE guideline for dementia specifically mentions depression and anxiety as non-cognitive symptoms of dementia rather than a comorbid long-term condition. It recommends that people with mild to moderate dementia with depression and/or anxiety are considered for psychological treatments (*Recommendation 1.7.11*) and not routinely offered antidepressants unless indicated for pre-existing severe mental health problems (*Recommendation 1.7.12*). This is consistent with previous research highlighting the need for different treatments of depression in dementia (Banerjee et al., 2013).

The NICE guideline for dementia comments on the assessment and management of other long-term conditions in people with dementia (*Recommendation 1.8)* (NICE, 2018c). Sections include recommendations relating to pain, falls, diabetes, incontinence and sensory impairments. For guidance on assessment and managing multimorbidity the guidelines signpost to the following: ‘NICE guidelines for multimorbidity’ (NICE, 2016) and ‘Older people with social care needs and multiple long-term conditions’ (NICE, 2015a). These include information on general principles such as: care planning, integrating health and social care, and supporting carers.

Guidelines for older people complement NICE guidelines for dementia, with dementia being classified as a long-term condition that health and social care professionals should be ‘able to recognise, consider the impact of, and respond to’ (*Recommendation 1.7.2*) (NICE, 2015a). However, guidelines for multimorbidity do not mention the management and organisation of care for dementia. This was critiqued by the International Longevity Centre UK in 2016 with the suggestion that these guidelines could usefully promote preventative care (specifically diabetes annual review) in people with dementia (Scrutton & Brancati, 2016).

2.7.3 Clinical guideline summary

My review of clinical guidelines has highlighted how dementia is conceptualised as another long-term condition within multimorbidity. As demonstrated in the literature presented in section 2.2 and 2.5, managing long-term conditions in the context of dementia is different to the general older population in important ways. The signposting to other relevant guidelines poses the risk of losing the nuance and complexities of managing long-term conditions in dementia. In the remainder of this thesis, I highlight how the management of multiple long-term conditions in the specific context of dementia warrants further consideration than is currently present within the guidelines review presented here.

2.8 Guiding principles to primary care management

I will next discuss the guiding principles, models of care and policies that underpin the implementation of clinical guidelines in a UK context. First, I describe two guiding principles to primary care management of long-term conditions and dementia: proactive management and person-centred care.

2.8.1 Proactive management

Proactive health management, or preventative care, relates to the prevention of illness or disease through lifestyle modification and ongoing monitoring of health. Preventative and proactive management can reduce unplanned hospital admissions which pose a higher risk of mortality for people with dementia (Benthien et al., 2020; Sampson et al., 2009) and support holistic management (Winther et al., 2020). Primary prevention could potentially reduce the prevalence of dementia (Steyaert et al., 2021), through addressing risk factors such as hypertension, diabetes, stroke and depression (Patterson et al., 2007).

Supported self-management from primary care to patients involves a range of activities from information provision to behaviour change with the aim of improving health related behaviour and clinical outcomes (de Silva, 2011). It is a core component of proactive health support interventions which have been associated with small but significant improvements in quality of life for diabetes, cardiovascular, respiratory and mental health conditions (Panagioti et al., 2014). A recent review found self-management interventions to have the greatest evidence of effectiveness for older adults with complex conditions (Frost, Rait, et al., 2020). Promoting prevention and supported self-management are considered core components of person-centred care (Manthorpe & Samsi, 2016) which I will discuss next.

2.8.2 Person-centred care

Recommendations for dementia management are informed by person-centred care (NICE, 2018c). Kitwood's theoretical framework (Kitwood, 1997) posits that person-centred care involves people with dementia through paying attention to an individual's thoughts, feelings and preferences, whilst recognising the interdependence of family carers and professionals. The main principles include valuing the person with dementia, treating them as individuals, considering the world from their perspective, and creating an environment that enables the person to experience relative wellbeing (Brooker, 2003).

Enriched models of dementia care seek to get to know a person as an individual by exploring their previous life, personality and social context (Fox & Kilvert, 2019). Thus, person-centred care can be seen as a mechanism for maintaining personhood in dementia to achieve wellbeing (Manthorpe & Samsi, 2016). While person-centredness is universally accepted as desirable in dementia care, some have criticised how it has become an 'umbrella term' which is 'all pervasive' in descriptions of dementia care, whilst services are still described by users as anything but person-centred due to inflexibility (Manthorpe & Samsi, 2016).

Person-centred care planning, originating in the 1970s (Manthorpe & Samsi, 2016) has since been theoretically implemented across long-term conditions through a policy focus on personalised care (NHS, 2020b). Primary care can facilitate person-centred medication management plans by ensuring targets for comorbidities such as diabetes and hypertension are appropriate and based on goals of care (Lee et al., 2018). However, the practical implementation of person-centred care may be difficult in primary care due to barriers such as time constraints and professional attitude (Moore et al., 2017). As part of the NHS Long Term Plan (see section 2.10), the personalisation agenda aims to give control to patients to manage their physical and mental health needs. This links with person-centred approaches as individuals identify their own needs and make choices about support (Social Care Institute for Excellence, 2021).

2.8.3 Shifting perspectives model of chronic illness

The philosophy of person-centred care often contrasts with the traditional medical model of responding to symptoms, by focusing on knowing and responding to the needs of the individual, which may change over time as disease progresses (Fazio et al., 2018).

Based on a meta-synthesis of 292 qualitative studies, the Shifting Perspectives Model of Chronic Illness challenged traditional notions that illness follows a linear trajectory (Paterson, 2001). The model proposed in reality, people living with chronic illness continually shift focus from perspectives of wellness in the foreground to perspectives of illness in the foreground. Varying perspectives reflect the needs of an individual and determine responses to long-term condition management. For example, those with illness-in-the-foreground might emphases symptoms of disease while those with wellness-in-the foreground might assume a holistic stance. Changes in perspective may occur in response to illness-related factors or to changes in social circumstances.

Previous research has used this model to understand the experiences of people living with dementia. In one qualitative study on the experiences of resilience, participants described repositioning their dementia from the foreground to the background over time as part of a process of personal adjustment to diagnosis (Buggins et al., 2021). In a meta-synthesis of qualitative research on lived experience of dementia, awareness of dementia-related changes lead to adaptive strategies to maintain continuity (Górska et al., 2018). The aforementioned studies highlight how insight can enable people with dementia to identify and respond to changing illness perspectives, therefore this model may be more applicable to people in the early stages of dementia.

2.9 Care delivery strategies and models

The growing prevalence of people living with chronic disease has led to the increased need to identify effective ways to manage complex care needs (Goodwin et al., 2010). Common elements of such frameworks involve a shift from traditional symptom-focused medical models of care towards holistic, proactive, preventative, and person-centred care (Coulter et al., 2013).

In this section, I first describe how primary care is delivered to people with dementia through care planning and case management. Next, I describe models that have been proposed to guide care delivery in people with long-term conditions.

2.9.1 Care planning

Care planning seeks to enable holistic, person-centred care for people with long-term conditions and is a priority for NHS dementia care (Coulter et al., 2013; NHS, 2017). It is the key structure for long-term condition management in primary care and strives for a 'better conversation' between patients and healthcare professionals. The process of care planning is described in seven steps: Preparation, Goal Setting, Action Planning, Documenting, Coordinating, Supporting and Reviewing. The intention is that clinicians and patients collaboratively identify individual needs, agree goals, and develop, implement, and monitor action plans (Brown et al., 2018; Coulter et al., 2013, 2015, 2016; Eaton et al., 2015; NHS, 2017; NHS England, 2019b). In practice, use of care planning discussions are high however a small minority transfer discussions to a written care plan (Burt et al., 2012; Reeves et al., 2014). I outline these attempts to incentivise care planning in section 2.10.

A 2015 Cochrane review assessing the effects of care planning approaches found no studies involving people with dementia (Coulter et al., 2015). The review included adults over 18 "with any long-term physical, psychological, sensory, or cognitive condition" but did not search for dementia despite including other neurological conditions. It included one study of potential relevance to this thesis, an evaluation of an intervention for people living with diabetes or coronary heart disease and depression (Katon et al., 2010).

Patients set self-care goals in structured visits every 2-3 weeks. A nurse then monitored progress in depression management, disease control, and self-care activities. Follow-up telephone calls ensured the maintenance plan was being followed with visits offered if disease control worsened. The intervention followed all seven stages of personalised care planning and led to improvements in blood pressure, cholesterol, glycated haemoglobin, depression, and self-care. Regular review and active follow-up were considered to be a key element in the above intervention.

2.9.2 Case management

Case management is an established tool for integrating services around the needs of an individual with long-term conditions, including physical, mental and social care (Ross et al., 2011). It is a wider system of care of which care planning is one part. The key components of case management include screening, problem identification, planning, implementing, monitoring and evaluating (Reuben, 2002). Case management offers intensive professional supported self-management with input from multi-disciplinary teams for coordinating care for people with dementia and their carers (Panagioti et al., 2014; Prince et al., 2016).

Intensity of case management is associated with degree of improvement in clinical outcomes (Somme et al., 2012). The systematic follow-up of people with dementia and their carers has been recommended for integration in primary care (Robinson et al., 2010). Models of care including case management have been found to improve behavioural symptoms for people with dementia, and compared to usual primary care, have positive effects on physical health outcomes for long-term condition management (Frost, Rait, et al., 2020). A recent review found post-diagnostic dementia care led by a case manager, with input from primary care professionals for specific aspects of care planning, reduced carer burden and neuropsychiatric symptoms (Frost, Walters, et al., 2020).

Care coordination interventions have been found to have greatest impact for improving outcomes for older people with multimorbidity (Kastner et al., 2018).

In the context of dementia, collaborative care models using a case manager to coordinate individual care, including liaising with primary and secondary care has been recommended (Robinson et al., 2010). Admiral Nurses (UK Dementia-specialist nurses) use a case management approach, which has been associated with reduced hospital admissions (Knight & Dening, 2017).

Care planning and case management are both care delivery strategies that have been used within primary care, where they form part of a complex system of care provision. Yet the feasibility of such strategies have been found to be influenced by primary care professional engagement in building capacity for dementia care (Frost, Rait, et al., 2021). In the next section, I provide an overview of models of care which integrate these strategies, with the aim of enabling person-centred, proactive care.

2.9.3 The Chronic Care Model

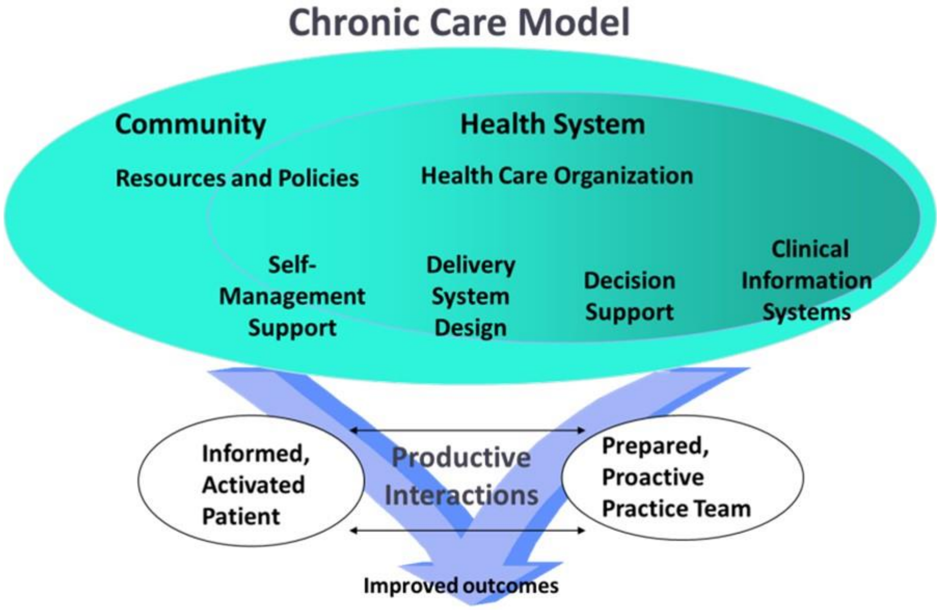
In response to increasing demands on medical delivery systems, Wagner (1998) developed the 'Chronic Care Model.' This is a longitudinal, preventative, community-based, integrated approach for effective primary care management for long-term conditions (Wagner et al., 2001; World Health Organisation, 2016).

The multidimensional model suggests that clinical outcomes improve when 'informed, activated patients interact with prepared proactive teams' (Bodenheimer et al., 2002). A review of chronic disease management interventions for adults with physical health problems implemented in primary care confirmed self-management to be the most frequent Chronic Care Model intervention associated with significant improvements in diabetes and hypertension (Reynolds et al., 2018).

Essential elements of high-quality chronic disease care include self-management support, delivery system design, decision support and clinical information systems in addition to community resources to meet the needs of patients (Kadu & Stolee, 2015). This model of care applies to a broad range of chronic conditions and promotes system re-design to meet the complex needs of individuals with chronic conditions (Grover & Joshi, 2015). A visual representation of the Model is presented in Figure 2.3.

This theoretical framework of care delivery has influenced health policy internationally by highlighting the need for healthcare to be proactive (Coulter et al., 2015). In terms of dementia, the principle of informed and empowered patients in managing their own physical health may not be fairly implemented (Knight & Dening, 2017). There is also no clear blueprint on how components of the model can be implemented in primary care practice (Kadu & Stolee, 2015), with very few implementations targeting people with multimorbidity (Boehmer et al., 2018). Compared to usual care, a recent review of reviews found use of the Chronic Care Model had little impact on outcomes for people with frailty, however it did improve mental health outcomes for people with multimorbidity (Frost, Rait, et al., 2020; Hopman et al., 2016).

Figure 2.3. Chronic care model



2.9.4 House of Care model

The ‘House of Care’ model (Coulter et al., 2013) expands on the Chronic Care Model by translating the framework into a coordinated service delivery model for UK primary care (Coulter et al., 2016). NHS England have adopted this model in an attempt to achieve a holistic approach within integrated care systems (NHS England, 2021d). The model encompasses all people with long-term conditions (as opposed to high-risk groups) and assumes an active role for patients (Coulter et al., 2013).

At the centre of the model is care planning. Four ‘walls’ around the concept of person-centred coordinated care define the interdependent components required to achieve it: 1) appropriate and robust organisation and supporting processes, 2) health professionals working in partnership, 3) engaged and informed individuals and carers, and 4) responsive commissioning. A visual representation of the model is presented in Figure 2.4.

The model has been developed and tested in the Year of Care diabetes programme. Researchers found improvements in patient experience of care and self-care behaviours, and in professional knowledge and skills (Year of Care, 2011). The model has since been expanded and developed to other long-term conditions to provide an implementation framework for care and support planning in primary care, namely the Year of Care model (Roberts et al., 2019).

Figure 2.4. House of care model

In the next section, I will provide a brief overview of how health policy in England has sought to influence dementia care and long-term condition management by implementing the abovementioned principles, strategies and models of care.

2.10 Health policies in England

In this section I will describe policy driving developments, first in the area of long-term conditions, and then in dementia care.

2.10.1 Quality outcome framework

One mechanism by which policies can leverage change is through incentivising certain performance indicators of care. The Quality and Outcomes Framework (QOF) began in UK primary care in 2004. It is a voluntary annual reward which provides general practices with financial incentives for using evidence-based performance indicators (Forbes et al., 2017). NICE became responsible for developing and reviewing QOF indicators in 2009 (NICE, 2019b).

The QOF initiative aimed to facilitate implementation of standards for management to improve quality of care for prevalent long-term conditions. The single condition focus means QOF does not directly consider multiple long-term conditions. Dementia is included as one of the clinical areas incentivised through QOF, but does not include aspects of care for comorbidities (Goodwin et al., 2010). QOF guidance on care plans for dementia suggest reviews should address physical and mental health, communication arrangements with secondary care and identification of a carer (NHS England, 2021a).

QOF demonstrate the important role of general practice in the management of long-term conditions despite overall impact being contested and the limited scope of QOF indicators on single, biomedical dimensions of care (Forbes et al., 2017; Goodwin et al., 2010). The initiative has been criticised for its focus on performance measures, rather than equipping healthcare professionals with the skills and confidence required to individualise and tailor care based on quality of life rather than clinical targets (Bunn, Goodman, et al., 2017).

2.10.2 Five Year Forward View

In 2014, the NHS ‘Five Year Forward View’ (NHS, 2014) set out a direction for the NHS, including how services need to change, and what models of care will be required in the future. Policy focused on prevention and public health, greater control for patients of their care, and integration of health services to address barriers to how care is provided (Ham & Murray, 2014). This included the integration of physical and mental health, and health and social care services. The strategy also outlined models of care and the delivery of services locally and in specialist centres, creating out of hospital care to support people with multiple health conditions (Maruthappu et al., 2014). In relation to preventative healthcare for older people in pilot areas, the integration of GP, community health, mental health and hospital services resulted in reduced hospital admissions and length in over 75s (NHS England, 2019b).

2.10.3 NHS Long term Plan

The ‘NHS Long Term Plan’, published in 2019, builds on the Five Year Forward View (Charles et al., 2019; NHS England, 2019a). It focuses on the need for integration of services from mental and physical health care, and for multiple long-term conditions. The plan also specifies changes to QOF incentives schemes to encourage personalised care (Charles et al., 2019). The importance of integrated care and the provision of quality personalised care for people with dementia has been highlighted in a recent House of Commons Committee report (Health and Social Care Committee, 2021).

The NHS Long Term Plan priority of ‘ageing well’ has important considerations for dementia care, including multidisciplinary working and support for carers (Palmer, 2019). The NHS Long Term Plan focuses on the establishment of Sustainability and Transformation Partnerships and Integrated Care Systems to address experiences of disjointed care (Durgante et al., 2020; NHS England, 2019a, 2021f). While there was general support from patient advocacy organisations that the above measures present a unique opportunity to transform dementia care and support (Alzheimer’s Society, 2020a), some authors cautioned that consideration and evidenced frameworks are required to address challenges of successfully integrating physical and mental health services (Tracy et al., 2019).

Adopting an individualistic approach to personalisation in terms of Personal Health Budgets (NHS England, 2019c) also poses a greater risk to people with dementia of exploitation and abuse rather than providing empowerment and control (Manthorpe & Samsi, 2016). These are means-tested, direct payments (to the person needing care or their proxy) or combined with local authority services based on individual support needs. There have been criticisms that such an approach may be difficult for older people, and people with dementia, to coordinate (Glendinning et al., 2008).

2.10.4 Dementia policy in England

Despite components of personalised care being recognised in public policy, implementation for people with dementia has not always been successful (All-Party Parliamentary Group on Dementia, 2016). Dementia is a key priority for both NHS England and the UK Government (NHS England, 2021c). Since the publication in 2009 of the first National Dementia Strategy, a number of policy documents have outlined the government's priorities for dementia care in England. The Dementia Challenge was launched in March 2012 by the then Prime Minister, David Cameron. The Dementia Challenge work programme superseded the national strategy and focused on three main areas: bringing about improvements in health and care, creating dementia friendly communities and improving research.

The Prime Minister's challenge on dementia set out the aim for England to become a world-leader in dementia care and research by 2020 (Department of Health, 2016). The implementation plan focused on four priorities: risk reduction, health and social care, awareness and social action, and research. Of relevance to this thesis was the aspiration of this pathway to join up health and social care and to ensure all people with dementia have personalised care plans. General practice were identified to lead the continuity of care for people with dementia (Department of Health, 2016). The implementation plan for the

Prime Minister's challenge on dementia includes details of the 'Dementia well pathway.'

2.10.5 Dementia well pathway

The NHS 'well pathway for dementia' (NHS England, 2021e) describes a framework of care and support for people with dementia, from diagnosis to end-of-life, and includes preventing well, diagnosing well, living well, supporting well and dying well. Similar to the management of long-term conditions, the pathway contains key concepts for self-management (providing information, carer support) and personalised care (care planning, care coordination). However, researchers have argued that specialist models of dementia care do not facilitate care coordination for complex multimorbidity, which is a core function of primary care, further evidencing the need for service integration including across the health and social care system (Prince et al., 2016).

2.11 COVID-19 and dementia

Before summarising the literature presented in this Chapter, I will provide an overview of the implications of coronavirus disease 2019 (COVID-19) on the health and wellbeing of people with dementia and multiple long-term conditions.

In March 2020, a mid-point in my PhD, the World Health Organisation declared COVID-19 to be a pandemic (World Health Organisation, 2020). Older people and people with underlying health conditions such as cardiovascular disease, hypertension, diabetes, and chronic respiratory diseases are at increased risk of severe COVID-19 (Clark et al., 2020; Emami et al., 2020). Risk factors for Alzheimer's disease, such as the APOE e4 genotype, have been found to increase the risk of severe COVID-19 (Kuo et al., 2020). Consequently, people with dementia have an increased risk of hospitalisation and mortality (Atkins et al., 2020; Wang et al., 2021), and accounted for 25% of deaths from COVID-19 in the UK (Suárez-González et al., 2020). This high mortality rate disproportionally impacted people in care homes and those with advanced dementia (Bianchetti et al., 2020).

In the UK, the Government implemented public health measures to reduce virus transmission and protect those at risk of severe disease following infection. These included maintaining a social distance of two meters between individuals, and self-isolation if experiencing symptoms of the virus or after being in contact with someone who has tested positive. People over 70 and those ‘clinically extremely vulnerable’ were instructed to shield by not leaving their home and minimising contact with others (NHS, 2021b). Such restrictions were found to have far reaching consequences for vulnerable older people (Brown et al., 2021) and people with dementia (Barry & Hughes, 2020; Tuijt, Frost, et al., 2021). The symptoms of dementia may impact a person’s ability to comprehend and implement government guidance (Alzheimer’s Society, 2020b) and to recognise or communicate with people required to wear a face covering (Nazarko, 2021).

On a population level, psychological distress increased and wellbeing decreased during the pandemic (White & Boor, 2020; Zhang et al., 2020). Rates of agitation, anxiety and depression have been associated with feelings of isolation due to limited contact with friends and family (Velayudhan, 2021). For people with dementia, reduced social contact during quarantine resulted in worsening cognition (Boutoleau-Bretonnière et al., 2020; Schroeter et al., 2021) and higher carer stress or burden (Borelli et al., 2021; Cagnin et al., 2020).

From a service perspective, implications of national lockdowns included postponing of routine health check-ups and non-urgent medical treatments (Alzheimer’s Society, 2020b). The transition to remote contact resulted in reduced usage of social care (Giebel et al., 2021) and primary care (Joy et al., 2020). Older people with multiple long-term conditions experienced cancelled appointments (Schuster et al., 2021) or avoided seeking medical attention over fears of COVID-19 infection (Fisher et al., 2021; Masroor, 2020; McKinlay et al., 2021). New physical health needs for people with dementia were harder to assess in telephone consultations (Tuijt, Rait, et al., 2021). Thus, diagnosis rates of dementia, diabetes, depression and stroke were found to decrease compared to the previous year (Michalowsky et al., 2021).

2.12 Summary

In this chapter, I introduce the topics of dementia and long-term conditions. I have outlined how people with dementia are more likely to have long-term conditions, receive poorer care, and have worse outcomes. The optimal management of long-term conditions in dementia is therefore paramount. Self-management is key but can be severely impacted by symptoms of dementia. I outlined theoretical models for the self-management of long-term conditions and how taxonomies of self-management are impacted by the symptoms of dementia. I then summarised the literature on how people living with dementia are supported in day-to-day self-management of long-term conditions by family carers and homecare workers in the community.

By introducing the primary care context to managing long-term conditions in dementia, I highlighted the importance for care to be organised according to need rather than disease. I discussed clinical guidelines, guiding principles, care strategies, models, and policies that determine how primary care services in England are delivered to people with dementia and multiple long-term conditions. Finally, I considered the impact of COVID-19 on the health and wellbeing of people with dementia.

The majority of the literature discussed in this Chapter relates to either the management of long-term conditions, or the management of dementia. There is little evidence on how the management of long-term conditions needs to be modified in the context of dementia and implemented in practice. This gap will be addressed in the remainder of my thesis. I am particularly interested to explore in this thesis how the theoretical frameworks I outline in this Chapter apply to people at different stages of cognitive decline. I will also consider how the process of self-management may evolve as dementia progresses through the lens of transition theory.

In the next chapter, I will discuss the aims and objectives for each of the three streams I have completed for my PhD.

Chapter 3 Aims and objectives

The overall aim of my PhD was to understand how people living with dementia manage, and can be supported to manage co-occurring long-term conditions, by family carers, homecare workers and primary care in the community. My specific objectives for each stream of my PhD are described below.

3.1 Stream One: Systematic review

For my systematic review my objectives were:

1. To systematically review and synthesise evidence on enabling and inhibiting factors to supporting self-management of long-term conditions in dementia.
2. To use the results to inform objectives of stream two and three.

3.2 Stream Two: Secondary analysis of qualitative interviews

For my secondary analysis of qualitative interviews with people with dementia, family carers, health and social care professionals and homecare staff, my objectives were:

1. To explore how the management of long-term conditions is experienced and negotiated by people with dementia and their carers.
2. To use secondary analysis of stakeholder experiences to understand how the management of long-term conditions in dementia is best supported.
3. To use the results to inform objectives for stream three.

3.3 Stream Three: Multi-data qualitative study

In stream three, I aimed to develop an understanding of how care for long-term conditions is provided by primary care for people with dementia, and to understand how various networks support the implementation of care recommendations in the community.

Taking a multi-data approach to data collection, using interviews and document analysis, my objectives were:

1. To explore how care for long-term conditions is provided in UK primary care to people with dementia, including the extent to which care for long-term conditions is tailored to account for dementia.
2. To understand how advice or information given in primary care including care plans and self-management activities are implemented in the community by people with dementia and other long-term conditions and those who support their care.

As data collection for stream three coincided with COVID-19, I included two further objectives relevant to this unique context:

1. To explore how care provision for long-term conditions in dementia were affected by COVID-19.
2. To develop methodologies for remote research for people with dementia in light of social distancing restrictions.

Chapter 4 Stream One: Systematic review

In Chapter Four, I describe and present the findings of stream one of my PhD. My systematic review aimed to identify and synthesise existing research on enabling, supporting, and inhibiting factors in the self-management of long-term conditions in dementia. This work has been published in the International Journal of Nursing Studies (Rees, Tuijt, et al., 2020) (See Appendix 2).

This chapter begins with a rationale for investigating support for self-management of long-term conditions in dementia.

4.1 Rationale

The evidence I reviewed in Chapter Two highlights the important role of self-management in managing long-term conditions. I described how theoretical conceptualisations of self-management (Lorig & Holman, 2003) are contextualised in dementia (Ibrahim et al., 2017). I discussed how impairment in different cognitive domains might impact self-management and require increased support from family carers (Bunn, Goodman, et al., 2017), social care (Carter, 2016), and primary care (Browne et al., 2017). In this review I extend this discussion, by exploring how self-management of long-term conditions can be supported in people with dementia. I defined management as either self-management, or management supported by a proxy (where people carry out self-management activities for those unable to do so).

When I searched the literature in October 2018, I found no previous systematic reviews investigating strategies to support self-management of long-term conditions in dementia. Instead, the literature focused on the impacts of cognitive impairment on self-management for conditions such as COPD (Baird et al., 2017), diabetes (Santos et al., 2018) and heart failure (Currie et al., 2015). The reviews I identified focused on a single long-term condition despite the rise in multiple long-term conditions (Kingston et al., 2018) and the complications this creates in providing person-centred care for chronic disease (Guthrie et al., 2012). In addition, I found that studies relating to self-management interventions in dementia did not specifically mention the management of multiple long-term conditions (Laakkonen et al., 2016; Quinn et al., 2016).

One scoping review focused diabetes, stroke and visual impairments in dementia (Bunn et al., 2014). The majority of included studies reported prevalence and service provision for people with dementia and these co-occurring long-term conditions. I sought to expand on this by including a broader range of physical health conditions in dementia as identified by Browne (2017), where cognitive impairment can effect self-management. Other reviews focused on medication management in people with dementia yet did not specify long-term conditions (Aston et al., 2017; Lim & Sharmeen, 2018). In this review, I expanded on previous work by searching for specific terms such as ‘medication adherence’ in addition to searching for broader terms relating to self-management for example ‘nutrition management’, ‘appointment retention’ and ‘lifestyle modification’.

4.1.1 Aims

In this review I aimed to systematically search the literature and identify evidence on how the management of long-term conditions in people with dementia can be supported. My objectives were to synthesise evidence on which factors enable or inhibit the effective management of long-term conditions in dementia.

4.2 Methods

4.2.1 Pre-registration

I developed the methodology for my review using Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) guidelines (Page et al., 2021) and registered the protocol for the review on PROSPERO (reference number: CRD42019122072).

4.2.2 Search strategy

I systematically reviewed the literature up to the 28th of November 2018 with no limits applied to date of publication, using the following databases: MEDLINE, PsychINFO, Embase and Allied and Complementary Medicine. I searched using terms related to ‘dementia,’ ‘physical health’, and ‘management’ which I combined using the Boolean operator ‘AND.’ The Boolean operator ‘OR’ linked search terms within each concept. The full search strategy is presented in Appendix 3. I updated my search on 20th of August 2020 using the same search strategy.

4.2.3 Eligibility criteria

Studies were eligible for inclusion if they explored an element of self-management, or management by a proxy, of a long-term condition of interest in people living with dementia. I identified long-term conditions of interest based on prevalence rates reported in a recent, large epidemiological survey of long-term conditions in dementia: Hypertension (53.4%), Chronic Pain (33.5%), Coronary Heart Disease (21.6%), Stroke (17.2%), Diabetes (14%), Asthma (8.3%), COPD (6.9%), Heart Failure (6.3%) (Browne et al., 2017). Studies of long-term conditions in people with dementia were included if they encompassed elements of self-management including: attending clinical appointments, using medical devices, medication adherence or lifestyle change (Lorig & Holman, 2003). Although the focus of my PhD is the home setting, an initial scoping search found few studies focusing on self-management strategies for dementia and multiple long-term conditions. I therefore extended my search to include supported self-management for long-term conditions in dementia by staff in community settings, care homes or residential facilities.

I excluded studies that solely focused on prescriber behaviour, prevention or reduction in cognitive impairment, and long-term conditions requiring support in secondary care such as cancer. I excluded studies that focused on dementia care management without a physical health element (i.e. mental health). For this review I considered mental health self-management to be conceptually different due to the complex relationship between dementia and depression (Curran & Loi, 2013). As depression is often a consequence of long-term conditions, previous reviews have also adopted this rationale (Coulter et al., 2015).

No restrictions were applied to study design, including case studies, however reviews, editorials, theses, conference proceedings and studies not written in English were excluded.

4.2.4 Methodological quality

I assessed the methodological quality of included studies using the Mixed Methods Appraisal Tool (Hong et al., 2018). The MMAT was developed to appraise the quality of quantitative, qualitative, and mixed methodology studies. I used a validated checklist to provide a quality rating for each study. Research has demonstrated the efficacy and reliability of this tool (Pace et al., 2012). I worked with my colleague RT as independent reviewers to assess the quality of each study with any discrepancies resolved through discussion. To appraise each study, we chose an appropriate category (qualitative, quantitative, mixed methods) and rated according to five criteria (yes, no, can’t tell). If our ratings differed, we revisited studies and compared presented information with the relevant category checklist to agree on a final rating. The authors of the MMAT discourage the calculation of an overall score, and the exclusion of studies based on low methodological quality. In the results section, I therefore present a discussion of ratings for each study to inform study quality.

4.2.5 Synthesis and analysis of data

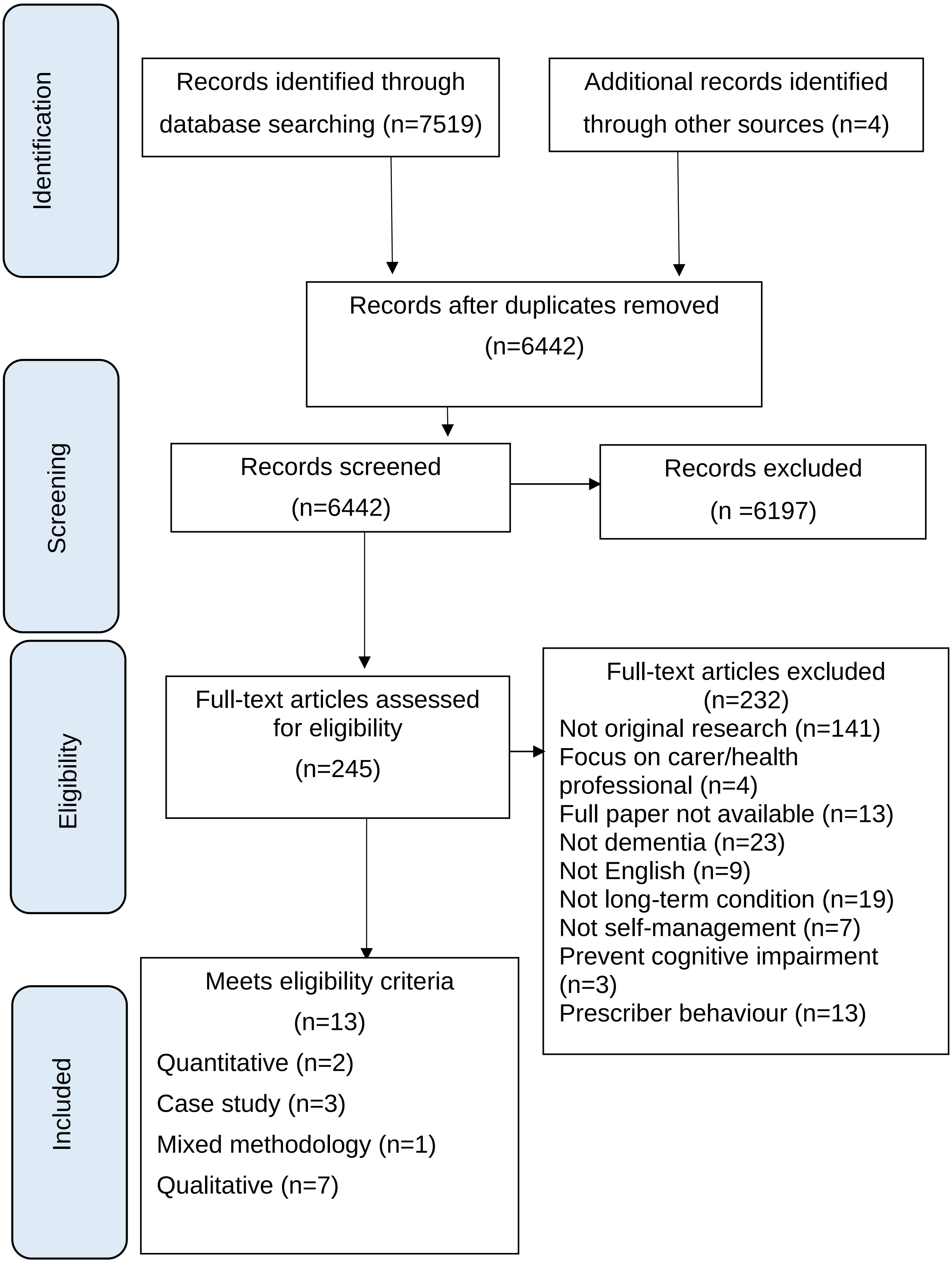
As outlined above, I followed the stages of a systematic review (Popay et al., 2006) which includes: mapping the available evidence (section 4.1), specifying the review question (section 4.1.1), identifying studies to include (section 4.2.2), data extraction (section 4.2.3) and appraisal of study quality (section 4.2.4). For the synthesis stage, I used a data-based, convergent synthesis approach (Hong et al., 2017; Pluye & Nha Hong, 2014). The integration of qualitative and quantitative studies using this approach has previously been used in dementia-focused mixed methodology reviews (Aston et al., 2017). A data-based convergent synthesis is when results from qualitative, quantitative and mixed-method studies are combined in a complementary manner and synthesised using the same method (Hong et al., 2017). In a convergent synthesis design, the results of included studies are integrated using data transformation. For my analysis, I transformed quantitative data into qualitative data to develop themes using a thematic synthesis (Thomas & Harden, 2008). For example, I coded author discussion on the results of a blood glucose intervention for people with dementia and type two diabetes (Chen, 2017) as 'personalised care' which informed my theme relating to 'Interface with healthcare professionals'.

After summarising the descriptive characteristics, I uploaded all included studies onto NVivo 11 (QSR International Pty, 2018). The first stage of the process is to code line-by-line the results of included studies. For my review, this consisted of authors interpretations (from results and discussion sections for all papers) and participant accounts (from qualitative papers). One of my supervisors (AB) and I independently developed an initial coding framework using line-by-line coding of the result and discussion sections for four included papers. I applied this coding frame to all studies. In the second stage, I grouped together codes from my inductive analysis to develop descriptive themes. To do this, I wrote summaries of findings from included studies highlighting key codes to then organise line-by-line codes based on conceptual meaning. Finally, I considered my descriptive themes with my supervisory team to develop analytic themes by reflecting on and interpreting the similarities and differences between studies within each theme. I focused theme write up on enabling and inhibiting factors to respond to my research questions (Thomas & Harden, 2008). I present the synthesised results in the next section.

4.3 Results

I identified 5505 studies through my electronic search in 2018, of which 224 were reviewed at full text. Eight articles were deemed eligible for inclusion. I identified four additional articles from references of identified papers resulting in 12 studies in total being included in the review. In my updated search in 2020, I identified a further 1018 papers. After de-duplication, 913 studies remained. 17 studies were reviewed at full text. I found one additional study meeting eligibility criteria (Kamimura, 2019). Figure 4.1 presents full details in a PRISMA diagram combining figures from the original and updated search.

Figure 4.1. PRISMA diagram of study selection [3]



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[3] Adapted from (Moher et al., 2009)

4.3.1 Characteristics of included studies

The included studies were conducted in the USA (n=5), the UK (n=3), Australia (n=2), China (n=1), Japan (n=1) and Brazil (n=1). Ten studies used qualitative methodologies, including three case studies. Two studies were quantitative (randomised controlled trial and survey) and one was a mixed methods study. Four studies focused on a single long-term condition, specifically diabetes. The other studies included participants with a range of long-term conditions, including hypertension (n=4), osteoporosis (n=3), stroke (n=2), arthritis (n=1), COPD (n=1) and heart failure (n=1). All qualitative studies interviewed family carers (n=7). Studies included family carers only (n=4), family carers and people with dementia (n=1), family carers and healthcare professionals (n=1), or all three stakeholders (n=1). The majority of studies included people with dementia who lived in the community (n=10). For the remaining studies, people with dementia lived in assisted living facilities (n=1) or care homes (n=1). For one study (Chen et al., 2017), residential status was unclear (community or hospital). Detailed characteristics of studies are presented in Appendix 4.

4.3.2 Methodological quality

Overall, methodological quality of included studies was mixed. The MMAT provides five questions to assess methodological quality in categories based on study design. I gave a score of one for each ‘Yes’ answer to produce the overall scores described below.

Five out of ten qualitative studies scored five out of five on the MMAT (Bunn, Burn, et al., 2017; Feil et al., 2011; Gillespie et al., 2015; Poland et al., 2014; While et al., 2013). One study scored four out of five because it did not provide sufficient interpretation of qualitative results (Sadak et al., 2017). For studies that were rated three out of five, reasons included lack of information about blinding or adherence to the intervention (Chen et al., 2017), lack of information on data source, collection and analysis (Brauner et al., 2000), incoherence between data collection, analysis and interpretation (Sadak et al., 2018) or due to inappropriate statistical analysis (De Oliveira et al., 2014). The case study and case report scored two out of five for appropriateness of measurement (Allen et al., 2017; Kamimura, 2019). The mixed methodology study scored one out of five for absence of reporting on criteria such as integration of mixed methods results (Yarnall et al., 2012). See Appendix 5 for quality assessment ratings.

4.3.3 Synthesis

I identified four over-arching themes that responded to my research aim to explore enabling, supporting or inhibiting factors in the self-management of long-term conditions in dementia.

Dementia symptoms inhibited self-management of long-term conditions (theme 1), while adaptations to routines enabled self-management (theme 2). Family carers enabled self-management by proxy when strategies described in theme 2 to support self-management were no longer effective (theme 3). Healthcare professionals were integral to supporting both people with dementia and family carers to manage long-term conditions (theme 4). Table 4.1 provides a summary of themes identified from included studies.

Table 4.1. Summary of themes identified from included studies

Theme 1: Dementia Symptoms **Enablers:** • Long-term condition pre-existing dementia **Inhibiters:** • Understanding disease • Behavioural and psychological symptoms (acceptance of care) • Communication (of symptoms)	**Theme 2: Adapting Routines** **Enablers:** • Establishing routine • Memory aids **Inhibiters:** • Physical ability • Complex regime
Theme 3: Negotiating Support **Enablers:** • Availability of carer (supervision) • Wider support networks • Empowerment • Acknowledgement of carer role by support network **Inhibiters:** • Loss of independence • Safety concerns • Deskilling • Negative attitudes towards support	**Theme 4: Interface with Professionals** **Enablers:** • Recognise change • Personalised treatment plans (Explore values/beliefs) • Continuity of care • Long-term condition specific education **Inhibiters:** • Reliance on healthcare professionals • Communication between professionals

Theme 1. Dementia symptoms impeding treatment regimes

Cognitive symptoms impeded adherence to dietary and physical activity regimes recommended for self-management of long-term conditions, and medication adherence. In a questionnaire study of 217 carers of people with Alzheimer's disease and diabetes or hypertension, higher dementia severity was associated with reduced adherence to lifestyle advice regarding activity, diet and medication regimes. No individuals with severe impairment practiced physical activity regularly, whereas people in the earlier stages of dementia used exercise as a treatment for diabetes or hypertension (De Oliveira et al., 2014).

Qualitative studies explored how cognitive symptoms were sometimes a barrier to self or proxy self-management. Often this was because they impaired a person's understanding of the disease and related treatments.

> *'I give him insulin, I give him his medicine. He takes it, but he questions me, what is this for, why do I have to take so many medicines for. He doesn't remember he's diabetic.' (Feil et al., 2011) (Family Carer)*

Communication difficulties often impaired a person with dementia's ability to report symptoms to family carers or healthcare professionals, and this could inhibit long-term condition management. Family carers reported guessing what symptoms the care recipients were experiencing.

> *'…I want to do the right thing by him, but he has not been able to tell me when he is ill or hurting for over a year now.' (Sadak et al., 2017) (Family Carer)*

Behavioural and psychological symptoms increased the likelihood of a person refusing assistance to manage their long-term condition. This was described in two qualitative studies that interviewed family carers of people with dementia. Persecutory beliefs could reduce adherence, as one study on medication adherence found people with dementia to have '*altered perceptions about the purpose of the medication(s*).' This led to reduced adherence due to the belief that medications were poisonous (Gillespie et al., 2015). Family carers reported finding refusal of care and persecutory beliefs difficult to cope with in the management of diabetes in dementia.

> *'He's really angry at me-he tells me I'm the cause of his eye sight being what it is because of the medications I made him take.' (Feil et al., 2011) (Family Carer)*

Lack of acceptance of care by the person with dementia hindered family carer management of long-term conditions.

