Living at Home with Dementia:
The Role of Informal Carers and Experience of Integrated Care –
A Mixed Methods Study

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Dedicated...

in loving memory of ….

Mrs C. C. Thompson and Mr. R. Biswas

Abstract

Dementia is a major cause of disability in old age. Since an effective cure has not yet been discovered, dementia care poses major challenges for health and social care services, families, and society as a whole. In 2015, the UK Government pledged to transform dementia care by improving and delivering integrated person-centred care and support at home in the community, for people with dementia and their informal carers. This research seeks to enhance understanding of dementia care at home and the role played by the informal carer in the community.

The study used an exploratory sequential mixed methods design. Following literature reviews, in an initial phase, in-depth interviews were conducted with participants based on purposive sampling. The results of this phase generated the important themes that were then used to design and carry out an online informal carers survey. In the final phase, focus group discussions with informal carers and dementia service providers provided an opportunity to triangulate the research findings and finalise results.

The study identifies essential care domains in dementia and demonstrates that an enhanced understanding of these domains can improve the quality of care for people living at home with dementia. Informal care is a complex phenomenon, often representing a lifetime investment in social capital, which the person with dementia can utilize to meet care needs. The study concludes that the informal carer is insufficiently accounted for in the current integrated care models. It suggests the need for a person-centred holistic assessment as well as appropriate care education and skill training for informal carers to improve carer readiness. A theoretical contribution is made by proposing a widened interpretation and application of resources in determining needs in care assessment and delivering care packages, in person-centred, integrated dementia care at home.

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Abbreviations and Acronyms

APPG	**All Party Parliament Group**
ARUK	**Alzheimer's Research UK**
AT	**Assistive Technology**
CCG	**Clinical Commissioning Group**
CQC	**Care Quality Commission**
DFC	**Dementia Friendly Communities**
DFID	**Department for International Development**
FA	**Framework Analysis**
HEE	**Health Education England**
LGA	**Local Government Association**
NICE	**National Institute for Clinical Excellence**
NSFT	**Norfolk and Suffolk Foundation Trust**
OECD	**Organisation for Economic Co-operation and Development**
OT	**Occupational Therapy**
PPI	**Patient and Public Involvement**
PWD	**Person with Dementia**
SLF	**Sustainable Livelihood Framework**
UK	**United Kingdom**
WHO	**World Health Organisation**

Chapter One: Introduction and Thesis Roadmap

1.0 Dementia Context

Dementia describes *'a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language'* (Alzheimer's Society UK, 2020), comprising several diseases such as Alzheimer's disease, vascular dementia, Lewy body disease, and frontotemporal dementia. In the United Kingdom (UK), the health and social care services define dementia as 'a term used to describe a range of cognitive and behavioural symptoms that can include memory loss, problems with reasoning and communication and change in personality, and a reduction in a person's ability to carry out daily activities, such as shopping, washing, dressing and cooking' (National Institute for Health and Care Excellence, 2018a).

Globally, in 2015, an estimated 46.8 million people were living with dementia, a figure which was set to double every 20 years, reaching 74.7 million in 2030. Annually, an estimated 9.9 million new dementia cases are added worldwide, which equates to one new case every 3.2 seconds (Prince *et al.*, 2015). This estimate represented an increase of 30% over the 2010 estimate. In the UK, the population is as well ageing and by 2030 one in five people (21%) is projected to be 65 or over, and the over-85 age group is the fastest growing demographic, set to double in the next 20 years (Office for National Statistics, 2017, 2019). According to a prediction in 2014, today, in 2020, an estimated 980,844 people are living with dementia in the UK, and this number is expected to exceed a million by 2025 and to reach two million by 2051— an increase of 132% over the next three decades (Knapp *et al.*, 2014, p. 16). Each year an estimated 225,000 people develop dementia, equating to one person every three minutes (Prince *et al.*, 2015). One in 14 people over the age of 65 (7%), increasing to one in 6 people over the age of 80 (17%) (APPG, 2019) is likely to develop dementia.

Although dementia is not an inevitable part of human ageing, older people are most at risk of developing dementia. As the risk of developing dementia increases significantly with age, older spouses/partners find themselves having to assume an increasing responsibility of care. There are no effective curative treatments yet available for dementia, and the majority (91.8%) of those living with dementia also have other health conditions, known as comorbidities (Poblador-Plou *et al.*, 2014). People living with dementia who are aged over 65 have on average four comorbid health conditions, compared to someone without dementia, who typically has two (Browne *et al.*, 2017; ARUK, 2020). People with dementia are more prone to falls, hip fractures, urinary and chest infections, which are preventable conditions, but which cause emergency hospital admission if not prevented. Effective care is therefore very important for keeping a home-focused care system.