> *'So I got a big problem…because he's got osteoporosis, he's got a big lung problems. But he doesn't want to take it. I can't do anything.' (Gillespie et al., 2015) (Family Carer)*

Interviews exploring the challenges to diabetes care in people with dementia reported how family carers sometimes misinterpreted refusal of care or behavioural and psychological symptoms as a difficulty in their personal relationship rather than a symptom of dementia, which caused distress (Feil et al., 2011). The presence of a long-term condition before dementia development was often associated with fewer difficulties with self-management of that condition following a dementia diagnosis. This was described in a qualitative study of the experiences of people with dementia from Australian minority ethnic groups, who successfully managed medication for long-term conditions when they had already been taking the medication prior to developing memory problems.

> *'My husband he remembers, he takes his own medication what he like [sic] but he only takes the blood pressure tablets because the other tablets he thinks do not do anything to him so it's no worth to take it.' (Gillespie et al., 2015) (Family Carer)*

Future care plans may usefully consider how potential barriers to self-management (including poor memory, communication abilities, behavioural symptoms and acceptance) may be impacting an individual. They should also consider the point at which a long-term condition developed and be open to the possibility that effective self-management may be possible even with more advanced dementia, where skills were learnt prior to the dementia developing.

Theme 2. Adapting routines and strategies

In qualitative interviews, a barrier to adherence was regime complexity, specifically confusion around differing daily schedules and varying brand names (While et al., 2013). For people with dementia who self-administer medication at home, and family carers who support them, simplifying medication regimes enabled self-management. Family carers reported valuing medication reviews in which healthcare professionals reduced the number of daily medications for carers to manage (Gillespie et al., 2015). Memory aids, such as pill organisers, could enable self-management of medication in milder dementia.

> *'... the medication ... he wasn't taking it properly. But now he is taking it regularly ... the Chemist they just fix up the blister pack ... it seems to be excellent.' (Gillespie et al., 2015) (Family Carer)*

The findings of a qualitative study using a mixture of focus groups (n=3) and semi-structured interviews (n=7) with carers of people with dementia demonstrated how physical limitations from long-term conditions such as arthritis affected ability to adhere to medication regimes.

> *'I think she's starting to have arthritis as well, and she couldn't open the bottles…so she put them in vitamin jars…and I didn't know what was what.'(Gillespie et al., 2015) (Family Carer)*

Establishing a routine together with memory aids enabled self-management of medication (While et al., 2013). In a case study, the use of technologies supported diabetes insulin self-management in a person with dementia demonstrating how adapting routines is broader than just assisting with oral medication (Allen et al., 2017).

One case report described the experiences of four people with Alzheimer's Disease using automatic medication dispensers to manage medication for chronic diseases (gastritis, diabetes, hypertension, dyslipidaemia) in the community, living independently (n=2) or with a partner (n=2). Use of an automatic medication dispenser improved adherence and reduced carer burden. Prior to use, family carers were found to prompt medication in-person or over the telephone daily (Kamimura, 2019).

Theme 3. Negotiating self-management support

Included studies described a process towards proxy-management, with transition of responsibility for the management of long-term conditions from people with dementia, either partly or totally, to family carers, where they were available. People with dementia and their carers began to negotiate support for self-management when strategies such as memory aids ceased to be effective, or at a critical point in memory decline (Bunn, Burn, et al., 2017). Carers supported self-management through managing self-care activities for long-term conditions and monitoring for complications through supervision. A case study of a person living with dementia and diabetes demonstrated a continued ability to appropriately self-manage hypoglycaemia through supervision by staff in assisted living facilities (Allen et al., 2017). One study, exploring the impact of dementia on provision of services for long-term conditions, discussed the vulnerabilities of people with dementia when support for self-management was not available.

> *'The greatest difficulty is when that individual lives alone and doesn't have an able partner, because then their care can come very disjointed or they're not, they're not able, often they, an appointment's made or they, and they won't answer the door or they forget and so it's when somebody's on their own that you have the biggest issues and lack of joined up care.' (Bunn, Burn, et al., 2017) (Healthcare Professional)*

Negotiating support for self-management through proxy-management was a dilemma, in which carers struggled to balance the desire to support independence with that of ensuring good physical health care. A Patient and Public Involvement (PPI) group exploring medication management in dementia described the impact of accepting help for self-management, in terms of loss of independence.

> *'I think she felt a loss of independence when the dementia hit. But not only that but as soon as her control over her own medication, that she was so used to, was taken out of her hands.' (Poland et al., 2014) (Family Carer)*

The family carers interviewed considered empowerment a part of their caregiving role and sought ways to support people with dementia to retain control (Poland et al., 2014). However, a mixed methodology study auditing diabetes care in UK care homes found little evidence of empowerment. People with dementia were dependent on staff for disease management, including foot care and diabetes management with only one of eight residents on insulin treatment self-injecting or self-monitoring blood glucose (Yarnall et al., 2012). Some studies noted that a desire to deliver good quality physical care could risk deskilling the person with dementia due to high levels of supervision (Feil et al., 2011).

A case study of a person with dementia and osteoporosis highlighted the complex risk-benefit assessment in treating non-dementia illnesses (Brauner et al., 2000). Family carers found it difficult to balance the risk of non-adherence to treatment with the benefit of independence through self-management.

> *‘It’s length of life versus quality of life and that we are carers we’re very loathe to face.’ (Poland et al., 2014) (Family Carer)*

Family carer knowledge of cerebrovascular risk factors such as diabetes and hypertension enabled medication and dietary therapy adherence in one study (De Oliveira et al., 2014). In this study two-thirds of carers reported an awareness of the need to control hypertension and/or hypercholesterolemia due to the influence of these factors on dementia. This awareness was found to influence adherence to dietary therapy and pharmacological treatment.

Negotiating wider support enabled management by a proxy. Included studies found support groups provided medication information for family carers whose first language was not English (Gillespie et al., 2015). Accessing support from paid carers was found to be hindered by negative beliefs, such as the fear of strangers being incompetent in managing the needs of their relative (Feil et al., 2011). Family carers also reported an ambivalence to involve additional family members, based on past experienced of family members declining to help or causing more harm when involved in care, suggesting the need for advice on how to access wider support (Feil et al., 2011).

An important element of negotiating self-management support was acknowledgement of the family carer role in the management of long-term conditions. This was expressed mainly in terms of healthcare professional acknowledgement but also from extended family (Feil et al., 2011). One study suggested this acknowledgement as a potential intervention target for primary care to prevent healthcare crises.

> *'Celebrate with caregivers. Offer encouragement and advise to continue keeping symptom monitoring checklists and communicating concerns if they arise. Offer acknowledgement when (the) caregiver performs home safety evaluation and modification.' (Sadak et al., 2017) (Study Finding)*

Theme 4. Interface with professionals

Healthcare professionals contributed to self-management of long-term conditions by recognising when changes in cognition occurred (Bunn, Burn, et al., 2017) and supporting the family carer to in turn manage or support the care recipient (Sadak et al., 2017). Collaboration with General Practitioners (GPs), pharmacists, case managers and homecare workers can support self-management and management supported by a proxy (While et al., 2013). GPs were described as the main support and pharmacists as important in medication management. However, family carers reported feeling healthcare professionals did not always alert them to symptoms to look out for.

> *'Maybe his doctor could have instructed me better what to do to prevent these episodes, ask me if I know what to do or whom and when to call.' (Sadak et al., 2017) (Family Carer)*

The provision of symptom checklists, key information on medication and condition-specific education by healthcare professionals helped family carers to manage by proxy (Poland et al., 2014). One randomised controlled trial compared diabetic glucose control and complication rates between participants allocated to three different protocols for diabetes management of different intensities. Of relevance, the arm advocating less intensive control by health professionals, with personalised treatment plans and a focus on client and family-led management resulted in fewer diabetic complications.

> *'The personalized treatment plan is recommended by the moderate blood glucose control strategy. This strategy emphasizes on the control of blood glucose according to the actual conditions of patients, including the patients themselves and their families. This strategy recommends the physicians' intervention only in the cases of higher and wider fluctuation range.'(Chen et al., 2017) (Study Finding)*

Improved blood glucose control in dementia was also associated with more physician attention, patient cooperation, and frequency of follow up (Chen et al., 2017). Healthcare professionals were the primary source of information for medication management, especially during decision making (Gillespie et al., 2015). In interviews with healthcare professionals and family carers of people with dementia, collaboration with professionals was facilitated when family carers felt more able to ask questions, and understand which symptoms to monitor and report (Sadak et al., 2017). However, the belief that a good patient does not bother or question professional advice was a barrier to successful collaboration.

> *'I don't bother them, asking more questions about it, I just am a good patient, I just take it.' (While et al., 2013) (Person with Dementia)*

One study using semi-structured interviews to explore the differences between the medication management experiences of people with dementia (n=8) and carers (n=9), found that health professionals were not considered to adequately explore an individual's values and beliefs underpinning their motivations and incentives to adhere to medication, or current attitudes to health, life and medication (While et al., 2013).

Values and beliefs of healthcare professionals also influenced the management of physical health care in people with dementia. In focus groups conducted with over fifty healthcare professionals, factors such as the clinician's previous experience and attitudes towards risk influenced access to care.

> *'I wouldn't refer someone who was uncooperative. I have had a patient who got up in the middle of a cataract operation and refused*

> *to have anything further done and lost the vision in his eye.'(Bunn, Burn, et al., 2017) (Healthcare Professional)*

Ineffective communication and practices around confidentiality hindered collaboration between professionals. Included studies found continuity of care could overcome these barriers.

> *'…one of the big stumbling blocks we have is the fact that services or parts of different Trusts … so they don't use the same system as us so we can't share notes, the GPs use a different system again so it makes it very difficult to communicate to even find out what services people are under, you know, if that could be improved, if we could all be on the same system that would be good.' (Bunn, Burn, et al., 2017) (Healthcare Professional)*

In a case study of diabetes and dementia management using technologies, collaborative working could ensure effective use of technology, which enabled the management of long-term conditions through empowering individuals to self-care.

> *'There was concern that the patient would pull the pump site out or press the buttons on the pump. To avoid any concerns related to the patient wearing the insulin pump, a soft waist belt with a pocket was used to keep the insulin pump out of the patient's view. The safety lock was on the pump at all times to avoid accidental bolus.'* (Allen et al., 2017) *(Study Finding)*

4.4 Discussion

4.4.1 Main findings

For this systematic review I synthesised qualitative and quantitative findings regarding how self-management of long-term conditions in dementia can be supported. Four overarching themes encompassing the enabling and inhibiting factors to effective self-management of long-term conditions in people with dementia were identified: 1) Dementia symptoms impeding treatment regimes, 2) Adapting routines and strategies, 3) Negotiating self-management support, and 4) Interface with professionals.

Most included studies investigated self-management of physical health care across long-term conditions, though a few focussed specifically on medication management, or the care of people with diabetes and dementia. Reduced cognition impeded adherence to medication, exercise and diet due to an impaired understanding of long-term conditions and their sequelae. Previous research has identified a relationship between adherence and cognitive capacity, specifically the risk of impaired executive function and decreased awareness of illness on adherence (Arlt et al., 2008). This review found adherence to be less affected if the long-term condition preceded memory loss. This suggests that adherence may be related to habit formation in addition to an individual's understanding of the consequences of non-adherence.

Behavioural and psychological symptoms of dementia were often associated with the person with dementia refusing help from carers and consequently non-adherence. This was further complicated when people with dementia were unable to report symptoms or pain. Pain in dementia has been associated with depression, agitation and aggression (Van Dalen-Kok et al., 2015). As pain is signalled through verbal communication, people with dementia, especially in the advance stages, have a greater risk of poor pain control, due to under-recognition and under treatment of pain (Morrison & Siu, 2000; Shega et al., 2007).

The role of primary care in long-term care for people with dementia at home is thought to involve provision of information, carer support, management of behavioural and psychological symptoms of dementia and the use of a structured case management approach (Frost, Walters, et al., 2020; Robinson et al., 2010). Healthcare professionals in this review supported adherence by simplifying daily routines. Physical barriers such as difficulties opening bottles due to arthritis could be overcome through introducing pill organisers, while cognitive barriers were helped by memory aids. Similar strategies, including timed tablet dispensers and timed cap for insulin pens, have been identified to maintain independence in early dementia (Fox & Kilvert, 2019).

Included studies described a shift in responsibility for self-management as dementia progressed, from full autonomy through carer support, to carers undertaking self-management activities on behalf of the person with dementia. This process has been previously described in a systematic review of self-care concepts (Matarese et al., 2018). Research has identified complex patterns of transition among carers in response to declining health and cognition (Ploeg, Northwood, et al., 2020). Transition theory highlights the complex and multi-dimensional transitions triggered as a result of changes in health and illness, including changes in relationships and environments (Meleis et al., 2000). Included studies in this review reported that safety concerns were of paramount importance to family carers and often precipitated the transition of responsibility for self-management. People living with dementia often experienced a loss of independence during this transition. Carers acknowledged the dilemma of balancing good physical healthcare when self-efficacy declines, with the importance of empowerment and respecting the wishes of the person living with dementia to be involved in their own care. Empowerment and engagement of people with dementia is a crucial element of person-centred dementia care in the community (Downs & Lord, 2017; Lord et al., 2019).

Models within the literature conceptualise self-management as a partnership between healthcare providers, family members and the individual themselves (Matarese et al., 2018). Healthcare professionals support the process of management by proxy through providing condition-specific education, information on medication, and symptom checklists. Healthcare professionals can usefully explore the values and beliefs of stakeholders, such as attitude to life, health and medication, to avoid a sense of reliance and overcome the belief that a good patient does not question professional advice. For progressive neurological conditions such as dementia, a more holistic approach to self-management support is required. However, in previous literature healthcare professionals cited cognitive impairment as a reason not to prioritise such support (Davies et al., 2018). Collaborative working between professionals is required to improve communication between services to achieve continuity of care, especially during the transition between primary care and the home (Grover & Joshi, 2015).

Family carers are often critical in supporting adherence to treatment and in recognising and managing long-term condition specific complications. Without an available carer, people with dementia are vulnerable to disjointed healthcare. Acknowledging interdependence, especially the importance of support from family carers in self-management (Manthorpe & Samsi, 2016; Smebye & Kirkevold, 2013). Identifying and supporting a paid carer to take this role where a family carer is unavailable is likely to be key to the wellbeing of people living with dementia and long-term conditions without regular family help.

4.4.2 Strengths and limitations

This is the first systematic review to focus on self-management of long-term conditions in dementia. Previous reviews have focused on one long-term condition (Santos et al., 2018), excluded nursing home populations (Bunn, Goodman, et al., 2017) or described the impact of cognitive impairment on long-term condition management rather than strategies to overcome this (Baird et al., 2017).

Most included studies were qualitative. This methodology is more likely to relate to the research question of this review, as strategies are more likely to be suggested using qualitative approaches (Alsaeed et al., 2016). This review conducted a systematic original search of relevant studies using pre-determined eligibility criteria without any limitation to residential status.

The generalisability of results are limited by the extent of study findings. Most included studies reported on hypertension, diabetes or general health and medication management. Generalisability of findings is also constrained by the inclusion of papers written in English only. The case studies and mixed methodology studies included were rated as lower quality than qualitative studies. The guidelines for the MMAT do not suggest excluding studies based on quality. However, this has implications for the conclusions of this review due to the quality of included papers, specifically the limited reporting of relevant information in lower quality studies. This was particularly apparent in studies reporting on people with dementia in assisted living facilities (Allen et al., 2017) and care homes (Yarnall et al., 2012) meaning their findings relating to the management of long-term conditions in dementia should be interpreted with caution.

Using a data-driven convergent synthesis enabled the inclusion of the results from quantitative studies in the synthesis for this review. Despite this, the themes from this review are primarily based on the findings of qualitative papers due to their higher quality and richness of relevant data.

4.4.3 Conclusions and implications for PhD

The findings of this review highlight the importance of collaboration between stakeholders in the management of long-term conditions in dementia, of developing an understanding of how the person's cognition may be influencing their self-care and adherence, and how they are supported by the care network that surrounds them.

In this first review of enabling and inhibiting factors for self-management of long-term conditions in dementia, I identified a number of gaps in the current research evidence that I planned to address in my PhD. Most studies interviewed family members of people with dementia and focused on medication management. I found limited evidence of how other stakeholders can support self-management, and for how self-management beyond adherence to oral medication is best supported. I therefore planned to explore in my subsequent studies how other stakeholders, including homecare workers, support long-term condition management in dementia. I also sought to explore a broad range of self-management activities, beyond the focus on self-medication of previous research.

In the next chapter, I describe how I conducted a secondary analysis of qualitative interviews, to explore how a range of stakeholders' experience and negotiate care for long-term conditions in dementia.

Chapter 5 Stream Two: Secondary analysis of qualitative interviews

In Chapter Five, I describe the methods and results of my secondary analysis of qualitative interview data from the New Interventions for Independence in Dementia Study (NIDUS). This analysis was not part of the original aims of the qualitative study in NIDUS which collected data to explore factors affecting independence at home in dementia. Through an analysis of these semi-structured interviews, I explored the experiences of people with dementia, family carers, health and social care professionals and homecare staff, to identify how the management of long-term conditions is best supported in dementia. This work has been published in BMJ Open (See Appendix 6) (Rees, Burton, et al., 2020).

This chapter begins with a rationale for why this secondary analysis was most appropriate for the aims of this stream of my PhD. I will then describe the methods used, my analytic approach and results before discussing implications of methodology for my multi-data qualitative study, which I then present in Chapter Six.

5.1 Rationale

As described in Chapter Two, researchers have highlighted the need for guidance on how to tailor and individualise care for long-term conditions in the context of dementia (Baird et al., 2019; Bunn, Goodman, et al., 2017). Clinical guidelines tend to focus on single conditions and thus may not reflect the difficulties in management of multiple long-term conditions (Guthrie et al., 2012; Mutasingwa et al., 2011). The first step towards the development of relevant clinical guidelines involves an understanding of the physical health care needs of people with dementia (Welsh, 2019), including how long-term conditions interact with each other and impact a person’s ability to self-manage (Subramaniam, 2019). I therefore decided to conduct a qualitative investigation to understand the lived experienced of stakeholders in supporting the management of long-term conditions in dementia.

My systematic review of the literature, described in Chapter Four, highlighted limited evidence about how stakeholders other than family carers, such as homecare workers, can support the management of long-term conditions in dementia. Through access to a large qualitative dataset collected during the NIDUS programme, I had an opportunity to consider experiences from a broad range of stakeholders, including health and social care professionals and homecare managers and staff. Additionally, I describe in Chapter Four the limited literature on aspects of self-management broader than adherence to oral medication. I used the breadth of experience captured in the large NIDUS qualitative dataset to seek to address this gap.

The NIDUS qualitative dataset was originally collected to explore the views of stakeholders on how to maintain independence at home for people with dementia. Based on the literature presented in Chapter Two, I conceptualised good quality management of long-term conditions as an important determinant of independence for people with dementia living in the community.

5.1.1 Aims

In this secondary analysis of interviews with people with dementia, family carers, health and social care professionals and homecare staff, my objectives were:

1. To explore how the management of long-term conditions is experienced and negotiated by people with dementia and their carers.
2. To analyse a range of perspectives in stakeholder experiences to understand how the management of long-term conditions in dementia is best supported.

5.2 Data collection

5.2.1 NIDUS programme

NIDUS began in March 2018 funded by the Alzheimer's Society Centre of Excellence grant [330]. The five-year research programme aimed to develop and test evidence-based training and support programmes to provide high quality care for people with dementia. To inform subsequent work, the NIDUS team conducted qualitative, semi-structured interviews with people with dementia, family carers, health and social care professionals and homecare staff. The primary analysis of this qualitative data explored how people with dementia can be supported to live as independently as possible in their own homes (Rapaport, Burton, Leverton, et al., 2020), including a separate analysis on the experiences of South Asian family carers (Herat-Gunaratne et al., 2020). The findings from this work have been used to co-produce: a manualised intervention programme tailored to personalised goals of people with dementia and their family carers (NIDUS-family), and a training programme for homecare workers to increase skills in supporting people with dementia at home (NIDUS-professionals). A module on manging physical health has been developed and is being tested as part of the NIDUS-family intervention. Feasibility of both interventions are being tested in pragmatic trial and a randomised feasibility trial respectively (Rapaport, Burton, Palomo, et al., 2020).

In the next section I describe the recruitment and procedure for interviews undertaken as part of the NIDUS programme. As referenced in my statement of contribution at the beginning of this thesis, I was not involved in the data collection or primary analysis of qualitative interviews. I then outline details of my original analytic approach in section 5.3.

5.2.2 Recruitment

London (Camden and Kings Cross) Research Ethics Committee approved stream one of NIDUS in November 2017 (reference: 17/LO/1713). People with dementia and family carers were approached by staff working in three UK NHS memory services and private home care services. Participants could also respond directly to the research team via social media advertisements on Twitter. The Alzheimer’s Society Experts by Experience group were approached to participate and circulated information to their networks. People with dementia were eligible to participate if they had a documented diagnosis of dementia of any severity and lived in their own home. Family carers were eligible to participate if they were in regular (at least weekly) contact with the person with dementia.

People with dementia considered to have capacity and family carers were contacted by the researcher at least 24 hours after being sent the study information to answer any questions and to arrange an appointment to take informed consent. Recruitment included people with dementia considered by the research team to not have capacity to consent for themselves. In such cases, recruiting services approached a family carer with study information who would than act as personal consultee. If no personal consultee could be identified, then a professional consultee would advise on the preferences of the person with dementia without capacity on study participation. The research team abided by the Mental Capacity Act of England and Wales (2005).

Health and social care professionals were recruited through NHS memory services, social services and clinical academics with links to University College London (UCL). For the homecare staff interviews, ten homecare agencies were recruited across England and managers, office support staff and homecare workers were invited to participate. Managers of participating memory clinics and homecare agencies were contacted and asked to circulate study information to their teams. Clinical academics at UCL also approached health professionals directly. A researcher contacted participants after 24 hours of sending out the study information to determine whether they would like to proceed. Health and social care professionals were eligible to participate if they were involved in the commissioning or provision of home care for people with dementia. Homecare staff were eligible to participate if they worked as ‘hands-on’ carers within participating homecare agencies. Managers of homecare agencies were also eligible to participate.

Purposive sampling was used to ensure cultural, socioeconomic, and geographic diversity. People with dementia were purposively selected for age, gender, ethnicity, physical disability and use of homecare services. In addition to the aforementioned factors, family carers were recruited based on diversity of their relationship to care recipients. Health and social care professionals were purposively selected for diversity in age, gender, ethnicity, professional role, and experiences with supporting people with dementia.

5.2.3 Procedure

Participants were invited to take part in a single semi-structured qualitative interview between April and September 2018. All participants gave written informed consent. Interviews lasted on average one hour and were conducted in participants' homes, workplaces or at University offices depending on participant preference. Interviews followed a semi-structured topic guide which explored how people with dementia live independently at home and what support they need to do so. They were audio-recorded then transcribed verbatim and anonymised by an external transcription company. A token payment of £20 was offered to acknowledge participants time or to reimburse homecare agency time taken to participate in the study.

Interviews were conducted by a team of researchers with experience of working in dementia. Following the collection of demographic information, researchers used a semi-structured topic guide to explore how people with dementia live independently at home and what support they need to do so. The topic guide was co-produced with experts by experience and was designed to explore goals and priorities for people with dementia and family carers, explore the meaning of independence, and elicit feedback on the content, structure and implementation of the planned NIDUS interventions.

I reviewed each topic guide prior to ethical approval to ensure prompts for information about long-term conditions were included. Across stakeholders, slightly amended versions of the topic guide were used. The topic guide for people with dementia and family carers included specific questions about how long-term physical or mental health conditions affected the person with dementia's ability to remain living independently at home. Topic guides for health and social care professionals, and homecare staff did not directly ask about physical health. However, all interviews included a list of goals and priorities including 'getting the right medical treatment for other physical or mental conditions' that was presented to participants for discussion. Full topic guides for all participants are available in Appendix 7.

5.3 Analytic approach

Secondary analysis involves using pre-existing qualitative data collected from previous research studies to investigate new or additional research questions (Heaton, 2008, 2021). Within qualitative research, secondary analysis approaches have grown in acceptance as a means of using data collected from past research projects to gain additional insights (Bishop & Kuula-Lummi, 2017). To establish the suitability of this analytic approach, firstly I considered the ethical implications of secondary analysis on the NIDUS dataset (Long-Sutehall et al., 2010). Issues around consent have been identified as an important consideration when deciding on secondary analysis (Yardley et al., 2014). As outlined in section 5.2, all participants involved in NIDUS qualitative interviews provided informed consent. Although not the main component of interviews, participants were explicitly asked about and did provide information on long-term conditions during primary data collection due to the impact of physical health on independence. Thus, I considered further exploration of the content of interviews relating to long-term conditions to be in line with the study parameters consented to by participants.

Lastly, I considered the nature of the primary dataset such as: the quality of the data to answer secondary research questions and context of the primary dataset (Long-Sutehall et al., 2010; Thorne, 2013). To establish whether the NIDUS dataset contained sufficient information on the management of long-term conditions for people living at home with dementia, I liaised directly with members of the research team who conducted the interviews. Researchers involved in data collection confirmed that content relating to long-term conditions were present in each stakeholder group. I outlined the context of the NIDUS dataset in section 5.2 and I considered the use of qualitative methodologies adequate for the aims of my secondary analysis. Researchers have used the NIDUS dataset to explore emerging questions from the original analysis, such as the experiences of South-Asian carers (Herat-Gunaratne et al., 2020). Similar to this ‘analytic expansion’ (Thorne, 2013) I considered the use of secondary analysis suitable to explore new perspectives on the management of long-term conditions in dementia.

5.4 Data analysis

In this section, I outline how I followed the stages of a thematic approach to reach my analytic findings (Braun & Clarke, 2006, 2019, 2021).

5.4.1 Familiarisation with dataset

I began with familiarising myself with the original dataset. This involved reading transcripts for each stakeholder group. I also listened to audio-recordings of transcripts to immerse myself in the data. I began with health and social care professionals, before reading transcripts for people with dementia, family carers, and finally homecare agency managers and staff. During this process, I highlighted information in transcripts relating specifically to long-term conditions in addition to dementia. No stakeholder group had precedence, yet I iteratively considered how information of interest were represented in preceding stakeholder groups. Decisions around relevant information was decided by consensus with my supervisory team. I included information relating to enduring mental health problems such as chronic depression and schizophrenia if they pre-existed dementia diagnosis. I included information on medication for long-term conditions and excluded any information relating to dementia medication management. I included lifestyle factors such as nutrition, fluid intake and mobility due to its impact on physical health.

I made notes of content related to long-term conditions for each participant in an excel sheet. As I had not conducted the interviews myself, familiarisation with the data was an important step. To do this, I discussed my perceptions of the data with researchers involved in the original data collection. This enabled me to bring inside knowledge of context during analysis to overcome the problem of ‘not having been there’ (Heaton, 2008).

5.4.2 Coding

I uploaded all transcripts onto NVivo 12 software (QSR International Pty, 2018). I then began to generate succinct labels for relevant sections of transcripts related to participant experiences of long-term conditions in dementia. I used an inductive approach where I focused on meaning within the data to develop codes which capture interesting sections of data related to the research question. I wanted to use a data driven approach to develop new ideas and understanding of the experiences of people with dementia and long-term conditions.

I allocated each supervisor (CC, KW, AB) one transcript per stakeholder to read (n=4). We independently and systematically labelled codes based on meaningful fragments of transcripts and met to agree on re-occurring codes. I then applied the coding framework to all transcripts. During coding, I noticed how health and social care professionals and homecare staff spoke more generally about long-term conditions compared to people with dementia and their family carer. I reflected on how I would have been able to prompt further with these stakeholders to gather information about the management of long-term conditions had I conducted the interviews myself.

5.4.3 Generating initial themes

I developed a coding framework based on line-by-line coding of highlighted sections of transcripts from each stakeholder (presented in Appendix 8). To do this, I grouped codes into categories based on broader patterns of meaning. I reviewed and refined the coding framework by discussing ideas for themes corresponding to the research question with members of my supervisory panel.

I began analysis on transcripts shortly after completing my systematic review of the literature. At times I noticed a bias in terms of my own attention towards familiar or previously identified themes. I reflected on this with my supervisors and made memo notes on concepts that I identified as similar to my systematic review. I found memo writing during my analysis helpful to remind myself of the general content of interviews as it was conducted over the first and second years of my PhD, and also due to the broad range of stakeholders.

5.4.4 Reviewing and developing themes

I revisited codes looking at commonalities and differences in managing long-term conditions across accounts of all stakeholders. I compared data within and across codes to further refine the central organising concept of themes. I then merged or renamed codes to ensure they were consistent with developing themes and created sub-codes within themes where relevant. I looked for distinction within themes, recoding where needed and considering the research question. I created definitions of themes, which were descriptive at first then developed to be analytical throughout the iterative analysis process and through discussions with my supervisory team. To facilitate the understanding of shared meaning within themes, I created mind maps to show the interactions between codes and themes.

5.4.5 Defining and naming themes

I used supervisory discussion to further define and name themes. I created a table which included descriptions of each theme and sub-theme, in addition to key findings of each theme. This was then presented to my supervisors who challenged and discussed the central concept underlying each theme. The names of themes, and placements of sub-themes, were iterated over time to reflect ongoing interpretation.

5.4.6 Writing up

This final stage further facilitated the development and naming of themes. I wrote up draft sections of results which included descriptions of themes evidenced by participant quotes. During this stage I merged sub-themes based on organising concepts, and re-named themes based on refined definitions. The results presented in section 5.5 reflect the core themes evident throughout analysis which involved collaboration of stakeholders (support provided, responsibilities), self-management roles (communication, decision making) and holistic care (physical and mental health).

5.4.7 Reflexivity

As described in section 5.2, interviews for the NIDUS dataset were collected by researchers prior to the beginning of my PhD. Therefore, I can only retrospectively consider the influence of researchers on the data collection process. I acknowledge my positionality as a young, white, female, PhD student and I consider my personal and academic biography to be reflective of the researchers involved in data collection. Despite this, I am unable to assume the perceptions and beliefs of the researchers involved in data collection.

For stream two, my reflexivity focuses on my influence on the analytic process. During analysis I considered how factors such as ethnicity and gender might intersect with themes. While I have no personal experience with chronic disease, I have a background in health psychology with an interest in chronic disease research. I acknowledge how these factors may have impacted my interpretation of findings. My use of secondary analysis meant I had no relationships with the participants and thus no preconceptions from data collection during the analytic process.

5.5 Results

5.5.1 Participant demographics

In total, 82 qualitative interviews were conducted as part of the NIDUS programme with 11 people with dementia (Mean Age= 78.6, SD=7.8), 22 family carers (Mean age= 57.7, SD= 14.3), 19 health and social care professionals (Mean Age= 41.4, SD= 10.9) and 30 homecare staff (Mean Age= 48.3, SD=11.6). To respond to the needs and preferences of participants, eight interviews were dyadic involving people with dementia and family carers together. Details of participant characteristics are presented in Table 5.1 and Table 5.2.

Table 5.1. Characteristics of people with dementia and family carers

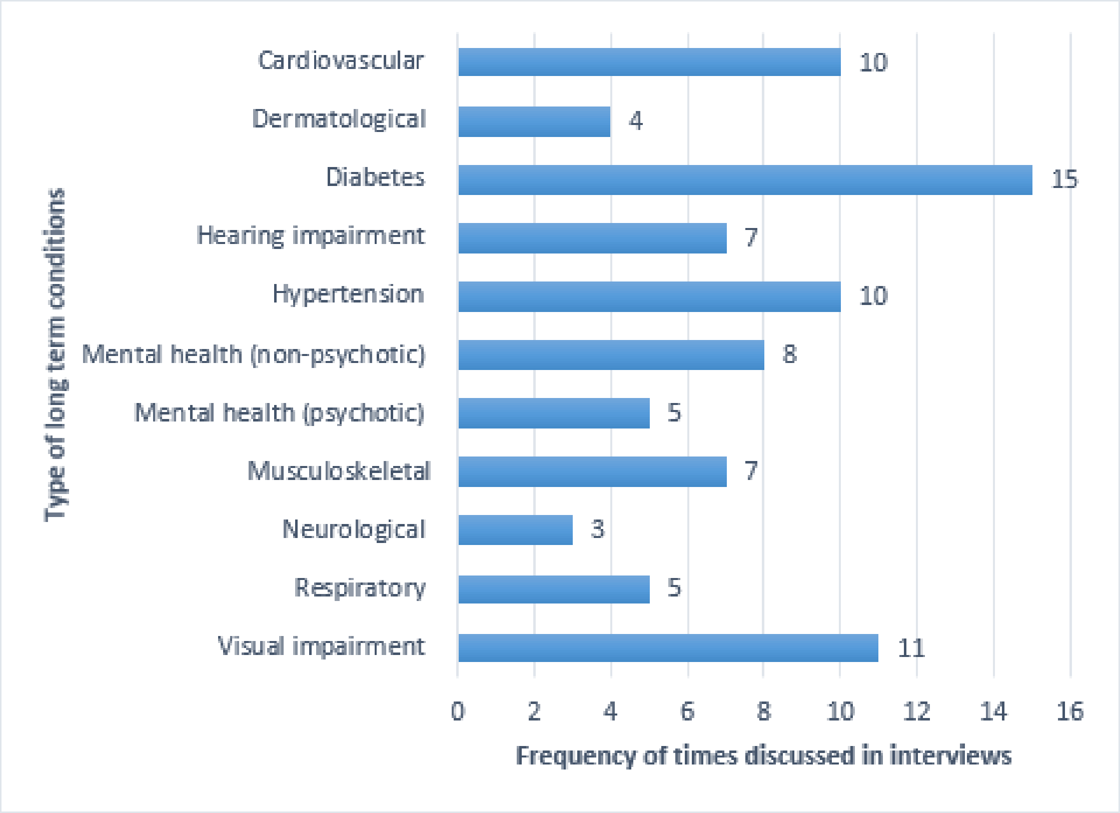
		Person with dementia	***Family carer***
Characteristics		***n***	***n***
Gender	Female	5	12
	Male	6	10
Ethnicity	White British	8	9
	White other	1	0
	Indian	0	6
	Bangladeshi	0	4
	Other	2	3
Living arrangements	Lives alone	5	7
	Lives with relatives	6	15
Type of dementia	Alzheimer's disease	3	8
	Vascular	2	4
	Other	2	4
	Not specified	4	6
Relation to person with dementia	Son/daughter	-	11
	Spouse	-	6
	Niece	-	2
	Friend	-	1
	Sibling	-	1
	Daughter in law	-	1

Table 5.2. Characteristics of professional carers

		Homecare staff	***Health and social care professional***
Characteristics		***n***	***n***
Gender	Female	25	13
	Male	5	6
Ethnicity	White British	22	9
	White other	2	5
	Black/Black British	5	0
	Asian/Asian British	1	0
	Indian	0	2
	Other	0	3
Professional role	Managerial	7	0
	Homecare worker	19	0
	Other Care Staff	4	0
	Commissioner	0	3
	Social worker	0	2
	Dementia lead	0	2
	Service manager	0	2
	Psychologist	0	2
	Support worker	0	2
	GP	0	2
	Geriatrician	0	1
	Nurse	0	1
	Physiotherapist	0	1
	Psychiatrist	0	1

All interviews conducted with family carers and nine interviews with people with dementia (82%) explicitly mentioned long-term conditions and support needs. Fourteen interviews with healthcare professionals (74%) and seventeen interviews homecare staff (57%) included information on specific long-term conditions, but they often spoke more generally about medication management and holistic aspects of health for example, falls and mobility. Figure 5.1 presents a full overview of reported long-term conditions by people with dementia, family carers, health and social care professionals and homecare staff.

Figure 5.1. Frequency of long-term conditions discussed



NB:

Category	Long-term condition
Cardiovascular	Heart problems Stroke
Dermatological	Eczema Psoriasis Dermatitis
Mental health	Anxiety and depression (non-psychotic) Psychosis and Schizophrenia (psychotic)
Musculoskeletal	Arthritis Osteoporosis
Neurological	Epilepsy Parkinson's
Respiratory	Asthma Pulmonary fibrosis Chronic obstructive pulmonary disease

5.5.2 Themes

I identified three main themes that responded to my research objectives to explore how people with dementia, family carers, healthcare professionals and homecare staff experience and negotiate the management of long-term conditions in dementia. These were: 1) The process of substituting self-management (1a: Autonomy verses risk, 1b: Prescriptions and role restrictions), 2) Communication in the care network, and 3) Impact on and from dementia when managing physical health (3a: Interrelatedness of cognition on physical health, 3a: Limitations of physical health treatments in people with dementia).

Theme 1. The process of substituting self-management

Sub-theme 1: Autonomy verses risk

People with dementia valued autonomy when managing their physical health. In the earlier stages of dementia, prompting enabled self-management and a sense of ‘still carrying on’, with a greater degree of dependence required as dementia became more advanced.

> *“It depends what issues they have, what they struggle with. Because some people can live well with dementia for years and years and years. And might not need family or anything until very much the end of their dementia. And where a bit they are maybe at risk because of memory issues, not going to appointments, not taking their tablets, not eating, not drinking, etc.” (Allied Health Professional 1)*

The prospect of requiring more help was a concern to this person living with dementia suggesting how multiple long-term conditions in dementia can heighten fears of dependence due to increased risk.

> *“You see I’m praying and I’m hoping that I won't need carers because I want to rely on myself. But I know at some stage I won't be able to. I don’t know when. Maybe my health will get worse, physically worse, and this dementia will get worse and I will have to.” (Person with Dementia 1, Arthritis and hypertension)*

Accepting support felt more agreeable to people with dementia when the decision was made autonomously. For example, one participant accepted home deliveries from the pharmacist when mobility issues prevented prescription collection.

> "*I did tell my pharmacist now, when it's windy, I won't go out so much. So I said to her now, I'm going to let you bring all my medicine and medication to the door*." *(Person with Dementia 2, Thyroid, Hypertension, Dermatitis)*

Homecare workers acknowledged the wishes of people with dementia to retain decision making control where possible and to be involved in their own care.

> *"I say every time, this is for your memory, this is your thyroid, this is for your Addison's, this is for your blood pressure… And they say, oh thank God you told me because what you're doing is you're controlling them if you don't involve them." (Homecare Worker 1)*

Family carers balanced the wishes of people living with dementia to retain autonomy as far as possible with the potential consequences of lower adherence to medical treatment. Family carers described their discomfort in providing care against the wishes of the person with dementia but acknowledged the importance of such tasks when memory impeded medication administration.

> *"He then lost his eyesight in the left eye, due to the diabetes medication being missed. He was reporting to my mother daily that he is consuming his medication. Of course, because of the dementia, his memory was deceiving him and telling him that he had done it, but this was a past memory." (Family Carer 1, Son)*

Sub-theme 2: Prescriptions and role restrictions

Monitoring or administering medication was the most frequently discussed form of support for long-term condition management. While self-administration of medication is a routine part of long-term condition management, when a person with dementia required support of another person, this role occupied an intermediate position between a personal care activity, and a medical task that required a nursing qualification. Rules around who administered medication could be complex and confusing.

> *“Although we were told that the [home]carers are not allowed to medicate, because they’re not insured. So, that’s a difficult one.” (Family Carer 2, Son)*

One healthcare professional described the difficulties that could arise because of this when prescriptions changed.

> *“It falls through when they’re on, say steroids, like emergency steroids if they’ve got COPD or if they’re on antibiotics for infection. Where the person with dementia will get really poorly because they’re in boxes and [home]carers can’t give out boxes, it has to be in a nomad [pre-packed medication].” (Community Mental Health Nurse)*

Theme 2. Communication in the care network

In healthcare settings, it was often the family carer who communicated with services and made decisions about how to implement medical advice. Being an implementer of medical advice but not the doctor, and the recipient of advice but not the patient, sometimes felt like a dilemma for family carers working in partnership with people with dementia.

> *“.... I suppose at the end of the day I should go down and make an appointment to see the GP…. to tell them that I feel she needs that done…. but I don't want to go down and sort of feel that I'm…. telling them what to do, coming heavy-handed on it either.” (Family Carer 3, Sister)*
>
> *“…and he’s been diagnosed with COPD. Essentially what I understand of it, I'm not a medical professional, but his lungs are slowly, slowly shrinking, and the capacity to retain air is reducing. So he has to ensure that he is constantly taking steroid pumps to allow him to breathe normally. Now, you can imagine how imperative it is to make sure that this medication is administered” (Family Carer 1, Son).*

Family carers experienced additional challenges in communication when developed relationships with primary care came to an end, as a change in practitioner impacted continuity of care.

> *"You know you rely on good relations don't you, with the GP and now being the person we dealt with has gone away and knew us and understood us and that. It's like starting all over again really." (Family carer 3, Sister).*

Where people with dementia experienced difficulties with communication, family carers offered support in healthcare appointments to ensure correct reporting of symptoms.

> *"…she would tell them things that were factually incorrect and they would believe that they were correct. Because they just thought she might be a bit old and her literacy wasn't great…But she was on drugs that were negatively affecting her …she was on something that were actually negative to her heart." (Family Carer 4, Son)*

Regardless of the presence of a proxy, participants with dementia highlighted the importance of continued acknowledgement within appointments.

> *"I think that's the problem, some people, because you've got diagnosed with it they think, oh he can't digest this, we'll talk to the relative." (Person with Dementia 3, Visual Impairment)*

In situations where family carers or homecare workers were not substituting self-management, it could be challenging for GPs to identify changes in self-management and decide when to intervene.

> *"But I'm not quite sure that the mechanisms are very good for picking up on that, you know, the bit where they're in between, where they're potentially sort of just well enough to go out and about, and do things for themselves, but maybe things at home aren't good and they're not coping, and actually, as a GP, maybe it's really difficult to pick up on that." (General Practitioner 1)*

Theme 3. Impact on and from dementia when managing physical health

Sub-theme 1: Inter-relatedness of cognition and physical health

As the outcomes associated with physical health and cognition were found to be inter-related, healthcare professionals sought to optimise physical and preventative healthcare in ways that improved cognition.

> *"Yes, so, I think, you know, the physical health of someone has a really big impact on how they're dementia... they experience their dementia. So, they might just have a really poor diet which means that... or they might not be able to manage their diabetes and therefore they're feeling rubbish all the time." (Memory Service Manager)*

> *"Physical problems as well. You know? Because they have, not only possible dementia, but they also may have physical illnesses. Parkinson's, stroke, any sort of medical condition, as well, on top. So, we don't just concentrate on the dementia. We concentrate on the person. And it's a very much a holistic approach." (Occupational Therapist)*

Sub-theme 2: Limitations of physical health treatments in people with dementia

Some treatments prescribed for long-term conditions were considered to be unhelpful for people with dementia, for example because the strategies they used depended on memory and could not or had not been adapted to the context of dementia. In this next quote, a family carer explains how a person with dementia was too impaired to benefit from suggested strategies.

> *"Well, she did have a visit from an occupational therapist [following a stroke]. They arranged that for a few weeks but he, it was when she was at her most florid time and he was recommending that she did things like writing a list down of things that interested her and what she would like to do and things like that. But she wouldn't do any of those. And he said, you know, he came about four or five times, no point in me coming because she doesn't take any notice of what I say, or do anything." (Family Carer 3, Sister)*

Healthcare professionals and homecare workers sometimes felt that family carers were unable to accept that available treatments may not be helpful to people with dementia. They reported that this sometimes led to the continuation of treatments of questionable benefit, even when it went against the preferences of the person with dementia receiving them.

> *"I suppose family members are sometimes trying to keep people as they would see them, well and physically well for as long as possible and doing these things that their diabetes or anything else,*

> *and so they'll want them to do certain things whereas that's no longer what is important to that person." (General Practitioner 2)*

> *"I have a lady that's quite old and her mother, she wants the physio in and it's just not possible. She physically can't do it, but she thinks it'll keep her strong a little bit. And it's really not doing her any good, even the physio said that. But the daughter wants it." (Homecare Worker 2)*

The above quotes highlight how the perspective of people living with dementia can be lost when determining the benefits of treatment. Family carers appear to adopt an 'all or nothing' approach to physical health decision making due to the lack of flexible interventions which successfully account for dementia.

At other times, family carers and professionals discussed and agreed approaches in collaboration with people with dementia. One family carer described how this was helpful where difficult, end of life decisions, balancing comfort with quality of life, needed to be taken.

> *"Kidney is only about 6% working. So because of that, you know... And we've decided not to go on dialysis. Not just we, but the specialist kidney doctor, we went to see him a couple of months ago and he suggested as well not to put him on dialysis because of his age…And he didn't think it was going to be beneficial to him..." (Family Carer 5, Daughter)*

5.6 Discussion

5.6.1 Main findings

In my analysis of the experiences of a broad range of stakeholders, I sought to understand how the management of long-term conditions is experienced and negotiated for people with dementia. This analysis found that the process of substituting self-management (theme 1) evolves with advancement of dementia symptoms and relies on communication in the care network (theme 2), whilst considering the impact on and from dementia (theme 3) to achieve holistic physical health management.

The first theme focused on the transition of roles which occurred in relation to advancement of dementia symptoms, with support increasing in accordance with level of need. Substituting self-management, especially medication, presented conflicts for family carers and homecare staff, to balance involving people with dementia in their care with safety concerns. The second theme identified communication as a key concept in the management of long-term conditions in dementia. Partnership working between people with dementia and family carers sought to overcome communication difficulties as a result of dementia. Without a family carer, changes in an individual’s ability to self-manage may be difficult for health professionals to detect, especially when people with dementia infrequently accessed primary care. The final theme highlighted the inter-relatedness of cognition and physical health and the importance of adapting physical healthcare to the context of dementia. Best interest decision making is likely to be improved with increased awareness of likely harms and benefits of treatment based on evidence such as age and stage of dementia. Cardiovascular conditions and diabetes were the most commonly reported long-term conditions and medication was the most discussed self-management activity.

Addressing the research gap recently identified in the field of dementia and multiple long-term conditions, these findings describe the interacting effects between cognition and physical health and provide an understanding of the care needs of this population (Subramaniam, 2019; Welsh, 2019). In dementia care, family carers often experienced a role transition from a ‘care-partner’ (who provides assistance to a person who continues to manage much of their own care themselves) to ‘care-giver’ (who provides care) with increasing disability (Lazaroff et al., 2013). My analysis demonstrates the critical role of family carers in communicating with primary care (Health Education England, 2018). In addition to impacting memory, judgment and orientation, the impact of dementia on language skills has previously been identified as a barrier to reporting symptoms in healthcare appointments (Ibrahim et al., 2017). Relevant theoretical models of independence at home in dementia suggest that professionals should also be viewed as partners, rather than experts, when supporting self-management (Lord et al., 2019). Models of care must acknowledge feelings, foster dignity, and treat patients (and carers) as active participants in care (Fox & Kilvert, 2019). The integrated logic of care model suggests that psychosocial and physical needs have a great influence on each other, and should therefore be addressed simultaneously (Hansen et al., 2017). Through highlighting their interconnectedness, my analysis suggests how physical health and cognition should also be addressed simultaneously. as opposed to care being organised around physical need. My findings also suggest that due to the limitations of physical health treatments, dementia care may be more aligned with ‘renouncement logic’ where physical need is prioritised over psychosocial need.

One of the main self-management tasks across long-term conditions is medication adherence (Ibrahim et al., 2017; Lorig & Holman, 2003). Similar to the findings of Rapaport et al (2020), my analysis highlights the role of homecare workers in adopting a facilitative approach, specifically ‘doing with not for’ during medication management. The need for both family carers and homecare workers to prevent harm often conflicts with the desire of a person with dementia to remain autonomous (Smebye et al., 2016). The balancing of roles is complex for homecare worker especially involving boundaries between advocating for independence and the implementation of medical advice (Leverton et al., 2019). My findings demonstrate this dilemma extends to the management of long-term conditions in dementia.

One of the five core self-management skills is decision making (Lorig & Holman, 2003) impacted by dementia due to impairments in executive functioning (Ibrahim et al., 2017). Non-dementia health decisions, such as end of life care, has previously been identified as a problematic decision making area for family carers (Livingston et al., 2010). In this context, care decisions involving all stakeholders require a focus on quality of life over a target-driven approach (Bunn, Goodman, et al., 2017) which is continuously re-assessed according to changes in disease state (Baird et al., 2019). People with dementia and carers often have different goals and priorities for care (Rapaport, Burton, Leverton, et al., 2020; Rapaport, Burton, Palomo, et al., 2020). Judging at which point a person loses capacity to refuse care, and when to intervene in their best interests can be challenging. Research has indicated the need for professionals to facilitate conversations around the decision to move to care homes (Lord et al., 2016). My findings related to decision making in collaboration with all stakeholders suggest how support from healthcare professionals may also be beneficial for family carers during proxy-decision making for physical health needs. Recent research into end of life decision making in dementia encouraged the continued revisitation of decisions with healthcare professionals to support changing needs (Davies et al., 2021).

5.6.2 Strengths and limitations

This is the first qualitative analysis to consider how people with dementia can be best supported to manage long-term conditions from the perspective of all stakeholders. Specifically, I expanded on previous research by considering the role of the homecare worker in the care network, previously described in the literature as a triad between the person with dementia, their family carers, and healthcare professionals (Bunn et al., 2016; Fortinsky, 2001). My analysis included interviews from a large and varied sample of multidisciplinary health and social care professionals. Participants in the original study came from a range of locations across the UK, however this limited my analysis to the context of English health and social care.

I used a secondary analysis to explore sections of transcripts that discuss long-term conditions in dementia. A limitation of this analytic approach is that the data was originally collected to explore how to support independence at home in dementia. I was aware that interviewers conceptualised independence in dementia to include physical health. However, as I had no involvement in data collection I was unable to prompt in-depth on topics related to my research question. I was able to review each topic guide prior to ethical approval and ensure prompts for long-term conditions were included. Nevertheless, I had no way to ensure such prompts were used by the researcher conducting the interview. To overcome this limitation, I familiarised myself with the context of interviews through listening to audio-recordings. I was able to reflect on my interpretation of interviews with the researchers involved in data collection whom I worked closely with in an office environment.

Participants spontaneously discussed experiences of long-term conditions due to their salience, enabling further exploration in this analysis. All family carers explicitly discussed the management of long-term conditions, which may account for large representation from this stakeholder group in the analysis, while people with dementia, healthcare professionals and homecare staff discussed more general topics of medication management and physical health. Two researchers involved in the original data collection (AB, PR) were involved in the analytic process and checked for consistency with original codes to ensure dependability of findings (Lincoln & Guba, 1985).

5.6.3 Conclusions and implications for PhD

My findings highlight that management of long-term conditions in dementia exists on a continuum with support usually increasing in intensity with increasing severity of dementia. To best support people with dementia to manage long-term conditions, stakeholders described in interviews how treatments should be congruent to need and consider the impact of dementia on engagement. Findings highlighted the importance that clinicians consider the impact of dementia on language skills and communication ability, and work with family carers acting in dyadic care relationships with people with dementia. Greater consideration of how healthcare professionals communicate the limitations of treatments that are not in the best interest or of questionable benefit to people with dementia and family carers might improve physical health decision making. Such discussions are often complex. Involving various stakeholders and ensuring the perspective of people with dementia is heard when deciding on treatment benefits can be challenging. Service development must identify mechanisms for detecting change in self-management ability when family carer or homecare workers are not involved in supporting self-management at home for example, alerts for appointment non-attendance and medication under-utilisation.

In this chapter, I analysed a large qualitative dataset to consider a breadth of experiences in managing long-term conditions in dementia. While these interviews are a rich source of information regarding what stakeholder consider the priorities are for care delivery, few studies have explored in-depth the experiences of people with dementia and long-term conditions. In the next chapter, I describe how I used multiple qualitative data sources to explore experiences of managing long-term conditions in greater depth.

Chapter 6 Stream Three: Methods

In Chapter Six, I describe the methodology for a multi-data qualitative study exploring how dementia care networks provide and support care for long-term conditions. Due to COVID-19, I adapted the study to be conducted remotely and used longitudinal telephone or video-call interviews with people with dementia, their family carers and healthcare professionals. I carried out a complementary document analysis of primary care records of participants living with dementia, who I also invited to complete event-based diaries if they were able. In this chapter, I outline the rationale for this study, then I review the literature for remote data collection which informed my study design before presenting the methodology used.

6.1 Rationale

I used multiple qualitative data sources to develop an in-depth understanding of the management of long-term conditions for people with dementia. Streams one and two of my PhD highlighted the importance of collaboration between people with dementia, family carers, healthcare professionals and homecare workers in supporting the management of long-term conditions. Therefore, I conceived the idea for this study and developed the protocol to explore how care is provided by primary care, and how people with dementia are supported by care networks to implement care recommendations in the community. I defined a care network as a person with dementia and their support network which included, but was not limited to, family members, homecare workers, and/or health and social care professionals. By taking an idiographic approach I was able to explore the diversity of each care network and build on the findings from stream two of my PhD.

6.1.1 Remote data collection

I used remote methods of data collection, which involves studying people and communities while not co-located using telephone or online methods. One example is the use of video-calling technologies, such as Skype or WhatsApp, to conduct interview research (Deakin & Wakefield, 2014; Hanna & Mwale, 2021). Video interviewing enables the researcher to interpret non-verbal cues (Sullivan, 2013). Conducting interview via telephone can overcome any technology related barriers associated with video software yet limits visual cues from participants (Saarijärvi & Bratt, 2021). Video and telephone interviews are both synchronous communication in time thus provide an experience similar to a face-to-face interview. However, people with dementia may find the required technologies confusing and the formation of relationships remotely challenging (Hellström et al., 2007). Despite cost and time benefits of remote methodologies, face-to-face interviews were generally preferred pre-pandemic. In section 6.8, I outline the remote data collection methods used for this study as a result of the COVID-19 pandemic.

6.1.1 Triangulating data sources

Collection of data from multiple sources enables triangulation, or the comparison of different data sources (Roper & Shapira, 2000). For stream three of my PhD, I combined interview data with document analysis, each producing different knowledge to answer my research questions (Flick, 2007). This is defined at methodological triangulation (Denzin, 1978). The triangulation of multiple data sources can improve validity by expanding understanding of health and social issues (Farmer et al., 2006; Mays & Pope, 2000).

Adopting a triangulated approach to combine multiple qualitative method has previously been used in dementia research. Researchers have used observations, interviews and analysis of case notes and patient care records to explore the treatment and support experiences of people with dementia and cancer in outpatient settings (Farrington et al., 2022), and factors influencing decision making when people with dementia access emergency services (Voss et al., 2020). In the latter study two levels of data analysis were employed, firstly analysing each data source independently before triangulating data sources to explore similarities and differences.

When developing the methodology for stream three of my PhD, I drew learnings from the BOUGH study (Broadening our Understanding of Good Homecare) where data sources such as participant observation, diary completion, interviews, surveys and document review were used to understand homecare for people with dementia (Schneider et al., 2019). From this study I learnt how a variety of data sources can be used in combination to provide in-depth accounts from the participant.

6.1.1 Documentary analysis

For stream three of my PhD, I sought to include qualitative methods which enabled the involvement of people with dementia (Bond & Corner, 2001; McKillop & Wilkinson, 2016). Previous research has identified diaries as a useful data collection tool when observations are not practical (Jacelon & Imperio, 2005). The use of diaries has been adapted successfully in previous research involving people with dementia. One study used modified formats (either written, audio or photo) to enable participants to have control over the pace of data collection (Bartlett, 2012). Providing a variety of format options for participants to complete diaries has been previously used to overcome functional limitations of community dwelling adults with chronic disease (Jacelon & Imperio, 2005). In a study of family carers of people with dementia, diaries were useful in stimulating memory prior to interviews yet could be an additional source of stress for participants due to time commitments (Välimäki et al., 2007).

Unobtrusive methods of data collection, such as document analysis, can reduce biases associated with research compared to methods (such as interviews) which rely on information obtained directly from participants (Lee, 2020). I included analysis of consultation notes as a data source without the requirement for in-person contact which was not practically possible due to COVID-19. In section 6.2, I provide an overview of my original study design before outlining my COVID-19 contingency plan.

6.1.2 Aims

I aimed to triangulate participant accounts with primary care records, and to include the perspectives of people with dementia in research through field notes from video interviews and diary analysis. My specific objectives and associated research questions were:

- To explore how care for long-term conditions is provided in UK primary care to people with dementia, including the extent to which care for long-term conditions is tailored to account for dementia.
    - How is care for long-term conditions provided for people living with dementia?
- To understand how advice or information given in primary care including care plans and self-management activities are implemented in the community by people with dementia and other long-term conditions and those who support their care.
    - How do care networks support the management of long-term conditions in dementia?

As outlined in Chapter Three, additional objectives for this study unique to the context of COVID-19 included:

- To explore how care provision for long-term conditions in dementia were affected by the pandemic.
- To develop methodologies for remote research with people with dementia, in light of social distancing restrictions.

6.2 Study design

6.2.1 Face to face protocol

I originally planned to conduct participant observations with people with dementia both in healthcare settings (e.g. attending medical appointments, dementia annual reviews) and at home. Planned face-to-face observational protocols included a one-month period of familiarisation with up to two observations per participant with dementia, and a three-month period of observation (up to five visits per participant with dementia). As I would be associated with participants with dementia in primary care settings, and interacting with them within the community, I planned to adopt a participant-observational stance (Laurier, 2016). Within observations I planned to consider how health professionals, homecare workers, and family carers incorporated considerations of dementia into the formation and review of care plans and the implementation of recommendations for care and self-management activities.

During observations in general healthcare appointments and in the community, I planned to use unstructured field notes to record any action related to the management of long-term conditions for people with dementia and any support required. For care plan based consultations, I planned to use guided observational recording sheets based on NHS guidance for good dementia care planning (NHS, 2017). Separate to observations, I planned interviews (up to two per network) to ask about participants' knowledge of existing care plans, any health problems and self-management activities, who is involved in care and any upcoming appointments, any additional needs which arise and how these are managed and planned for. I intended for interviews to focus on aspects of care observed and explore participant reaction and perspective on events.

6.2.2 Remote study protocol

I outlined in section 2.11 the implications of the COVID-19 pandemic on the health and care of people with dementia. In this section I consider the implications of the pandemic on the conduct of my research. As a result of social distancing guidelines, I was required to develop a contingency plan and implement a remote study protocol throughout stream three of my PhD. The COVID-19 pandemic saw traditional fieldwork options disrupted and interaction in the 'virtual realm' becoming a requirement to continue with planned research (Krause et al., 2021). Transferring in-person methods such as interviews and participant observation to a remote format facilitated this move of fieldwork (Howlett, 2021). Learning from the collective move from face-to-face to virtual research is reflected in a crowdsourced document titled 'Doing Fieldwork in a Pandemic' (Lupton, 2020). The document collated measures to support researchers in re-designing studies to avoid in-person interactions while achieving similar outcomes. I drew on this document to adapt my face-to-face protocol to a remote study protocol in order to commence fieldwork.

I solicited feedback on my remote study protocol from experts by experience in the Primary Care and Population Health PPI group, and the UCL Qualitative Health Research Network. My remote study involved two complementary data collection methods. Firstly, qualitative semi-structured interviews (telephone or video-call) with participants, followed by a series of longitudinal follow-up interviews over four months. This approach of longitudinal interviews was designed to substitute, as far as possible, for participant observations. I sought to conduct video-interviews when possible and record observational field notes of dyadic interactions between participants living with dementia and those involved in their care. Secondly, I undertook document analysis of consultation notes and care plans provided by primary care, and of event-based diaries completed by participants with dementia.

6.3 Epistemological position

I adopted a post-positivist, or critical realist approach to my research. Critical realism is a philosophy of science developed by Roy Bhaskar as a challenge to positivism (reality can be empirically known) and interpretivism (reality is socially constructed) (Gorski, 2013). Namely, that ontology (the nature of reality) cannot be reduced to epistemology (the knowledge of reality) (Fletcher, 2016). This critique is known as the ‘epistemic fallacy’ (Bhaskar, 1979).

My data consisted of primary care records from consultation notes in addition to participant reflections on the provision of care and support in the community. As a middle point between positivism and social constructivism, I felt that approaching the data from a critical realist positioning would enable me to explain the relationship between natural and social sciences (Gorski, 2013). I also considered critical realism to align with the nature of my enquiry as previous researchers have highlighted how primary care occurs within a social reality (Sturgiss & Clark, 2020).

In line with this approach, I adopted the position that participant accounts reflected their underlying reality, yet this reality can never be fully apprehended as it is mediated by their own (and my) perceptions. From a participant perspective, I interpreted meaning from accounts to develop theories to understand causal mechanisms which generate events (Fletcher, 2016). I viewed my data sources as different reflections of participants realities and acknowledged how one data source (e.g. primary care records) told a different study to another data source (e.g. interviews).

Critical realism assumes that ‘reality’ is required to be interpreted and that this interpretation reflects possibilities rather than certainties (Willig, 2012). From a researcher perspective, I used critical examination of my own positionality (outlined in Chapter Seven) to understand my own influence in interpretating participant’s ‘realities.’ The importance of deep reflection and interpretation of data is consistent with the principles of reflexive thematic analysis (Braun & Clarke, 2019a). Consistent with critical realist approaches, I used theory in Chapter Nine to understand casual mechanisms for clinical implications to primary care.

6.4 Eligibility criteria

Participants were eligible to take part in the study if they had a documented diagnosis of dementia of any severity. Participants were required to have an additional, diagnosed long-term condition, defined as “the presence of more than one or multiple chronic long-term diseases or conditions, including both physical and mental diseases” in addition to dementia (Almirall & Fortin, 2013). I was specifically interested in conditions that require ongoing support from primary care or significant elements of self-management, and recruited purposively to include people with diabetes, asthma, COPD, arthritis, stroke and heart failure/disease. I excluded people with dementia who were receiving palliative care support and considered to be in the last six months of their lives, as end-of-life care was not the context of this study. Participants with dementia who lacked capacity to decide whether to take part were only included in the study if an appropriate person willing to act as personal or nominated consultee completed a Consultee Declaration Form, and if the person with dementia appeared to assent to participation. I discuss study involvement of people without capacity in section 6.7.

We asked participants with dementia (and capacity) for permission to contact family members who they identified as supporters. We included family carers who were identified as providing regular support (at least weekly contact) to the person with dementia to manage their health-related activities. This included medication and appointment management, medical device use and broader aspects of health such as exercise and nutrition. Participants with dementia and/or their family carers were then asked to identify health and/or social care professionals who supported the participant with dementia to self-manage, or the family carer to proxy self-manage, any co-occurring long-term conditions. Such stakeholders were deemed eligible if they were involved in the care of long-term conditions. No exclusions were applied to healthcare professionals, including support from memory services or secondary care if identified by participants with dementia and their carers as supportive of the management of long-term conditions. Family carers and healthcare professionals who lacked capacity to consent were not eligible to take part.

6.5 Recruitment

I used purposively sampling to ensure a diverse range of experience. I selected participants based on diversity with respect to the following characteristics: type of long-term condition(s), stage of dementia, age, gender, ethnicity, involvement of family carer and/or homecare workers. I iteratively reviewed the characteristics of participants involved in the study and adapted recruitment accordingly.

Due to recruitment freezes at NHS sites as a result of COVID-19, initial recruitment used public methods. I recruited by sharing a study poster (see Appendix 9) on social media (Twitter) inviting eligible people with dementia to contact me directly. I approached participants from a previous UCL dementia study (NIDUS feasibility trial) who had agreed to be contacted about involvement in future research. I also registered the study on Join Dementia Research (JDR), an online service which enables people with dementia and their carers to self-register their interest in participating in research. I emailed or telephoned eligible ‘research matches’ and sent them the study information using contact details provided on JDR, for either the volunteer (person with dementia) directly, or if indicated, a representative.

When permitted by the Health Research Authority (HRA), participants were approached through six general practices supported by NIHR Clinical Research Network (North Thames), specifically the Noclor research support service. Participating services imported a database search provided by Noclor then screened the list for eligible patients according to a GP research summary (see Appendix 10). Once the number of eligible patients had been confirmed, I sent manual mail out materials to the practice (freepost stamp inside a stamped envelope plus address stickers). Services then personalised the invitation letter with reply slip, completed labels with patient addresses, and printed the participant information sheet (see Appendix 11) and study poster before mailing to eligible patients. No participants were recruited through the initial mail out, so using contacts from my supervisors and support from Noclor, I recruited directly from two GP surgeries. Eligible patients were identified by the GP, presented with study information, and asked for permission to be contacted by the researcher.

I sought permission from people living with dementia (or family carers where people living with dementia lacked capacity to consent) to contact health and social care professionals who supported their care. I sent identified professionals the study invitation and information by email. Contact details for professionals were obtained through public websites or the information was forwarded on from general surgery emails. I sent a letter of invitation (see Appendix 12) by email to homecare agency managers before inviting homecare staff to participate in the study. Again, contact details for homecare agencies were available publicly, with information then being forwarded internally to the relevant person.

6.6 Consent

I telephoned potential participants to confirm eligibility and assess capacity, then sent them consent/consultee forms (via email or post). Participants were provided with a freepost envelope to return the form. If the form was not returned ahead of the first qualitative interview, I recorded verbal consent for participants in line with ethical approval. Professionals provided verbal consent only for interviews with a copy of the participant information sheet and consent form sent by email in advance.

Abiding by the Mental Capacity Act 2005, I included people with dementia who lacked capacity to decide to take part in the study. In such cases, family members were invited to act as personal consultee. My protocol and ethics approval included provisions for cases where no personal consultee was available, where a health or social care professional would be identified to act as nominated consultee. In cases where the person with dementia lacked capacity, I explained the process of being a personal consultee to relevant family members, and how this was separate to their own consent to participate in the study.

6.7 Ethical considerations

6.7.1 Ethical approval

London (Camden and Kings Cross) National Research Ethics Committee approved the study on the 2nd of April 2020 (reference: 20/LO/0288). Amendments for COVID-19 contingency plans were approved on the 30th of June 2020. Substantial amendments for the inclusion of a nominated consultee in cases where a personal consultee was not available were approved on the 6th of January 2021.

6.7.2 Safeguarding

During data collection, I used standard protocols developed within UCL Division of Psychiatry for reporting concerns about potential abuse or neglect. If a participant disclosed information which led me to believe a person with dementia or their carer was at significant risk, I would first discuss this with my primary supervisor (CC). If appropriate, I would then approach the participant to seek their consent for disclosure to their GP. If the risk was considered high or there was reason to believe harm was occurring, I would follow the standard protocol to do so without consent if it was refused.

6.7.3 Confidentiality

All information collected during the study was kept strictly confidential in accordance with the Data Protection Act (2018) and General Data Protection Regulation (2016). Each participant was assigned an identification number to pseudoanonymise data. Sensitive information from primary care records was redacted before being stored on password protected UCL computers. I used an encrypted audio-recorder for all interviews. Audio-recordings were deleted from the dictaphone when stored on UCL-password protected computers. Personal information from interviews and event-based diaries were redacted at the point of transcription. To enable follow up, contact details of participants were stored on a password protected Excel sheet. Access to study data was restricted to members of the research team.

6.8 Data collection

6.8.1 Demographic information

I collected demographic information from all participants, including age range and gender. For family carers, I collected marital status, employment, and living arrangements. In addition to this, for people with dementia, I collected information on the date dementia diagnosis was made, dementia subtype and any long-term conditions. For healthcare professionals and homecare workers, I recorded their role, professional qualifications and duration of employment. Based on information provided by the person with dementia, their family carers and their primary care records, I categorised stage of dementia using the Global Deterioration Scale for Assessment of Primary Degenerative Dementia (Reisberg et al., 1982).

6.8.2 Initial qualitative interview

An initial qualitative interview was organised with participants following consent procedures. Participants indicated their preferences for telephone (landline or mobile) or video interviews (Zoom, Microsoft Teams, WhatsApp video). I used a semi-structured topic guide which was amended for each participant type (See Appendix 13). The topic guide for people with dementia and/or their family carers focused on the person with dementia’s health history, how they manage their long-term conditions on a daily basis, members of their care network who support the management of long-term conditions, interactions with professionals including understanding of current care plans, and a general discussion on the impact of COVID-19 on the management of health.

For interviews with healthcare professionals, topic guides focused on their role in supporting the management of long-term conditions, examples of when memory may have impacted long-term condition management, recommendations/approaches used to support management, decision making around changes to care, and the impact of COVID-19 on health management. I tailored the above topic guide with context from interviews with participants with dementia and/or family carers to facilitate examples.

6.8.3 Follow-up interview

For participants with dementia or their family carers, at the end of the initial qualitative interview I asked whether they had any upcoming health appointments. This related to primary care contacts (GP appointments, blood tests, health checks), secondary care appointments (ophthalmology, neurosurgery, oncology), dementia (memory service or neurology review), and/or general health appointments (podiatrist, dentist, opticians). The frequency of follow-up interviews depended on health-related activities happening in participant’s lives. If participants informed me of an upcoming appointment, I conducted follow-up interviews with participants before and/or after the appointment. If not, I arranged a follow-up interview in one-months time.

I conducted between one and four follow-up interviews with participants with dementia and/or their family carers after the first semi-structured qualitative interview. I remained in contact with participants for up to four months after the initial interview. This consisted of email, video or telephone contact, around once a month. The follow-up interviews were unstructured and participant-led. The purpose of follow-up interviews was to gain a longitudinal perspective on care provision and support for long-term conditions in dementia. I prompted on how issues raised at the initial interview evolved, and any new issues which arose or where managed since our last conversation. Prior to follow up interviews, I developed a list of prompts based on issues raised in previous interviews. I began with an open question enquiring about their health in the past month, then prompted for any appointments or changes in health status (detailed in section 6.9.2).

6.8.4 Participant observations

To achieve my additional objectives of developing remote methodologies for research involving people with dementia, I intended to conduct participant observations using video-conferencing technologies such as Zoom or Facebook Portal. During these interactions, I intended to maintain a participant observational stance as I would be interacting with participants directly rather than purely observing (Laurier, 2016). Due to practicalities which I reflect on in Chapter Seven, for this study all interactions with participants were instead interview based using telephone or video-calls. I sought to mitigate this gap by maintaining some elements of observations in data collection. During video interviews, in addition to audio-recording the conversation, I made unstructured observational field notes in my reflective diary. I noted the dynamics between the person with dementia and the family carer in dyadic interviews. I also made notes of my rapport with the participants and how this impacted data collected. I made notes of the environment visible on the video, and any technological challenges that occurred during the interviews.

6.8.5 Document analysis

6.8.5.1. Event-based diary

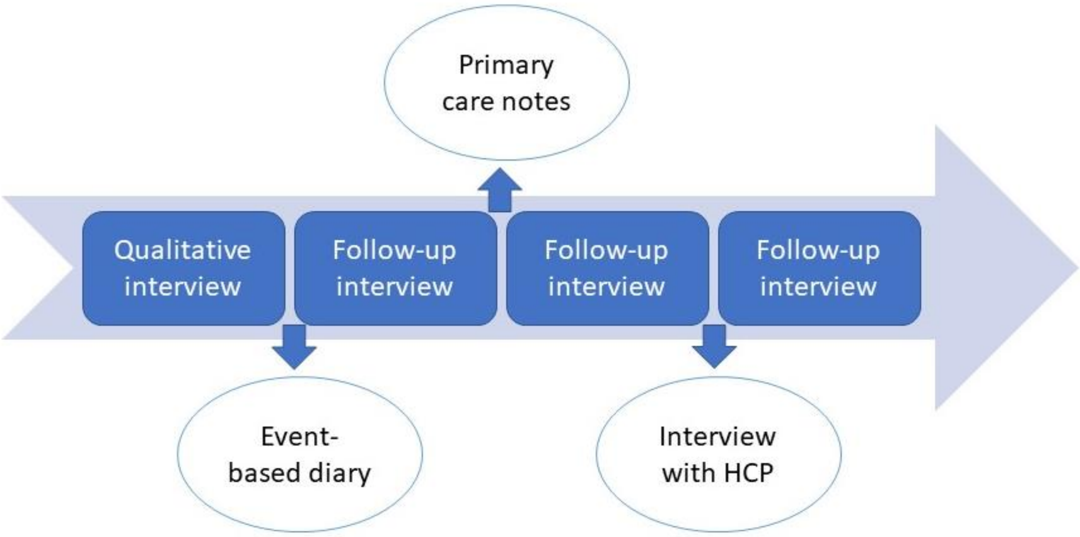
To support the inclusion of the perspective of the person with dementia, I invited participants to keep an event-based diary. Over a two-week period, I asked participants to record what they did to look after their health, and who was involved. This also enabled insight into how care and support for long-term conditions in dementia varied on a daily or weekly basis, compared to monthly data collected from participants interviews. I sent participants a pen and notebook by post along with diary instructions (see Appendix 14). I contacted the participant after one week to answer any questions and then again at the end of the two-week data collection to arrange for the diary to be returned for analysis. Previous research has specified that the optimum length of diary studies should be two weeks to reduce respondent fatigue (Jacelon & Imperio, 2005).

6.8.5.2. Consultation notes

To triangulate accounts of participants in interviews I collected consultation notes from GP surgeries. With participant (or consultee where appropriate) consent, I contacted the GP surgery of participants with dementia via email to request consultation notes from the last ten consultations with any attached care plans. The majority of consultation notes were sent in a specified format including date of consultation and corresponding notes. Care plan documentation varied but often included six-month or annual reviews from the memory services which had been shared with the GP. This approach was taken to enable the healthcare professional perspectives to be included within the pandemic context of increased pressure on services. Document analysis of primary care records enabled me to understand the perspective of the healthcare professional in interactions regarding the management of long-term conditions in dementia. I was also able to use information from primary care records to develop interview prompts accordingly for follow-up interviews.

In Figure 6.1, I provide an example of the data collection process for stream three of my PhD.

Figure 6.1. Visualisation of data collection process



6.9 Analysis

6.9.1 Analytic approach

I took a thematic approach to qualitative analysis first outlined by Braun and Clarke (2006). I decided on thematic analysis over other pattern-based qualitative methodologies due to its theoretical flexibility (Braun & Clarke, 2021). As outlined in section 6.3, the critical realist perspective adopted for my analysis aligns with thematic analysis. In addition, as I collected data from various sources, I considered thematic analysis appropriate to identify themes within and across datasets. I considered the use of the qualitative paradigm, or ‘Big Q’ qualitative (Kidder & Fine, 1987) to align with “the project's purpose, theoretical assumptions, research question and methods…” (Willig, 2013). Through taking an inductive approach, I chose thematic analysis to explore participants’ subjective experiences of physical health care in dementia.

I chose reflexive thematic analysis (Braun & Clarke, 2019) as it allowed me to use my subjectivity as an analytic resource, to reflect on theory, data and use interpretation throughout the analysis process (Braun & Clarke, 2020). Within reflexive thematic analysis, the depth of interpretation relies on the skill of the researcher to actively generate themes based on coding (Braun & Clarke, 2020). This is distinct from other thematic analysis procedures, which have a positivist epistemological positioning, and focus on the use of codebooks, multiple coders and consensus coding.

To understand the nuances of providing care in particular contexts over time, I used an idiographic approach which is a concept associated with Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009). Within IPA, analysis has a dual focus by firstly, focusing on the unique details of each case before developing themes across cases (Braun & Clarke, 2021). In this way, I used reflexive thematic analysis to develop themes within case studies before considering themes across cases. This approach of using a thematic structure to present findings whilst using examples of individual experiences to evidence themes has been previously used in ethnographic studies of mental health settings (Clarke & Waring, 2018). I considered IPA, critical realism and reflexive TA to complement each other as they all use reflexive processes to understand the role of the researcher in the interpretation of participant accounts. I used reflexive thematic analysis over IPA to identify themes across cases as my data collection involved sources other than interviews and my sample size was larger than ten (Braun & Clarke, 2020).

6.9.2 Analytic procedure

As part of the familiarisation process, I transcribed verbatim all qualitative data myself. I substituted the names of participants with a pseudonym based on their gender and ethnicity. I transferred anonymised transcripts to NVivo 12 for analysis (QSR International Pty, 2018). I read through all documentation related to each care network prior to each interview so that I could follow up on ideas for emerging concepts and themes in subsequent data collection. My process of coding was systematic, in that I analysed data by care network making comparisons between sources and stakeholders. I organised meetings with my supervisors (CC, KW, AB) to discuss key concepts and reflected on interpretation of meaning when grouping codes to generate initial themes. Consistent with reflexive thematic analysis (Braun & Clarke, 2019), I used this ongoing discussion to review and develop themes, returning to original data sources to ensure internal coherence within themes. To further refine and name themes, I described core concepts in sentences.

I analysed any instances where participants with dementia and/or family carers described someone in their social or care network (e.g. family member, healthcare professional) to create a visual representation of support networks including frequency of contacts. I used inner circles to indicate more frequent contact and outer circles to indicate less frequent contact. I did not specifically ask participants to formally quantify frequency of contact (e.g. daily, monthly, annually). To mitigate this, I used the accounts of participants to determine where I placed each network member in the diagrams based on any organic mention of frequency of contact (e.g. annual neurology review in outer circle) or closeness of relationship (determined by frequency and content of network member discussion within interviews).

I triangulated data from multiple sources to examine phenomena in different settings and at different times (Reeves et al., 2008). I applied codes from my analysis of interview transcripts to the content of documents and vice versa as a strategy "to integrate data gathered by different methods." Using this 'back-and-forth' approach, I triangulated data across data sources, across stakeholders and across time. During analysis, I reflected on questions such as: What kind of ideas are mentioned in both interviews and primary care records? How is this care network similar to, or different from, the preceding care network? Do these ideas change over time or are they consistent? (Bowen, 2009; Fereday & Muir-Cochrane, 2006).

Next, I developed and summarised themes across care networks. After exploring themes within each case study, I reflected on the central organising concept of each theme and considered how they applied across care networks. I grouped themes from case studies based on shared patterns of meaning and used supervisory discussion to refine themes from descriptive to interpretative representation of participants accounts. During write up, I use a thematic structure to describe shared patterns of meaning across case studies and use exemplars within case studies to further evidence themes.

6.9.3 Data saturation

I acknowledge the perspective that the determination of saturation prior to data analysis is not consistent with reflexive thematic analysis (Braun & Clarke, 2019b). In this section, I outline the process used to determine when I had a rich and adequate sample during data collection and analysis.

I began analysis in NVivo 12 after I completed data collection for all care networks. As described in the previous section, this was an iterative process, analysing all data for one care network before beginning analysis on the next care network. After each interview I would begin transcription. Prior to each follow-up interview I would re-read transcripts and reflective notes to develop points for discussion. I considered this the beginning of my analysis for each care network as it informed the content of subsequent interviews. Such reflections facilitated my awareness of when an adequate sample was reached. This process accounts for the variation in the number of follow-up interviews across care networks.

As outlined in section 6.6, I used my personal judgement during purposive sampling to select participants based on their “information power” (Sebele-Mpofu, 2020). For example, streams one and two of my PhD highlighted the specific difficulties of managing diabetes in dementia yet having reached at mid-point in data collection I had not identified and recruited a person with dementia and diabetes. Thus, I purposively sampled for diagnosis of a specific long-term condition.

I reflected on when I felt “no further insights” originated at an individual interview level and where I felt “viewpoints, variations, accurate and deep understanding of information” were reflected in the data (Hennink et al., 2017, 2019). I acknowledge the subjectivity in this judgement which I consider to be consistent with the values of reflexive thematic analysis. I recognise that further information may have arisen in future interviews, yet I was constrained by the study timeframe of four months.

6.10 Summary

In this Chapter, I have outlined the methodology for stream three of my PhD: a multi-data qualitative study of how care for long-term conditions is provided and supported in dementia. In the next Chapter, I describe my reflexive practice and consider my positionality as a researcher, before reflecting on my experiences during this research study, including those of collecting remote data during the COVID-19 pandemic.

Chapter 7 Reflexivity and reflections

As distinguished by Chiseri-Strater (1996) “to be reflective does not demand an ‘other,’ while to be reflexive demands both another and some self-conscious awareness of the process of self-scrutiny” (p. 130). In this chapter I outline my reflexive practice where I consider how my life experiences and perspectives might have influenced the study (Reeves et al., 2008). Consistent with the aims outlined in section 6.2, I then discuss my reflections on the use of remote methodologies when researching people with dementia.

7.1 Reflexive practice

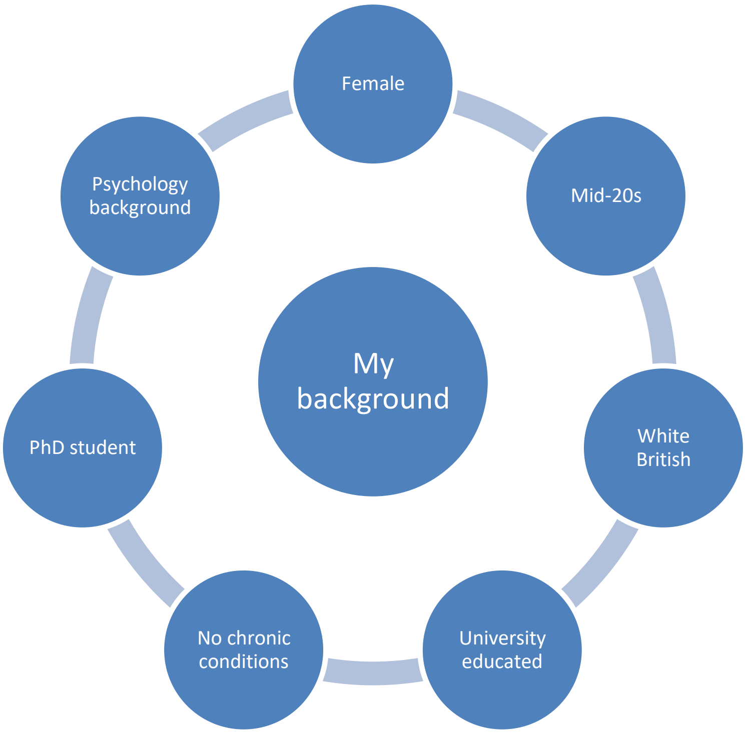
Reflexivity is core component for qualitative research (Rankl et al., 2021). It is defined as the “act of self-reflection that considers how one’s own opinions, values, and actions shape how data is generated, analysed and interpreted” (Castree et al., 2013). The concept of reflexivity emerged from feminist theory, particularly the idea of ‘situated knowledge’ which assumes that “all forms of knowledge reflect the particular conditions in which they are produced” (Haraway, 1991). Reflexivity is the concept that researchers inherently shape and bias their project through their assumptions and the position they occupy. It is therefore an important methodological consideration for researchers to self-critique how they participate in knowledge production through the research process (Pillow, 2003).

If knowledge reflects the identity of its producers (Haraway, 1991) then it is important for researchers to acknowledge their influence on the research process. Researcher subjectivity (i.e. how does who I am, who I think I am, and how I feel affect data collection and analysis) is a methodological tool and analytic resource in qualitative research (Braun & Clarke, 2020). In the next section, I consider how my personal and academic biography, my emotional responses and relationships with participants may have affected my research (Mauthner & Doucet, 2003).

7.1.1 Positionality

Positionality is where the researcher recognises and declares their own position in a piece of academic work (Castree et al., 2013). As part of the process of reflexivity as recognition of self, here I consider how my positionality (see Figure 7.1) influenced data collection, interpretation of accounts during analysis, my relationships with participants and ultimately the knowledge produced (Pillow, 2003).

Figure 7.1. Self-location of my own positionality as a researcher



7.1.1.1. Personal biography

During data collection, I reflected on how my personal biography as a young, white, female may have influenced the research process. When conducting interviews, my awareness of these factors heightened with comments made by participants. I acknowledged how this heightened awareness may have impacted my ability to ask questions in interviews. In one example, the family carer would follow up his answers with statements such as '*let me know if I am talking down to you*.' I recorded in my reflective diary how this made me feel uncomfortable as I felt the family carer did this due to his perception of me as a young woman. I acknowledged how this feeling made me more withdrawn in interviews as I did not want to further contribute to his 'perception' that I lacked understanding of the research topic.

I experienced similar discomfort when my physical appearance was referenced in a video-interview. The person with dementia commented that he found me attractive. The family carer found this response amusing however I then became mindful of the presence of his wife, who also had dementia. I had observed how protective this person with dementia was of her husband, and I was concerned his comment would impact her acceptance of me as a researcher and thus impact the research process. I was unable to interpret how she responded to the comment as the family carer was not pointing the camera at her. I considered how I might have been able to navigate the situation better if the interview had been in-person.

Towards the end of data collection, I felt more experienced in uncomfortable reflexive practice (Pillow, 2003). Thus, I felt better prepared to deal with feelings of discomfort related to references to my personal characteristics. For example, when one person with dementia became frustrated due to the inability to hear me over Zoom, he referred to both my accent ('*you need elocution lessons*') and my age ('*I'm going to treat you like a little girl because that's what you are*'). Despite feeling uncomfortable, I felt able to navigate the situation by calmly responding with a direct question which the family carer was able to repeat. This facilitated data collection as the person with dementia accepted the invitation to complete an event-based diary to overcome his hearing impairment.

During data analysis, I reflected on how my background of being White British may have impacted my ability to interpret data from participants from a South-Asian background. In these examples, participants lived with grandparents, parents, and children in the same home. My personal biography means I am not familiar with the context of living in a multi-generational household. As I describe in the next chapter, key themes for these care networks involved independence. I considered how my lack of understanding of cultural context may have limited my inquiry. For example, on reflection I did not ask about hierarchies or roles within the home, cultural perceptions of ageing and independence or support from broader social circles.

7.1.1.2. Academic biography

I am a university-educated, PhD student with a background in Psychology. I considered how this academic biography influenced data collection. In one example, the person with dementia asked about my qualifications and seemed reassured by my answers that I had some expertise in the topic. This appeared to enable a sense of trust between us. I reflected that my personal characteristics (young female) may have led him to seek this reassurance.

My background in Psychology, and qualitative health research, influenced my choice of research design during study conception and my epistemological positioning. I acknowledge that my assumptions about life with a chronic condition developed from participant accounts I heard during my undergraduate and masters degree research projects. As I have no personal experience of living with dementia or a chronic condition, I would position myself as an 'outside researcher' (Hellawell, 2007) while acknowledging, in line with my epistemological positioning that interpretation of participants accounts are always mediated by my own assumptions and biases.