Regardless of the dementia someone develops, and their age, gender, and socio-economic status, there is always some combination of loss of vision, memory, cognition, and executive functioning leading to severe disabilities and eventually, high levels of dependency. Levels of decline for someone with dementia also vary—for some people there is a quick and sharp decline, whilst for others, the process of decline can take decades. In either case 'care' generally becomes one of the most important aspects in managing the decline, reducing preventable hospital admissions and achieving and maintaining a good quality of life. Although dementia is not a static condition the changes are often small during initial phases of the disease, but it can become severe enough to affect daily life. A person with dementia may also experience changes in their mood or behaviour. Inevitably, dementia has physical, psychological, social and economic impacts, not only for those being diagnosed and living with the condition, but also for their caregivers, families, and society as a whole. The majority of these diagnoses also affect the elderly person's spouse or partner, family and friends and many of these people come to find themselves in the role of informal carer.

In the developed world, including in the UK, significant efforts have been made in preparation to tackle the predicted surge in the high numbers of senior citizens with dementia. The UK assumed a leading role by developing its own set of goals and strategies focusing on the future to ‘transform dementia care, support and research’ (Department of Health, 2015, p. 3). Currently, the UK aims to be the ‘best country in the world for dementia care and support for people with dementia and their carer and families to live’ (Department of Health, 2015, p. 3). Such transformation in dementia care often refers to care in the community as it is less costly and more desirable for people with dementia to stay at home; however, it comes with huge unseen costs borne predominantly by informal carers. What constitutes dementia care in the community is not entirely clear, nor is it known how, or why family members are prepared to undertake the role of carer.

The aspiration to undertake this research on informal community care comes from not only the realisation of dementia care being a national and international priority, but also from my personal experience as an informal carer. My years caring at home for a close relative with dementia and witnessing the progression of the condition provided a deep motivating factor for this research, and this researcher positionality is reflected on later in the thesis.

1.1 About the Study

The study undertaken consisted of a review of the literature, qualitative semi-structured interviews with a sample of informal carers and separate interviews with service providers; followed by online survey of carers. Subsequently, a focus group discussion was conducted with a mixed group of carers and service providers for the purposes of considering emerging findings. Interviews and focus group discussion were held in a large rural county in England, whilst the online survey was not restricted geographically.

1.2 Terminology

In order to clarify for the reader, it is important at this point to make some general comments about aspects of the terminology that is used in the thesis.

Informal carer - Throughout the course of this thesis the term ‘informal carer’ has been used interchangeably with ‘caregiver’, ‘family carer’, ‘carers’ and this term denotes that these individuals provide care on an unpaid basis.

Dementia - ‘Dementia’ is used as a collective term which encompasses different types of this condition.

Service provider - ‘Service provider’ refers to someone who works for statutory, voluntary, private sector or community organisation in a paid or voluntary capacity, to provide a service in the community to a person with dementia and / or their carers.

Integrated care – ‘Integrated care’ refers to a system of care delivery that emphasises the coordination of services centred on the multiple needs of a person with dementia, particularly in relation to health and care.

1.3 Thesis Road Map

This thesis is comprised of nine chapters. This chapter (Chapter One) presents a brief introduction and describes the research contexts and provide the road map to the thesis. Chapter Two presents a review of the literature that discusses key concepts and ongoing debates within this research scope, primarily dementia care at home, informal carers in dementia, and integrated care in dementia. This chapter provides the justification for this research and finally presents the research questions for the study.

Chapter Three focuses on the methodological approaches of the research that address the research questions regarding dementia caregiving at home. It describes the pragmatic approach that provides the philosophical and theoretical basis for the research and the conceptual framework that guide this research. It further presents the mixed methods that were implemented in different but interrelated-sequential exploratory stages. The chapter further lays out the sequence of data gathering and analysis at each stage and presents the ethical considerations related to the study. It also provides details on Patient and Public Involvement (PPI) in this research.

Chapters Four, Five and Six present results from the analysis of the qualitative interviews with informal carers and service providers, focusing on the research questions. Chapter Four presents findings on the role of informal dementia carers, including the process of becoming a carer, and the knowledge, skills, attitude and strategies reported as needed to cope with caring responsibilities. Chapter Five shifts to presenting what constitutes dementia care at home in the community, presenting key aspects of dementia care in six inter-connected care domains. Chapter Six presents integrated care in dementia by describing how informal care and carers interact with formal care services, and the contribution of this interaction to person-centred well-coordinated service delivery as part of integrated care systems.

Chapter Seven provides the results of the online informal carers' survey and analyses that followed the qualitative analysis. As an element of validation, it seeks to expand understanding of the variability of key elements of informal care identified in the qualitative phase. This chapter includes the survey objectives, describes the process of survey design, piloting and sampling, and presents the analytical strategy used to generate research outcomes.

Chapter Eight, presents the outcome of the Focus Group Discussion (FGD), which was carried out at the final phase of this research with service providers and informal carers.