I acknowledge how my lack of medical background made interpretation of consultation notes more challenging. In one example, my supervisory panel discussed how the participant's swollen feet were a symptom of heart failure. This was not previously clear to me, and this medical knowledge led me to explore the participants' understanding of this. It is also important to acknowledge the academic biographies of my supervisors: an old age psychiatrist (CC), a GP (KW), and a qualitative researcher with expertise in social support and health outcomes (AB). I consider how my supervisory panel may have influenced my epistemological positioning. Although their training in bio-medical models of healthcare may be more aligned with a positivist stance, my supervisors adopt a bio-psycho-social approach to their professions and regularly engage in reflexive practices as mixed-methodology health researchers.

7.1.1.3. Relationship with participants

I considered how my relationship with participants may have influenced the research process. This was especially pertinent to my analyses of two case studies. In one example, the family carer saw the study as an opportunity to increase the amount of information he had from primary care. In particular, he wished to find out the rationale for the GP surgery conducting a stroke review for the person with dementia he cared for. As part of data collection, I did obtain primary care records and care plans from surgery administrators. I was unable to get in contact with the GP directly, thus unable to ask questions of interest to the participant. If I was able to contact the GP, I was conscious of the impact the participants request for information would have on the credibility of the case study as naturalistic. In this example, I felt closer to a fact finder or detective rather than a story listener or person-centred counsellor (Willig, 2012).

I often found remaining impartial during interviews difficult. I felt this was the case for one case study, where I spoke to the family carer over a period of four months and where progression of dementia and caring responsibilities changed drastically. I felt that the family carer was struggling with his caring responsibilities. I found myself reflecting on whether data collection was an additional burden on his time or whether interviews were an opportunity for him to reflect (as he said no professionals had asked about his wellbeing). The participant was very amenable to interview times, organising for his daughter to come to the house so he could speak to me. I felt a sense of guilt for taking up his time with interviews and this may have influenced how I engaged with follow-up questions.

7.2 Reflections on conducting remote research

7.2.1 Participant observation

When developing the face-to-face protocol for my PhD, I was looking forward to conducting participant observations in the home settings of participants and in primary care. I felt that the use of this methodology would provide useful insights into the management of multiple long-term conditions in dementia, similar to previous ethnographies into diabetes self-management (Hinder &

Greenhalgh, 2012). When social distancing restrictions were announced March 2020 as a response to COVID-19, I needed to adapt my fieldwork to a remote protocol. I wanted to maintain participant observation as a data source as it was relevant to my research question, enabling me to see the difference in what is being said and what is being done in practice. I attempted to conduct one participant observation using Facebook Portal however this was not practical due to technical difficulties. On reflection I felt the use of this technology might be confusing for participants with dementia as my face would have appeared on the television.

7.2.2 Video verses telephone interviews

I felt that interviews conducted via video-call provided useful information for me as a researcher to understand the dynamics between participants which I was then able to visualise if future contact happened via telephone. In one case study where both participants had dementia, video-calls enabled me to see how these participants interacted with their daughter. The family carer moved from sofa to sofa to include each parent, shouting across the room to ask questions and moving the camera so they could see me. However, the visual element may have detracted from interview content at times. One family carer expressed concern during video-calls about the way she looked, saying she would have to '*put on make-up now'* and during the call she was focused on adjusting the light. I reflected on how this differed to face-to-face interviews as during video-calls participants were able to see themselves on screen which heightened awareness of their own visual appearance.

By contrast, conducting interviews over the telephone with participants might have felt more comfortable, as many of whom were not used to using video-call technologies. In one example, the family carer requested the interview to be conducted via telephone after an initial zoom and ate her lunch during one interview over the telephone. In two case studies, I felt that interaction without visual cues may have been beneficial. Both were older males, a person with dementia and family carer respectively, who spoke about their difficulties in coping with dementia diagnoses and caring responsibilities. I considered whether the anonymity of speaking over the telephone with a researcher influenced their openness or whether this interaction would have been the same in face-to-face interactions.

For people living with dementia, interviews via video-call could have been confusing and relied on the family carer for participation. In one example, the person with dementia was unsure how to use Zoom therefore the telephone was positioned on her lap looking up at her face. I could see the person with dementia looking away from the camera and waiting for her son to return. In another example, the person with dementia expressed frustration about being able to see me on Zoom yet unable to hear me due to hearing impairments.

Overall, I felt video-calls allowed me to access one view of proceedings, only the person with dementia’s reactions, or only the family carer. Thus, while providing useful visual information, this was partial relative to the rich experience of visiting someone’s home.

Chapter 8 Stream Three: Results

In this Chapter, I present the results of my multi-data qualitative study describing six themes which relate to the experiences of providing and supporting care for long-term conditions in dementia, before discussing the strengths and limitations of stream three of my PhD.

8.1 Participant characteristics

I collected data from 18 participants between September 2020 and May 2021. Participants comprised of eight care networks, including nine people with dementia, seven family carers and two healthcare professionals. Table 8.1 shows the socio-demographic and health characteristics of participants with dementia.

Table 8.1. Characteristics of participants with dementia

	Number of participants
Age	
70-79	3
80-89	3
90+	3
Gender	
Female	5
Male	4
Ethnicity	
White	7
South Asian	2
Marital status	
Married	6
Widowed	2
Divorced	1
With family	8
Alone	1

Type of dementia	
Alzheimer’s disease	5
Vascular	1
Mixed	1
Frontotemporal	1
Posterior cortical atrophy	1
Stage of dementia	
Early	2
Moderate	4
Late	3
Long-term conditions	
Diabetes	3
Cardiovascular conditions*	6
Visual impairment	2
Hearing impairment	2
Respiratory conditions	3
Renal failure	2
Arthritis	3
Depression/anxiety	3

** included hypertension, stroke and heart failure.*

Out of the seven family carers participants, four were female and three were male. Four were spousal-carers and three child-carers. Two healthcare professionals participated, a GP and a consultant neurologist.

8.2 Overview of data collection and recruitment

For each care network I collected data through serial interviews and document analysis from the primary care records of the person with dementia, supplemented by event-based diaries where possible. I conducted 26 interviews in total, which included an average of three interviews per care network (range 1-5) longitudinally over a period of four months. I collected primary care records for all nine participants with dementia. Two people with dementia recorded health events in a diary. I recorded observational field notes from four video interviews. Details of the number of contacts per data source, per care network is available in Appendix 15.

For the majority of care networks, I spent most time talking to the family carer (Mean time: 41 minutes). Interviews with healthcare professionals (Mean time: 23 minutes) were shorter than participants with dementia (Mean time: 31 minutes). I conducted the majority of interviews on a one-to-one basis. In the case of three care networks, I conducted dyadic interviews with persons with dementia and their family carer (Mean time: 23 minutes).

I interacted with eight participants with dementia directly (from seven care networks), via telephone or on video-call. One care network included a husband and wife who both had dementia. In another care network, I was not able to speak to the person living with (advanced) dementia and spoke only with the family carer.

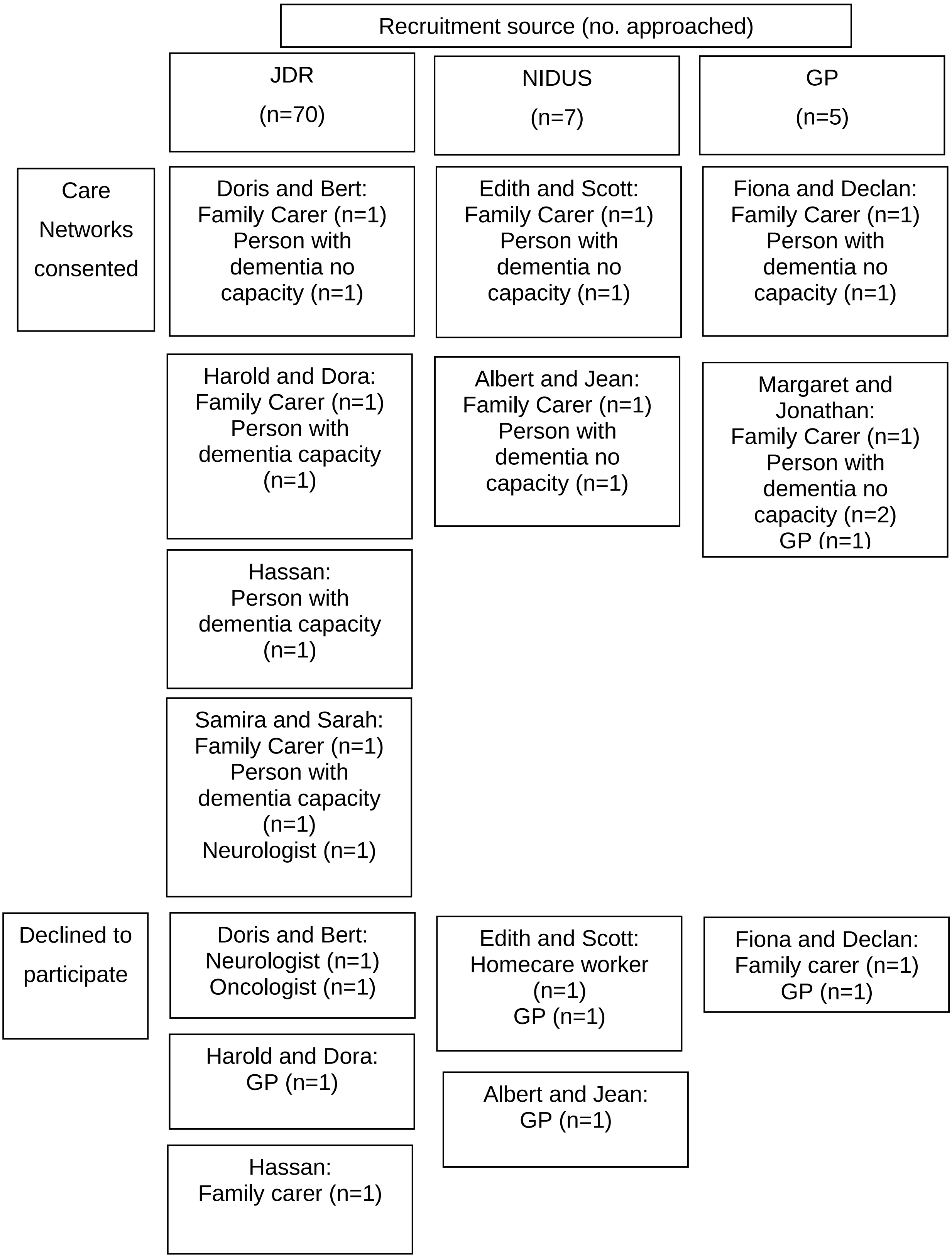
Three people with dementia had capacity to consent to research. For the remaining six, a family member acted as a personal consultee. Although I obtained an ethical amendment to do so, I did not recruit any participants for whom a nominated consultee was involved.

I recruited the majority of care networks (n=4) through JDR. The remaining care networks were recruited through previous UCL studies (n=2) and through GP direct contact (n=3). See Table 8.2 for an overview of data collection and recruitment methods per care network. Figure 8.1 shows how participant recruitment was divided between the eight care networks.

Table 8.2. Overview of data collection and recruitment

	Number of networks
Data sources	
Family carer interview	7
Person with dementia interview	2
Dyadic interview	3
HCP interview	2
Video-interview (field notes)	4
Primary care records	9
Event-based diary	2
Capacity to consent	
Yes	3
No	6
Referral route	
UCL studies	2
JDR	4
GP direct contact	3

Figure 8.1. Flowchart of participant recruitment



	Recruitment source (no. approached)		
	JDR (n=70)	NIDUS (n=7)	GP (n=5)
Care Networks consented	Doris and Bert: Family Carer (n=1) Person with dementia no capacity (n=1) Harold and Dora: Family Carer (n=1) Person with dementia capacity (n=1) Hassan: Person with dementia capacity (n=1) Samira and Sarah: Family Carer (n=1) Person with dementia capacity (n=1) Neurologist (n=1)	Edith and Scott: Family Carer (n=1) Person with dementia no capacity (n=1) Albert and Jean: Family Carer (n=1) Person with dementia no capacity (n=1)	Fiona and Declan: Family Carer (n=1) Person with dementia no capacity (n=1) Margaret and Jonathan: Family Carer (n=1) Person with dementia no capacity (n=2) GP (n=1)
Declined to participate	Doris and Bert: Neurologist (n=1) Oncologist (n=1) Harold and Dora: GP (n=1) Hassan: Family carer (n=1)	Edith and Scott: Homecare worker (n=1) GP (n=1) Albert and Jean: GP (n=1)	Fiona and Declan: Family carer (n=1) GP (n=1)

8.3 Results

In the following sections, I present six themes that respond to my research question regarding how care for long-term conditions in dementia is provided and support. A visualisation of themes and the case studies in which they are reflected is presented in Table 8.3. Each name is a pseudonym based on sociodemographic characteristics of participants. I include a visualisation of support networks for each case study in Appendix 16 and a list of themes with corresponding case studies and supporting quotes in Appendix 17.

Table 8.3. Cross cutting themes and care networks

Theme	Care Network
1) Balancing support and independence	Harold and Dora Hassan Samira and Sarah
2) Implementing and adapting advice for dementia contexts	Doris and Bert Fiona and Declan
3) Balancing physical, cognitive and mental health needs	Edith and Scott Harold and Dora Albert and Jean
4) Competing and entwined needs and priorities	Edith and Scott Margaret, Jonathan, and Sophie Albert and Jean
5) Curating supportive professional networks	Edith and Scott Doris and Bert Samira and Sarah
6) Family carer support and coping	Fiona and Declan Margaret, Jonathan and Sophie Doris and Bert

8.3.1 Balancing support and independence

Balancing the need for increased support with declining cognition was an important process due to the value of independence for people living with dementia. Hassan, a participant living with mild to moderate dementia, emphasised the importance for him to feel he did not depend on others. He stated '*I do it myself*' eleven times across both interviews relating to his self-administration of insulin twice daily. GP consultation notes record that he was '*taking all his meds.'* However, it is unclear whether this was the GP's own assessment or Hassan's self-report.

This strong sense of independence may have been related to insight into increasing dependence on others. I observed this in the case of Harold, another participant in the early stages of dementia, who found the continuum from independence to interdependence difficult. Harold only had partial insight into his self-management abilities and required increasing support from his wife, Dora. In his event-based diary, Harold stated he self-managed his medication: "*I have my medication (many pills) well organised.*" He acknowledged that he forgot his medication '*occasionally (and rarely)*' but felt he did not '*depend*' on help from his wife. There was a suggestion in interviews that Dora supported medication management more than Harold reported. For example, in the evenings, she put '*the pills in front of him and make sure he takes it.*'

In the context of dementia, the desire for independence could at times lead to compromised quality of disease management. For example, GP notes indicated that Hassan's diabetic control had worsened over the past two years. The quote below describes how Hassan '*passed out'* several times from hypoglycaemia, implying he may have had difficulties self-managing his insulin injections.

> *"Once in the bathroom I passed out and couldn't get up. Couldn't get up at all. So I had to call my son and he had to call the ambulance and all that. And I was lying down in the bathroom for some time. And then slowly they pulled me up. This happened two, three times." (Hassan, Interview 1)*

Case description: Hassan

Hassan is in his late 80s and was diagnosed with Alzheimer's disease in 2019. Hassan lives in a multi-generational household with two sons and his daughter-in-law. Hassan described having a '*long list'* of physical health conditions including type 2 diabetes (diagnosed in 1989) and arthritis. Hassan felt that he managed his dementia well. Records indicated that a '*foot exam and assessment'* were required however Hassan had no knowledge of this, suggesting how dementia may have impacted his awareness of upcoming health monitoring activities. His HbA1c increased between 2019 and 2021 indicating worsening diabetic control. His estimated glomerular filtration rate fell slightly over the last five years, indicating that his renal function was impaired but stable. My second interview with Hassan was conducted shortly after a telephone medication review with his GP. He was aware of medical decision making around changes to medication and that blood tests were monitoring his kidney function.

I interviewed Hassan over his landline number twice in February and May 2021. Hassan declined the invitation to complete an event-based diary. His son facilitated the returning of Hassan's consent form but did not participate directly in interviews. Hassan had capacity to consent to research and was recruited through JDR.

In the management of Harold’s eye condition, accounts reflect a difficult balance, between supporting Harold to feel autonomous and safeguarding his vision. For glaucoma, Harold was aware of which medications were required. However, interviews with his wife Dora acknowledged how Harold’s administration of the eye drops may have been ineffective. At an ophthalmology appointment doctors explained to Harold how his poor vision was due to his eyes not being properly moistened. In this instance, the family carer monitored risks to ensure the challenges posed by self-management in dementia were within acceptable limits. Dora was conscious of a need to balance Harold’s care needs and his need to perceive himself as autonomous, as she does not ‘*want him to lose his independence*.’

> *“So I think [Harold] is sometimes not careful enough you know doesn’t do things with precision anymore and maybe it didn’t clear his eyes properly. So I clean his eye and he could see better, and I have insist [sic], he never remembers to put his drops on.” (Dora, Interview 3)*

In contrast, the neurologist involved in Samira’s dementia care acknowledged that her diabetes was ‘*mild*’ and ‘*under control’* with medication. The level of risk was low and her diabetes was not at the level he would ‘*think it could be a disaster if this was left to get out of control*.’ A facilitator of this appeared to be the slow rate of Samira’s cognitive decline (‘*the most slowly progressive patient…I’ve even seen*’) enabling her to maintain relative independence.

> *“From a communication point of view she has a limited vocabulary but she’s still able to get her point across and lead a reasonably…not independent but I mean she can still take part in activities that she has taken part in for a long time.” (Neurologist, Interview 1)*

A commonality across these accounts was the support provided by family carers to ensure appropriate management of long-term conditions. For physical health appointments, Hassan explained ‘*I usually go with my sons*’ who supported with transport and reporting of symptoms (‘*my son will tell them what happened’*), yet also described how he ‘*can get the bus if needed’* to and from appointments if his son was unable to assist.

> *“That’s why I want to keep myself busy in a way. That I don’t have to depend on others. So I’m more independent than any sick man like me could be [laughs].” (Hassan, Interview 1)*

From Harold’s perspective, Dora attended appointments ‘*to accompany me and to make sure I’ve understood what they are saying.*’ Dora asked questions at appointments, advocating on his behalf. She gathered information about management and care in appointments as she described how Harold did not like to question medical advice.

> *“…because he doesn’t ask. It’s due to his Britishness that he never complains. And you just accept whatever the doctor says. So I have to enquire and to ask for more information, you know to see if he can suggest some test or whatever.” (Dora, Interview 1)*

Samira provided an account, supported by the neurologist’s narrative and GP notes, that she was successfully able to take an active role in managing her healthcare and care decisions with daily support from her daughter, Sarah.

> *“She’s on the ball with taking her medicine. I think if there was an issue there, I don’t know what I’d do…just get back in contact with the doctor I presume and he will take it from there.” (Sarah, Interview 1)*

During a video-call, I observed how Samira managed her appointments by keeping letters near her bed. In her event-based diary, Samira showed an awareness of her medical issues.

> *“Last Monday I had a chiropodist appointment with [area] health centre. Doctor will ring me on Monday the 26th March to talk about dementia. Hospital doctor on the 29th March. I have to see the doctor to discuss about my leg pains to discuss about root injection or surgery or an epidural.” (Samira, Event-based diary)*

Samira and Sarah described how she was successfully able to make many decisions independently, for example about having surgery. Sarah described not agreeing with, but nonetheless accepting, Samira’s decision to undergo further surgery due to her other long-term conditions.

> *"I didn't really want her to have it. I thought obviously age, diabetes and the health and stuff, it's not really conducive to do it. But I mean she did it. It was okay and the pain came back. And there was always the possibility the pain would not go away…But it's part of, the complications were she probably end up with more back pain and she was happy to go through with the surgery." (Sarah, Interview 2)*

Sarah's enabling approach to decision making may have been made possible by Samira's low severity of cognitive decline. Looking closer at the experiences of Harold and Dora, insight into medical conditions due to severity of cognitive decline impacted support and independence. In this instance, a recent medical concern had been the progression of cardiac failure, resulting in swollen feet. Harold was unaware that the cause of his swollen feet was his heart and considered that a reduction was due to increased exercise. Despite the relationship between swollen feet and heart failure potentially not being immediately clear to those without a medical background, Dora understood Harold's foot problems to be cardiac-related.

> *"Now he has got a very swollen feet, extremely swollen and he just dismissed it as if nothing was wrong with it. I want him to go to the doctor. I have to insist for him to make an appointment, and at this stage I don't want him to lose his independence. I just try to help as much as I can but I want to go to the doctor with him for that reason otherwise he does everything for himself." (Dora, Interview 1)*

8.3.2 Implementing and adapting advice for dementia contexts

Implementing the advice given by healthcare professionals in the home to manage physical health conditions was a challenge for family carers as care was required to be adapted to overcome symptoms of dementia. Their role in adapting condition-specific advice to dementia contexts was a prominent theme for Bert and Declan, both husband carers for a person in the later stages of dementia. The symptoms of advanced dementia complicated the management of physical health conditions. As Declan explained, he was now taking his wife, Fiona, to a hygienist '*once a month now instead of once every three months*' to support with cleaning. He reported how this related to her preference for sweet foods, a common symptom in Alzheimer's disease.

> *"Err…the problem is she's starting to, her teeth are starting to, her gums are starting to bleed. So we've been using Corsodyl which has helped a lot. But she's not brushing her teeth…until about two weeks ago she was able to take it, the Corsodyl and rinse around. But she swallowed it two or three times. That's not a disaster but it's not great. So I don't do that anymore with her. I just put it on a brush and rub it around." (Declan, Interview 4)*

This example highlights Declan's proactivity in promoting Fiona's healthcare at home, where he continued to adapt care to account for changing abilities and needs. For his wife Doris, Bert supported the management of symptoms by '*keeping an eye'* on the impact of dementia on her ability to eat a balanced diet. Bert described how he used his knowledge of dementia symptoms to reflect on what caused her weight loss, whether apathy or swallowing issues impacted nutrition maintenance.

> *"I keep a very close eye on her to see if she has difficulty swallowing, which is a very difficult late-stage symptoms and she doesn't seem to, if she doesn't eat it's because she says she full, or she is bored and switched off." (Bert, Interview 1)*

The management of swallowing issues was a common difficulty across accounts. Declan described his responsibility for contacting services to adapt care in response to changes in dementia. For example, requesting orodispersable tablets.

> *"Aricept is now the dispersible one. Because she won't take that pill anymore. And I have to crunch up the other two. Her cholesterol medication and levothyroxine medication. I crunch it up and put it in with yogurt. And hopefully she gets that." (Declan, Interview 3)*

Case description: Doris and Bert

Doris is in her mid-70s and has a diagnosis of Alzheimer’s disease recorded in GP notes from 2018. Doris was in the later stages of dementia, and the main physical health issues described in interviews related to nutrition, frailty and toileting. Doris lived with Chronic Myeloid Leukaemia for 16 years and is now in remission. Prior to dementia diagnosis, Doris experienced chest pains, which were of a vascular cause and treated with an arterial stent.

She lives with her husband, Bert who discussed supporting Doris to manage tremors during mealtimes and medication administration. Doris and Bert are supported practically and emotionally by their son, who lives locally. They also have neighbours and ‘*real*’ friends who they are in regular contact with.

I interviewed Bert via telephone in November 2020. After my initial interview with Bert, Doris was admitted to hospital due to a ‘*serious event’* and was being assessed for palliative nursing care. As a result, Bert felt unable to continue study participation. Doris did not have capacity to consent to research and Bert acted as personal consultee. I recruited this care network through JDR.

Both husbands also described the challenge of interpreting symptoms due to impaired communication ability as a result of dementia. Bert described how providing care for constipation involved a '*long, long battle'* with medication to understand efficacy of treatment. He acknowledged how his ability to interpret symptoms with limited feedback was facilitated by his knowledge of Doris.

> *"You rely on the patient you say what works, how are you feeling, did that hurt, if I push you here what does… it is notoriously difficult because you get no, all medication requires patient feedback. And with Alzheimer's that gradually diminishes to zero. You have to interpolate [sic], and if you know someone very well like [Doris] and I do, that makes life very difficult…very easy. It must be incredible difficult for people who handle this with strangers I would guess." (Bert, Interview 1)*

Similarly, Declan observed how Fiona's '*power to explain herself has been severely affected'* by dementia requiring him to interpret her non-verbal cues. Declan acknowledged that communication difficulties compounded Fiona's ability to articulate '*where the pain is coming from and why*.'

> *"She has very little cognition about anything really. No there is no way she can express what is wrong with her." (Declan, Interview 4)*

Declan found this difficult and perceived a lack of integrated services for dementia and physical health made this harder. He felt primary care focused on physical health management and ignored any problems relating to dementia. In an annual consultation with neurology, Declan reported how little he perceived dementia to be mentioned by Fiona's GP.

> *"Err…well they are dealing with the attending problems of dementia, but they never really speak about the dementia itself or how I'm coping with it or what's happening in her life. How she and I are coping with it. They completely ignore that. Just medical problems they're concerned with. They don't really want to know about anything else you know. I think that's probably in the domain of [area] people as well. The memory service and that sort of thing." (Declan, Interview 4)*

8.3.3 Balancing physical, cognitive and mental health needs

The co-occurrences of physical, cognitive and mental health needs in people with dementia led inevitable trade-offs during the prioritisation of care needs. For Edith, a person living with moderate dementia, her social and mental wellbeing was balanced with other physical health priorities, such as the need to reduce falls risk. Her son Scott described how remaining on the first floor of her home as a fall risk management strategy was a condition of her returning home from a rehabilitation centre.

> *"We had to make her promise not to go down the stairs…So on that understanding, on that basis, she was released home." (Scott, Interview 1)*

The main issues described in interviews with Albert and Jean also involved managing the risk of falls. For Albert, a person living with late onset dementia, risk of falls related to balance problems which developed after his stroke. When I first met Albert and Jean, they were worried about the effect of taking too many medications on Albert's mobility. They decided against starting anti-dementia medication, as Jean recounted the potential side effects included dizziness '*which is the last one he needs.*' In later interviews Jean described how Albert's dementia had worsened. His memory service notes record how he can become '*another self'* being '*rude*' and '*bad tempered'* when forgetting things. I also observed how Albert became agitated when unable to engage in conversation due to his hearing impairment. At this point, supported by primary care, Jean re-considered the need for antipsychotic medication '*although not been keen on medication in the past*' suggesting a repositioning of care priorities.

A commonality across accounts included the low positioning of mental health needs in the hierarchy of condition management. For Albert, risk of falls appeared related to mental health, with consultation notes from the physiotherapist to the GP reporting '*reduced dynamic and static balance with occasional involuntary jerky movement increasing anxiousness when mobilising*.' From a family carer perspective, Scott frequently mentioned Edith's medication for depression as one he would like reviewed. During one interview, Scott emphasised the size of the medication which he appeared at times to equate to the severity of depression.

> *“The last half. It's a half a tiny half of one. And at the end of the day is for depression…I don’t know how deep the depression went…I think kind of a depression set in a way of, you know, is my life worth carrying on. If I can’t do what I want to do… they prescribed a small amount of a half, it's called Mirtazapine. It's just a little, a half to be taken at night. I mean, I have asked for a review the medication. To see if she needs to…but we decided to carry on with that one.” (Scott, Interview 1)*

As the above quote suggests, Scott attributed his mother’s mental health difficulties to her reduced ability to do activities she used to enjoy. Edith’s memory service care plan stated the priority of living at home as a patient identified goal (“*I would like to live in my own home for as long as possible even if it means not being able to go down the stairs*”). In practice the compromises required to remain at home seemed to include having very limited social contact which Scott felt affected Edith’s mental health.

Case description: Edith and Scott

In 2018, Edith was diagnosed with mixed Alzheimer's disease and vascular dementia. She is in her 90s, lives alone and is supported by her son, Scott who visits three times a week. In 2016, prior to her dementia diagnosis, Edith had a Cerebrovascular Accident. One of the main issues for Edith was reduced mobility due to osteoarthritis in the left knee. Edith's dementia diagnosis was made around the time of her admission to a rehabilitation centre after a fall. Edith was prescribed medication (Mirtazapine) in the rehabilitation centre which Scott understands to be for depression. Since her admission, Edith has received four home care visits a day to support her with meal preparation, personal care, and medication. Edith uses a walking frame to move around the first floor of her house and mainly accesses services via home visits by social workers, opticians and nurses for example, for influenza vaccination. Neighbours provide professionals with access to her home when Scott is not available.

I interviewed Scott four times between September and December 2020, and I met Edith in a Zoom call facilitated by Scott. Edith did not have capacity to consent to participate in the research so Scott acted as personal consultee. I recruited this care network from a previous UCL study.

Despite this, GP consultation notes made no mention of Edith's pharmacological treatment for depression. This was also the case for Harold who described not discussing his dementia with his GP as he '*assume[d] it's just going to progress*.' Harold's mental health is also not referenced in the last ten GP consultations which focused on physical health concerns, specifically vision impairment and cardiac problems. In his event-based diary, Harold described his mental health as '*not stable'* and he sought to self-manage his low mood through daily jogs which '*settled my thoughts.*' Harold did not consider his mental health a problem prior to his dementia diagnosis. In the quote below, he describes a sense of hopelessness towards his diagnosis.

> *"In a way it's just there, it's like having arthritis. You can't suddenly get rid of it. It goes on for maybe a couple of days and then I'm alright. I'm alright today and it's very hard to explain it. It's not something I had before I got the diagnosis. And I think it was a reaction to the diagnosis as much as anything. You know we all, all human beings rely hugely on memory and I thought I wasn't going to have any memory. Pretty awful. And of course now I forget things which I ought to remember and that reminds me that things aren't good." (Harold, Interview 3)*

Harold and Dora both attributed his sadness to insight into physical and cognitive decline and anticipated future decline. Harold found increasing dependence on Dora a challenge to his determination to hold onto his sense of self. In his event-based diary, Harold provided detailed examples of changes in roles for him and his wife which created a sense of dependency.

> *"I considered my desperation, not suicidal but feeling greatly inferior to [Dora], how our roles have reversed..." (Harold, Event-based diary)*

Dora shared this sense of loss, describing how '*someone who has got a lot has to lose a lot'* which he found difficult to cope with. He described receiving sessions with a psychologist from the memory service '*gave me no comfort*' in adjusting to his dementia diagnosis. These examples suggest how Harold's proactive approach to physical health management appeared not to extend to his management of cognitive and mental health.

Case description: Harold and Dora

Harold is in his mid-80s and was diagnosed with Alzheimer’s disease in 2016. He has mild dementia, for which he is prescribed medication by the memory service. Harold described his main issue to be visual impairment from cataracts and glaucoma. He also has inner ear deafness and wears a hearing aid. Harold takes medication for atrial fibrillation. Since 2020, Harold has been under investigation for heart failure and recently saw a cardiologist to investigate the cause of his swollen feet. He self-monitors his heart using electrocardiograms through a smartphone app. Harold is in regular contact with his GP, by whom he feels well supported, to manage his physical health.

Harold lives with his wife, Dora, whose role as a carer has progressed over the past year as Harold’s dementia symptoms, including impaired short-term memory and focus (‘*muddled thoughts*’) have worsened. I interviewed Harold and Dora separately in November 2020. Harold recorded his health experiences in an event-based diary for two weeks. I then interviewed Harold prior to an ophthalmology appointment in February 2021 and spoke to Harold and Dora together after the eye appointment. Harold had capacity to consent to research and was recruited through JDR.

8.3.4 Competing and entwined needs and priorities

The interconnection between family carers and the people living with dementia they supported led to sense of competing and entwined needs. A commonality across accounts was the tension, or potential enmeshment between family carer proxy decision making for the person living with dementia, and decisions about their own needs and priorities.

Scott spoke openly about how some care could not be provided to Edith as she would not be able to attend appointments. Scott's decision making appeared to limit Edith's access to services, as he considered some services to be logistically difficult to attend and feared that visits might be '*too disruptive'* for Edith.

> *"She can't come out, she can't get down the stairs, you can't get her down the stairs, get her into a taxi, you're going to upset her during the day, her routine, and maybe give her another heart attack." (Scott, Interview 4)*

I considered whether these accounts reflected Scott's attempts to set some limits to the amount of labour required from him to provide care, or if they related to Edith's lack of insight into her own functional abilities. In her memory service care plan, Edith felt she could '*make it down the stairs if she's careful'* suggesting how her perception on risk management may differ from Scott's. The ability to attend appointments due to mobility issues were discussed as a factor in Scott's decision to remove Edith from the waiting list for her cataract operation. Scott also felt pressure from ophthalmology to '*free up the slot*' if Edith was unable to make appointments.

> *"As I said, I felt rotten that I had to, well she's been taken off the list. Removed. Because other people need the slots. I would have kept it on, I would have kept on but eventually it was not right for me, morally wrong to keep saying yes, yes she'll be there, she'll be back there again, she'll be in there again for another. When I know that she couldn't possibly get there." (Scott, Interview 1)*

Similarly, Margaret and Jonathan, a married couple who both had a diagnosis of dementia, experienced family carer proxy decision making in a similar way.

From my interactions with their GP, there was a sense that care was complicated by entanglement with the anxieties of their daughter Sophie.

> *"And the anxieties that are projected from the carers are very valid, because they are with them the whole time, but you wonder how much you are treating the carer rather than actually treating your patient." (GP, Interview 1)*

I observed a number of scenarios in which it felt care decisions were influenced by Sophie's anxieties. I record how '*Sophie is very aware about talking about dementia in front of parents*.' As the quote below suggests, Sophie found it challenging to balance her own concerns about her parent's ability to cope with information regarding their dementia diagnosis with medical recommendations.

> *"When I go to the hospital I say please don't mention my parents condition [dementia]. I know personally it would worry them, they wouldn't be able to handle it. I mean obviously they were told in the beginning, they've forgot. But doctors have said no it's important they should know. But I know my parents would…and if someone told me and I couldn't remember that I had it I would panic. It would make me worse." (Sophie, Interview 1)*

Care needs for Margaret and Jonathan were described by the GP as '*difficult to unpick'* due to the couple's presentation together in primary care. A letter from Jonathan's cardiologist recorded how the telephone appointment was conducted '*on the speaker phone so he and the wife could hear as well*.' The quote below highlights how the provision of individualised care for Margaret and Jonathan was impacted further by dementia diagnosis.

> *"But definitely with these two I mean I think if they didn't have dementia I'm sure they'd still probably come to see me in, you know, in their couple but I think it would be easier to disentangle it. Just because I could be a bit more like, well I actually do think we need separate appointments. You felt that was a valid reason to do things." (GP, Interview 1)*

Case description: Margaret, Jonathan and Sophie

Margaret and Jonathan are husband and wife who both have a diagnosis of dementia. Margaret is in her 80s and was diagnosed with Alzheimer's disease in 2012 with her cognitive decline being described by her GP as a '*slow progression*.' Margaret lives with depression and anxiety from childhood trauma. She has Chronic Obstructive Pulmonary Disease, diagnosed post-dementia, which is managed with an inhaler. Margaret was diagnosed with renal failure in her 30s which impacts medication regimes and she has regular Urinary Tract Infections.

Jonathan is in his 90s and was diagnosed with vascular dementia in 2018 following a stroke in hospital when admitted for pneumonia. His cognitive function was described by the GP as '*deteriorating quicker*' than his wife. Jonathan's dementia causes agitation and anxiety leading to compulsive habits such as checking money. Jonathan has COPD managed with an inhaler, renal failure, and diet-controlled borderline diabetes. Because of his diabetes he is invited to regular appointments with the chiropodist and optician. Their GP described how Jonathan's dementia meant he was '*solely dependent'* on others for his physical healthcare and had limited '*ability to take control himself.*'

They live with and are supported by their daughter Sophie who is their full-time carer. I interviewed Sophie by telephone in January 2021 and on Zoom in February 2021. In between, I interviewed Margaret and Jonathan's GP. In March 2021, I met Margaret and Jonathan, facilitated by Sophie in their home, where I recorded observational fieldnotes. I first tried a Facebook portal yet switched to a video-call through WhatsApp due to technical difficulties. Both lacked capacity to consent to research themselves and Sophie was personal consultee. I recruited this care network through GP direct contact.

The dynamic of attending appointments together was described by Margaret and Jonathan's GP as common among people over 60. The situation for Albert and Jean was similar as their care needs were practically entwined. At times, linked care due to age and health status achieved positive outcomes in relation to access to services. For example, on the day of Albert's fall reported in our second interview, a physiotherapist attended the home to provide neurotherapy treatment for Jean's vertigo. As evidenced in Jean's account and GP consultation notes, knowledge of Albert from previous sessions meant the physiotherapist was able to assess him following his fall and report information to the GP.

> *"It just so happened that the physiotherapist had come here to see me... later that morning. So she very kindly, because they know [Albert] anyway from previous sessions of physio. So she did all the observations, you know, take him temperature and pulse, blood pressure. And everything was normal so when I reported that to the doctor." (Jean, Interview 2)*
>
> *"Review by community therapy team following a fall at home and difficultly completing exercise. Full multi-factorial risk assessment completed. Ferrules on frame replaced. The nature of the fall seemed to be mechanically-related due to losing his footing when transferring to the sofa. Completing daily exercises under supervision and mobilising indoors with frame." (Letter from Physiotherapist to GP, March 2021)*

Case description: Albert and Jean

Albert is in his 90s and has a diagnosis of late onset Alzheimer’s disease and moderate frailty. He records battery changes for his hearing aids in a diary. In 2015, Albert was fitted with a pacemaker following a diagnosis of heart block which contributed to a fall. About a month after his fall, he had a stroke. Albert uses a walking aid inside the home to stabilise him if his knees ‘*give way’* from involuntary muscle movements. Albert’s poor balance and ‘*jerking*’ movements appeared to have started after his stroke. GP notes indicate that they worsened when he had a chest infection.

Albert lives at home with his wife Jean. Their son, who lives locally, visits at least once a week to provide Jean with respite. Organised by a social worker, they are supported by a homecare worker who visits twice daily in the morning and evening. For Albert, this support includes personal care. For Jean, this includes support with household cleaning. Albert and Jean are supported by their GP by telephone consultation, and home visits when necessary. For example, by the district nurse for vaccination and by the GP for assessment of worsening involuntary movements.

I interviewed Albert and Jean over Zoom in March 2021, I then had two interviews with Jean via telephone in April and May 2021. Albert agreed to participate in the event-based diary but did not complete it. Albert did not have capacity to consent, so Jean acted as personal consultee. I recruited this care network through a previous UCL study.

8.3.5 Curating supportive professional networks

To navigate the health system and access care when needed, family carers actively curated and managed relationships with professionals, in some cases developing personal closeness. At times, this was required due to challenges of access to care during the pandemic. Throughout our interview, Bert highlighted his perception that '*the people have been nice and the system lousy*' when managing Doris's healthcare. Here, Bert used his assertiveness to facilitate access to Doris's general practice yet acknowledged this approach may not be possible for everyone.

> *"Almost impossible to get through to the, wonderful GPs, no fault with them, their medical treatment has been top notch, but trying to get through, I mean they are just too busy. Too many patients trying to get through reception, just to get to talk to anybody is a real effort. I do because I'm just that sort of guy, but there must be a lot of people that must have a lot of trouble." (Bert, Interview 1)*

Samira and Sarah experienced the challenges of access to care during the pandemic in a different way. Sarah described having a '*close relationship'* with the neurologist involved in Samira's dementia care after volunteering in their research group. In their third dyadic interview, Samira described the confusion of waiting for a telephone consultation when they were expected to attend in-person.

> *"One was supposed to ring me, we waited for four, five o clock in the evening. Nobody ring. And then [Sarah] ring them at the hospital and the professor we had to see him, he answered the phone and said I was supposed to come into the hospital. I said the letters says, [Sarah] read the letter, it says 'do not come to the hospital we will ring you'.'" (Samira, Interview 3)*

In response, Sarah was able to organise a video consultation with the neurologist to discuss Samira's dementia care.

Case description: Samira and Sarah

Samira is in her 70s and was diagnosed with primary progressive aphasia (fluent variant) in 2014/15. Annual neurology appointments focused on monitoring language and personality changes such as disinhibition. Samira describes her main problem to be pain, from arthritis in the left knee and a trapped nerve in her back. Prior to COVID-19, Samira underwent surgery to manage pain in her left leg caused by a trapped nerve in her spine. Samira had a back operation last year and is awaiting another surgery as the pain had returned. Samira has asthma which is managed with a daily inhaler. Samira has lived with type 2 diabetes for '*a long time'* which is managed by medication and diet. Samira takes her medication independently morning and evening and collects monthly blister packs from the pharmacist.

Samira lives in a multi-generational household with her son, daughter and two grandchildren in a '*close knit family*.' Her daughter, Sarah, who was on furlough at the time of interviews, is known to the GP as Samira's carer. Sarah attends appointments with Samira and supports her with finances, shopping and cooking. I conducted four dyadic interviews with Samira and Sarah between February and May 2021, with one interview conducted via WhatsApp video. During this interview, Sarah pointed her phone camera towards Samira who was sat on her bed. Samira completed an event-based diary for two weeks in March 2021 and had capacity to consent to research and was recruited from JDR. I interviewed her neurologist via Microsoft Teams in March 2021.

As the quotes below suggest, Sarah’s relationship with the neurologist led to improved communication as she felt able to ‘*talk on the phone with him’* or email with any concerns.

> *“Communication is very easy. In some ways, it should be, and it is mostly for all patients I see with these long-term conditions, they have either my email or some form of point of contact, my secretaries’ email. My phone number. One of the nurse specialists. I mean in [Sarah’s] case it’s very easy isn’t it because you know I’ve got to know her quite well. So yeah she can contact me any time.” (Neurologist, Interview 1)*

> *“They did give her a number for a nurse at [name of hospital] they have a nurse. So if you have any concerns you can give the nurse a call. But like I mentioned before, because I know [name of doctor] I can just drop him an email and say I’ve got concerns.” (Sarah, Interview 1)*

Similarly, Bert experienced improved communication with specific clinicians with whom he felt he had close relationships. He recounted how the oncology department kept in touch reporting ‘*we don’t want you to fall through the cracks*.’ Curating such supportive networks meant professionals were aware of need and adapted care accordingly. For example, consultants coordinated care to accommodate Bert’s preference of not wishing to attend hospital during COVID-19 due to concerns about Doris’s frailty.

> *“Doris needed a blood test check. And I was reluctant to go into hospital for that. So they, the senior nurse there who I’ve got on with for years, very kindly said she’d sort out with the GP to do it…But when I was talking to [name] the neurologist he spotted on the computer notes that the consultant, [name], had been in touch with the GP, and that he’d arranged, they are in the same hospital, so he arranged for one of the girls, well the nurses there, to take Doris’s blood and send it off. So they arranged it that way and I haven’t had to go to doctors at all.” (Bert, Interview 1)*

In contrast, Scott described his relationship with the homecare agency who provided the majority of support for Edith’s daily needs as ‘*healthy, it’s a positive one*’ however also referred to contacting them as a ‘*delicate situation.*’ This suggested a perceived fragility in the relationship. Scott worried the request to participate in the study would upset the agency and lead to a complaint, which would impact Edith's care. His fear of losing the support of homecare workers may reflect the importance of the agency in Edith's care. He also stated '*I have my own views on the company which I will say off the record*' suggesting an element of dissatisfaction with care that Scott may be tolerating as he perceived homecare as a critical care provision on which he and his mother depended. Despite this, Scott worked in collaboration with homecare workers, noting the limits of the role they were able to provide, and working around this to coordinate care. For example, by adjusting Edith's diet to manage constipation.

> *"That's the one area that she can't, we can't, they can't do that they're not they're not allowed health and safety, obviously. The carers. What they can do is microwave and do her a sandwich. So I have to think about things I know that she likes, that's healthy for her, nutritional wise. That's another issue I have, I walk around the shops. Well, I'll get some dates or prunes. We tried to shift things with prunes." (Scott, Interview 1)*

8.3.6 Family carer support and coping

Family carer attitude towards acceptance of support influenced their ability to cope, with COVID-19 impacting the availability of support. For example, Declan acknowledged the invaluable support provided by his daughter, Maeve, who became the primary carer for Fiona during his recovery from open heart surgery. Declan was appreciative that Maeve's furlough coincided with his surgery and acknowledged how support would change when Maeve returned to work.

> *"Well I'm just about okay. Up until about two weeks ago my daughter was here. Because I couldn't have done it without her for the first two weeks. I couldn't have coped. I had absolutely no energy." (Declan, Interview 1)*

In contrast, Sophie experienced decreased support during the pandemic. Family members were unable to attend the home to provide respite care due to concerns of COVID-19 transmission. The following quote demonstrated how some remote decision making support from family was retained, for example relating to COVID-19 vaccination.

> *"Yeah it is left up to me but I'm really really indecisive. Really indecisive. Like with the vaccination for example I wasn't sure I was a bit worried about letting them have it, and I asked all my other members of family. I'm not very assertive. And I've got good support with my family." (Sophie, Interview 1)*

Perceptions of family carer ability to support the healthcare needs of people with dementia fluctuated. By my fourth interview with Declan, he described Fiona's challenging behaviour as '*impossible to manage'* and began considering care home options with his daughter Maeve. The quote below demonstrates how needs waxed and waned as Declan balanced his own feelings relating to Fiona's admission to a care home with Maeve's concerns about his ability to cope.

> *"I mean it's really hard to say exactly when [she will need to move to care home]. But when things are really bad I'm thinking it's going to be within the next month but then things calm down a bit, I think maybe I could hold out for a bit longer." (Declan, Interview 4)*

Fiona presented with a variety of challenging behaviour for Declan to manage. This resulted in '*mental stress'* for Declan as challenging behaviour became more frequent and contributed to carer burden. In Sophie's case, high levels of carer stress and burden impacted her decision making ability, such as judgement around medication administration.

> *"I was suffering from depression and exhaustion. I went to give my dad his tablets and left the tablets on the side, and when my dad got up… 'I've took all my tablets'. I'd left the tablets on the side and he took about 14 of his tablets…So I had to take him to the hospital. I felt awful. I felt so bad that I could have killed him you know." (Sophie, Interview 1)*

Case description: Fiona and Declan

Fiona is in her early 70s and was diagnosed with posterior cortical atrophy in 2016. In the last year, dementia progression had led to '*catastrophic*' changes in cognition impacting '*food, toilet, agitation, distress and sleep.'* Fiona is reported to not '*have many physical health problems.'* She uses daily inhalers for Chronic Obstructive Pulmonary Disease, diagnosed prior to dementia. Fiona is underweight, and refusal of food has led to concerns about frailty. Following a blood test in 2020, Fiona was prescribed medication to manage cholesterol.

Data collection began while Declan was in recovery from open heart surgery. During the time Declan was in hospital, their daughter Maeve became Fiona's primary carer. I interviewed Declan via telephone four times between January and April 2021. I was introduced to Fiona during one telephone discussion. Fiona did not have capacity to consent to research herself so Declan acted as personal consultee. I recruited this care network through GP direct contact.

Family carer acceptance of support was a commonality across narratives. Declan considered the coordination of support from signposted services an additional responsibility, which contributed to (rather than reduced) carer burden. He expressed a sense of feeling '*left on your own'* to follow up on signposting recommendations. In response to changes in behaviour and increasing carer burden, Declan's negative cognitions such as '*nothing will help'* grew more apparent in later interviews. This sense of futility was expressed in relation to every service involved in Fiona's care including the referral to the continence team ('*I can't see how they can help with that it's just a very…visceral problem you know. How do you deal with it*?'), following advice from a nutritionist ('*so apart from that nothing much of any use really talking to the nutritionist you know*'), when awaiting a care assessment ('*really I don't know what they can do in the end'*), and when day centres re-opened following COVID-19 (*'I'm ready to be disappointed'*).

Family carers expressed concerns that although burden was overwhelming, sharing it with homecare workers risked increasing their burden. Declan organised homecare worker support yet discontinued after one session due to due to need for additional coordination. In another example, memory service care plans recorded how Sophie was untrusting of homecare workers after hearing of family members having bad experiences. Care notes documented how Sophie felt her parents do '*not take too kindly to strangers'* which contrasted with my experience of meeting Margaret and Jonathan during observations.

> *"I don't trust carers or other…so many bad experiences my partner with his mum with carers coming in. Just so many bad experiences. My sister worked in that area and you know they don't turn up and you know just sign my sheet that's all they are interested really. But it's finding the right person. Because it is really challenging and it is hard." (Sophie, Interview 2)*

Bert also discussed his reluctance to involve homecare workers as he described feeling it would not be useful as he would not leave Doris unattended. In 2018, GP care plans recorded Bert reporting he was '*coping well'* whilst taking sole responsibility for managing Doris's care. The quote below highlights how healthcare professionals may have recognised the burden associated with such responsibilities.

> *"No paid carers at all. I've been reluctant to do that. The neurologist is a lovely chap, he keeps saying you've got to look after yourself. But I must admit it won't work on the moment. If I left her with someone I wouldn't go out or do anything, I'd only sit out there fretting. So I'm really managing myself." [Bert, interview 1]*

I considered whether Bert would access support if he was not coping as his comments around homecare workers suggested he was reluctant to involve others to provide social care or for carer support.

8.4 Discussion

8.4.1 Main findings

In this multi-data qualitative study, I developed eight in-depth case studies using multiple data sources to explore how care for long-term conditions is provided and supported in dementia. Case studies highlighted how dementia can complicate long-term condition management. Across group analysis highlighted six interrelated themes.

The first theme **Balancing support and independence** focused on the perspective of people with dementia, and the value of independence in health management, yet how this was required to be balanced with the need for increased support as cognition declined. The second theme **Implementing and adapting advice for dementia contexts** related to how family carers implemented and adapted condition-specific recommendations in the home. This included integrating advice for dementia and other long-term conditions where this was not considered at a service level. The third theme **Balancing physical, cognitive and mental health needs** considered the inevitable trade-offs between physical, cognitive and mental health, often creating a hierarchy, which rebalanced according to changing needs. Within this hierarchy mental health needs (i.e. the impact on mood) seemed to take a lower priority. The fourth theme **Competing and entwined needs and priorities** described the interconnectedness of the needs of people with dementia and their family carers and the influence of this on proxy-decision making. The fifth theme **Curating supportive professional networks** focused on the role of the family carer in curating supportive professional relationships, from primary, secondary and social care, to facilitate healthcare. The final theme **Family carer support and coping** considered how carers decided when to access support and how this was influenced by their perceptions of their capacity to cope with the demands of caring. This included their expectations regarding whether to involve homecare workers to support the management of long-term condition in dementia.

I discuss these themes further with reference to the wider literature in Chapter Nine.

8.4.2 Strengths and limitations

This is the first remote multi-data qualitative study to explore how care for long-term conditions is provided by primary care and supported by carers for people living with dementia in the community. The use of remote data collection methods has increased since the start of the pandemic, including research on the healthcare experiences of people with dementia (Tuijt, Rait, et al., 2021). However, to my knowledge this is the first study to use multiple data sources to triangulate perspectives of people with dementia, their family carers and healthcare professionals. In the absence of observations in primary care, analysis of consultation notes was particularly useful to compare the accounts of people with dementia and those who provide care.

Consistent with previous research, I tailored interviews in accordance with need and IT skills to engage older people remotely (Melis et al., 2021). However, conducting research remotely changed the degree of inclusivity for participants with dementia. Use of remote methodologies may have excluded some participants with low digital literacy or sensory impairment. The majority of interviews were conducted via telephone which may have been preferred in this population due to familiarity and access (Unnithan, 2021). Nonetheless the rich multisensory experience of in-person research could not be replicated via video or telephone interviews. The use of longitudinal interviews with participants enabled me to understand changes in management of long-term conditions over time. Ongoing communication with participants over four months helped me to build rapport (Tong et al., 2007) and mitigated the impact of remote interviewing on richness of data collection. I included a diverse range of people with dementia through purposeful sampling to explore how various long-term conditions are managed at different stages of cognitive decline with varied support networks. Nonetheless, my sample was small and not generalisable outside the context of primary care in England (Smith, 2017).

The use of public recruitment methods, such as JDR, bridged the gap during recruitment freezes in services authorised by the HRA at the beginning of the pandemic. Participants recruited through JDR were likely to have higher levels of digital literary or had support from a family member. I was not able to recruit any participants through mail-outs from NHS settings (e.g. from GP practices or memory clinics) which might have reached a wider variety of people compared to direct invitation by their GP. The latter recruitment method is also at risk of selection bias, with participants with a positive relationship with primary care more likely to be approached and consent to research. Recruitment of healthcare professionals and homecare workers was limited due to additional service pressures during the pandemic. As a result, I was unable to directly observe interactions between these stakeholders and participants living with dementia which limited my understanding of support from the community perspective.

Service provision between September 2020 and May 2021 was impacted by the two national lockdowns in England from November 2020 to April 2021. This included the closure of services relevant to this PhD and the pandemic context is frequently reflected in the narratives of participants. The shift of GP services to be predominantly remote was evident, with many consultations occurring on the telephone. This modality tended to exclude the person with dementia as the conversation was often with the carer. Thus, the experiences observed were specific to the unique circumstances of the time and may not be readily generalisable to post-pandemic contexts. However, it is likely that remote healthcare will continue longer term, and with continued concerns regarding access to in-person GP appointments (NHS England, 2021b). Thus, this small but in-depth study of the experiences of eight care networks during lockdown may indeed include some generalisable lessons.

8.4.3 Conclusion and implications for PhD

In this Chapter, I have described six overarching themes relating to how care for long-term conditions is provided and supported in dementia. These findings indicate that advice around self-management of long-term conditions need to be tailored for the stage of dementia. For people with mild dementia supporting independence is an important priority. As dementia progresses, care is often organised using a family-centred approach that acknowledges the daily realities of implementing and adapting advice at home to a dementia context and balancing competing risks. Realistic self-management plans which are deliverable in practice must consider the interacting nature of physical, cognitive and mental health needs, and acknowledge that these needs are often conflated with carers in the context of dementia. Care networks curated support from wider family, healthcare professionals and homecare workers to facilitate the management of long-term conditions. Access to support was influenced by carers perception of their own capacity to cope in addition to the anticipated benefits of services. In the next Chapter, I discuss the meaning and implications of my PhD as a whole.

Chapter 9 Overall discussion

In this chapter, I summarise, integrate and interpret my main findings. I consider the strengths and limitations of this thesis and discuss future directions for research, clinical practice and policy.

9.1 An integrated summary of findings

In this section I integrate findings from my systematic review (chapter four), secondary analysis (chapter five) and qualitative study (chapter eight). In Table 9.1, I group the themes I identified in each stream of my PhD into three main topic areas.

The first of these areas, **continuum of support** describes how support increased over time with severity of dementia and health needs, from self-management to interdependence. I found how people with dementia valued independence yet how this was balanced with need for care and treatment access. A second area, **holistic and adapted care** describes the interrelatedness of cognitive, physical and mental health needs. I found how care in this context requires consideration of the fundamental impact of dementia on treatments for long-term conditions. In addition, how family carers adapt recommendations based on their knowledge of the person with dementia to implement advice. The third and final area, **networks of care** explores how family carers are positioned between health and social care professionals and people with dementia, making decisions and curating supportive networks on their behalf. I saw how family carer needs were often entwined with those of the person living with dementia.

Table 9.1. Integrated findings from the three streams of my thesis

	(1) Systematic review	**(2) Secondary analysis**	**(3) Qualitative study**
Continuum of support	Theme 3: Negotiating self-management support	Theme 1: Process of substituting self-management	Theme 1: Balancing support and independence
Holistic and adapted care	Theme 1: Dementia symptoms impeding treatment regimes Theme 2: Adapting routines and strategies	Theme 3: Impact on and from dementia	Theme 2: Implementing and adapting care in dementia context Theme 3: Balancing physical, cognitive and mental health needs
Networks of care	Theme 4: Interface with professionals	Theme 2: Communication in the care network	Theme 4: Competing and entwined needs and priorities Theme 5: Curating supportive networks Theme 6: Carer support and coping

9.1.1 Continuum of support

The management of long-term conditions in dementia exists on a continuum from independence to interdependence, with transition to greater support related to advancing dementia and level of need. The findings of each stream of my PhD reflect this dynamic nature of dementia care. My systematic review included evidence from previous studies about how, when strategies to facilitate self-management became less effective, the process towards proxy management began. My secondary analysis included accounts from family carers and homecare workers regarding the challenges of managing this transition to greater support while valuing independence. For example, how homecare workers supported independence by keeping people with dementia informed about their medication regime, and how family carer prioritised safety when memory impeded medication administration.

In my qualitative study, I was able to explore in greater depth how this transition occurred. I saw the difficult balance for those involved in the care of people with dementia, to respect autonomy and agency whilst also enabling quality care to prevent avoidable ill-health. People living with dementia recounted how important it was to them to manage their healthcare independently. I identified examples where despite memory concerns, people living with milder dementia were able to maintain their wellbeing with a degree of independence. However, in all the case studies this involved family carers or professionals monitoring potential adverse consequences of non-adherence closely. By comparison, in my interviews with care networks of people with moderate to advanced dementia, the person with dementia appeared to have relatively little agency in their long-term condition care. This was due to the impact of dementia on their ability to communicate and understand disease-specific treatments. Telephone consultations, which were the primary route of communication with healthcare providers (both primary care and secondary care) during the pandemic, seemed to make it harder for the person with dementia and their family carer to be positioned as care partners. In these instances, the voices of people with moderate to advanced dementia were particularly absent.

9.1.2 Holistic and adapted care

The need to integrate an understanding of the impact of dementia on self-management ability into care planning was an important conclusion from each stream of my PhD. Studies identified in my systematic review described the association between increased dementia severity and reduced adherence to medication, exercise and dietary recommendations for the management of long-term conditions. They highlighted how healthcare professionals responded to this by simplifying routines and providing condition-specific information to family carers to facilitate symptom recognition. Most studies I found focused on strategies to overcome physical and cognitive barriers to medication adherence such as memory aids, with limited evidence around how to adapt condition-specific advice (such as inhaler use or insulin administration) to dementia contexts.

The inextricable link between physical and cognitive health was a key theme in my secondary qualitative analysis. Participants described how physical health treatments often required adaptation for people with dementia, for example to circumvent memory loss. I found how best interest decisions about whether and how to treat long-term conditions also needed to take account of the impact of dementia on adherence to treatment and the likelihood of treatment success. In my qualitative study I described how needs, for example mental health and fall management needs, were balanced when managing long-term condition in dementia. Physical and mental health needs often conflicted with cognitive need, with prioritisation changing as the person’s health needs changed. Accounts of family carers varied from feeling well supported by primary care with tailored recommendations for home management of health conditions, to accounts describing how perceived lack of integration of physical and cognitive health across primary and secondary care, meaning family carers felt left alone to adapt advice to the particular context of the person they care for with dementia.

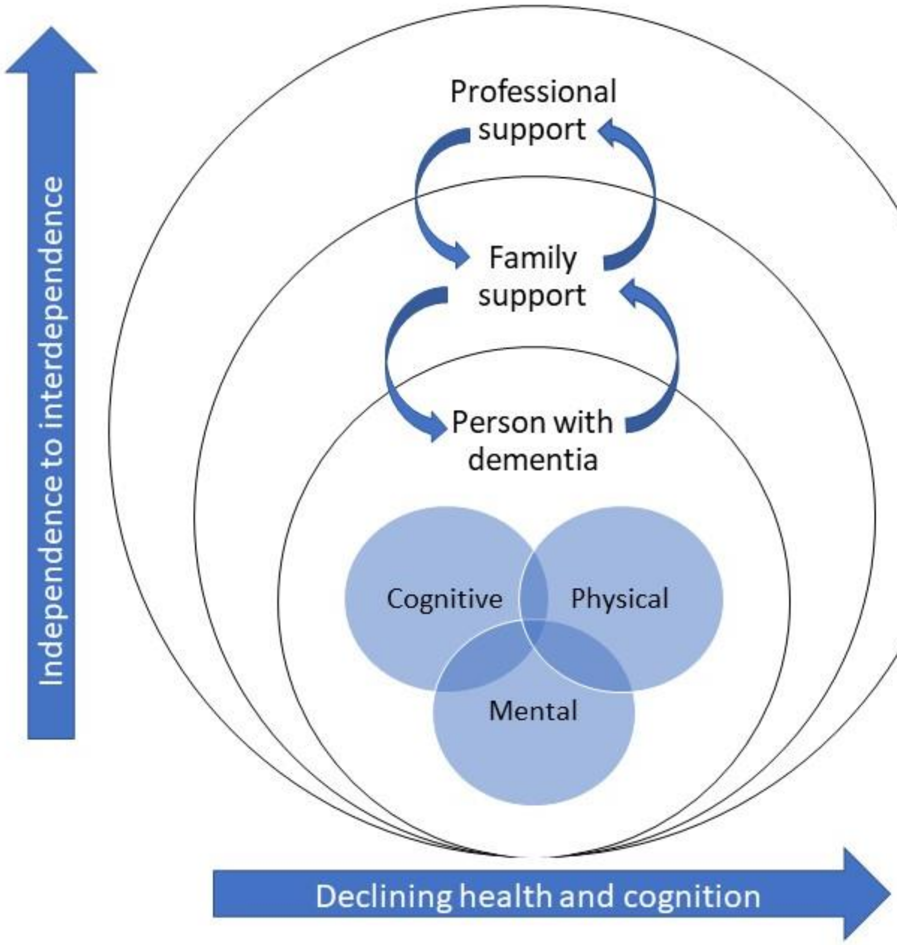
9.1.3 Networks of care

Across my three studies, I saw how care networks compensated for communication difficulties that impaired a person with dementia's ability to report symptoms. For example through family carers reporting symptoms on their behalf in healthcare appointments. The accounts of healthcare professionals in my secondary analysis highlighted the difficulties in identifying changes in self-management ability as dementia progresses without the involvement of family carers, and also the sensitivities of managing care relationships in which family carers are both supporter and sometimes the primary contact.

At times, the family carer was such an integral part of the person with dementia's care, that it was difficult for professionals to disentangle the person with dementia and the family carer's own needs and preferences. In my secondary analysis, professional participants noted such challenges when treatments for people with dementia were of questionable benefit but family carers wished them to continue. In my qualitative study there were also instances of a lack of distinction between proxy-decision making and decisions based on the family carers own needs. A key theme in my qualitative study was how family carers curated supportive relationships with healthcare professionals. While most family carers actively sought help from healthcare professionals, some expressed reluctance to involve social care professionals, specifically homecare workers due to perception of burden or past negative experiences.

In Figure 9.1, I visualise how support for long-term conditions in dementia should be: **flexible** to account for changes in health and cognition on the trajectory towards interdependence, **holistic** to adapt care based on physical, mental and cognitive need, and **consider networks of care** where people with dementia and their family carers are supported by professional networks (from primary and social care).

Figure 9.1. Visualisation of support for long-term conditions in dementia



9.2 Interpretation of findings

In this section I will discuss the interpretations of my key findings in the context of relevant literature and theory and consider how my findings may extend or develop existing understanding.

9.2.1 Continuum of support

My thesis illustrates the continuum of support that is needed when managing long-term conditions, as people with dementia transition from independence to interdependence. Loss of independence has been identified as a key stage in the dementia journey (Forbes et al., 2012). While previous literature has also described the transition from self-management to dependence in the context of long-term conditions in dementia (Bunn, Burn, et al., 2017), the specific contribution of my study included exploring the impact of COVID-19 on service access in this context. My findings highlighted the dynamic nature of dementia care which had implications for people with dementia and their family carers accessing services annually for long-term conditions. Participants experienced cancelled appointments or changes to mode of delivery, impacting the adaptation of care and support based on the trajectory of change.

9.2.1.1. Transition experiences

Findings from each stream of my thesis highlighted the transition from relative independence in care of long-term conditions to greater dependence over time. The types of transitions reflected in my findings mirror those described in Transition Theory, which I outlined in section 2.6 (Meleis et al., 2000). These include declining cognition and/or physical health, especially where this was due to declining adherence (health and illness transition), and the change of roles from spouse/child to carer (situational transition).

Transitions related to changing roles (situational transitions)

My findings illustrate how, over time, family carers had increasing responsibility for supporting medication, nutrition management and monitoring medical conditions. A recent review found how two-thirds of family carers for people with dementia in the United States performed these activities and how multiple long-term conditions complicated tasks (Lee et al., 2019). My findings expand on previous literature by demonstrating the complexities of family carer support needs, both practically and emotionally, as they tailored care in response to changing needs and abilities. For example, in the later stages of dementia when issues with swallowing impacted nutrition management and required adaptation of advice to ensure adherence.

Two of my case studies in particular described the transition from spouse or child to carer. I found how loss of independence was difficult to accept for people in the early stage of dementia. Previous research has found that husband carers of people with dementia and multiple long-term conditions adopt the role of ‘protector’ of personhood in addition to personal and medical care (Sanders & Power, 2009). I also witnessed how family carers often took on this role. My thesis expands knowledge as I found how this sense of protection over people with dementia was influenced by family carer anxieties. For example, where a daughter asked healthcare professionals to not mentioned dementia diagnosis to her parents due to her own concerns they would not be able to cope.

Transitions related to the pandemic (organisational transitions)

I now consider how my findings might extend current understandings of transition experiences. In terms of organisational transitions, my qualitative study findings suggest how pandemic-related factors may have contributed to a transition towards greater dependence. Three networks described not having an in-person GP appointments in over 18 months. Instead, consultations were conducted over the telephone. This is consistent with a recent qualitative study investigating the experiences of remote healthcare for people with dementia and their family carers during COVID-19 (Tuijt, Rait, et al., 2021), where family carers were found to organise and handle telephone consultations to overcome the barriers of memory or hearing problems. My findings expand on this highlighting how remote consultations often excluded people with dementia, especially those in the later stages.

My case studies highlighted how in-person healthcare was a source of social interaction for people with dementia, especially those who were housebound. Reduction in support networks and social connectedness during the pandemic has been noted in various populations, including those with mild memory problems (Cooper et al., 2021). A second qualitative study of the experiences of family carers of people with dementia in Italy reported how activities considered to be crucial for cognitive stimulation were reduced during the pandemic (Cipolletta et al., 2021). My findings expand on previous literature by highlighting how the holistic needs of people with dementia, specifically social and mental wellbeing, may not have been met during the pandemic.

Complexity of transitions within care networks

Transition theory has been used previously as a framework to understand the experiences of family carers of people with dementia and multiple long-term conditions (Lam et al., 2020; Ploeg, Northwood, et al., 2020). By considered transition across the care network, my findings relating to the entwined needs of people with dementia and their family carers extend this work, highlighting the interacting nature of transitions in this context. I saw in my qualitative study how transitions for people with dementia and those who provided care interacted. For example, the lack of insight of a person with dementia into the severity of health issues (heart failure) lead to the increased involvement of his wife (primary carer) and a transition to greater dependence on the family carer for care of long-term conditions. Such findings have implications for when support fails to acknowledge the interrelated nature of health and illness transitions of the person with dementia, and changes in the roles and responsibilities of family carers. As outlined in section 2.6, a web-based intervention for family carers of people with dementia and multiple long-term conditions did not find any significant results relating to self-efficacy, hope and quality of life (Duggleby et al., 2018). I consider that the lack of significant results in this study may be attributable to the focus on family carer transition alone.

9.2.1.2. Balancing autonomy and safety concerns

Findings from my qualitative study about how care networks sought to balance autonomy with safety concerns have been previously reported from the NIDUS qualitative data (Rapaport, Burton, Leverton, et al., 2020; Smebye et al., 2016). Previous research has highlighted how various stakeholders have different thresholds for risk-tolerance (Stevenson et al., 2016). For example, professionals have been found to conceptualise risk by consequences rather than likelihood (Stevenson & Taylor, 2017), while homecare workers report the tension between duty of care and risk management (Backhouse & Ruston, 2021; Sandberg et al., 2020). Through focusing purely on physical safety, there is a risk of overlooking a person with dementia's social and psychological wellbeing (Clarke & Mantle, 2016). On the other hand, when positive risk approaches for maintaining daily activities (i.e. going into the garden, household chores) were encouraged by professionals, family carers felt responsibility for 'holding' the risk (Rapaport, Burton, Leverton, et al., 2020). My findings would certainly support this notion that family carers often feel burdened by the risks posed by the self-management of long-term conditions in the context of cognitive decline. This has implications on family carer acceptance of support, which I found to be influenced by perception of their own ability to cope with carer burden.

Research has demonstrated how many family carers respect their relative with dementia as an individual who has capacity to make decisions and negotiate care needs (Yin et al., 2017). When incongruence exists between perception of risk and actual adverse outcomes (Stevenson et al., 2016) stakeholders can promote agency by developing strategies to enable the person with dementia to take calculated risks (Yin et al., 2017). My findings evidenced how empowering approaches can be promoted yet often how this depended on stage of dementia. In my case studies with people with moderate and advanced dementia, there appeared to be limited opportunities for active engagement in self-management and most activities were proxy-managed by family carers.

One previous study sought to conceptualise the meaning of independence for older people living in their own home, living with support, and those in residential settings (Hillcoat-Nallétamby, 2014). Across settings, people were able to maintain a sense of agency where they accepted help from friends and family as a means of remaining independent. I identified a similar theme in my secondary analysis of qualitative interviews, where accepting support felt more agreeable to people with dementia when the decision was made autonomously. Similarly, in one case study, the person in the early stages of dementia was able to maintain an active role in healthcare management with facilitating support from her daughter. These findings are consistent the concept of interdependencies, where ‘autonomy cannot be viewed as separate from relationships which the individuals are embedded’ (Perkins et al., 2012). The authors also highlighted how adapting to physical and cognitive changes were integral to a sense of independence. My findings suggest adopting a person-centred approach to risk may preserve physical and mental abilities and enable care networks to continue to support individuals as dementia progresses.

9.2.2 Holistic and adapted care

9.2.2.1. Adapting care to dementia context

Medication management

In my systematic review I found that most previous studies around self-care for long-term conditions in dementia have explored how healthcare professionals supported adherence through simplifying routines and providing condition-specific information. This is consistent with consensus recommendations on prescribing for long-term conditions in dementia (Page et al., 2016) and with previous research on medication management in dementia which found strategies were adopted to account for deterioration in cognition, sight and dexterity (Lam et al., 2020; Lim & Sharmeen, 2018). Factors that influence a person with dementia’s ability to manage their medication include carer availability, regime complexity and healthcare professional awareness of cognitive impairment (Elliott et al., 2015). Researchers have considered how the multifaceted aspects of medication management (prescribing, dispensing, administration, adherence and review) may have been impacted by COVID-19 due to less contact with primary care and local pharmacies (Barry & Hughes, 2020). Participants in my qualitative study did not discuss less contact with local pharmacies, rather differences in access, for example the use of face covering or queuing outside to maintain social distancing. These findings provide further insight into how dementia care networks adapted during the pandemic to access support for long-term conditions.

Inhaler competency

In my qualitative study, I saw how the impact of dementia on self-management extended beyond adherence to oral medication. In one case study, inhaler use was challenging. Previous research has highlighted how motor skill impairment in dementia can impact the use of therapeutic devices (Ibrahim et al., 2017). The GP described how direct observations of inhaler technique was beneficial to detect changes in self-management ability as dementia progressed. Research into use of inhalers in community dwelling older people suggest how perceived inhaler skill competency poorly correlates with actual performance thus requiring in-person review by a professional (Ho et al., 2004). Through comparing qualitative interviews and GP consultation notes, the specific contribution of my thesis includes demonstrating the implementation gap between policy and the care received by people with dementia and long-term conditions. Such as the lack of consideration of cognitive impairment in clinical guidelines for asthma and COPD. My findings suggest how observation of a person's abilities without a family carer was beneficial in one case study, as presentation together in primary care made it difficult for the GP to disentangle care needs.

Behaviour change

My findings highlight the family carer role in proxy decision making, a role which was at times shared with the person with dementia or made on their behalf. One useful framework for understanding this finding is the Theory of Planned Behaviour (Ajzen, 1991). This theory posits how intention is critical in deciding to engage in a behaviour, which is in turn determined by: attitude towards the behaviour, subjective norms and perceived behavioural control. In this context, decisions should ideally be based on the attitudes and norms of the person living with dementia. However, I found that decisions were often in practice made based on family carer attitudes and norms.

I consider these findings in line with the COM-B model (outlined in section 2.4) which suggests how behaviour change is related to capabilities, motivation and opportunity (Michie et al., 2011). I saw how people with mild dementia might be supported to self-manage despite declining capacity, where they had the opportunity to do this and especially where motivation was high. Unfortunately, there was a clear impact of the pandemic on reducing opportunities for this, through the challenges posed by the shift to remote working and cancelled routine services. In several of my case studies, I saw how family carer motivation was key for opportunities and reduced where they could not see the utility of a certain service or treatment for the person they cared for. For example, the decision of a son to remove his mother from a cataract waiting list as he perceived her mobility issues to be a barrier to attending appointments. This builds on previous studies which have applied behaviour change constructs to models for physical activity in dementia (Lorito et al., 2019), specifically how capabilities (i.e. actual rather than perceived abilities) and motivation (i.e. apathy, physical and cognitive deterioration) can be impacted by dementia-specific factors. My findings related to the role of the family carer in providing opportunity for people with dementia to be involved in care for long-term condition management suggests how further decision making support may be required in this context, specifically in relation to addressing family carer motivations.

9.2.2.2. Balancing health needs

Shifting perspectives

Living well with dementia will have a different meaning to each individual thus necessitating a holistic approach to care (Quinn et al., 2021). In a secondary qualitative analysis of the experiences of family carers of older people with multiple long-term conditions in the community, participants commonly prioritised conditions that require immediate or ongoing attention such as safety and pain (Ploeg et al., 2020). In my qualitative study, I found that the experience of providing and supporting long-term conditions in dementia is dependent on salient issues, which may be physical, mental or cognitive depending on the stage of cognitive or physical decline. My findings emphasise how people with dementia and family carers are adaptive in prioritising needs in a holistic way.

I consider how this finding aligns with the Shifting Perspectives Model of Chronic Illness (Paterson, 2001). As outlined in section 2.8, this model proposed how chronic disease is a continually shifting process rather than a linear trajectory, with either illness or wellness in the foreground at any time. Paterson considered insight and awareness integral to identifying and responding to changes in perspectives therefore the original model would not apply to people in the advance stages of dementia. My findings indicate how people with dementia and those involved in their care perceive issues around cognition, physical and/or mental health to take precedence at different times depending on severity and salience. Such findings expand on knowledge suggesting that as people progressed into the later stages of dementia, due to declining insight, family carers took on responsibility for prioritising care needs. Thus, the Shifting Perspectives Model of Chronic Illness may be a helpful paradigm applied to the decision making of family carers in the context of long-term conditions in dementia.

Hierarchy of needs

This thesis expands knowledge relating to the support needs of people with dementia and long-term conditions. I found that avoidance of falls was often prioritised over other presenting issues (physical, mental, cognitive), due to fears about the potentially severe consequences. People with dementia have a higher incidence of falls compared to people without dementia (Allan et al., 2009). Previous research supports the adoption of a holistic approach to fall management due to the association with psychosocial factors such as social isolation and depression (Wheatley et al., 2019). Yet due to safety concerns, professionals have been found to prioritise physical need over psychological need (Stevenson et al., 2016). In my qualitative study I recorded several examples where risk of falls led to participants being housebound, anxious or lonely, and it was not apparent that these needs were recognised and actively considered alongside the risk of falls.

Previous literature has identified how depressive symptoms can impact a person with dementia’s motivation to engage in self-management behaviours (Ibrahim et al., 2017). On the contrary, in one case study, a person in the early stages of dementia engaged in self-care activities (i.e. daily jogging) to manage his low mood, symptoms of which were exacerbated by recognition of cognitive decline. In this example, the person with dementia did not discuss mental health with the GP as they conceptualised it as part of living with dementia. This is consistent with studies exploring primary care professional attitudes towards later-life depression, where low mood was not seen as a legitimate topic to discuss with the GP. In this study, the concept of ‘justifiable depression’ was used for older adults experiencing loneliness and reduced function (Burroughs et al., 2006). My findings suggest that depression may not be managed in the same way as other long-term conditions as it is conceptualised as a symptom of dementia.

9.2.3 Networks of care

9.2.3.1. Family-centred approaches

The findings of my PhD, related to the central role of the family carer, support the assertion that the acceptance of interdependence is required to achieve person-centred care in dementia (Manthorpe & Samsi, 2016). The role of family carers in supporting the management of long-term conditions in dementia has been demonstrated in previous research (Bunn, Goodman, et al., 2017). This thesis expands on these findings illustrating the responsibilities of carers in supporting the management of long-term conditions beyond diabetes, stroke and visual impairment and also how these responsibilities were exacerbated during the pandemic.

Family carers were important care partners supporting people with dementia to manage their long-term conditions. These findings are consistent with The Theory of Dyadic Illness Management (outlined in section 2.4) which recognises the importance of adopting a dyadic perspective to illness management (Lyons & Lee, 2018). Lyons and Lee described that addressing incongruence between appraisal of illness within dyads is key for better health through collaborative management. My findings expand on this theory, recognising how dementia impacted a person's ability to appraise long-term conditions. As a result, appraisal of illness became the responsibility of family carers as dementia progressed. The specific contribution of my thesis includes the illustration of the challenges of managing dyadic health appointments during the pandemic. As discussed in section 9.2.1, remote consultations often excluded people with dementia in the later stages resulting in their appraisal of illness not being included in care planning.

I observed how the closeness between people with dementia and their family carers at times led to competing and entwined needs and priorities. This led to incongruence between the values and needs of people with dementia and their family carer. At times, it was also unclear whether decisions made by the family carer aligned with the wishes of the person with dementia. For example, where family carer reconsidered the initiation of anti-dementia medication in response to increased agitation. This finding is consistent with previous research into pain assessment in dementia, which found that it was often difficult to separate the person with dementia and family carer's perspective (Amspoker et al., 2021).

In addition, consistent with previous research (Lam et al., 2020), I found how care provision and self-management support can be impacted by carer ill health. In one example from my qualitative study, the recovery of a primary carer from open heart surgery necessitated additional support from his daughter, who then became a carer for her mother with dementia. These findings support the dyadic health concept of the theory and thus have implications for when a family carer is not available to support a person with dementia to manage their long-term conditions.

9.2.3.2. Role of the homecare worker

My PhD expands on previous literature which consider healthcare interactions to be triadic with persons with dementia, family carers and healthcare professionals (Fortinsky, 2001). In this section, in line with previous research I consider how homecare workers hold an important position in care networks (Leverton et al., 2021). In my secondary analysis, I had the opportunity to explore how homecare workers engaged with care for long-term conditions. Participants reported how rules around medication administration were complex. Previous research has highlighted the frequency of medication errors in homecare which can impact patient safety (Berland & Bentsen, 2017). My findings expand on this as I found how the provision of emergency medication was impacted as such medication administration fell between a personal care and medical care task.

A similar pattern of role restrictions for homecare workers was described in my qualitative study, where the preparation of fruit and vegetables to support constipation was not possible due to health and safety rules. Researchers have highlighted how the collaborative relationship between homecare workers and family carers to manage nutrition for older adults in the community may improve health related outcomes (Marshall et al., 2017). I observed how such a collaboration was difficult to achieve in practice especially during COVID-19.

Participants at times expressed strong views regarding homecare workers with two care networks declining support due to negative past experiences or difficulties relinquishing control of responsibilities for care to another. I found decision making around home care to be related to carer perception of value added to care compared to burden of coordination. Decision making processes around involvement of homecare workers may have been influenced by COVID-19 due to risk of transmission and adequate use of Personal Protective

Equipment (PPE; Giebel et al., 2020). In the transition to post-pandemic healthcare delivery, family carers may require additional decision making support to consider the risks and benefits of involving homecare workers to support the management of long-term conditions for people with dementia.

9.2.3.3. Importance of professional support

Primary care has been identified as being well placed to support long-term condition management (Browne et al., 2017; Greenwood et al., 2016). My findings highlight the multitude of services accessed by people with dementia (and their carers) to manage co-existing long-term conditions. These mirror a recent mapping study, which found post-diagnostic dementia care in England to include physical health reviews in primary care, mobility and fall services, nutrition advice, and hearing support in secondary care, while foot and vision services were found to be accessed privately (Frost, Walters, et al., 2021).

Previous research into the management of diabetes in dementia suggests how regular contact with a supportive professional improves management by providing flexible individualised care which develops over time (Bunn, Goodman, et al., 2017). In my qualitative study I found how family carers curated supportive professional networks. In several case studies I observed how professionals adapted care based in collaboration with the family carer to support the health needs of a person with advanced dementia. These findings are consistent with House of Care Model, where healthcare professionals commit to working in partnership to achieve personalised care (Coulter et al., 2013). As outlined in section 2.9, this model assumes that individuals (and carer) are active, engaged and informed. My findings expand on this theory, suggesting how the ability of a person to fulfil the aforementioned criteria reduced as cognition declines. This highlights the importance of dyadic care in the context of dementia, and the support required from professional to ensure family carers are engaged and informed.

In my qualitative study, participant accounts did not disclose any evidence of care planning with people with dementia directly. This is consistent with national health data which reports only 14.7% of those with a record of received a dementia care plan by their GP in January 2021 had their medication reviewed in the preceding 12 months (NHS Digital, 2021). This may have been related to changes in service provision during COVID-19, which impacted the quality of consultations with primary care particularly when addressing physical health needs (Tuijt, Rait, et al., 2021).

In Table 9.2, I summarise how the findings from my PhD support the existing theories I outlined in Chapter Two.

Table 9.2. Summary of theoretical discussion

Topic	**Theorical framework**	**Supporting findings**	**Additional findings**
Continuum of support	Transition Theory (Meleis et al., 2000)	Situational transition (changes in role for family carer). Health-illness transition (family carer).	Health-illness transition (person with dementia). Organisational transition (COVID-19). Interacting transitions (family carer and person with dementia).
Holistic and adapted care	Shifting Perspectives Model of Chronic Illness (Paterson, 2001) COM-B model (Michie et al., 2011)	Fluctuating perspectives of illness over time. *Capabilities* and *motivation* of person with dementia impacted by cognitive decline.	Physical, cognitive or mental health prioritisation- perspective of family carer or person with dementia (depending on insight). Role of family carer in providing *opportunity.*
Networks of care	Theory of Dyadic Illness management (Lyons and Lee, 2018) House of Care Model (Coulter et al., 2013)	Dyadic health (family carer and person with dementia). Incongruence between needs of people with dementia and family carer. Partnership working with professionals.	Impact of dementia on ability to appraise and manage long-term conditions. Support when ability to be *active* and *informed* declines.

9.3 Strengths and limitations

In this section, I consider the strengths and limitations of my thesis as a whole as I provide discussion for each individual study in Chapter Four (section 4.4.2), Chapter Five (section 5.5.2) and Chapter Eight (section 8.4.2).

9.3.1 Research value

This thesis makes a novel contribution to knowledge relating to support for the management of long-term conditions in dementia. My qualitative study was the first study in this area to combine data sources including consultation notes and event-based diaries. The pandemic context meant that I observed interactions at an unprecedented time of healthcare delivery. While the need to avoid face-to-face contact meant opportunities lost for potentially richer data collection, it also enabled me to explore how to adapt methodologies to engage participants with dementia remotely. I combined breath of experiences through my secondary analysis of a large number of interviews with diverse stakeholders to complement my qualitative study.

Each stream informed the subsequent study which enabled me to develop knowledge iteratively and design primary data collection for my PhD to address identified gaps. In stream one, I found limited research beyond the perspective of family carers and medication management in dementia. Thus, a novel contribution of this thesis is the inclusion of the experiences of people living with dementia themselves, alongside family carers, health and social care professionals and homecare workers, and experiences of self-management beyond medication adherence. Throughout this thesis, I have explored the breadth and depth of experiences of supporting the management of long-term conditions in dementia. A major strength of this thesis is the diversity in stakeholder perspectives and experiences including type of dementia, long-term conditions, level of cognitive impairment, degree of carer support and interaction with services.

9.3.2 Trustworthiness

Each stream of my PhD used qualitative approaches to understand the lived experience of people with dementia and multiple long-term conditions. Throughout data collection and analysis I was rigorous and transparent and used qualitative reporting guidelines to ensure credibility, namely: Consolidated criteria for reporting qualitative research (COREQ) checklist (Tong et al., 2007), and Standards for reporting qualitative research (SRQR) (O'Brien et al., 2014).

Lincoln and Guba (1985) suggest the trustworthiness of qualitative research can be evaluated using four criteria: credibility, transferability, dependability and confirmability. By triangulating a large dataset of qualitative interviews with in-depth case study analysis, I was able to include a range of perspectives to ensure findings represented the participants' 'truth' thus enhancing credibility. As data collection in my qualitative study covered a period of four months, I was able to enhance credibility through prolonged engagement with participants. I provided 'thick descriptions' of qualitative themes across this thesis, with similar findings present in each stream of my PhD, which enhances the transferability of my findings. My findings may be transferable to different yet similar contexts such as older and/or frail populations. However, the purpose of this thesis was to explore the management of long-term conditions in a dementia specific context. Through presenting an integrated summary of findings, I have been able to demonstrate the dependability of my findings as I found consistent themes across each stream of my PhD. To ensure confirmability that findings represent participants perspectives, I engaged in reflexive practice throughout my PhD to consider my positionality and acknowledge the impact of personal bias on research findings.

9.3.3 Representativeness

9.3.3.1. Sampling

Neither my secondary analysis nor qualitative study sought to be representative. Sampling for both streams were not geographically diverse with participants only having experience of English health systems. Recruitment challenges such as lack of awareness of research opportunities has led to concerns about the generalisability of dementia research (Bartlett et al., 2019). Thus, it is possible that the views of people with dementia not included in my PhD may differ from those represented in my findings. Research has indicated that participants in dementia intervention studies are more likely to be highly educated, white, men (Cooper et al., 2014). My sample was diverse in terms of gender and ethnicity yet recruitment strategies for my qualitative study meant my sample was not geographically diverse potentially underrepresenting the experiences of people living in rural areas.