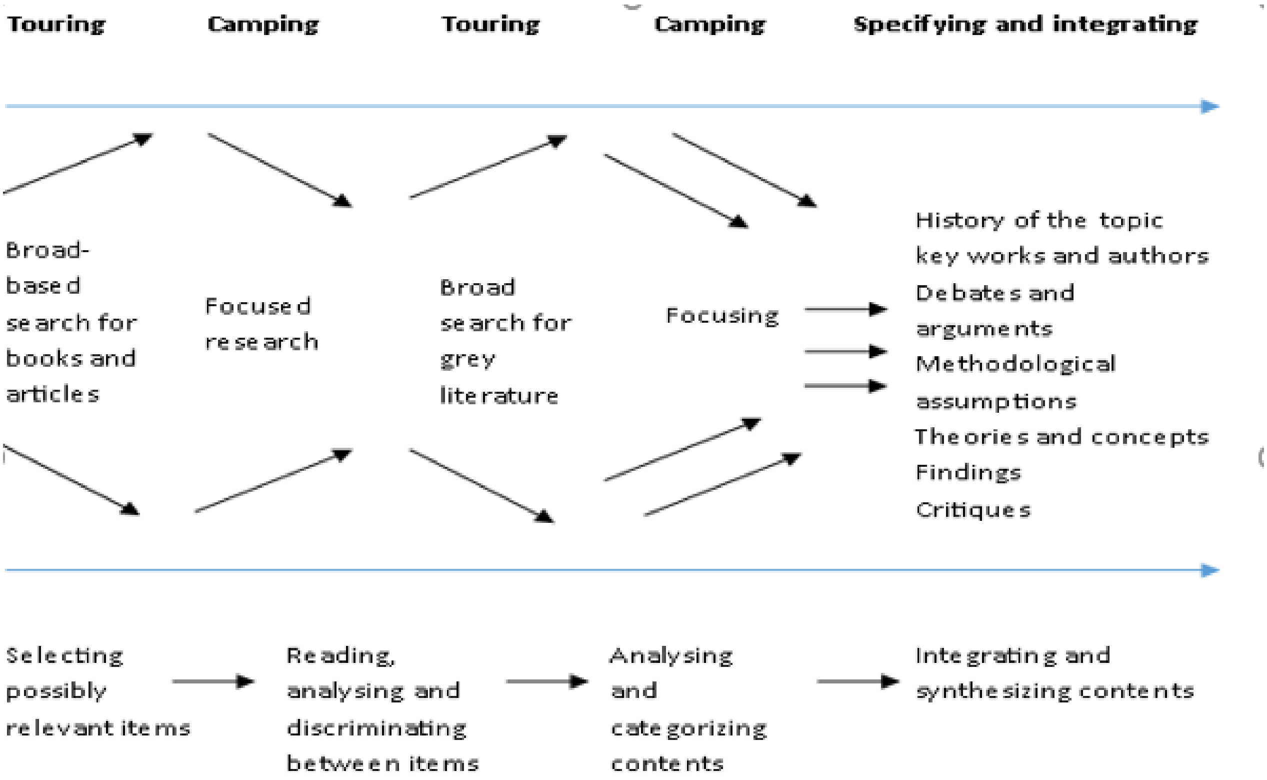
Chapter Nine, the final chapter presents the discussion and conclusion, in line with the three key research questions. It further presents some strengths and limitations of the research, discusses future implications in research and practice of this study, and offers concluding insights.

Chapter Two: Literature Review

2.0 Introduction

The following chapter presents a review of the literature on four key aspects pivotal to the research questions of the thesis: dementia care at home, informal carers in dementia, support for dementia carers and integrated person-centred care in dementia. To assess the existing literature, I adopted Gray's model of touring, camping, specifying and integrating as summarized in Figure 2.1 (Gray, 2014, p. 47). Adapted from Hart (2001), this model offers researchers an organized structure while promoting a flexible 'open mindedness' (Hart, 2001, p. 11) in covering a range of views.

Figure 2.1: Gray's model of literature review



Gray (2014), P- 47

The aim of this literature review was to assess the existing evidence to enhance my understanding and appreciation of the edge of the current knowledge base in this area, locate a niche beyond the edge and to inform the development of the research question and design the study accordingly. Gary's model offered an openness and flexibility to the approach and to enable interests in both academic as well as relevant grey literature as well as for literature review to be in different stages.

2.1 Literature Review Strategies

To start with one key reference point for this research was the UK Government's policy document 'The UK Prime Minister's Challenge for Dementia 2020' (Department of Health, 2016). The recommendations aim to improve dementia care in the community by providing support to the carers of the people living in the community with dementia and this, combined with my own experience as a family carer, created an interest in current practices. Subsequently, a systematised literature review was carried out to develop an understanding of the subject, identify the types of research methods used, gain an understanding of the expert views in the field, as well as to help formulate research direction within this area of study and development of relevant research questions. In keeping with several key texts on Social research methods, some of the essential aspects of the literature review are outlined below (Webster and Watson, 2002; Aveyard, 2007; Gray, 2014).

Although a systematic review was briefly considered, it quickly became apparent that a systematic review might not be the best option for this research. A systematic review aims to locate, identify evidence with strict inclusion and exclusion criteria, undertake an appraisal and then synthesise all evidence relevant to the specific issue in order to answer a specific question. To shape this study, it was essential to review the widest possible range of existing literature, and it was considered that a systematic review would not have been able to synthesise the wide range of literature that frames this study. Therefore, a scoping review was deemed to be more appropriate for this research, as it would allow for a wider range of academic and grey literature alike to be appraised and included as necessary. Notwithstanding that this was not a systematic review, a systematised approach to the review was used to ensure that the review was robustly undertaken.