An important element explored in my PhD included support from networks of care. A limitation of my findings therefore is the underrepresentation of people with dementia who live alone without support. Participation of people with dementia may depend on the availability of a ‘study partner’ who negotiate access to research (Bartlett et al., 2019). Interviews in the NIDUS dataset I used for secondary analysis did include people with dementia who lived alone, but all had a family carer. This was also true of my qualitative study. I was unable to recruit anyone living with dementia who did not have regular family carer support. I tried to mitigate this limitation with ethical approval for a nominated consultee although this proved difficult to obtain in practice highlighting the challenges of involving this population in research.

9.3.3.2. Data collection

I acknowledge the bias towards family carer accounts, especially in the availability of supporting quotes for themes across my thesis. This is a common methodological challenge in dementia research (Moore & Hollett, 2016).

Based on the findings of stream one and two, in my qualitative study I used event-based diaries to further include the perspective of people with dementia in research.

A limitation of all three streams of my PhD involved the lack of in-person data collection. Using a narrative synthesis in stream one, and secondary analysis in stream two meant I did not collect data from participants directly. My qualitative study used complementary data sources (interviews, document analysis) to explore management of long-term conditions in dementia, yet all data collection was conducted remotely. In the next section, I reflect on my experience of using remote data collection as part of my PhD to provide recommendations for future methodology.

9.4 Future directions

In this section I outline recommendations from my PhD for research, practice and policy.

9.4.1 Research

9.4.1.1. Recommendations for future methodology

Previous research has illustrated that participant observations are an effective methodology to involve people in the later stages of dementia in research (Leverton et al., 2021). My qualitative study was one of the first to use multiple data sources remotely to explore long-term condition management in dementia. However, the methods used could not substitute the rich data collection that would have been possible through in-person observations. It was however interesting to use methods in consultation with a research community making similar shifts (Krause et al., 2021). For example, I learnt from previous research, that the use of event-based diaries supported the engagement of people with dementia and sensory impairments (Välimäki et al., 2007), while documentary analysis of primary care records enabled me to include the perspectives of healthcare professionals whom I otherwise found difficult to recruit due to COVID-19 service pressures. I would recommend this triangulation with consultation notes to future researchers.

For research involving people with dementia, the use of technology to enable remote methods presented challenges. For future researchers interested in using remote methods, I recommend remaining mindful of participants use of technology, providing a variety of modalities to engage (Barry & Hughes, 2020). Practical and technological difficulties meant participant observation using Facebook Portal, where the whole room is visible compared to handheld devices or laptops, was not possible. Developing methods for remote observation of people with dementia is an interesting direction for future research. To increase the feasibility of this technology use, I recommend working with families in advance to plan room set up.

9.4.1.2. Recommendations for future research topics

This thesis adds to the growing body of literature around supporting the management of long-term conditions in dementia. Based on my findings, future research may usefully consider mechanisms for networks of care to map the impact of dementia on co-existing long-term conditions (and vice versa), and how to effectively intervene at points of transition. Research to date in this context has focused on the experiences of family carers (Ploeg et al., 2020). Future research should consider ways to involve networks of care in interventions to organise and utilise resources to support the management of long-term conditions in dementia. Future research could explore interactions with stakeholders I was unable to observe in my qualitative study, such as homecare workers, district nurses, friends and/or community groups who provide support for people with dementia and long-term conditions.

Exploring how long-term conditions in people with dementia without support are managed could be an important direction for future research. Research recommendation by NICE include exploring effective care planning methods for people who do not have regular contact with a carer (NICE, 2018c). People who dementia who live alone are more likely to use homecare services, and experience unmet social and medical needs (Miranda-Castillo et al., 2010). I would be interested to explore how my findings might be adapted to be relevant for people without a family carer.

9.4.2 Clinical Implications

9.4.2.1. Holistic care

Living with multiple long-term conditions in dementia requires the management and prioritisation of a variety of physical, cognitive and mental health needs. My findings illustrated how intertwined psychosocial and physical needs are, yet how psychological needs can be overlooked if they are conceptualised as inevitable sequelae of dementia. The bi-directional impact of physical, cognitive and mental health needs suggest they should be considered together in clinical practice. These findings accord with the integrated logic model of care which posits that psychosocial, mental, cognitive and physical needs should be addressed simultaneously due to their influence on each other (Hansen et al., 2017).

Researchers have argued that, due to the consequences of dementia on health, primary care should be organised around dementia rather than long-term conditions (Lazaroff et al., 2013). Identifying a ‘clinically dominant condition’ to consider all other long-term conditions against has been used as a framework in diabetes (Piette & Kerr, 2006). However, such approaches contrast with the management of multimorbidity which refers to no hierarchy of conditions with a focus on the individual (Almirall & Fortin, 2013). The adoption of generic rather than specific approaches to self-management has been criticised (Hinder & Greenhalgh, 2012). My findings support these calls for dementia to be the organising principle of care when managing co-existing long-term conditions due to the variety of ways dementia can impact both self-management, physical and mental health.

9.4.2.2. Flexible approach

Adopting a flexible approach, where those who provide care for people with dementia and multiple long-term conditions continually review abilities, will facilitate the adaptation of support in response to changing care needs. Such an approach may be used to develop individualised management plans to support independence by focusing on a person with dementia's skills and abilities, and to identify strategies to overcome the impact of cognitive impairment on self-management. One strategy to achieve this may be the use of prompts in primary care systems during dementia annual review to include an assessment of self-management abilities, care priorities, and to review the support provided by care networks. This method has been found to be effective in increasing uptake of NHS Health Checks (Gold et al., 2021).

9.4.2.3. Consider networks of care

Due to their integral role in negotiating symptoms and implementing medical advice in the community, my findings underline the importance of considering the needs of family carers. Building discussions of partnership working, understanding support requirements (such as proxy decision making) and being explicit about stakeholder responsibilities is necessary to achieve holistic management. Person-centred approach which focuses on 'need not disease' may support family carers to implement medical recommendations for people with dementia in the community through improved coordination and planning. For example, the adoption of a patient-centred model of care in a six-monthly comprehensive review (with a GP, nurse and pharmacist) to replace disease focused reviews which use specific data entry screens or templates based on QOF has been suggested (Salisbury et al., 2018).

A major finding from my work is the extensive implementation gap between aspirations for holistic care that permeate current policy and the lived experiences of some people living with dementia and their families. The House of Care model Framework sought to address the gap between 'rhetoric and reality' in person-centred care (Coulter et al., 2016; Mathers & Paynton, 2016). In practice, family carers usually took responsibility for implementing medical recommendations in the community, often needing to adapt care based on evolving needs with little support. This is especially important to consider in light of COVID-19 where I found reluctance to accept support from homecare agencies, and reduced contact with wider family members and healthcare professionals.

In Figure 9.2 I summarise how my thesis might inform primary care practice. These areas relate to understanding the needs of dyads, enabling self-management for people with dementia, and how supportive approaches might be embedded in practice.

Figure 9.2. Clinical implications

Understanding

- Identify how/when cognitive impairment impacts self-management ability (adherence, communication, decision making).
- Recognise the value of independence for people with dementia.
- Understand the challenges carers may face when implementing advice in practice.

Enabling

- Develop individualised management plans focusing on skills and ability of the person with dementia (memory aids, prompts, deprescribing).
- Ensure the voice of the person with dementia is maintained during proxy communication in appointments.

Supporting

- Partnership working in care networks based on need and support requirements.
- Support family carers in best interest decision making.
- Communication to ensure care respond to evolving support needs.

9.4.3 Policy

Supporting the management of long-term conditions in dementia needs to be considered within the wider context of health and social care policy in England. In the context of multiple long-term conditions, there is limited understanding of how national guidelines are implemented in practice, which management approaches work best, and how COVID-19 has impacted service delivery and patient outcomes (Chudasama et al., 2021). My findings would support calls to move away from single disease frameworks of condition management (Welsh, 2019). My review of clinical guidelines outlined in section 2.7 found that dementia is usually not specifically referenced within guidelines for other long-term conditions. My findings highlight the need for clinical multimorbidity guidelines to recognise the specific impact of dementia on the management of long-term conditions, rather than being considered separately. Dementia-specific contexts include the need to adapt care to changing cognitive severities, organising care through multiple stakeholders, and managing long-term conditions based on the potential to impact cognition.

Dementia-specific care pathways are more explicit than guidelines and may be more suited to supporting holistic, personalised planning for multiple long-term conditions. Care pathways are an organisational approach to planning, resourcing and managing the care process for a defined group. Access to a specialist care pathway, rather than a dementia pathway, has been recommended for people with complex dementia and multiple long-term conditions (Prince et al., 2016). My findings suggest how care pathways for dementia and multiple long-term conditions must consider the impact of dementia on other long-term conditions, in addition to functional and self-management abilities.

Previous research into living with multimorbidity in the community suggests that older people do not necessarily differentiate between co-existing conditions, so find it challenging when services focus on a single disease (Ploeg et al., 2017). My finding related to perceived lack of integration between physical and cognitive health across primary and secondary care is supported by wider literature relating to caring for multimorbidity. Integrated Care Systems aim to connect and align primary and specialist care, physical and mental health services and health and social care services at a funding level to meet patient needs (NHS England, 2021f). Such systems have the potential to support management of multiple long-term conditions (Mahiben Maruthappu et al., 2016) yet require embedding of care coordination and navigation (Robertshaw & Cross, 2018). My findings would suggest that despite calls for the integration of physical, mental and cognitive health services, at a patient level, care is often not experienced as integrated. As policy develops, research such as this, which observes the realities of care can add a useful perspective to discussions with policy makers.

Chapter 10 Conclusion

In this PhD, I have explored how people with dementia manage, and can be supported to manage co-occurring long-term conditions, by family carers, and networks of care in the community. I explored the breadth and depth of experience from a diverse range of participants in both pre-and-post pandemic contexts. To my knowledge, my PhD is the first to use complementary data sources such as interviews and documentary analysis in this context, and my research provides further insights into the use of remote data collection in this population.

The findings presented in this thesis were developed iteratively, with each of my three streams informing the next. My systematic review was the first to consider enabling and inhibiting factors to self-management, rather than purely focusing on the impact of dementia on the management of long-term conditions. My findings highlighted the importance of collaboration between stakeholders, yet perspectives beyond the family carer were limited. My secondary analysis sought to address this gap and included a range of stakeholder perspectives including people living with dementia, family carers, health and social care professionals, and homecare workers. I found how the management of long-term conditions in dementia, which consisted of factors broader than medication management, existed on a continuum with support increasing with dementia severity. In my final study, I used multiple data sources to understand in-depth how this support happened in the community. Based in the context of COVID-19, my findings demonstrated the importance of independence for people in the early stages of the disease, and how family-centred approaches were required to acknowledge the realities of implementing care recommendations in the community. Participants described how cognitive, physical and mental health needs of the person with dementia often conflated with the needs of the family carers and how networks were curated to support the management of long-term conditions in dementia.

I conclude that support for managing long-term conditions in dementia should be holistic, flexible, and consider networks of care. To achieve holistic management, changing cognitive needs are required to be addressed in line with physical and mental health needs due to their interrelated presentations and impact. Flexible approaches will enable care to be adapted according to shifting care priorities, while the continuous review of the impact of dementia will facilitate the development of management plans to organise support based on individual ability. In the context of dementia, it is important to acknowledge the interdependencies with those who support care. The adoption of a dyadic perspective will incorporate the needs of each network member who negotiate and implement recommendations in community. Future research should investigate how care networks can effectively map the impact of dementia on long-term conditions to identify strategies for intervention.

The organisation of care based on ‘need not disease’ is a core component of person-centred management of multiple long-term condition. However, due to the impacts on and from dementia, this thesis highlights the need for dementia to be the organising principle of care. I found how the ideals of personalised care were difficult to achieve in practice and were exacerbated during the pandemic due to the challenges of including people with moderate to advanced dementia in remote consultations. Integrated Care Systems have the potential to coordinate the multitude of services involved in the planning of care for long-term conditions in dementia. Partnership working between primary and secondary care with those who support the implementation of care in the community may facilitate the continuous review and adaptation of care and support needs to effectively support the management of long-term conditions in dementia.

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Appendices

Appendix 1. Table of clinical guidelines

Clinical Guideline	*Date*	*Link*	*Statement and recommendation about issues related to dementia (or cognitive impairment)* [4]
Diabetes (Type 2)	2019	https://www.nice.org.uk/guidance/ng28	No specific mention of dementia 1.2.5 Ensure that the patient-education programmes available meet the cultural, linguistic, cognitive and literacy needs within the local area. [2009]
Hypertension	2019	https://www.nice.org.uk/guidance/ng136	No specific mention of dementia. "High blood pressure (hypertension)... is a major risk factor for stroke, myocardial infarction, heart failure, chronic kidney disease, cognitive decline and premature death."
Chronic heart failure	2018	https://www.nice.org.uk/guidance/ng106	No specific mention of dementia. 1.7.1 All people with chronic heart failure need monitoring.

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[4] Each guideline searched for 'Dementia' and 'Cognitive'

			This monitoring should include: a clinical assessment of functional capacity, fluid status, cardiac rhythm (minimum of examining the pulse), cognitive status and nutritional status
Cardiovascular disease	2016	https://www.nice.org.uk/guidance/cg181	No specific mention of cognitive impairment Controversy also exists about the efficacy of statins in preventing or promoting other chronic diseases of ageing such as dementia, Parkinson's disease, or age-related macular degeneration.
Stroke	2019	https://www.nice.org.uk/guidance/ng128	Cognitive abilities identified in section of optimal positioning. 1.7.1 Assess the individual clinical needs and personal preferences of people with acute stroke to determine their optimal head position. Take into account factors such as their comfort, physical and cognitive abilities and postural control. [2019]
Parkinson’s	2017	https://www.nice.org.uk/guidance/ng71	1.5.21 For guidance on hallucinations and delusions in people with dementia, see managing non-cognitive symptoms in the NICE guideline on dementia. [2017] Parkinson's disease dementia 1.5.22 Offer a cholinesterase inhibitor [5] for people with mild or moderate Parkinson's disease dementia. [2017]

			1.5.23 Consider a cholinesterase inhibitor [6] for people with severe Parkinson's disease dementia. [2017] 1.5.24 Consider memantine [7] for people with Parkinson's disease dementia, only if cholinesterase inhibitors are not tolerated or are contraindicated. [2017] 1.5.25 For guidance on assessing and managing dementia, and supporting people living with dementia, see the NICE guideline on dementia. [2017] Parkinson's disease has historically been recognised as a primary movement disorder. However, other symptoms may be prominent, such as depression, cognitive impairment and dementia. Research recommendations 1 Combination treatment for Parkinson's disease dementia What is the effectiveness of combination treatment with a cholinesterase inhibitor and memantine for people with Parkinson's disease dementia if treatment with a cholinesterase inhibitor alone is not effective or no longer effective? 3 Rivastigmine is commonly used to treat Parkinson's disease psychosis because it has shown some effectiveness in improving behavioural symptoms in people with Parkinson's disease dementia

Epilepsy	2020	https://www.nice.org.uk/guidance/cg137	No specific mention of dementia. 1.6.33 Referral for a neuropsychological assessment is indicated: • when an MRI has identified abnormalities in cognitively important brain regions • when a child, young person or adult complains of memory or other cognitive deficits and/or cognitive decline. [2004]
Depression	2009	https://www.nice.org.uk/guidance/cg90	No specific mention of dementia 1.1.4.4 When assessing a person with suspected depression, be aware of any learning disabilities or acquired cognitive impairments, and if necessary, consider consulting with a relevant specialist when developing treatment plans and strategies. 1.1.4.5 When providing interventions for people with a learning disability or acquired cognitive impairment who have a diagnosis of depression: • where possible, provide the same interventions as for other people with depression • if necessary, adjust the method of delivery or duration of the intervention to take account of the disability or impairment Information regarding cognitive functioning and ECT
Asthma	2020	https://www.nice.org.uk/guidance/ng80	No specific mention of dementia (or cognitive impairment)

COPD	2019	https://www.nice.org.uk/guidance/ng115	No specific mention of dementia. Most people with COPD – whatever their age – can develop adequate inhaler technique if they are given training. However, people with significant cognitive impairment may be unable to use any form of inhaler device.
Rheumatoid arthritis	2018	https://www.nice.org.uk/guidance/ng100	No specific mention of dementia (or cognitive impairment)
Osteoarthritis	2014	https://www.nice.org.uk/guidance/cg177	No specific mention of dementia (or cognitive impairment)
Osteoporosis	2017	https://www.nice.org.uk/guidance/cg146	No specific mention of dementia (or cognitive impairment)
Thyroid	2019	https://www.nice.org.uk/guidance/ng145	Several large population-based observational studies have shown that subclinical hyperthyroidism is associated with an increased risk of atrial fibrillation, osteoporosis, dementia, and death, including death from cardiovascular disease. Although most people with subclinical hyperthyroidism have no symptoms, an important question is whether treatment could improve long-term outcomes (for example, atrial fibrillation and dementia). Data on the long-term consequences of subclinical thyroid dysfunction largely come from people over 65. They indicate increased cardiovascular morbidity and mortality, an increased risk of osteoporosis and potential links to dementia.

Appendix 2. Systematic review paper IJNS

International Journal of Nursing Studies 116 (2021) 103432

Contents lists available at ScienceDirect

International Journal of Nursing Studies

journal homepage: www.elsevier.com/ijns

Supporting self-care of long-term conditions in people with dementia: A systematic review

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A R T I C L E I N F O

Article history:
Received 12 June 2019
Received in revised form 9 September 2019
Accepted 13 September 2019

Keywords:
Dementia
Long-term conditions
Management
Multi-morbidity
Physical health
Review
Self-care

A B S T R A C T

Background: Long-term conditions are common in people living with dementia; their self-management is an important determinant of wellbeing. Family carers often support or substitute self-care activities, and act as proxies for self-management, as dementia progresses.
Objectives: To conduct the first systematic review of how management of long-term conditions in people with dementia is best enabled and supported, including factors that facilitate or inhibit self-management and management by a proxy.
Design: Systematic review.
Data Sources: We systematically searched MEDLINE, PsychINFO, Embase and Allied and Complementary Medicine databases up to November 2018.
Review methods: We identified the long-term conditions most prevalent in people with dementia that require an element of self-management. We then developed our inclusion criteria to identify qualitative and quantitative studies describing the self-management (or self-management assisted by family carers) of long-term conditions in people with dementia. Two authors independently rated study validity using a standardised checklist. We synthesised qualitative and quantitative findings using a data driven convergent synthesis approach.
Results: We included 12 articles meeting predetermined inclusion criteria: seven qualitative, two case studies, two quantitative and one mixed methods study. We identified four main themes across these studies: (1) dementia symptoms impeding treatment regimens (forgetfulness, decreased understanding, ability to communicate symptoms and behavioural and psychological symptoms); (2) adapting routines to be simpler, (using memory aids and accommodating physical limitations); (3) negotiating self-management support (carer availability and knowledge; balancing needs for safety and empowerment); and (4) interface with professionals, (Routine simplification, condition specific education, and acknowledging carer role).
Conclusions: People living with dementia can be supported to manage their own health for as long as possible, through simplifying routines and reminding, but where this can no longer be negotiated, carers take over responsibility for self-management, often due to safety concerns. Empowerment of people with dementia to remain involved in their care reduces the loss experienced by this transition. Communication and partnership between clinicians and carers is critical when supporting people living with a long-term condition and dementia. Care planning for people living with dementia and a long-term condition should include explicit discussion of how these partnerships will work and guidance on strategies carers can use to support people to self-manage long-term conditions.

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https://doi.org/10.1016/j.ijnurstu.2019.103432

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Appendix 3. Systematic review search terms

	MESH terms	Free text terms
Management	Self-Management Self-Care Patient Education as Topic Health promotion Disease management Medication adherence Patient Compliance Healthy Diet Exercise Smoking cessation Nebulizers and Vaporizers Breathing exercises	self manag* or Self-manag* or Self-car* or self-care or self-monitor* or self-regulat* or drug manag* or medication concordance or prescription manag* or prescription concordance or medicine manag* or adherence or long-term medication or diet* advice or fluid intake/ or fluid restriction or nutritional status or physical activity or breathing control or peak flow or health coaching or appointment* or manage*or disease manage* or glucose
AND		
Dementia	Dementia Alzheimer's Disease	dementia* or alzheimer's*
AND		
Physical Health	Health Status Chronic Disease Long-Term Care Primary Health Care	physical health or primary care or long-term condition or long-term effects or long-term condition or chronic condition or chronic disease or chronic illness
OR		
Conditions	Pulmonary Disease, Chronic Obstructive Osteoarthritis Cardiovascular disease Heart Failure Coronary disease Diabetes Mellitus, Type 1, Type 2	asthma or bronchitis or inhalation or chronic pain or arthritis or Heart disease or heart failure or Rheumatology or diabetes or diabetes mellitus

Appendix 4. Characteristics systematic review included studies

Author & Location	Study Aim	Sample	Study type, Data analysis	Main Finding
(Allen et al., 2017), USA	Describe technology use for diabetes and dementia.	2 people with dementia & diabetes.	Case study.	Wearable diabetes technologies reduced glucose variability, hypoglycaemia & improving wellbeing and care.
(Brauner et al., 2000), USA	Understand how dementia affects treatment for non-dementia illnesses.	1 person with dementia & osteoporosis.	Case study.	Decision making capacity, altered benefits and burdens, ability to adhere and report adverse events and availability of carers important in treating non-dementia illnesses.
(Gillespie et al., 2015), Australia	Medication management experiences of ethnic minority family carers of dementia.	29 family carers for dementia and diabetes, arthritis, hypertension, osteoporosis.	Focus group and semi-structured interviews, thematic analysis.	Themes: 1) Medication management is stressful for family carers, 2) Medication management may be a point of conflict, 3) Family support is critical, 4) family carers want external information and support.
(Poland et al., 2014), UK	Views of medication management in dementia through patient and public involvement.	9 carers from research network for people with pain, hypertension, diabetes osteoporosis.	Workshop, focus group, thematic and narrative analysis.	Themes: (1) Medication use and administration practicalities, (2) Communication barriers and facilitators, (3) Bearing and sharing responsibility, (4) Weighing up medication risk and benefits.

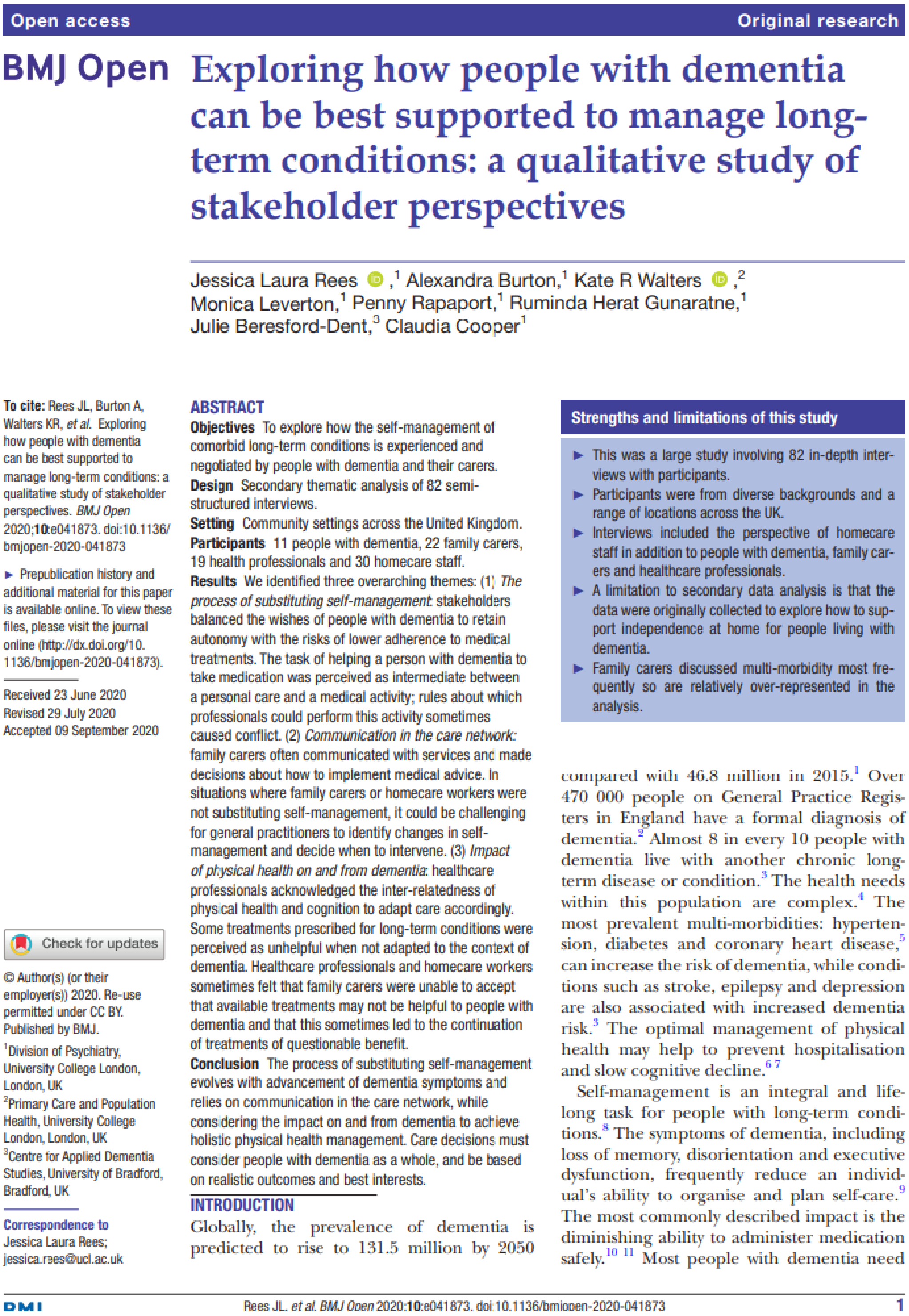
(Sadak et al., 2018), USA	Develop measure to monitor family carer management of dementia healthcare.	16 healthcare professionals, 35 family carers of dementia focus on general health.	Focus groups, stepwise attribute manner.	Themes: (1) Dementia influences health/Family carers responsible for health needs, (2) People with dementia and family carers are a unit of care/self-care not prioritised in family carers, (3) Activated family carers better/Family carers defer the expert role to clinicians, (4) Good self-care is necessary/Professionals disregard their views and opinions, (5) Family carers uncomfortable asking for help.
(While et al., 2013), Australia	Differences in medication management for people with dementia and family carers.	8 people with dementia and 9 family carers administering medication at home, discusses stroke.	Semi-structured interviews, grounded theory.	Themes: (1) Self-management, (2) Something changes, (3) Family carer advocacy, (4) The medication team.
(Bunn, Burn, et al., 2017), UK	Impact of dementia on access to non-dementia services.	28 people with dementia, 33 family carers and 56 professionals, people with diabetes, stroke, visual impairment.	Semi-structured interviews and focus groups, thematic analysis.	Themes: (1) Family carers facilitate access to care and continuity of care, (2) Dementia severity & management, (3) Communication and collaboration.
(Feil et al., 2011), USA	Family carer challenges experience of managing diabetes in people with dementia.	21 family carers of people with dementia and diabetes.	Focus group, grounded theory.	Themes: (1) Memory loss led to family carer intervention, (2) Behavioural and psychological symptoms disrupted diabetes care routine, (3) Diabetes and dementia highly burdensome, and more support required.

(Sadak et al., 2017), USA	Family carer experience of dementia health crises.	20 family carer of people hospitalised for heart failure, hypertension or COPD.	Semi-structured interviews.	Themes: (1) Uncertain act on the change, (2) Unable to provide necessary care, (3) Family carer experiences a personal crisis, (4) Mitigating factors may prevent caregiver crises.
(Yarnall et al., 2012), UK	Assess diabetes care in UK care homes and including resident views.	31 people with dementia living in 7 care homes, 5 managers and 7 staff.	Questionnaire and qualitative semi-structured interviews.	63% of people with dementia had glucose monitored unnecessarily. One staff with diabetes training. 90% saw a chiropodist and >80% had an eye screening. Themes: 1) Diabetes understanding/complications, 2) Information from professionals.
(Chen et al., 2017), China	To analyse the effects of intensive and mitigation blood glucose control.	90 people with dementia and diabetes randomly allocated to control (diet/exercise), insulin/medication or personalised treatment.	Clinical observation, quantitative.	Moderate control of glucose and proper increase of target value benefit diabetes management in people with dementia. Personalised treatment plan recommended.
(De Oliveira et al., 2014), Brazil	How awareness of cerebrovascular risks impact adherence.	Questionnaire for 217 family carer of dementia outpatients with diabetes and hypertension.	Questionnaires.	Family carer awareness of the need to control cerebrovascular risk has positive impacts for people with dementia.
(Kamimura, 2019)	Describe use of automatic medication dispenser for long-term conditions in Alzheimer’s disease.	Four older adults with Alzheimer’s disease and gastritis, diabetes, hypertension, and dyslipidaemia.	Case study.	Use of automatic medication dispenser for polypharmacy resulted in reduced caregiver burden, and medication adherence remaining good.

Appendix 5. Quality evaluation of systematic review included studies

		(Allen et al., 2017)	(Brauner et al., 2000)	(Bunn, Burn, et al., 2017)	(Chen et al., 2017)	(De Oliveira et al., 2014)	(Feil et al., 2011)	Kamimura (2019)	(Gillespie et al., 2015)	(Poland et al., 2014)	(Sadak et al., 2017)	(Sadak et al., 2018)	(While et al., 2013)	(Yarnall et al., 2012)
Qualitative Studies	1.1. Is the qualitative approach appropriate to answer the research question?	No	Yes	Yes			Yes		Yes	Yes	Yes	Yes	Yes	
	1.2. Are the qualitative data collection methods adequate to address the research question?	No	Can't tell	Yes			Yes		Yes	Yes	Yes	Yes	Yes	
	1.3. Are the findings adequately derived from the data?	Yes	Yes	Yes			Yes		Yes	Yes	Yes	Yes	Yes	
	1.4. Is the interpretation of results sufficiently substantiated?	Yes	No	Yes			Yes		Yes	Yes	No	No	Yes	
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?	Can't tell	Yes	Yes			Yes		Yes	Yes	Yes	Can't tell	Yes	
Randomised Trial	2.1. Is randomization appropriately performed?				Yes									
	2.2. Are the groups comparable at baseline?				Yes									
	2.3. Are there complete outcome data?				Can't tell									
	2.4. Are outcome assessors blinded to the intervention?				Can't tell									
	2.5 Did the participants adhere to the assigned intervention?				Yes									
Quantitative Descriptive	4.1. Is the sampling strategy relevant to address the research question?					Yes		Yes						
	4.2. Is the sample representative of the target population?					Yes		Yes						
	4.3. Are the measurements appropriate?					Can't tell		No						
	4.4. Is the risk of nonresponse bias low?					Yes		No						
	4.5. Is the statistical analysis appropriate to answer the research question?					No		N/A						
Mixed methodology Studies	5.1. Is there an adequate rationale for using a mixed methods design?													Yes
	5.2. Are the different components of the study effectively integrated?													No
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?													No
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?													No
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?													No

Appendix 6. Secondary analysis paper BMJ Open



Open access Original research

BMJ Open

Exploring how people with dementia can be best supported to manage long-term conditions: a qualitative study of stakeholder perspectives

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To cite: Rees JL, Burton A, Walters KR, *et al*. Exploring how people with dementia can be best supported to manage long-term conditions: a qualitative study of stakeholder perspectives. *BMJ Open* 2020;**10**:e041873. doi:10.1136/bmjopen-2020-041873

► Prepublication history and additional material for this paper is available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2020-041873).

Received 23 June 2020
Revised 29 July 2020
Accepted 09 September 2020

Check for updates

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ABSTRACT

Objectives To explore how the self-management of comorbid long-term conditions is experienced and negotiated by people with dementia and their carers.

Design Secondary thematic analysis of 82 semi-structured interviews.

Setting Community settings across the United Kingdom.

Participants 11 people with dementia, 22 family carers, 19 health professionals and 30 homecare staff.

Results We identified three overarching themes: (1) *The process of substituting self-management*: stakeholders balanced the wishes of people with dementia to retain autonomy with the risks of lower adherence to medical treatments. The task of helping a person with dementia to take medication was perceived as intermediate between a personal care and a medical activity; rules about which professionals could perform this activity sometimes caused conflict. (2) *Communication in the care network*: family carers often communicated with services and made decisions about how to implement medical advice. In situations where family carers or homecare workers were not substituting self-management, it could be challenging for general practitioners to identify changes in self-management and decide when to intervene. (3) *Impact of physical health on and from dementia*: healthcare professionals acknowledged the inter-relatedness of physical health and cognition to adapt care accordingly. Some treatments prescribed for long-term conditions were perceived as unhelpful when not adapted to the context of dementia. Healthcare professionals and homecare workers sometimes felt that family carers were unable to accept that available treatments may not be helpful to people with dementia and that this sometimes led to the continuation of treatments of questionable benefit.

Conclusion The process of substituting self-management evolves with advancement of dementia symptoms and relies on communication in the care network, while considering the impact on and from dementia to achieve holistic physical health management. Care decisions must consider people with dementia as a whole, and be based on realistic outcomes and best interests.

Strengths and limitations of this study

- ► This was a large study involving 82 in-depth interviews with participants.
- ► Participants were from diverse backgrounds and a range of locations across the UK.
- ► Interviews included the perspective of homecare staff in addition to people with dementia, family carers and healthcare professionals.
- ► A limitation to secondary data analysis is that the data were originally collected to explore how to support independence at home for people living with dementia.
- ► Family carers discussed multi-morbidity most frequently so are relatively over-represented in the analysis.

INTRODUCTION

Globally, the prevalence of dementia is predicted to rise to 131.5 million by 2050 compared with 46.8 million in 2015.[1] Over 470 000 people on General Practice Registers in England have a formal diagnosis of dementia.[2] Almost 8 in every 10 people with dementia live with another chronic long-term disease or condition.[3] The health needs within this population are complex.[4] The most prevalent multi-morbidities: hypertension, diabetes and coronary heart disease,[5] can increase the risk of dementia, while conditions such as stroke, epilepsy and depression are also associated with increased dementia risk.[3] The optimal management of physical health may help to prevent hospitalisation and slow cognitive decline.[6 7]

Self-management is an integral and lifelong task for people with long-term conditions.[8] The symptoms of dementia, including loss of memory, disorientation and executive dysfunction, frequently reduce an individual's ability to organise and plan self-care.[9] The most commonly described impact is the diminishing ability to administer medication safely.[10 11] Most people with dementia need help to manage care for comorbid long-term conditions—usually from a family carer or homecare worker, or both.[12–14] Partnership between this care network at home and primary care is critical for the management of long-term conditions in dementia.[15]

Research has highlighted a need for guidance on how to tailor and individualise care for people with dementia and long-term conditions.[16 17] Clinical guidelines aim to promote evidence-based best practice but tend to focus on single conditions, so may not reflect difficulties in managing multi-morbidity in dementia.[18–20] Understanding the lived experiences of stakeholders is critical to the development of relevant clinical guidelines, including considering interactions between comorbidities on the ability of an individual to self-manage their care.[21] The first step towards service development includes understanding the care needs of people living with dementia and coexisting long-term conditions.[4] A recent review of the literature found limited evidence about how self-management and support by other stakeholders, such as homecare workers, can support long-term condition management in dementia.[15]

This paper aims to explore the experiences of people living with dementia, family carers, healthcare professionals and homecare staff, to identify how the management of long-term conditions is best supported in dementia.

METHODS

The New Interventions for Independence in Dementia (NIDUS) Study (ISRCTN11425138/ISRCTN99460116) conducted qualitative, semi-structured interviews with people with dementia, family carers, health and social care professionals and homecare staff. The primary analysis of this qualitative data explored how people with dementia can be supported to live as independently as possible in their own homes,[22] including a separate analysis on the experiences of South Asian family carers.[23] We carried out a secondary analysis of the transcripts to explore the management of long-term conditions for people living at home with dementia.

Recruitment

People with dementia and family carers were recruited through three UK National Health Service (NHS) memory services, private homecare services, an Alzheimer's Society Experts by Experience group and Twitter. Health and social care professionals were recruited through NHS memory services, social services and clinical academics with links to University College London. For the homecare staff interviews, 10 homecare agencies were recruited across England and managers, office support staff and homecare workers were invited to participate. Purposive sampling ensured our sample of people with dementia and family carers was diverse in terms of age, gender and ethnicity; for family carers, their relationship to care recipients; and for professionals, their professional roles and experiences with supporting people with dementia.

Procedure

Participants were invited to take part in semi-structured qualitative interviews between April and September 2018. All participants gave written informed consent. Interviews lasted on average 1 hour and were conducted in participants' homes, workplaces or at university offices. Interviews followed a semi-structured topic guide which explored how people with dementia live independently at home and what support they need to do so. They were audio-recorded and transcribed verbatim. Across stakeholders, slightly amended versions of the topic guide were used. The interview schedule for people with dementia and family carers included specific questions about how long-term physical or mental health conditions affected the person with dementia's ability to remain living independently at home.

Data analysis

Secondary analysis involves using pre-existing qualitative data collected from previous research studies to investigate new or additional research questions.[24] We took an inductive thematic approach through focusing on meaning within the data to develop codes[25] using NVivo 12 software.[26]

First, the lead author highlighted information in transcripts relating specifically to long-term conditions in addition to dementia. A coding framework was developed with authors (CC, KRW, AB) based on line-by-line coding of highlighted sections (see online supplemental material). The authors systematically labelled codes based on meaningful fragments of transcripts. We met to agree on re-occurring codes, and the lead author applied the coding framework to all transcripts. After completed analysis of all interviews, we reviewed and refined the coding framework by discussing themes corresponding to the research question. We revisited codes looking at commonalities and differences in managing long-term conditions across accounts of all stakeholders for the thematic analysis.

Patient and public involvement

An advisory group of family carers and health professionals provided feedback on the findings from the NIDUS qualitative study which was incorporated into the analysis. We did not directly involve patients and the public in this secondary analysis, but we have invited members of the advisory group to help us develop our dissemination strategy.

RESULTS

Qualitative interviews were conducted with 11 people with dementia (mean age=78.6, SD=7.8), 22 family carers (mean age=57.7, SD=14.3), 19 health and social care professionals (mean age=41.4, SD=10.9) and 30 homecare

Table 1 Characteristics of participant demographics (person with dementia/family carer)

Characteristics	Person with dementia n	Family carer n
Gender		
Female	5	12
Male	6	10
Ethnicity		
White British	8	9
White other	1	0
Indian	0	6
Bangladeshi	0	4
Other	2	3
Living arrangements		
Lives alone	5	7
Lives with relatives	6	15
Type of dementia		
Alzheimer's disease	3	8
Vascular	2	4
Other	2	4
Not specified	4	6
Relation to person with dementia		
Son/daughter	–	11
Spouse	–	6
Niece	–	2
Friend	–	1
Sibling	–	1
Daughter-in-law	–	1

Table 2 Characteristics of participant demographics (professional carers)

Characteristics	Homecare staff n	Health and social care professional n
Gender		
Female	25	13
Male	5	6
Ethnicity		
White British	22	9
White other	2	5
Black/Black British	5	0
Asian/Asian British	1	0
Indian	0	2
Other	0	3
Professional role		
Managerial	7	0
Homecare worker	19	0
Other care staff	4	0
Commissioner	0	3
Social worker	0	2
Dementia lead	0	2
Service manager	0	2
Psychologist	0	2
Support worker	0	2
General practitioner	0	2
Geriatrician	0	1
Nurse	0	1
Physiotherapist	0	1
Psychiatrist	0	1

staff (mean age=48.3, SD=11.6). To respond to the needs and preferences of participants, eight interviews were dyadic involving people with dementia and family carers together. Five family carers were born outside the UK. Details of participant characteristics are presented in tables 1 and 2.

The lead author (JR) extracted information from interview transcripts about long-term conditions discussed across all stakeholders. Interviews with people with dementia (n=9) and family carer (n=22) explicitly spoke about long-term conditions and support needs. Healthcare professionals (n=14) and homecare staff (n=17) included information on specific long-term conditions, but often spoke more generally about medication management and holistic aspects of health for example, falls and mobility. Figure 1 presents a full overview of reported long-term conditions by people with dementia, family carers, health and social care professionals and homecare staff.

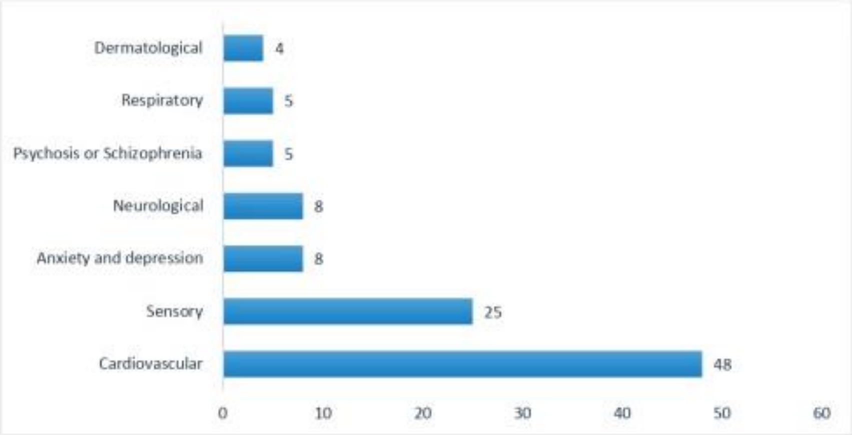
We identified three main themes that responded to our research objectives to explore the experiences of people with dementia, family carers, healthcare professionals and homecare staff in managing long-term conditions in dementia. These were: (1) the process of substituting self-management; (2) communication in the care network; and (3) impact on and from dementia (when managing physical health).

The process of substituting self-management

Autonomy versus risk

People with dementia valued autonomy when managing their physical health. In the earlier stages of dementia, prompting enabled self-management and a sense of 'still carrying on'. The prospect of requiring more help was a concern to this person living with dementia:

> You see I'm praying and I'm hoping that I won't need carers because I want to rely on myself. But I know at some stage I won't be able to. I don't know when. Maybe my health will get worse, physically worse, and



NB:

Category	**Long-term condition**
Mental health	Anxiety and depression Psychosis and Schizophrenia
Sensory	Visual impairment Hearing impairment
Musculoskeletal	Arthritis Osteoporosis
Respiratory	Asthma Pulmonary fibrosis Chronic obstructive pulmonary disease
Cardiovascular	Diabetes Hypertension Heart problems Stroke
Dermatological	Eczema Psoriasis Dermatitis

Figure 1 Frequency of long-term conditions discussed in interviews.