The literature search was conducted using specific search terms and included the following electronic databases: Allied and Complementary Medicine Database, CINAHL complete, MEDLINE complete, and Embase. These provided a broad range of health and social science journal articles relating to dementia care in the community. In addition, grey literature was sought by individually searching key online sources including websites, including the World Health Organisation (WHO), the Alzheimer's Society, Dementia UK, National Institute for Health and Care Excellence (NICE) database and the NHS.

Searches were undertaken using different combinations of key words and without date or geographical restrictions, which enabled development of an overall understanding of the evolution of the key aspects of person-centred dementia care within home settings and where an informal carer exists. The search terms used were under four categories – the first was 'dementia' or 'Alzheimer's disease', second was 'care at home', 'care in community', third, 'informal carer or caregiver', 'family carer or caregiver', 'informal dementia carer', 'support for dementia carer' and the fourth was 'integrated care' and 'person centred care'. Searches were limited to the key words in the title and article abstracts, or in case of grey literature the executive summaries.

A total of 132 papers were initially identified through a combination of electronic database (listed above) and other searches. This included searching articles through Google Scholar, searching of the grey literature and some additional manual searching of citation and references lists of key documents. All paper details were transferred into an Excel work sheet, to check for duplicates, which were found and removed (n=23). Abstracts were then screened and papers were excluded (n=41) applying exclusion criteria, e.g., the full paper was not written in English, the paper(s) focused on informal care for children, the paper(s) focused on adults under 65 years of age. A total number of 68 papers remained for full-text screening of which a further 20 were excluded, as the informal care of adults over the age of 65 was for health conditions other than dementia or Alzheimer’s disease. Thus, a total of 48 papers were included in the initial literature review and a further 18 papers were added during the course of this study as new publications became available. A total of 66 papers were included in the final literature review. Further details on literature identification, screening, inclusion and exclusion are provided within the PRISMA flowchart in Annex 2.

The literature collected was appraised and prioritised in two steps. First, based on the work of Hart (1998) and Aveyard et.al. (2015), a six-point critical appraisal checklist was used (Hart, 1998; Aveyard, 2007). Second, the literature was prioritised using a ‘hierarchy of evidence’ template, as developed by Evans (Evans, 2003). Annex 1 presents a diagram of this two-step critical appraisal process. This systematised two step approach made critical appraisal of the relevant literature easy and continuous throughout the study, as ongoing literature review was a constant phenomenon in this study.

All included literature was transferred and managed by an online reference management programme, Mendeley Reference Manager. A notification option was set for the programme to generate a reminder as and when any new relevant publication was available, and these were then periodically reviewed, using the same two steps: a check list followed by a hierarchal priority. Reference lists of these documents were also checked periodically for additional relevant material and references.

This review begins with an overview of the general topic that informed this research. It provides the dementia context and focuses on the role of informal carers in dementia care, dementia carers support. The concept of integrated care as a strategy for a more person-centred care concept is then examined, and finally, the review identifies current gaps in care within which this research intended to make its contribution.

2.2 Local Context – Norfolk

Norfolk has one of the most elderly populations in the country (Norfolk Insight, 2016). As a result, the highest percentage of people living with dementia in an NHS England Clinical Commissioning Group (CCG) is found in NHS North Norfolk CCG with 2.2%, a rate which is over five times higher than the lowest rate, 0.4% for NHS Tower Hamlets CCG (ARUK, 2020). According to a report published in 2014 (Ford *et al.*, 2014), there were an estimated 16,400 people in Norfolk living with dementia, either with or without a diagnosis; this is equivalent to 1 in every 53 residents in Norfolk. This figure for those with dementia is projected to rise to 25000 within 15-20 years. Nearly half of the Norfolk residents aged over 65 are living with some degree of frailty (Norfolk Insight, 2020).