> this dementia will get worse and I will have to. (Person with Dementia_1, Arthritis and Hypertension)

Homecare workers acknowledged the wishes of people with dementia to retain decision-making control where possible and to be involved in their own care:

> I say every time, this is for your memory, this is your thyroid, this is for your Addison's, this is for your blood pressure… And they say, oh thank God you told me because what you're doing is you're controlling them if you don't involve them. (Homecare Worker_1)

Family carers balanced the wishes of people living with dementia to retain autonomy as far as possible with the potential consequences of lower adherence to medical treatment. Family carers described their discomfort in providing care against the wishes of the person with dementia but acknowledged the importance of such tasks when memory impeded medication administration:

> He then lost his eyesight in the left eye, due to the diabetes medication being missed. He was reporting to my mother daily that he is consuming his medication. Of course, because of the dementia, his memory was deceiving him and telling him that he had done it, but this was a past memory. (Family Carer_1, Son)

Prescriptions and role restrictions

Monitoring or administering medication was the most frequently discussed form of support for long-term condition management. While self-administration of medication is a routine part of long-term condition management, when a person with dementia required support of another person, this role occupied an intermediate position between a personal care activity and a medical task that required a nursing qualification. Rules around who administered medication could be complex and confusing:

> Although we were told that the [home]carers are not allowed to medicate, because they're not insured. So, that's a difficult one. (Family Carer_2, Son)

One healthcare professional described the difficulties that could arise because of this when prescriptions changed:

> It falls through when they're on, say steroids, like emergency steroids if they've got COPD or if they're on antibiotics for infection. Where the person with dementia will get really poorly because they're in boxes and [home]carers can't give out boxes; it has to be in a nomad [pre-packed medication]. (Community Mental Health Nurse)

Communication in the care network

In healthcare settings, it was often the family carer who communicated with services and made decisions about how to implement medical advice. Being an implementer of medical advice but not the doctor, and the recipient of advice but not the patient, sometimes felt like a dilemma for family carers working as in partnership with people with dementia:

> … I suppose at the end of the day I should go down and make an appointment to see the GP… to tell them that I feel she needs that done… but I don't want to go down and sort of feel that I'm… telling them what to do, coming heavy-handed on it either. (Family Carer_3, Sister)

Family carers experienced additional challenges in communication when developed relationships with primary care came to an end, as changes in practitioner's impacted continuity of care.

Where people with dementia experienced difficulties with communication, family carers offered support in healthcare appointments to ensure correct reporting of symptoms.

> …she would tell them things that were factually incorrect and they would believe that they were correct. Because they just thought she might be a bit old and her literacy wasn't great… But she was on drugs that were negatively affecting her …she was on something that were actually negative to her heart. (Family Carer_4, Son)

Regardless of the presence of a proxy, participants with dementia highlighted the importance of continued acknowledgement within appointments:

> It was, I think that's the problem, some people, because you've got diagnosed with it they think, oh he can't digest this, we'll talk to the relative. (Person with Dementia_2, Visual Impairment)

In situations where family carers or homecare workers were not substituting self-management, it could be challenging for general practitioners to identify changes in self-management and decide when to intervene:

> But I'm not quite sure that the mechanisms are very good for picking up on that, you know, the bit where they're in between, where they're potentially sort of just well enough to go out and about, and do things for themselves, but maybe things at home aren't good and they're not coping, and actually, as a GP, maybe it's really difficult to pick up on that. (General Practitioner_1)

Impact on and from dementia (when managing physical health)

Inter-relatedness of cognition and physical health

As the outcomes associated with physical health and cognition were found to be inter-related, healthcare professionals sought to optimise physical and preventative healthcare in ways that improved cognition.

> Yes, so, I think, you know, the physical health of someone has a really big impact on how they're dementia… they experience their dementia. So, they might just have a really poor diet which means that… or they might not be able to manage their diabetes and therefore they're feeling rubbish all the time. (Memory Service Manager)
>
> Physical problems as well. You know? Because they have, not only possible dementia, but they also may have physical illnesses. Parkinson's, stroke, any sort of medical condition, as well, on top. So, we don't just concentrate on the dementia. We concentrate on the person. And it's a very much a holistic approach. (Occupational Therapist)

Limitations of physical health treatments in people with dementia

Some treatments prescribed for long-term conditions were considered to be unhelpful for people with dementia, for example because the strategies they used depended on memory and could not or had not been adapted to the context of dementia. In this next quote, a family carer explains how a person with dementia was too impaired to benefit from suggested strategies:

> Well, she did have a visit from an occupational therapist [following a stroke]. They arranged that for a few weeks but he, it was when she was at her most florid time and he was recommending that she did things like writing a list down of things that interested her and what she would like to do and things like that. But she wouldn't do any of those. And he said, you know, he came about four or five times, no point in me coming because she doesn't take any notice of what I say, or do anything. (Family Carer_3, Sister)

Healthcare professionals and homecare workers sometimes felt that family carers were unable to accept that available treatments may not be helpful to people with dementia. They reported that this sometimes led to the continuation of treatments of questionable benefit, even when it went against the preferences of the person with dementia receiving them:

> I suppose family members are sometimes trying to keep people as they would see them, well and

> physically well for as long as possible and doing these things that their diabetes or anything else, and so they'll want them to do certain things whereas that's no longer what is important to that person. (General Practitioner_2)
>
> I have a lady that's quite old and her mother, she wants the physio in and it's just not possible. She physically can't do it, but she thinks it'll keep her strong a little bit. And it's really not doing her any good, even the physio said that. But the daughter wants it. (Homecare Worker_2)

The above quotes highlight how the voice of people living with dementia can be lost when determining the benefits of treatment. Family carers appear to adopt an 'all or nothing' approach to physical health decision-making due to the lack of flexible interventions which successfully account for dementia.

At other times, family carers and professionals discussed and agreed approaches in collaboration with people with dementia. One family carer described how this was helpful where difficult, end-of-life decisions, balancing comfort with quality of life needed to be taken:

> Kidney is only about 6% working. So because of that, you know… And we've decided not to go on dialysis. Not just we, but the specialist kidney doctor, we went to see him a couple of months ago and he suggested as well not to put him on dialysis because of his age… And he didn't think it was going to be beneficial to him… (Family Carer_5, Daughter)

DISCUSSION

Main findings

We describe three themes exploring how the self-management of comorbid long-term conditions is experienced and negotiated by people with dementia and their carers.

The first theme focused on the transition of roles which occurred in relation to advancement of dementia symptoms, with support increasing in accordance to level of need. Substituting self-management, especially medication, presented conflicts for family carers and homecare staff, to balance involving people with dementia in their care with safety concerns. The second theme identified communication as a key concept in the management of long-term conditions in dementia. Partnership working between people with dementia and family carers sought to overcome communication difficulties as a result of dementia. Without a family carer, changes in an individual's ability to self-manage may be difficult to detect, especially when people with dementia infrequently accessed primary care. The final theme highlighted the inter-relatedness of cognition and physical health and the importance of adapting physical healthcare to the context of dementia. Best interest decision-making is likely to be improved with increased awareness of likely harms and benefits of treatment based on evidence such as age and stage of dementia.

Addressing the research gap recently identified in the field of dementia and multi-morbidity, these findings describe the interacting effects between cognition and physical health and provide an understanding of the care needs of this population.[4 21] In dementia care, family carers often experienced a role transition from a 'care-partner' (who provides assistance to a person who continues to manage much of their own care themselves) to 'caregiver' (who provides care) with increasing disability.[12] Our analysis demonstrates the critical role of family carers in communicating with primary care.[13] In addition to impacting memory, judgement and orientation, the impact of dementia on language skills has previously been identified as a barrier to reporting symptoms in healthcare appointments.[9] Relevant theoretical models of independence at home in dementia suggest that professionals should also be viewed as partners, rather than experts, when supporting self-management.[27] The integrated logic of care model suggests that psychosocial and physical needs have a great influence on each other, and should therefore be addressed simultaneously.[28] Our analysis highlights a similar need for physical health and cognition.

One of the main self-management tasks across long-term conditions is medication adherence.[8 9] Similar to the findings of Rapaport *et al*,[22] our analysis highlights the role of homecare workers in adapting a facilitative approach; specifically 'doing with not for' during medication management. The need for both family carers and homecare workers to prevent harm often conflicts with the desire of a person with dementia to remain autonomous.[29] The balancing of roles is complex for carers especially involving boundaries between advocating for independence and the implementation of medical advice.[30] Our findings demonstrate this dilemma extends to the management of long-term conditions in dementia. Future research is required to understand how calculated risks in care decision-making can enable freedom for people with dementia while managing carer safety concerns.[27] Living well with dementia has been conceptualised as living with quality of life, choice, autonomy, dignity and as independently as possible. There can be a tension between independence as an expression of autonomy and interdependence that can enable people with dementia to live in their own homes for longer. People with dementia and carers often have different goals and priorities for care. Judging at which point a person loses capacity to refuse care and when to intervene in their best interests can be challenging. Research has indicated the need for professionals to facilitate conversations around the decision to move to care homes.[31] A similar approach may be required during physical health decision-making.

One of the five core self-management skills is decision-making[8] impacted by dementia due to impairments in executive functioning.[9] Non-dementia health decisions, such as end-of-life care, have previously been identified as a problematic decision-making area for family carers.[32] In this context, care decisions involving all stakeholders require a focus on quality of life over a target-driven approach[16] which is continuously reassessed according to changes in disease state.[17] Quality of life is an important indicator of effectiveness for person-centred care interventions in dementia.[33]

Clinical implications

These findings highlight that management of long-term conditions in dementia exists on a continuum with support from all stakeholders developing across stages of dementia and severity of long-term conditions. To best support people with dementia to manage long-term conditions, treatments should be congruent to need and consider the impact of dementia on engagement. The development of dementia-specific consultation models must consider the impact of dementia on language skills and communication ability, and work with family carers acting in dyadic care relationships with people with dementia. Greater considerations of how healthcare professionals communicate the limitations of treatments that are not in the best interest or of questionable benefit to people with dementia and family carers would improve physical health decision-making. Such discussions are often complex, involving various stakeholders and ensuring the voice of people with dementia is heard when deciding on treatment benefits can be challenging. Service development must identify mechanisms for detecting change in self-management ability when family carer or homecare workers are not involved in supporting self-management at home for example, alerts for appointment non-attendance and medication underutilisation.

Strengths and limitations

To our knowledge, this paper presents the first qualitative analysis to consider how people with dementia can be best supported to manage long-term conditions from the perspective of all stakeholders. Specifically, this paper expands on previous research by considering the role of the homecare worker in the care network, previously described in the literature as a triad between the person with dementia, their family carers and healthcare professionals.[34 35] The analysis includes interviews from a large and varied sample from a range of locations across the UK.

We used secondary analysis to explore sections of transcripts that discuss multi-morbidity in dementia. A limitation of this analytic approach is that the data were originally collected to explore how to support independence at home in dementia. Nevertheless, participants spontaneously discussed experiences of long-term conditions due to their salience, enabling further exploration of multi-morbidity in this analysis. All family carers explicitly discussed the management of long-term conditions which may account for large representation from this stakeholder in the analysis, while people with dementia, healthcare professionals and homecare workers would discuss more generally about medication management and physical health.

We included coauthors involved in original data collection (AB, ML, JB-D, RHG) to bring an inside knowledge of context during analysis to overcome the problem of the lead author 'not having been there'.[24] In addition, the lead author listened to recordings of transcripts to become familiar with data. The use of additional methods such as participant observations in future research would enable triangulation of results on how stakeholders can best support people with dementia to manage long-term conditions.[36]

We purposively recruited a diverse sample in terms of ethnicity and gender, and while we considered during analysis how these factors might intersect our themes, unlike in our previous publications from this database on different topics,[22 23] we did not find any clear areas where themes were gendered or were reflected differently across ethnic groups or immigration status.[37] While this was part of the reflective analytic process, we did not include an intersectionality analysis as an a priori analytic step. Williams *et al* did this, and we will consider adapting this approach in our future work.[38]

CONCLUSION

Family carers and homecare workers support the management of long-term conditions in the home. Family carers act as proxies for communication in healthcare appointments. Healthcare professionals have a responsibility to identify changes in self-management ability as dementia progresses and adapt care accordingly. This process of substituting self-management evolves with advancement of dementia symptoms and relies on communication in the care network, while considering the impact on and from dementia to achieve holistic physical health management. Care decisions must consider people with dementia as a whole, and be based on realistic outcomes and best interests.

Contributors All authors made a substantial contribution to this work. JR, CC, KW and AB all contributed to the conception and design of the study and JR drafted the paper. All authors critically revised it and gave final approval for this version to be published. AB, ML, JB-D, PR and RHG collected the qualitative data. JR, CC, KW and AB all coded some of the interview transcripts. JR then organised the data into preliminary themes and led the subsequent analysis. CC, KW and AB further refined the thematic analysis in an iterative process.

Funding This work was supported by the Economic and Social Research Council [grant number ES/P000592/1]; and the National Institute of Health Research (NIHR) Collaboration for Leadership and Applied Health Research (North Thames). Data collection was carried out within the UCL Alzheimer's Society Centre of Excellence for Independence at home, NIDUS (New Interventions in Dementia Study) programme (Alzheimer's Society Centre of Excellence grant 330).

Disclaimer The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not required.

Ethics approval London (Camden and Kings Cross) Research Ethics Services approved the study in November 2017 (reference: 17/LO/1713).

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement All data relevant to the study are included in the article or uploaded as supplemental information. The qualitative data used and analysed during the current study are available from the corresponding author on reasonable request.

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Appendix 7. NIDUS Topic Guides

Family carer interview topic guide

INTRODUCTION

Thank you for agreeing to talk with me. This part of our study aims to help us understand better how to support people with dementia living in their own homes.

In order to make sure that I don't miss anything, I will record our conversation on a digital recorder and then it will be professionally transcribed. Once the interview has been transcribed, I will ensure that everything will be anonymous so you can't be identified. Once again, everything you tell me will be treated with complete confidence.

INTERVIEW

To start, I will ask some background information. Could you tell me a little about your relationship with [patient name]?

Do you live together?

How often do you see them?

What sort of support do they need?

Do you give them any support? What does this support look like?

Does anyone else support them e.g. other family members / paid carers?

- Prompt: If paid care how is this funded/arranged?
  e.g. self-funded – through a private agency or informal arrangement or

local authority (LA) funded – personal budget or arrangement with a specific provider by the LA

Have you had any education/ support with understanding dementia?

-where from?

Has that been useful?

Does [patient name] have any other long-term physical or mental health conditions (e.g. diabetes, hypertension, heart disease, asthma, COPD, other)?

What help do you and [name] have for their medical condition(s)?/ How do you and [name] manage it?

Independence at home

- To what extent is [the person you care for] currently able to live independently at home?
- What do you find independence means for the person you care for? What do you feel being independent looks like for them?
- Can you think of a time since [the person you care for] has had memory problems, when they have been able to achieve or do something independently that has been important for them? What happened? What made it easier?
- Can you think of a time since [the person you care for] has had memory problems, when they have not been able to achieve or do something independently that has been particularly difficult? What happened? What made it harder?
- What makes it harder / easier for the person you care for to live independently at home?
  - Prompt for: Impact of medical conditions/physical and mental health
  - Prompt for: professional home care

Goals and priorities of people with dementia

We are interested in what is most important to try to achieve when planning care for people living with dementia. Here are some of the areas that matter most to people:

- Moving around
- Cognition (memory and other areas of thinking)
- Being safe from falling
- Getting the right medical treatment for memory
- Getting the right medical treatment for other physical or mental health conditions
- Help at home
- Social activities

- Are there things you would add to this list? (prompt for behaviour, safety)
- What do you think is most important for [name of person with dementia]?
    - Why did you choose this?
- What else do you think is important for them? Why?
- Thinking more about the area selected, what do you think would be a realistic goal for [name] in the next 6 months?
    - What difference would this make to them (probe for independence/ safety/ social connection / health / being able to stay living at home)
    - What support might help [name] and you meet this goal?
    - Are there things that you think might make it easier or harder?
        - Prompt for:
        - Client factors: agitation (e.g. resisting care, verbal, physical aggression), personality/ culture/ethnicity/language, risks, physical or mental health
        - Family carer factors: (practical, emotional, relationship, health)
        - Home care agency/ management/legal/ NHS/ social services/ other
- [if home care recipient] How does the home care help [name] to work towards this? Are there ways of delivering it that would do this better?

- Are there any differences between what goals and priorities matter most to [the person you care for] and what matters to you as a carer?

Interventions to help with meeting goals

We want to develop a support programme to support people with dementia and their family carers to live independently at home and to meet the goals that they select.

What do you think this should include?

What do you think would work best?

What do you think you and the person you care for would find most useful?

We also want to develop some training for home carers working with clients living with dementia.

What do you think this should include?

Is there anything you wouldn't want this to include or be like?

Thank you - Is there anything else you would like to add?

Person living with dementia interview topic guide

INTRODUCTION

Thank you for agreeing to talk with me. This part of our study aims to help us understand better how to support people with dementia living in their own homes.

In order to make sure that I don't miss anything, I will record our conversation on a digital recorder and then it will be professionally transcribed. Once the interview has been transcribed, I will ensure that everything will be anonymous so you can't be identified. Once again, everything you tell me will be treated with complete confidence.

INTERVIEW

Independence at home

We are interested in how you are able to live independently at home.

What do you do? Do you get any help from anyone else (paid carer / family member)? What do they do?

- Prompt: If paid care how is this funded/arranged?
  e.g. self-funded – through a private agency or informal arrangement or local authority (LA) funded – personal budget or arrangement with a specific provider by the LA

What can make it harder / easier to stay independent?

  - ○ Prompt for: do you have any other long-term physical or mental health conditions (e.g. diabetes, hypertension, heart disease, asthma, COPD, other)? Do these conditions make it harder / easier to stay independent?

Your goals and priorities

Here are some things that people with memory problems say are most important to them:

- Moving around
- Cognition (memory and other areas of thinking)
- Being safe from falling
- Getting the right medical treatment for memory
- Getting the right medical treatment for other physical or mental health conditions
- Help at home
- Social life and activities
- Relationships

- What is most important for you? (prompt relationships)
    - Why did you choose this?
    - What are you already doing (in relation to this goal) that is going well?
    - Is anything not going well?
    - How would you like things to change? What difference would this make to you (probe for independence/ safety/ being able to stay living at home)
    - Are there things that you think might make it easier or harder?
        - Prompt for: how person feels about their current situation, mental or physical health, culture/ethnicity/language, risks
        - How might your health affect you meeting the goal?/ What help do you have for your medical condition(s)?/ How do you manage it?
    - What support might help you do this?
    - [if home care recipient] Does the home care you receive help to work towards this? Are there ways it could be better?

Interventions to help with meeting goals

We want to develop a support programme to support people with dementia and their family carers to live independently at home and to meet the goals that they select.

What do you think this should include?

What would you find most helpful?

What would you enjoy?

Is there anything that you would not like to happen?

We also want to develop some training for home carers working with clients living with dementia.

What do you think this should include?

If you could, is there anything you would like to tell/teach/show home carers or care agency managers?

Thank you

Is there anything else you would like to add?

Home manager/ health or social care professional interview topic guide

INTRODUCTION

Thank you for agreeing to talk with me. This part of our study is to help us understand better how to support people living with dementia in their own homes.

In order to make sure that I don't miss anything, I will record our conversation on a digital recorder and then it will be professionally transcribed. Once the interview has been transcribed, I will ensure that all identifying characteristics are removed. Once again, everything you tell me will be treated with complete confidence.

INTERVIEW

To start, could you tell me a little about your work? How are you involved with caring for people living with dementia?

Probe for employment and social support

- **How long have you been carrying out this role?**

<u>Independence at home</u>

- What do you find independence means for your clients with dementia? What do you feel being independent looks like for them?
- Can you think of a time when a client with dementia has been able to achieve or do something independently that has been particularly important for them? What happened?
- Can you think of a time when a client with dementia has been unable to achieve or do something independently that has been particularly difficult? What happened?
- What makes it harder / easier for your clients with dementia to live independently at home?
- How do your interactions/ relationships with family members affect your role in supporting your clients to be independent?
    - Can you give an example of when a family member has enabled you to support your clients' independence?
    - Can you give an example of when a family member has got in the way of you being able to support your clients' independence?

Goals and priorities of people with dementia

We are interested in what is most important to try to achieve when planning care for people living with dementia. Here are some of the areas that matter most to people with dementia:

- Moving around
- Cognition (memory and other areas of thinking)
- Being safe from falling
- Getting the right medical treatment for memory
- Getting the right medical treatment for other physical and mental health conditions
- Help at home
- Social activities

- ➢ Are there things you would add to this list? (prompt for behaviour, safety)
- ➢ Do you find there are sometimes differences between what goals and priorities matter most to the person with dementia and family carers? Can you say more about this?

Interventions to help with meeting goals

We want to develop a support programme to support people with dementia and their family carers to live independently at home and to meet the goals that they select.

What do you think this should include?

What do you think would work best?

We also want to develop some training for home carers working with clients living with dementia.

What do you think you and the person you care for would find most useful?

What do you think this should include?

Is there anything you wouldn’t want this to include or be like?

Thank you, is there anything else you would like to add?

Appendix 8. Secondary analysis coding framework

PROCESS OF SUBSTITUTING SELF-MANAGEMENT	Files	References
Autonomy verses risk	0	0
Consequences of non-adherence	2	3
Independence	5	8
Lock safe for medication	4	7
Reliance on others	3	6
Risk management	9	11
Safety concerns	8	14
Stages of dementia	5	5
Ability to self-manage	9	9
Capacity	5	8
Managing a spectrum of needs	5	6
Support increasing with level of need	7	9
Taking responsibility for tasks	8	11
Support in medication management	0	0
Blister packs	12	18
Encouragement to take medication	5	5
Family member managing medication	15	20

Home carer role in medication management	26	63
Training to improve limits to HCW role	6	9
Memory aids	8	9
Prompts	9	11
Role of HCP in medications	7	8
Understanding medication	13	15

COMMUNICATION IN THE CARE NETWORK	Files	References
Appointment	13	25
Family carer support in medical appointments	14	23
Organising support and care	12	14
Seeking and providing advice	3	4
Continuity of care	8	12
Relationships	7	8
Understanding PLWD	8	9
Monitoring change	11	12
Medication review	8	9
Review and monitoring	8	8

PLWD communication	9	12
Communication difficulties	7	12
Family carers proxy	4	4

IMPACT ON AND FROM DEMENTIA	Files	References
Aligned goals and different priorities	5	9
Decision making	8	9
Inter-relatedness of physical health and cognition	0	0
Dementia	7	8
Link between cognition and physical health	15	29
Managing dementia when supporting physical health	7	11
Physical health problems resulting in dementia diagnosis	8	12
Services congruent to need	1	1
Accessibility	17	27
Dementia services	3	5
HCP frustration with use of services	1	4

Appendix 9. Study poster

Research study

How can people living with dementia look after their health?

Why is this study happening?

We want to understand how physical health care is planned and delivered for people with dementia. We want to know what advice people involved in care provide and how people follow advice once they are at home.

This research study is part of a PhD project.

What will happen if I take part?

We would like to talk to people living with dementia and those who support them about how they manage their physical health conditions. After one interview, this will involve ongoing remote contact over phone, video and email to see how advice received at appointments helps to manage health conditions. You will be invited to record your experiences in a diary, and a researcher will look at care plans relevant to your care.

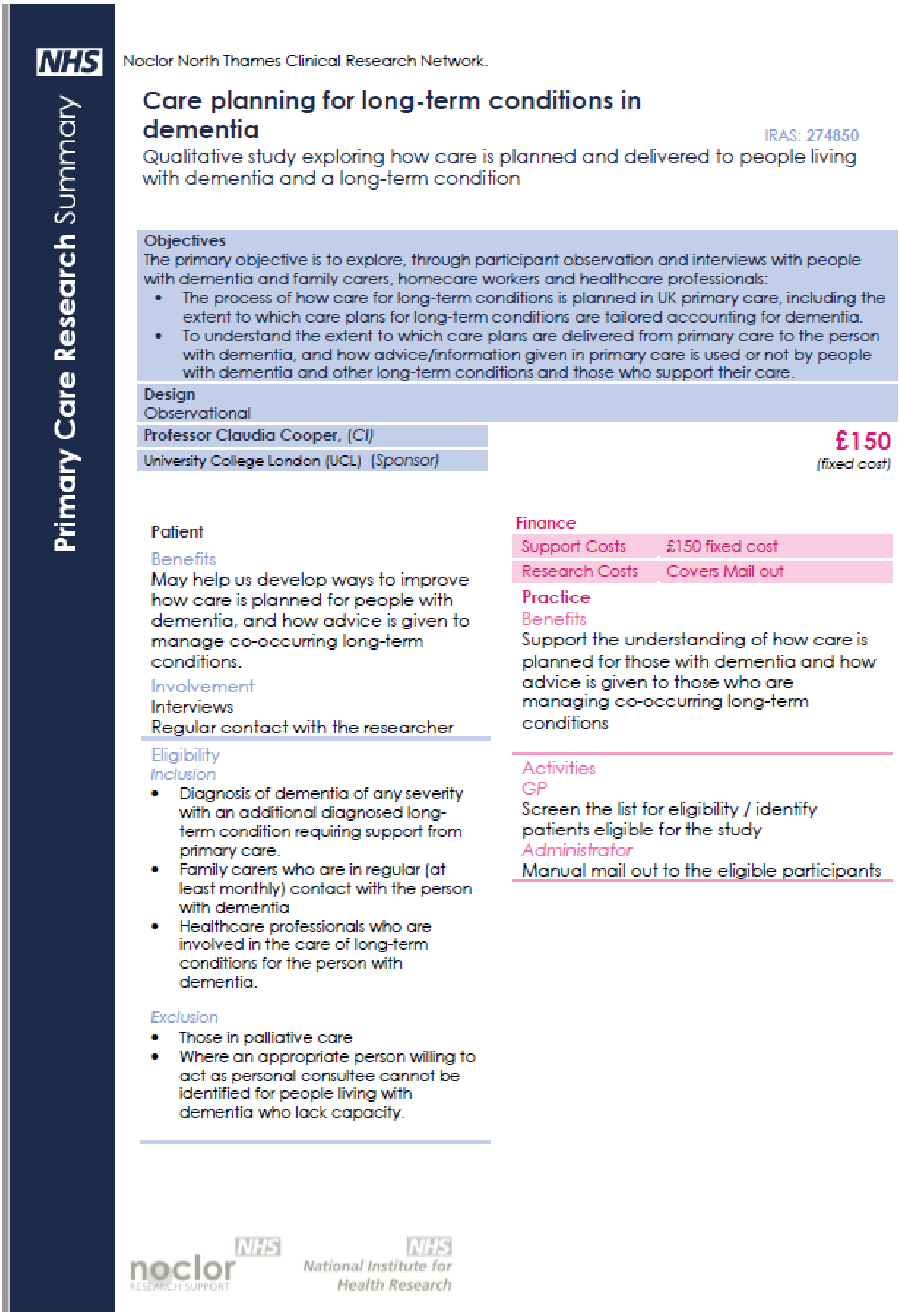
If you have any questions or if you would like to take part please contact:

Jessica Rees, PhD student:

Jessica.rees@ucl.ac.uk

020 XXX

Appendix 10. GP research summary



NHS

Primary Care Research Summary

Noclor North Thames Clinical Research Network.

Care planning for long-term conditions in dementia

IRAS: 274850

Qualitative study exploring how care is planned and delivered to people living with dementia and a long-term condition

Objectives

The primary objective is to explore, through participant observation and interviews with people with dementia and family carers, homecare workers and healthcare professionals:

- The process of how care for long-term conditions is planned in UK primary care, including the extent to which care plans for long-term conditions are tailored accounting for dementia.
- To understand the extent to which care plans are delivered from primary care to the person with dementia, and how advice/information given in primary care is used or not by people with dementia and other long-term conditions and those who support their care.

Design

Observational

Professor Claudia Cooper, *(CI)*

University College London (UCL) *(Sponsor)*

£150

(fixed cost)

Patient

Benefits

May help us develop ways to improve how care is planned for people with dementia, and how advice is given to manage co-occurring long-term conditions.

Involvement

Interviews

Regular contact with the researcher

Eligibility

Inclusion

- Diagnosis of dementia of any severity with an additional diagnosed long-term condition requiring support from primary care.
- Family carers who are in regular (at least monthly) contact with the person with dementia
- Healthcare professionals who are involved in the care of long-term conditions for the person with dementia.

Exclusion

- Those in palliative care
- Where an appropriate person willing to act as personal consultee cannot be identified for people living with dementia who lack capacity.

Finance

Support Costs	£150 fixed cost
Research Costs	Covers Mail out

Practice

Benefits

Support the understanding of how care is planned for those with dementia and how advice is given to those who are managing co-occurring long-term conditions

Activities

GP

Screen the list for eligibility / identify patients eligible for the study

Administrator

Manual mail out to the eligible participants

NHS noclor RESEARCH SUPPORT

NHS National Institute for Health Research

Appendix 11. Participant information sheet

Qualitative study exploring how care is planned and delivered to people living with dementia and a long-term condition

We are inviting you to take part in a research project. This study is part of a PhD looking at how to support people with dementia to manage their physical health. Before you decide whether to take part it is important that you understand why the research is being done and what this study will involve. Please take time to read the following information carefully and discuss it with others if you wish.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the study.

Ask us if anything is not clear or you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

Part 1

What is the purpose of the study?

We want to understand how people living with dementia are supported to look after their health when they also have a long-term, physical health condition, such as diabetes, asthma or arthritis. We want to know how professionals change care to account for dementia. We also want to know how people follow advice once they are at home.

Why have I been invited?

You are being invited because you are living with dementia and at least one additional long-term condition.

Do I have to take part?

No. It is up to you to decide whether to take part. You are free to withdraw at any time without giving a reason. If you do, it will not affect the care you receive in any way.

What will happen to me if I take part?

A researcher, called Jessica, will contact you to ask some initial questions about your age group, gender, and information about your dementia and any long-term conditions. She will also ask you about how you manage your long-term conditions. This initial interview will be taped (audio-recorded) and will last about an hour. She will ask who else supports you to manage your health such as family, friends or professional carers and for your permission to ask them to take part to give their views on how your healthcare is managed.

Jessica will then stay in touch with you and those who support you for up to four months, by phone, video-call and/or email. This contact will be at most weekly (and can be less if you prefer), to ask about how advice you receive at healthcare appointments helps you manage your health conditions. If you agree, she may observe how you receive care at home over video-call. Observations will only take place if everyone involved has provided informed consent. She will make notes during these discussions, and with the permission of all present, record brief interviews. She will also invite you to keep a diary to record your experiences of managing your health. We will let your GP (or another person involved in your healthcare) and homecare agency (if you have one) know you are taking part in this study. We will, with your consent, access your GP and home care records to compare the plans for care recorded with what we see happening in practice. We will ask you who you would like to make decisions about whether you should continue with the study on your behalf, if you ever became unable to decide this for yourself.

What are the possible disadvantages and risks of taking part?
Talking about your health can be tiring, and possibly distressing. We are aware of this and will regularly check if you are feeling alright to continue the observation, or otherwise would like to take a break or end the observation. Although the researcher will try to be as considerate as possible during observations, if taking part ever becomes too much, please feel free to ask the researcher to end the observation.

If you feel upset in any way, you may find it helpful to ring the Alzheimer’s Society National Dementia Helpline on 0300 222 1122. The Helpline is open from 9am to 8pm on Monday to Wednesday, 9am to 5pm on Thursday and Friday, and 10am to 4pm on Saturday and Sunday.

What are the possible benefits of taking part?
We cannot promise the study will help you but the information we get might help us develop ways to improve how care is planned for people with dementia, and how advice is given to manage co-occurring long-term conditions.

What will happen if I no longer want to take part in this study?

If at any time you want the researcher to leave they will do so immediately. You are free to withdraw from the study at any time, without giving a reason. If you withdraw from the study, you can also request that we do not use any of the information you may have already given us. Stored data that can still be identified as yours will be destroyed if you wish.

Will my taking part in the study be kept confidential?
UCL is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study, and will act as the

data controller for this study. This means we are responsible for looking after your information and using it properly.

We respect confidentiality but cannot keep it a secret if anyone is being harmed or is at risk of any harm. If this arises, you will be informed that confidentiality cannot be maintained in that particular regard, and the appropriate person will be informed.

Your confidentiality will be partially maintained. Personal data, such as your name, gender, age range and contact details will be kept separate from the information we collect. We will keep your contact details separately for the duration of the study so we can contact you when we need to for the study. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead to maintain anonymity for data analysis. You will not be identified in any publications, anonymised quotes will be used with your consent.

We will need to use information from you and from your medical records for this research project. This information will include your initials, name and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly. Individuals from UCL and regulatory organisations may look at your medical and research records to check the accuracy of the research study. We will keep all information about you safe and secure.

The information you provide will be stored securely on computers at UCL, in a form in which you cannot be identified. Only study staff will have access to the data. We will delete the recording after it has been transcribed. The transcript will be stored securely in accordance with UCL's archiving policy. The audio recordings will be transcribed by the researcher. Any identifiable information will be removed from the transcripts.

You can find out more about how we use your information by contacting data-protection@ucl.ac.uk or by going online and accessing the UCL research privacy notice: https://www.ucl.ac.uk/legal-services/privacy/participants-health-and-care-research-privacy-notice

Part 2

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with Prof Claudia Cooper (Study Principal Investigator on 07759703235) who will do her best to answer your questions. If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during the course of this study, you may contact the Research Governance Sponsor of this study, University College London. Please write to UCLH/UCL Joint Biomedical Research Unit, R&D Directorate, Roseheim Wing, Ground Floor, 25 Grafton Way, London WC1E 5DB quoting study EDGE

129041. In the unlikely event that something does go wrong and you are harmed during the research and this is due to someone‘s negligence then you may have grounds for a legal action for compensation against UCL but you may have to pay your legal costs.

What will happen to the results of the research project?

The results of the research project will be presented in the researchers PhD thesis. We also intend to publish results in relevant conference proceedings and publications. Please tell the researchers if you would like a copy of any publications and we would be happy to send them to you when they are published. We will write our reports in a way that no-one can work out that you took part in the study. The results of the study will be stored for the duration of the PhD and then deleted. The PhD is due to finish 2022.

Who is organising and funding the research?

The Economic Social Research Council and National Institute of Health Research Collaboration for Leadership in Applied Health Research and Care North Thames are funding it, and University College London are organising it.

Who has reviewed this study?

All research in health and social care is looked at by an independent group of people, a Research Ethics Committee. They protect participants' safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by a National Research Ethics Committee (REC reference 20/LO/0288).

Contact for further information

Please contact Jessica Rees on [redacted] or Jessica.rees@ucl.ac.uk for further information. The researcher, Jessica Rees, is a PhD student at UCL Division of Psychiatry Maple House, 6th Floor Wing A, London W1T 7BN.

Thank you for reading this information sheet and for considering taking part in this research study. Please keep a copy of this information sheet for your records.

Appendix 12. Letter of invitation

[DATE]

Dear [name],

RE: Qualitative study exploring how care is planned and delivered to people living with dementia and a long-term condition

I am writing to inform you that your client <insert name> and their family carer (if applicable) has/have agreed to participate in the above study. This study is being led and sponsored by University College London and has received ethical approval from Camden and Kings Cross research ethics committee (Reference: 20/LO/0288).

The study aims to understand how people living with dementia are supported to look after their health when they also have a long-term, physical health condition, such as diabetes, asthma or arthritis. We are currently in contact with <name of client> about how they manage their health conditions and we would also like to remotely observe up to two of their homecare visits. This will involve a researcher observing how home carers support <name of client> to manage his/her long-term conditions during these visits. At a convenient time, and separate to observations, we would invite the home carer/s to discuss their experiences and keep a diary of their experiences.

A member of staff from your agency who works with the participating client, <insert name/s> has/have been provided with an information sheet for the study which explains why s/he has been approached to take part, that their participation is entirely voluntary, and that they are free to withdraw at any time. I have enclosed a copy of the Participant Information Sheet (Version 2, dated 01/06/2020) for your reference, however if you have any queries or require further information please contact the researcher conducting this study: Jessica Rees; Tel: 020 XXX; Email: Jessica.rees@ucl.ac.uk

Yours Sincerely

Jessica Rees

[CC. participant]

Appendix 13. Stream three topic guide

People living with dementia

Introduction

Thank you for agreeing to talk with me. We want to understand how physical health care is planned and delivered for people with dementia. We want to know what advice people involved in care provide and how people follow advice once they are at home.

To make sure that I don't miss anything, I will record our conversation on a digital recorder and then it will be transcribed. When I write it up, I will ensure that everything will be anonymous so you can't be identified.

SECTION 1: Management of/support for long-term conditions

- I'd like to start by asking you about what physical health problems you have? [prompt: diabetes, heart, lung problems?]
    - How long have you lived with [condition]?
- How do your manage your [condition]?
  PROMPT: medication, insulin, inhaler, diet/fluids.
- What makes it harder to manage your [condition]?
    - PROMPT: memory, social factors, mood
    - What strategies do you use to overcome these problems?
- Do you get any help from anyone else (paid carer/family member/nurse/doctor)?
    - What do they do? PROMPT: advice, practical help, reminding, appointments
    - How often do you see/speak to them?
    - How do you keep in touch?
    - If no support, what would be helpful?

SECTION 2: Knowledge of care plan

- How do you get information/advice about what to do? Can you tell me about:
    - What advice has helped you? What it was and how it helped.
    - Any advice you haven't understood/ hasn't helped?

    - PROMPT: GP visit- What was discussed? Who attended? How was info recorded? How would others involved in care be updated?
- How would you tell your GP if your memory impacted how you manage your [condition]?
    - How could the GP change your care to make it easier to manage your [condition] due to your memory problems?
    - PROMPT: Example of changed physical health plan to account for dementia

SECTION 3: COVID-19

How has COVID-19 impacted how you manage your health? Prompt for:

- What has the pandemic made easier/harder when managing your health?
- Contact with healthcare providers/homecare workers/family members?
- Access to medical supplies? E.g. pharmacist.
- Experience of shielding? Practical- unable to get out, Psychological- worry about COVID-19.
- Experience of being cared for using PPE?

Thank you

Is there anything else you would like to add?

Family/friend carers

Introduction

Thank you for agreeing to talk with me. We want to understand how physical health care is planned and delivered for people with dementia. We want to know what advice people involved in care provide and how people follow advice once they are at home.

To make sure that I don't miss anything, I will record our conversation on a digital recorder and then it will be transcribed. When I write it up, I will ensure that everything will be anonymous so you can't be identified.

SECTION 1: Management of/support for long-term conditions

- I'd like to start by asking how you manage [names] physical health problems? [prompt: medication, insulin, inhaler, diet/fluids]
- What makes it harder to manage their [condition]?
    - PROMPT: memory, social factors, mood
    - What strategies do you use to overcome these problems?
- Do you get any help from anyone else (paid carer/family member/nurse/doctor)?
    - What do they do? PROMPT: advice, practical help, reminding, appointments
    - How often do you see/speak to them?
    - How do you keep in touch?
    - If no support, what would be helpful?

SECTION 2: Knowledge of care plan

- How do you get information/advice about what to do? Can you tell me about:
    - What advice has helped you? What it was and how it helped.
    - Any advice you haven't understood/ hasn't helped?
    - PROMPT: GP visit- What was discussed? Who attended? How was info recorded? How would others involved in care be updated?
- How would you tell the GP if [names] memory impacted how you manage [condition]?
    - How could the GP change care to make it easier for you and [name] to manage [condition] due to their memory problems?

    - PROMPT: Example of changed physical health plan to account for dementia
- If additional needs arise between appointments how are these managed/planned for?

SECTION 3: COVID-19

How has COVID-19 impacted how you manage [names] health? Prompt for:

- What has the pandemic made easier/harder when managing their health?
- Contact with healthcare providers/homecare workers/family members?
- Access to medical supplies? E.g. pharmacist.

Thank you

Is there anything else you would like to add?

Homecare workers

Introduction

Thank you for agreeing to talk with me. We want to understand how physical health care is planned and delivered for people with dementia. We want to know what advice people involved in care provide and how people follow advice once they are at home.

To make sure that I don't miss anything, I will record our conversation on a digital recorder and then it will be transcribed. When I write it up, I will ensure that everything will be anonymous so you can't be identified.

SECTION 1: Management of/support for long-term conditions

- I'd like to start by asking how are you involved with looking caring for [names] long-term conditions? PROMPT: advice, practical help, reminding, appointments
- What makes it harder to manage their [condition]?
    - PROMPT: memory, social factors, mood
    - What strategies do you use to overcome these problems?
- Do you get any help from anyone else (paid carer/family member/nurse/doctor)?
    - How often do you see/speak to them?
    - How do you keep in touch?
    - If no support, what would be helpful?

SECTION 2: Knowledge of care plan

- How do you get information/advice about what to do? Can you tell me about:
    - What advice has helped you? What it was and how it helped.
    - Any advice you haven't understood/ hasn't helped?
    - PROMPT: How would you be updated about change in care plan?
- How would you tell the GP if [names] memory impacted how you manage [condition]?
    - How could the GP change care to make it easier for you and [name] to manage [condition] due to their memory problems?
    - PROMPT: Example of changed physical health plan to account for dementia

SECTION 3: COVID-19

How has COVID-19 impacted how you manage [names] health? Prompt for:

- What has the pandemic made easier/harder when managing clients with dementia and long-term conditions?
- Contact with healthcare providers/family carers?
- Experience of providing physical health care in dementia using PPE?

Thank you

Is there anything else you would like to add?

Healthcare professionals

Introduction

Thank you for agreeing to talk with me. We want to understand how physical health care is planned and delivered for people with dementia. We want to know what advice people involved in care provide and how people follow advice once they are at home.

To make sure that I don't miss anything, I will record our conversation on a digital recorder and then it will be transcribed. When I write it up, I will ensure that everything will be anonymous so you can't be identified.

SECTION 1: Management of/support for long-term conditions

- I'd like to start by asking, what is your role in managing [names] long-term condition(s)? PROMPT: time involved, last contact.
- What makes it harder to manage their [condition]?
    - PROMPT: memory, social factors, mood, carer engagement
    - What strategies do you use to overcome these problems
- Can you think of a time when a client's memory impacted how they manage [conditions]?
    - What happened? How was care changed?
    - What worked/didn't work?
    - What best practice recommendations would you suggest?

SECTION 2: Knowledge of care plan

- What information/advice do you recommend for [name] to help management [conditions]?
    - What approaches do you find work best when you are managing physical health in people with dementia?
    - How would this care be different for someone without dementia?
    - Example of when physical health advice was not understood or followed by person with dementia?
- How would you make the decision to change physical health care to account for dementia?
    - How would this be monitored/reviewed as dementia progresses?

    - How would this be communicated to people with dementia and those in their care network?

SECTION 3: COVID-19

How has COVID-19 impacted how you manage [names] health? Prompt for:

- What has the pandemic made easier/harder when managing clients with dementia and long-term conditions?
- Experience of working? Practical- staff absences, remote contact.
- Experience of providing physical health care in dementia using PPE?

Thank you

Is there anything else you would like to add?

Appendix 14. Event-based diary instructions

Diary: Care planning for long-term conditions in dementia

I am asking you to keep a diary for two weeks, so I can see how you manage your health. Whilst it would be great if you were able to write a bit every day, you may not always have time or feel you have anything to record. This is fine. If you want to take a break or forget, that's okay, just start the diary again when you are able.

Please jot down anything you think will help me understand what it is like to manage your health when you have memory problems. We are specifically interested in the activities you are involved in to manage your long-term condition(s) (for example, collecting your prescription), and any support you receive (for example, reminding, practical help).

We would like to know:

WHAT did you do today to look after your health?

For example, taking medications, going to the doctor, having your blood pressure checked, etc. How did you feel/ what did you think before, during or after the activity.

WHO was involved?