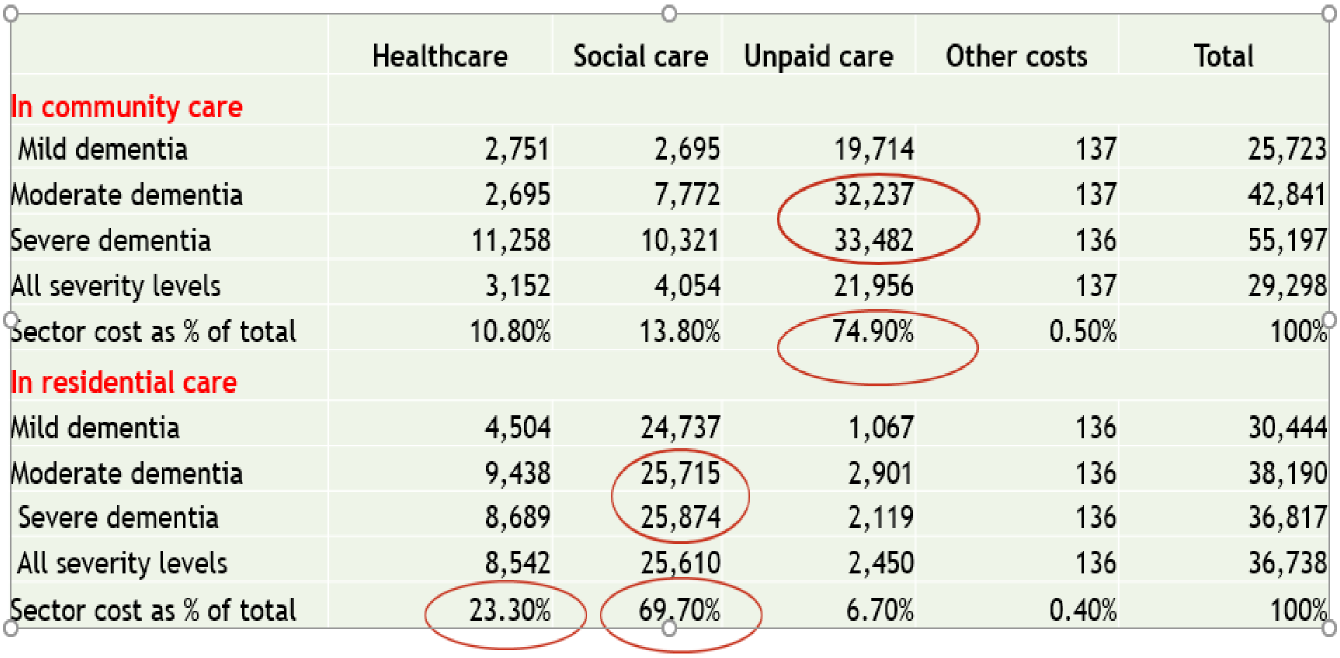
The estimated number of unpaid adult carers in Norfolk is just under 100,000 (Norfolk Insight, 2020) of which around 35% are 65 years old or over, and a further 40% are aged between 50 and 64 years (Norfolk Insight, 2020). According to an estimate by Carers UK, the care provided in Norfolk by local adult carers would cost £1.9 billion a year if it had to be paid for by public services (Carers UK, 2018). Three of every four people with dementia are supported by an unpaid carer and according to a Healthwatch Norfolk estimate, their contribution saves the local health and care systems £60 per minute (Fraser and Brooks, 2018).

2.3 Dementia Costs

In global terms it was predicted that by the year 2018, dementia was to become a 'trillion-dollar disease' (Prince *et al.*, 2015). In the UK, according to a 2014 report (Knapp *et al.*, 2014) dementia costs £26.3 billion yearly, and two-thirds of the cost (£17.4 billion) is shouldered by people with dementia and their families, either through paying for private social care or in unpaid care, and an estimated 1.34 billion hours of care are provided annually. The NHS pays up to £4.3 billion of the costs (including £85 million spent on diagnosis of the condition) and social care £10.3 billion, including £5.8 billion which people with dementia and their families pay out annually for help with everyday tasks provided by professional care workers (Knapp *et al.*, 2014). The total value of costs of unpaid care for people with dementia is £11.6 billion (44% of the total cost of dementia) (Alzheimer's Society, 2007; Knapp *et al.*, 2014). Table: 2.1 below presents costs by different sectors in the community and in residential care, by levels of severity.

Table 2.1: Distribution of dementia care cost per year (in £ millions) by sectors, severity and care settings

(Significant Values Highlighted in Circling)



	Healthcare	Social care	Unpaid care	Other costs	Total
In community care					
Mild dementia	2,751	2,695	19,714	137	25,723
Moderate dementia	2,695	7,772	32,237	137	42,841
Severe dementia	11,258	10,321	33,482	136	55,197
All severity levels	3,152	4,054	21,956	137	29,298
Sector cost as % of total	10.80%	13.80%	74.90%	0.50%	100%
In residential care					
Mild dementia	4,504	24,737	1,067	136	30,444
Moderate dementia	9,438	25,715	2,901	136	38,190
Severe dementia	8,689	25,874	2,119	136	36,817
All severity levels	8,542	25,610	2,450	136	36,738
Sector cost as % of total	23.30%	69.70%	6.70%	0.40%	100%

Source: Report - Dementia UK, 2014- Second Edition/ Overview p - 23

The cost of dementia care increases significantly as the level of severity of the disease becomes greater. Dementia care costs in institutional settings, such as residential care homes are considerably higher, some 1.8-fold, than care at home (Wübker *et al.*, 2015). When someone is cared for at home, three-quarters of the cost burden of care is borne by the informal carers (and patients) and when care arrangements shift from home to a residential care or nursing home, the public cost borne by the social and health sectors increases greatly, as shows on the table above (Knapp *et al.*, 2014). The accuracy of the informal carers contribution in these estimates are not without question – as these are often underestimated (Giebel *et al.*, 2019) and are dependent upon what elements of care are being included in the estimate, informal care costs can range between 36% and 85% (McDaid, 2001). There is no question however about the high level of care input that informal carers provide for people with dementia. In the context of the person with dementia living at home with an informal carer as well utilising formal paid care, formal care may supplement rather than substitute for informal care support (Schneider *et al.*, 2003) .

2.4. Dementia Care in Institutions

Over half of the UK population know someone who is living with a dementia diagnosis (ARUK, 2020). Older people with dementia are more likely to be admitted to hospital as emergency admissions although not admitted for dementia itself (Natalwala *et al.*, 2008) and tend to stay longer in the hospital. In the UK, at any one time, one in four hospital beds is occupied by someone with dementia (Lakey, 2009) and three quarters of all people with a dementia diagnosis recorded by hospital admissions are over 80 years of age (ARUK, 2020). Previous studies show that people with dementia experience three times more likelihood of preventable hospital admission and subsequent risks of readmission (Bynum *et al.*, 2004) and having dementia contributes to such admission or readmission (Pickens *et al.*, 2017). Readmissions are attributed to fragmented/poor ancillary care, resource availability and affordability, uncertain medication reconciliation, and the patient's cognitive decline, as well as poor social support and caregiver's ability to manage any complication (Cummings, 1999; Cumbler, Carter and Kutner, 2008) . Although a significant proportion of these admissions/ re-admissions may be preventable, at times the re-admission of older people with dementia contributes to a significant bed shortage in acute hospitals (Keady and Swarbrick, 2011). Such situations are often referred to as 'bed blocking' (Gaughan *et al.*, 2017), whereby an elderly person remains in the hospital due to no alternative suitable accommodation being available for care and recuperation despite no further medical intervention being necessary. Availability of an informal carer at home, such as a spouse or adult children is stated to have significant impact on the decision to discharge an elderly person back home or to a care home (Picone, Wilson and Chou, 2003; Gaughan, Gravelle and Siciliani, 2017). The harmful personal impact of older people spending more time in hospitals then necessary has been reported to be significant, e.g. 10 days of bed rest equates to 10 years of muscle loss which increases frailty (Vernon, 2017). Nevertheless, ‘delayed transfers’ from NHS acute hospitals’ beds remain a longstanding concern (Appleby, Thompson and Galea, 2013), and almost two thirds (over 60%) of people with dementia who receive acute hospital care and treatment are discharged to a care home or nursing home having been admitted to the hospital from their own residence (ARUK, 2020).

Dementia is one of the major reasons for admission to a care or nursing home for older people, and nearly 70% of care home residents are living with dementia—a growing trend (Matthews *et al.*, 2013). An increase in the number of older people in the population has led to an annual increased demand for residential and nursing care home vacancies. In contrast, although in some local authority areas there is an increase in the supply, in other areas there has been a significant reduction (58%) in the number of beds available in care homes, leading to an overall downward trend in the availability of beds in care homes (CQC, 2018b) as well as care home closure. Not only has bed availability declined, but the apparent declining standards in the quality of care in such institutions, especially for people with dementia and disabilities, since the previous year, has been detailed in a report (CQC, 2018a), and was highlighted and monitored by regulators as well as being raised by the media and investigative journalists. According to the most recent CQC report, over 40% of the care homes are not currently providing good enough care and do not ensure adequate quality care to their residents (CQC, 2018c). It does not therefore come as a surprise that older people often regard admission to a care home as their very last resort, including people who have been diagnosed with dementia. Two thirds of people with dementia live at home in the community and 60% of them receive home care support (ARUK, 2020). This support is usually provided by private domiciliary care providers and paid for either by the service users themselves, or by the local authorities with financial contributions towards the cost of provision determined by means testing (UKHCA, 2015; Thorlby *et al.*, 2018).

2.5 Dementia Care at Home

Based on the increasing prevalence and costs of dementia, as well as the preference of most older people to remain home for as long as possible, it becomes clear that the critical need to maintain care at home has never been greater (Rowles and Bernard, 2013). For people living with dementia ‘home’ has a much deeper meaning as the ongoing quest to find ‘home’ for the person with dementia is universal (Graham, Rowles and Chaudhury, 2005). Despite cognitive losses, the emotional significance of the concept of home is retained in the brain and therefore the sense of home appears to remain in the minds of people living with dementia for much longer (Frank, 2005).

According to a public opinion (YouGov) survey - 85% people would like to stay at home as long as possible after a diagnosis of dementia; however, far fewer, only 47%, thought they would actually be able to do so (You Gov, 2014). Staying at home with dementia requires appropriate support and assistance being delivered at home by formal services and informal carers where available. It is estimated that 60% of the people receiving home-care services at home are living with dementia (Carter *et al.*, 2015) and two thirds of the people diagnosed with dementia live at home and are supported by informal carers (Local Government Association, 2018). This portrays a scenario whereby people with dementia wish to remain at home, and yet in the year 2013 70% of care home residents in the UK were living with dementia (Knapp *et al.*, 2014), and evidence suggests a clear correlation between dementia-related issues and admission to institutional care (Callahan *et al.*, 2012).