Who reminded you, helped or supported you? You might write down who visited, a paid carer or district nurse? Did you need to contact anyone about your health? Please tell us how you did this and why?

Please record the **DATE** and **TIME**. Here is an example:

Diary 8th June 2020, 10AM

Linda (my paid carer) arrived at 9 this morning and reminded me to take my medication. She realised I was running low on my hypertension tablets. I said I would let Harrison (my son) know when he visited later. Linda made a note about the tablets and left it on the kitchen table. Harrison saw the note when he came around later and called the doctor for me. Harrison said my prescription would be ready in a couple of days and he would let me know when I was able to collect it. I was grateful to have to help to organise getting the tablets, but I would like to collect them myself if the weather is okay.

If you have any questions, ring Jessica on [redacted] or Jessica.rees@ucl.ac.uk

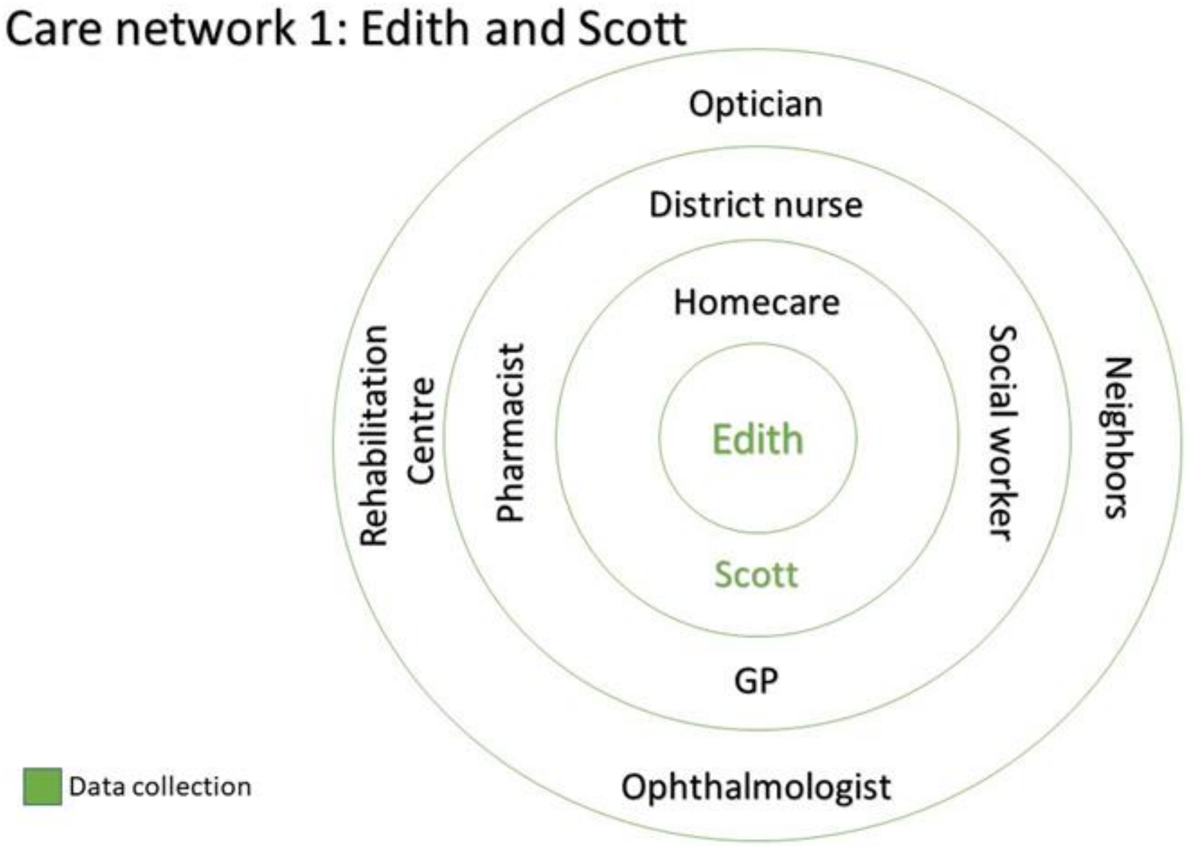
I will get in touch at the end of the week to see how you are getting on.

Appendix 15. Table of number of contacts per care network

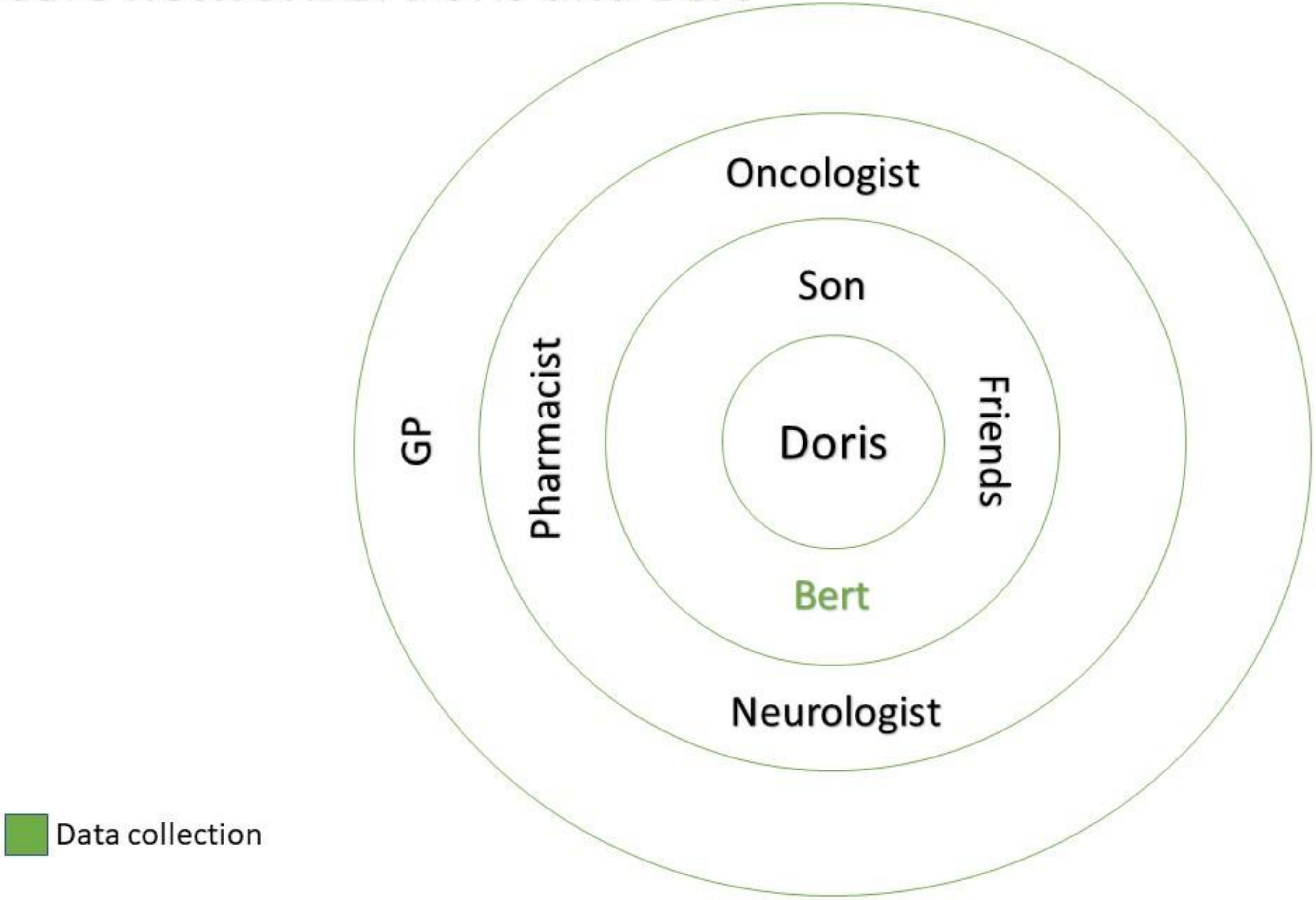
Care network	**Edith and Scott**	**Doris and Bert**	**Harold and Dora**	**Fiona and Declan**	**Margaret, Jonathan and Sophie**	**Hassan**	**Samira and Sarah**	**Albert and Jean**
Person with dementia								
Telephone call			3			2	3	
Video-call	1				1		1	1
Field notes	1				1		1	1
Diary			1				1	
Consultation notes	1	1	1	1	1	1	1	1
Family carer								
Telephone call		1	2	4	1		3	3
Video-call	4				1		1	1

Field notes					1		1	1
Healthcare professional								
Telephone call					1			
Video-call							1	
Field notes								

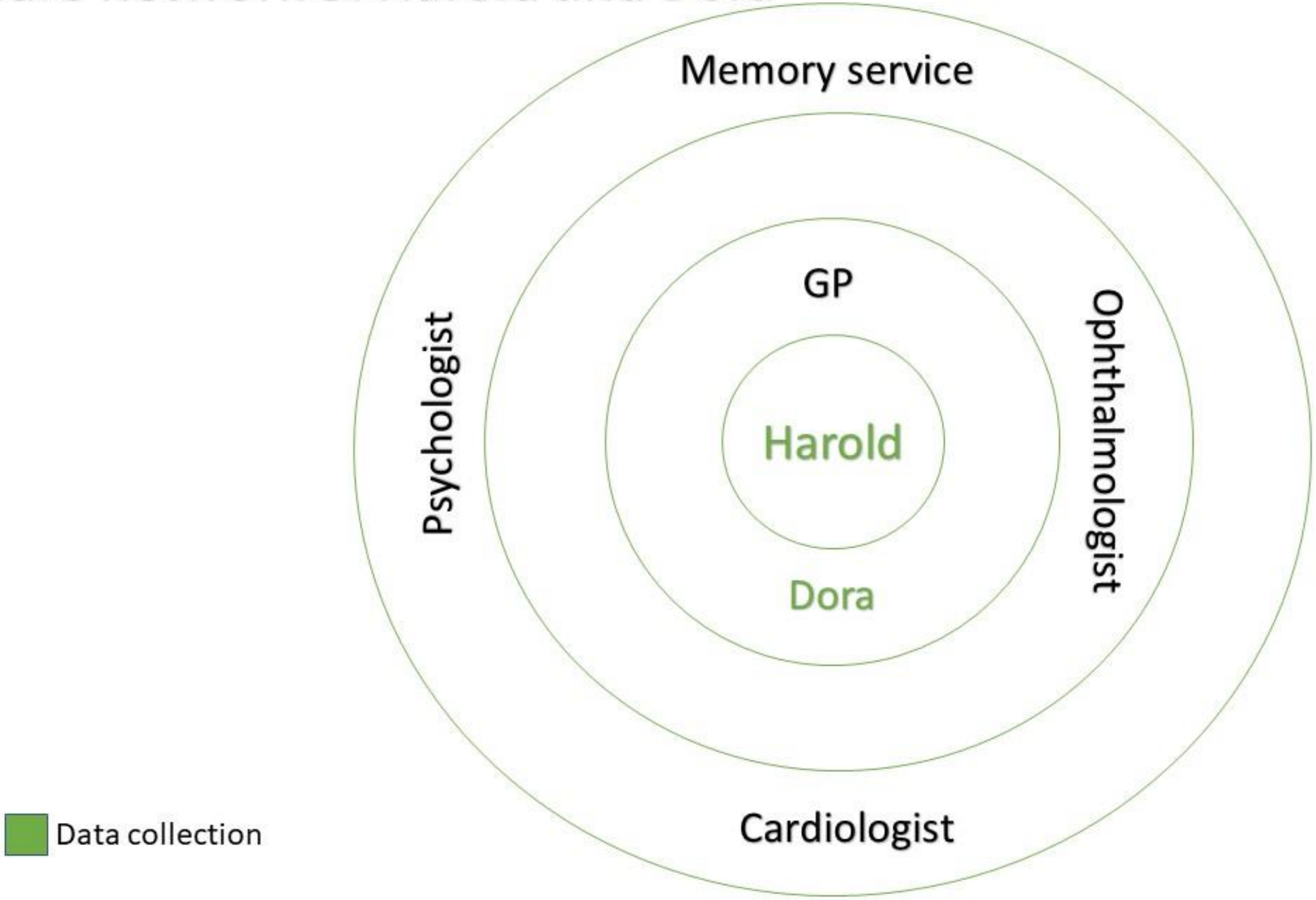
Appendix 16. Visualisation of support networks



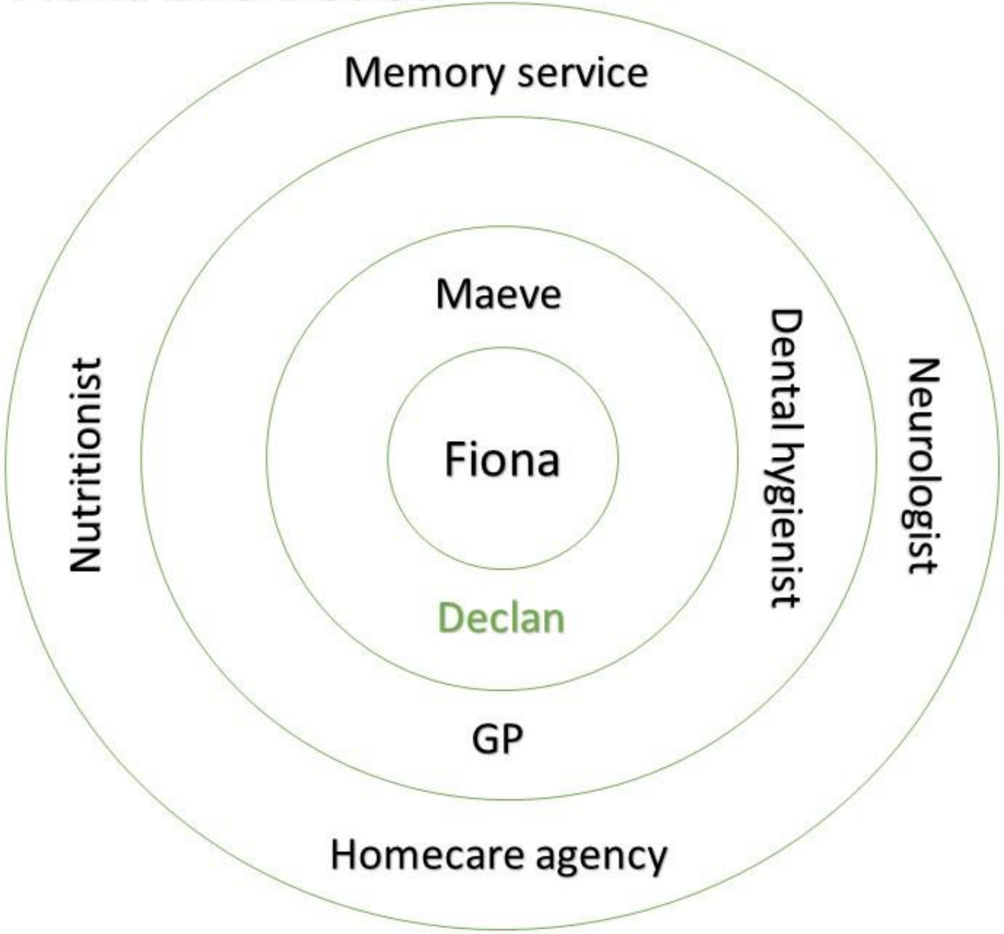
Care network 2: Doris and Bert



Care network 3: Harold and Dora



Care network 4: Fiona and Declan



Memory service

Maeve

Nutritionist

Fiona

Dental hygienist

Neurologist

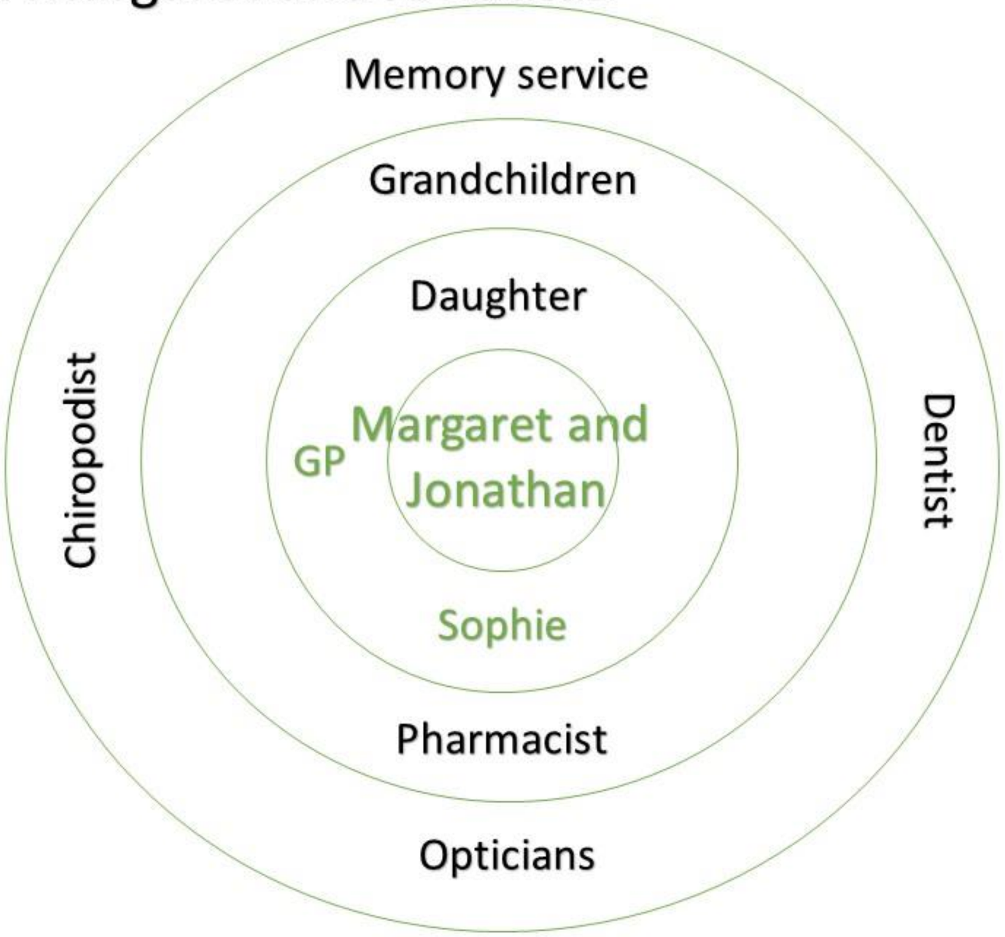
Declan

GP

Homecare agency

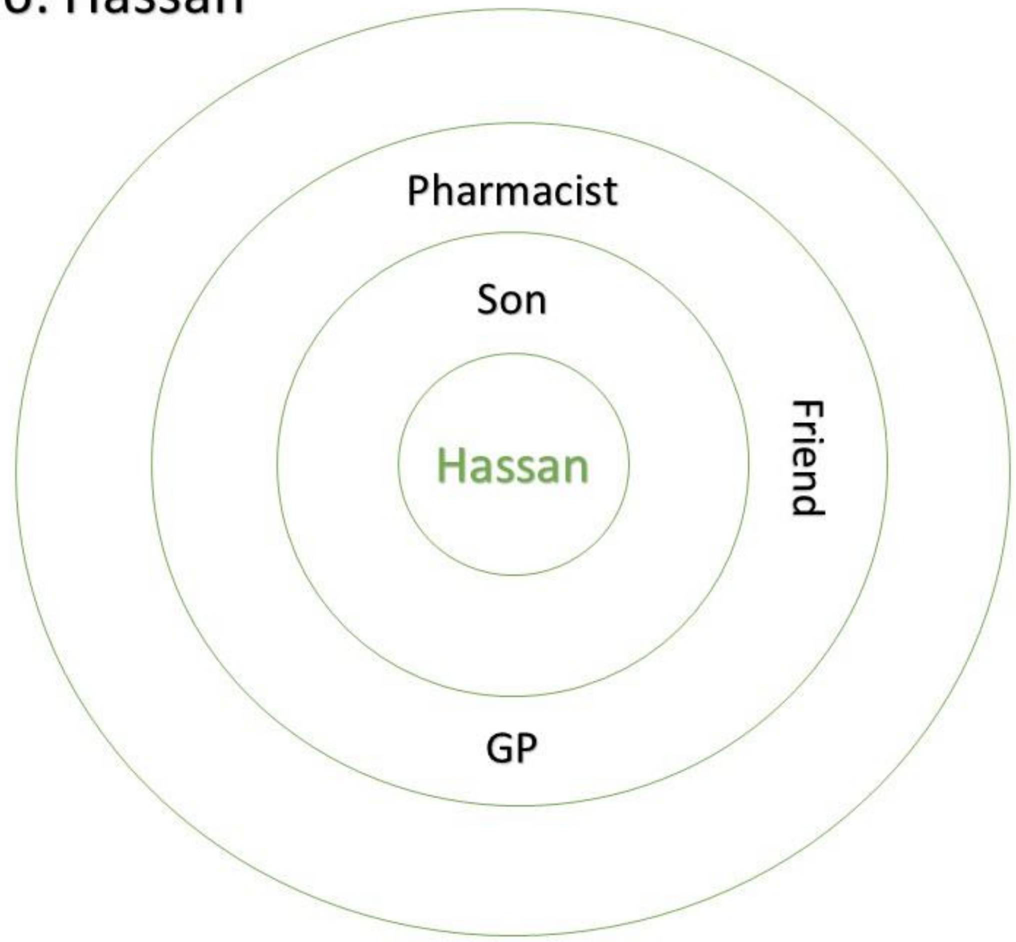
🟩 Data collection

Care network 5: Margaret and Jonathan



🟩 Data collection

Care network 6: Hassan



Hassan

Son

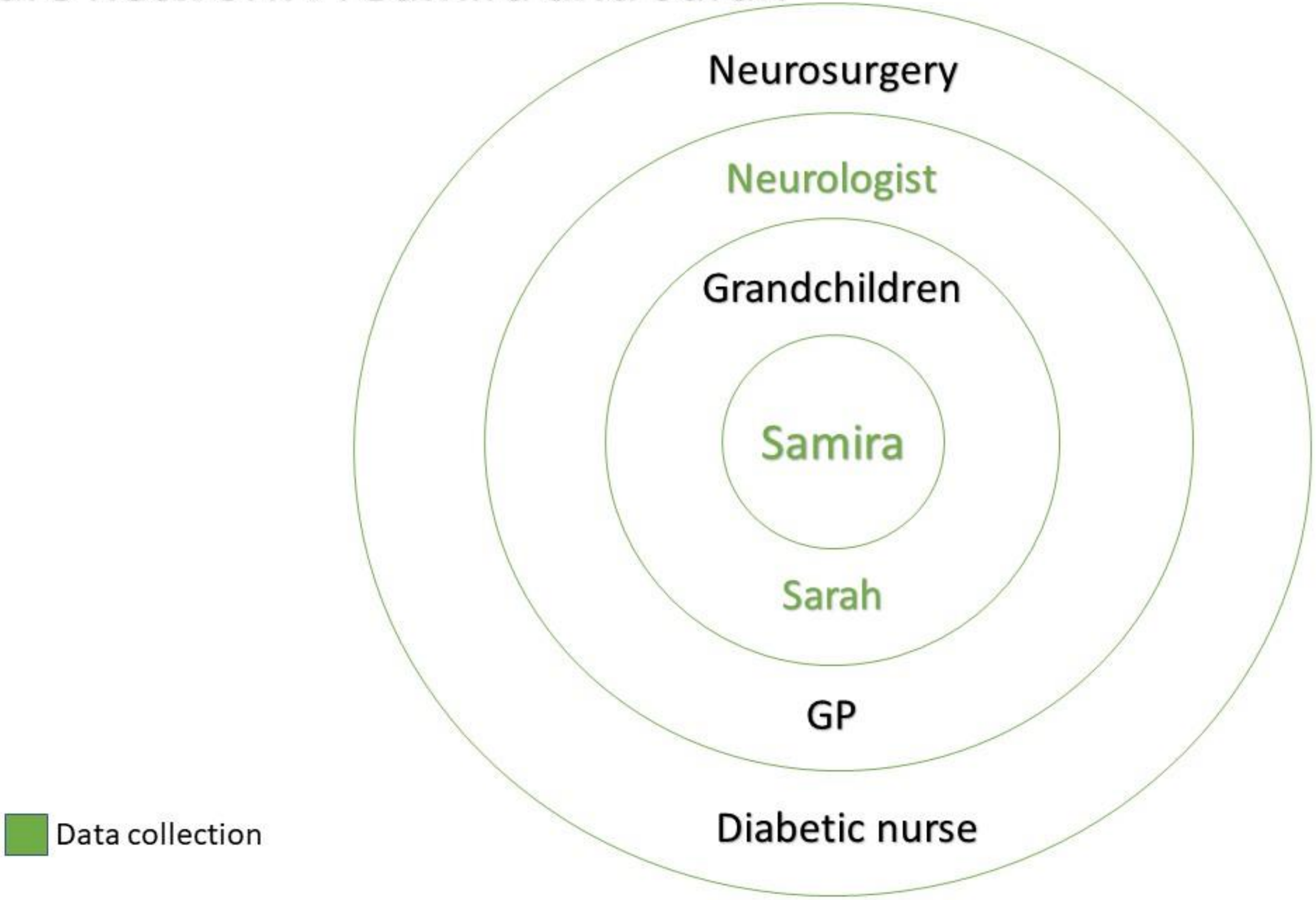
Pharmacist

GP

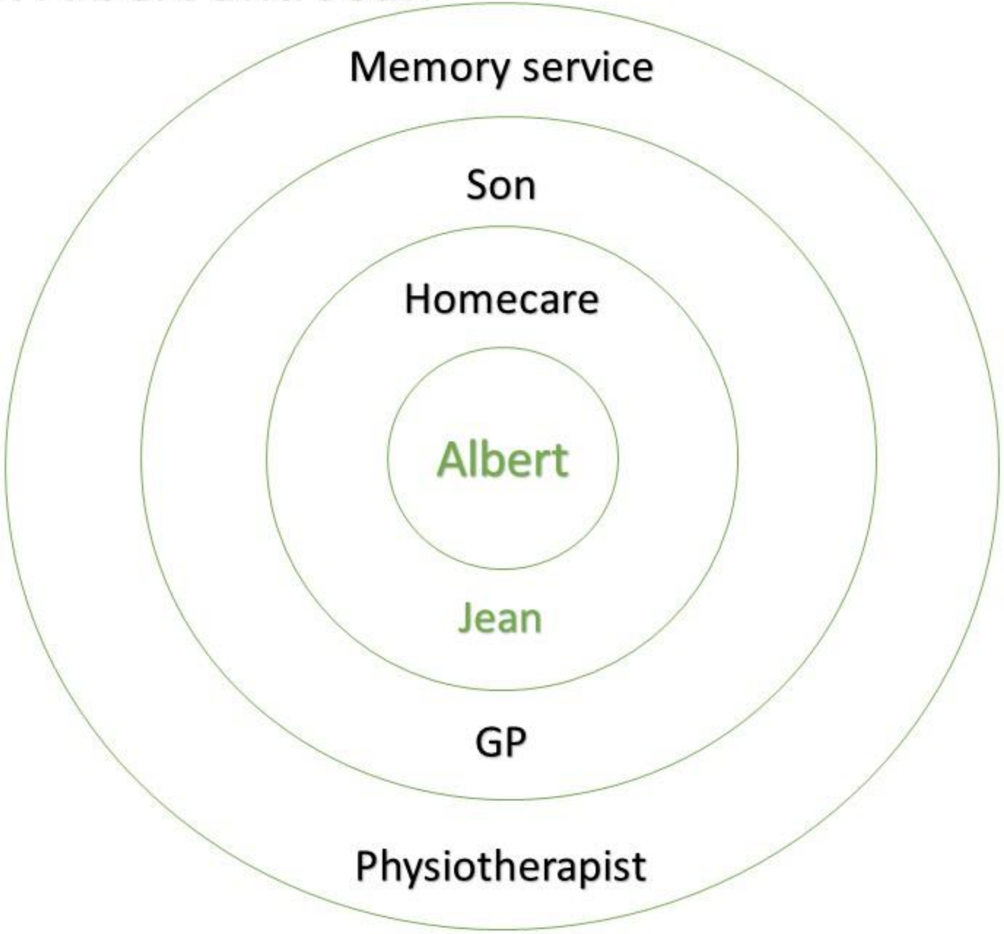
Friend

🟩 Data collection

Care network 7: Samira and Sarah



Care network 8: Albert and Jean



🟩 Data collection

Appendix 17. Across group themes with supporting quotes

Theme	Care network	Additional supporting quotes
Balancing support and independence	Harold and Dora	"They said send us a picture, and after that they didn't receive the picture so we have to, I have to do another picture and send it and we didn't hear from it since. I don't think [laughs] But it's not the doctors I think it's just the system at the moment is not working for people who haven't got COVID, that is a fact." [Dora, Interview 1] "Now he has got a very swollen feet, extremely swollen and he just dismissed it as if nothing was wrong with it. I want him to go to the doctor. I have to insist for him to make an appointment, and at this stage I don't want him to lose his independence. I just try to help as much as I can but I want to go to the doctor with him for that reason otherwise he does everything for himself." [Dora, Interview 1] "In the morning, sometimes he forget [sic] to take the pills. And that is my fault because I sleep more than he does. He's got, he has his breakfast before me, and after that he goes swimming. And accident, I discovered his little I don't know container with the pills, and he hasn't taken it and sometimes it's too late in the day to have it and that's it so that happens not regularly but sometimes." [Dora, Interview 1] "his vision is poor - recently seen glaucoma clinic but drops not helping…advised difficult to consult further without [Harold] being present." [GP consultation notes] "What they say is that I just have to put in drops all the time and you know it's very, the eye is drying out...And also the surface of the eye is no longer smooth and that of course makes the vision less clear. No joys in old age." [Harold, Interview 3]

		"Well I know that doctor of course…I don't think they are so concerned as they should be. Since they have got these huge feet, they are all swollen, skin is cracking and they say oh yes it's the heart…And I don't know if there is anything they could do but… no I wouldn't say that they are neglecting they are quite nice, but you know they are not so worried about his health as we are I would say." [Dora, Interview 1]
	Hassan	"Dementia is…I will say is under control. Can't remember things. But recently not so bad. In a way I can say I used to forget most of the things but now it seems to me that I am better managing dementia as well." [Hassan, Interview 2] "Err I get the medication and I...give me in that bag, you know, weekly bag. Morning, this tablet. Afternoon or evening, this tablet. They're all…the chemist give me a set of bags. So every time I take those tablets I do it myself. I don't ask anybody." [Hassan, Interview 1] "That's how, yeah he tends to come to the same conclusion. I think that's how it was, said that how to manage three times I got hypo and I was told that you must eat something." [Hassan, Interview 1] "Honestly I fell down three, four, five times but I know I am going down and I will just quietly, calmly lie down, and go down." [Hassan, Interview 1] "Err…they were going to do some changes in my medication. Like metformin and things like that you know. To increase or decrease or all together cancel it. But I'm aware of what they are trying to do." [Hassan, Interview 2] "Sometimes I think so many things that when I go there the discussion goes in different ways and whatever. I mean I should have told him this, that. But I forget all about it." [Hassan, Interview 2]

	Samira and Sarah	“Because the last time they gave me the injection it was really painful you know for me, it didn’t work. And it was even more pain, and pain and pain. So I said there is no point taking another injection like that.” [Samira, Interview 3]. “We were trying to minimise the contact with grandma. That was the only issue really. I think was our concern determining how…although she’s a little bit, she is overweight and the asthma and those kind of things, the trigger points you need to worry about with covid.” [Sarah, Interview 1]. “I know how to use them. They taught me how to use it. And they gave me this machine to use it.” [Samira, Interview 1] “And I just mentioned it to make sure she was getting her inhaler in. She got sick last year and we thought it could have been covid and they just gave her, just making sure she was having the inhaler and managed to get advice for it so.” [Sarah, Interview 1] “She managed a lot of pain. She has a lot of pain that she doesn’t really discuss, you know typical mum. You know I’m strong I can do it. But you don’t really get that she’s in pain but she in a lot of pain, she gets on and does it.” [Sarah, Interview 2] “I mean they said to exercise but don’t know how far init. I forced mum to do a lot of walking now. So it’s been a positive.” [Sarah, Interview 1]
Implementing and	Doris and Bert	“It’s very hard, and everybody says this, to treat these things in Alzheimer’s patients. Because you get no feedback on, you know, do you think this is working? How do you feel?” [Bert, Interview 1]

adapting advice for dementia contexts		“But it’s becoming increasingly difficult to get her to eat a good balanced diet, because she gets bored with food, the tremors now make it more difficult for her to handle a knife and fork, and it’s not uncommon I understand for Alzheimer patients to say they don’t want to eat.” [Bert, Interview 1] “She suggested that I get some kind of…err…thing you put on your arm. Blood pressure, monitor type thing. And she sort of explained how the tests are sort of presented. 100 years ago I was a research chemist so understood what she wanted, and she was happy I understood what she wanted. So for a while save us going in there I just used to send her the results. Three, best of two and all that sort of thing. And that sort of petered out, because it seems to stabilise... I still monitor it just out of habit now.” [Bert, Interview 1]
	Fiona and Declan	“She’s having problems with food. She kind of only likes…this is very common apparently in Alzheimer’s…the taste buds change. Or they, how the brain perceives taste, it prefers sweet things…Things she liked [coughs] maybe a month ago she now doesn’t” [Declan, interview 3]. “Anyway, she used to always take that [inhaler] no problem, sometimes she just looks at it and says no I’m not taking that. And you know that’s new.” [Declan, interview 1] “I think it’s because one of the things that has happened with her diet is that she developed a very sweet tooth. For the last year or so. And that’s possible why her cholesterol levels have risen I’m not really sure.” [Declan, Interview 1]. “I’m going to have to contact them myself to talk about possible, potential medications. I mean I’m not, I don’t want to turn her into a zombie I just want something that takes the edge off her anxiety.” [Declan, Interview 3].

		“I did mention to [name of hospital] that there is very little communication with [Fiona’s] GP about the dementia. And they, I think they have kind of stirred them up about that. Because I’m surprised how little it’s ever mentioned.” [Declan, Interview 2]
Balancing physical, cognitive and mental health needs	Edith and Scott	“Takes them when the pain is really bad. I bought them, I got hold of them separately. Because I didn't, I wasn't sure there was a painkiller in the cocktail of pills that she takes now. I wasn't sure if it was a strong enough painkiller in there. So I had to go back to the doctors and the health centre and I had to ask them to prescribe a strong painkiller which led to some constipation.” [Scott, Interview 1]. "I think erm there is a lot of things going on. The falling down, the dementia, and her knee. That was the main thing at the time. That’s what’s been the main problem recently which led to her being confined to home is the knee" [Scott, Interview 3]. “Well she’d like to go out... When you’re not plugged into that it’s…you lose interest in the world generally. That’s what I think a lot of it generally is. Just lost interest. Just doesn’t want to take an interest in things anymore... So she is gradually losing all the things that were around her that were important to her that she could connect with. People she would talk to, you lose that quality of life.” [Scott, Interview 4] "I think erm there is a lot of things going on. The falling down, the dementia, and her knee. That was the main thing at the time. That’s what’s been the main problem recently which led to her being confined to home is the knee." [Scott, Interview 3]

		"…being at home is great, but it does mean she doesn't see people day to day. Apart from the carers. I mean she's got…I had that phone call from the practice. The carers see her. The social worker checks up on her, so you know, she's not forgotten about, she just can't get out very easily." [Scott, Interview 4]
	Harold and Dora	"And that's the reason it's very sad. Because he was the sort of demi-god because he seemed indestructible. He had an extraordinary energy- physical, intellectual. And now you know he sees everything going, it's very hard for him I think." [Dora, Interview 1] "I have noted that this is meant to be about 'managing my health.' I think that for an 85-year-old, my health is good in the physical sense but my mental health is not stable" [Event-based diary]
	Albert and Jean	"We did reinstate him, the main physiotherapist and he came to have a look at your exercise. Oh yes you do your exercises with [Home carer] don't you? You do your exercises every morning. Again the ones where he stands at the table. [Home carer] stands behind him because he could suddenly nearly fall over." [Jean, Interview 1]. "So I might phone to say can somebody come to take him out again. Because he hasn't been out since he's had this fall." [Jean, interview 2]
Competing and entwined	Edith and Scott	"Because I'm not going to be there Christmas day afternoon, or Boxing day afternoon. I don't want to do the afternoons, or evening. Selfishly, I mean last year I had a football match to go to so I didn't want to be there." [Scott, Interview 3]. "And I felt that I could not, well, I didn't want to be away from there for two weeks. Now that I've got the milk in

needs and priorities		and there is plenty of food in there. If I had to self-isolate for two weeks I can do it now. I'm a bit happier about doing that." [Scott, Interview 3] "Because my situation is I'm not living there, I'm not a direct carer... You know there is lots of carers in this country do a fantastic job looking after their parents. I'm not in that category, I go around there, I facilitate." [Scott, Interview 4] "They text me, they text my number and say 'Dear [Edith]'. And I'll go down there and they recognise me." [Scott, Interview 4]
	Margaret, Jonathan and Sophie	"And it was a nightmare at first because you can't do that, it's hard work and so when she started with her memory deteriorating, she's forgotten all that now thankfully [laughs]. So I just give them all together." [Sophie, Interview 1]. "I think my mum was just panicking, a lot of it was the anxiety. Sometimes now she will just come in and puff on the spacer without having anything in it. And that's obviously regulating her breathing for her. So it's a lot of anxiety my mum." [Sophie, Interview 2]. "But definitely with these two I mean I think if they didn't have dementia I'm sure they'd still probably come to see me in, you know, in their couple but I think it would be easier to disentangle it. Just because I could be a bit more like, well I actually do think we need separate appointments. You felt that was a valid reason to do things." [GP, Interview 1].

		“I think the thing that would really benefit her [Margaret] is lung function, well some lung exercises, some breathing exercises, to help her. And I’ve talked with [Sophie] about that quite a lot. And I think there is an element that there is a bit of forgetting to do it or. But also some concerns that they just can’t do it and that they, [Sophie] worries that her memory is too impaired to help her do that. And it’s difficult, you know, it’s difficult to know how much that’s the case.” [GP, Interview 1]. “When we were first being allocated hours it was well you know when you’re doing breakfast for one do it for two, but they don’t have the same breakfast, they eat at different times, you’ve got to see to one. You know when they wake up you’ve got to get their clothes for them. So you can’t do that, you know you’ve got to treat them as individuals.” [Sophie, Interview 1] “Daughter called to say that she is getting very breathless on minimal exertion Can only go about 15 steps before she gets breathless. Realises she is very anxious which contributes and has lost her confidence.” [GP consultation notes] “I think pre-covid they used to very much have back-to-back appointments and they used to all come together, the three of them. And I would say look we need to do one at a time because it confuses me if we don’t, and I need to, for my you know, for me not to get mixed up I really need to manage them individually…What I have found actually during the pandemic and seeing people face to face, and the restrictions we have on our waiting area is that it has been a bit easier. So, it’s probably actually the first time I’ve seen [Margaret] by herself when she’s come in. And actually, I found that really useful because I can talk to her, we can have a chat, nobody is talking for her, I can observe her. And I found that really helpful.” [GP, Interview 1]

		"But yeah it is hard because when I took my dad for his foot appointment, my mum was refusing to go. I'll stay on my own. So I had this little bit of conflict with her, she didn't want to come and I said mum just come you can wait in the car. But I had no intention of leaving her in the car, just to get her in the car. As soon as we was there, she said I'll stay here. I said come with me it's cold in the car. Because I'd be worried! I couldn't leave her in the car. Even though she might have been okay, no I wouldn't leave her in the car. So I dragged her out." [Sophie, Interview 2] "I had an appointment with the dentist and I don't tell them they are going. I just say we are going for a drive and take them [laughs]. Because they will worry and they won't go." [Sophie, Interview 2] "I asked for more details about the eye appointment, but then realised that Sophie didn't want Jonathan to know there was an appointment happening. Sophie winked and said 'oh yes, my eye appointment, no I'm not that organised I haven't booked it yet but I need to'. Sophie mentioned there is an appointment on Monday and she will text me with details." [Observational notes]
	Albert and Jean	"Yeah I wasn't going out because of the vertigo thing I had but on Saturday I had to go out to the preliminary appointment for my cataracts at [name of eye hospital]. So [area] social services expanded, extended the hours for the carer. They gave an extra five hours so it was fantastic so I actually…because I'd been told by the hospital to allow four hours but that didn't happen it only took two." [Jean, Interview 2].

		“I declined the offer of another temporary carer. Because [Home carer] has gotten into such a great routine, I would have to train this person. Can’t leave him to it and that would just be as tiring as…so you know we…I think we were brave enough to have a shower twice. That was the only thing I was scared to do. So yeah that was hard. Because I then became a full-time carer.” [Jean, Interview 1].
Curating supportive networks	Edith and Scott	“That’s the one area that she can't, we can't, they can't do that they're not they're not allowed health and safety, obviously. The carers. What they can do is microwave and do her a sandwich. So I have to think about things I know that she likes, that’s healthy for her, nutritional wise. That’s another issue I have, I walk around the shops. Well, I'll get some dates or prunes. We tried to shift things with prunes.” [Scott, Interview 1].
	Doris and Bert	“During this covid of course I’ve relied more and more heavily on the internet. Good old Google and Alzheimer’s chat…discussion threads on those. More really I think, a lot of them are reassurance I think. Is this serious or not, and if two or three, or a lot of folks on websites say you know we are struggling with this you think you know I am doing my best and there is no secret that will solve it.” [Bert, Interview 1]
	Samira and Sarah	“He does more the physical. Like kind of cough, monitoring the asthma, any like, if mums got urine issues, she’s got bladder control issues so he used to do all that kind of thing...So that’s it. We don’t really do anything memory with him.” [Sarah, interview 1]

Carer support and coping	Doris and Bert	"No paid carers at all. I've been reluctant to do that. The neurologist is a lovely chap, he keeps saying you've got to look after yourself. But I must admit it won't work on the moment. If I left her with someone I wouldn't go out or do anything, I'd only sit out there fretting. So I'm really managing myself." [Bert, interview 1]
	Fiona and Declan	"Well I'm just about okay. Up until about two weeks ago my daughter was here. Because I couldn't have done it without her for the first two weeks. I couldn't have coped. I had absolutely no energy." [Declan, Interview 1] "It's a very difficult decision. You know the last thing I want her [Fiona] to think is that she is being abandoned. Or having the feeling that she is being abandoned. But my daughter is very worried about the impact on me" [Declan, Interview 3] "Oh yes, from several of the people that neurology said they would contact through doctor referrals they have been in touch. But really there's very little any of them can do... Because they can't really, [Fiona] just…there's not much they can do with her you know." [Declan, Interview 3] "Yeah I thought that wasn't going to work and it didn't. They just stopped, I told them to stop coming because they were offering to do housework and stuff but that's no good." [Declan, Interview 4]
	Margaret, Jonathan and Sophie	"Again I was worried about who I was letting in the house. Covid has had such a detrimental effect on everything regarding me and my parents' care. Just to protect them. And even now I'm worried about letting my sister back…My family have stepped up but obviously with the covid there is only so much they can do. So I still feel like the sole responsibility is on me." [Sophie, Interview 1]