A decision to end care at home and move into institutional care is a stressful life event for older people and their family carers (Ellis, 2010) and has significant impacts on older lives (Lee, Woo and Mackenzie, 2002; Ellis, 2010). An older person’s higher mortality risk is associated with the first year of transition from home to a care home, and the lowest mortality risk has been attributed to older people remaining at home (Robards *et al.*, 2014). Sustaining dementia care at home appears to be largely reliant upon informal carers being present and shouldering that care. As one study shows, the existence a co-resident carer makes admission to a care home 20 times less likely over a one-year period (Banerjee *et al.*, 2003).

Informal carers play a crucial role in sustaining care at home. The nature of informal dementia care in some cases is quite similar to the care provided for any elderly person, however, dementia care also has some unique characteristics. Critical differences in dementia care involve the assurance of appropriate nutrition and hydration (Abdelhamid *et al.*, 2016), supportive communication (Done and Thomas, 2001), managing behavioural and psychological symptoms (Ringer *et al.*, 2020) and carer coping strategies (Livingston *et al.*, 2013). It has been argued that the attitude, personality traits and coping strategies of informal carers influence the quality of dementia care (McClendon and Smyth, 2013). Georges et al. (2008) have identified managing activities of daily living and behavioural issues as the most common difficulties associated with care at home (Georges *et al.*, 2008). To address these difficulties, the World Health Organisation (2012) has recommended a number of interventions for family carers of people with dementia, including psycho-educational interventions offered at the time of diagnosis support, counselling, and/or cognitive-behaviour interventions to address carer psychological strain management of depression (World Health Organization, 2012). The training of informal carers in communication and coping with behavioural symptoms in people with dementia has been recommended (Downs and Bowers, 2014; Morris *et al.*, 2018) and also applied in some projects, such as TANDEM (Haberstroh *et al.*, 2011) and START (STrAtegies for RelaTives) (Livingston *et al.*, 2013). There are some aspects of dementia care that highlight carer stress such as the management of complex multiple medications (Travis, Kao and Acton, 2005; George and Steffen, 2015). In such a context, it is important to review the policy responses that have developed, which aim to improve care and support carers.

2.6 Policy Responses and Support for Dementia Care

In 2015 several global reports were published (OECD, 2015; Prince *et al.*, 2015; World Health Organisation, 2015) including declarations that dementia is a public health crisis and one that deserves global public health action. Dementia was spoken about at the OECD, G7 events, United Nations and the World Health Organisation, and global action plans were drafted and revised. The Global action plan on the public health response to dementia 2017-2025, produced by World Health Organisation aims to improve the lives of people with dementia and their carer families, whilst decreasing the impact of dementia on communities and countries. The global set of actions includes increasing awareness and reducing the risk of dementia; timely and early diagnosis; strengthening information systems for dementia research and innovation relating to treatment and care and support for dementia carers (World Health Organization, 2017). The worldwide aspirations are to find a cure and to prevent dementia by improving the overall health status of the population and additionally to improve care and support for people with dementia and their carers so they can live a meaningful life with dignity. These objectives have to be translated into action at national level in terms of research, policies and practices.

The UK has been in the forefront of global actions against dementia by providing leadership, and policy responses in all 4 nations are aligned with the global ones. In 2009, the first UK dementia strategy identified 17 key objectives that were intended to result in a significant improvement in the quality of services and promote a greater understanding of the causes and consequences of dementia (Department of Health 2009). Improving care and support for carers was also to be addressed. Three ‘champion’ groups were created to lead three main areas for action. These were driving improvements in health and care, creating dementia-friendly communities and improving dementia research. In March 2015, the UK Prime Minister’s Challenge for Dementia 2020 set out more than 50 specific commitments, aiming to make England the world leader in dementia care, research, and awareness (Department of Health, 2015). At that time the priority was to achieve two key goals by 2020: for the UK to be the best place for research into dementia and other neurodegenerative diseases and additionally the best country in the world for dementia care and support for people with dementia, their carers and families to live in. The whole focus was to transform dementia care, support and research at national level across the UK.

There have been variable though notable achievements made in all areas targeted to make a difference by the policy (Department of Health and Social Care, 2019). However, since my research aims to make a contribution to dementia care in the community, an overview of the policy achievements remains as a focus on aspects with closer affiliation to dementia care at home. There are three main areas where achievements have been celebrated – dementia friends and friendly communities; health and care workforce training; and recognition, assessments and support for informal carers.

2.6.1 Dementia Friendly Communities

The ‘Prime Minister’s challenge on dementia 2020’ (Department of Health, 2015) identified *dementia-friendly communities* (DFC) as being essential in order for people living with dementia to remain active and engaged members of society. The concept ‘dementia-friendly’ addresses the living experiences and needs of people living with dementia and their carers (Lin and Lewis, 2015). Dementia-friendly communities are identifiable places like a town or village where people are more aware of, hold positive attitudes towards, and have a better understanding about dementia, which enables people with dementia to continue to live in the community by being understood, respected and supported (Alzheimer’s Disease International, 2016). A dementia-friendly community therefore requires input from designated ‘Dementia friends’. Dementia friends are those people who establish and contribute to the dementia-friendly communities. They are people from all kinds of backgrounds who attend a short training course to learn about dementia, in order to then help develop their community through an enhanced awareness and understanding of living with dementia (Alzheimer’s Society, 2020).

The Alzheimer’s Society UK developed the training prototype for dementia friends and also monitor the uptake of the initiative by updating the numbers of dementia friends nationally (Dementia Friends, 2020). In England, to date, there are over 3.3 million people who have become dementia friends and a total of 348 towns, cities and villages have become dementia-friendly communities, of which 43 are in the East of England and 10 in Norfolk.

This two-hour long dementia friends training has been delivered to first-year undergraduate nursing students and an evaluation was found to have increased students' knowledge about dementia as well as their confidence in communication with and engagement of people living with dementia (Mitchell *et al.*, 2017).

The encouraging number of dementia friends and dementia-friendly communities indicates that there are many places across the country where at least some people, who are working in places like local businesses, supermarkets, cafes, banks and solicitors' offices, or on public transport, have acquired some understanding of dementia. They are able to recognise and help their customers who have dementia and may be able to adapt their businesses to make them dementia friendly. The Government's set target in 2015 was by 2020 to have over 50% of the population living in an area with a dementia friendly community, which has now been achieved as planned.

The DEMCOM study, which is the national evaluation of dementia-friendly communities, reported potentially lasting positive impacts of DFC activities, especially those which are linked with dementia-aware staff in key services and where the DFC is integrated into community resources. However, there was an 'unacceptable and unpredictable variation of DFC coordination' (Goodman *et al.*, 2019, p. 112) found to exist and there was no single model of a dementia-friendly community which is more likely to deliver the intended goals of inclusion and participation for people living with dementia and their carers. Furthermore, the existence of a dementia-friendly community does not ensure the person with dementia and their carers are connected to these or even aware of them. Nevertheless, key features and characteristics of dementia-friendly communities are likely to achieve this (Goodman *et al.*, 2019).

A dementia-friendly community has proved to bring a range of social and economic benefits to a place as well as to have a positive impact on the life of a person living with dementia (Alzheimer's Society Australia, 2015). However, these tend to be of more benefit to people who are at an earlier stage of dementia, and seem to be more effective where working in a more joined up way with Local Authority Public Health and NHS services (Alzheimer's Society Australia, 2015; Goodman *et al.*, 2019), when people are still physically able to access those places. The basic dementia friend's awareness-raising training is also likely to have secondary benefits in attendees' lives, should they ever need to deal with a friend or family member with dementia. Therefore, mass public awareness being achieved via dementia-friendly communities and dementia friends' initiatives is an encouraging achievement and undoubtedly contributes to successful dementia care in the community.

2.6.2 Workforce Development

The first UK dementia strategy (2009) prioritised training for the health and social care workforce on dementia awareness so that individuals could better support people with dementia. In the 'Prime Minister's Challenge on Dementia 2020' (Department of Health, 2015) progress was noted as an achievement by reporting the most recent quarter viz. the fourth quarter of 2014/15 as having 515,967 NHS staff in Tier 1 and over 100,000 social care staff who had been trained in dementia awareness (Department of Health, 2015). This referred to basic dementia awareness training for all NHS staff, which included porters, kitchen/ catering staff and receptionists. The competencies in Tier 1 training aim to get all staff recognising, assisting and signposting people with dementia appropriately (Department of Health and Social Care, 2015). The PM's ambition was profound and clear: all NHS staff, some 1.3 million people, from hospital porters to surgeons, were required to undergo dementia training so that people would have the know-how and understanding to provide the best standards of care to people with dementia. Progress in the past five years has also been encouraging, and as one audit reported in 2016, almost all (96%) hospitals reported to have established dementia training, which was a significant increase from 23% in 2010/11 and 78% in 2012/13.

A review of the Dementia Training Standards Framework was commissioned by the Department of Health and aimed to support further development and delivery of appropriate and consistent dementia education and training for the whole health and care workforce. This included not only staff working in acute hospitals and care homes but also staff who provide support to people living with dementia at home as well as their carers. The framework includes elements in each tier which would enable the workforce to improve their understanding of partnership working, which is an element of integrated care (Minkman, 2012). The Framework was structured in such a way as to reflect the scope of Health Education England (HEE)'s main mandatory requirements, with increasing levels of integration between health and social care services and their respective workforces. Integrated care will be further elaborated on later in this chapter.

As before, within the updated Training Standards Framework, the whole workforce was divided into three tiers containing a total of 14 dementia-related subject areas covered on training courses, starting from basic 'dementia awareness' for everyone, to 'leadership and transforming dementia care' for the higher-level health and social care workforce. Tier 1 for all health and social care staff is to raise basic awareness, Tier 2 training is for staff working directly with people with dementia and aims to raise basic knowledge and skills in dementia, and Tier 3 is for health and social care managers and dementia care trainers with advanced knowledge (Health Education England and Skills for Care, 2018). Despite this clarity in requirements on training, an absence of any registration or accreditation for dementia training leaves the quality assurance of such training in question (Surr *et al.*, 2019).

Despite the reported positive impact of the dementia training and education programme, even the brief package on care staff's knowledge and attitude as previously reported (Featherstone *et al.*, 2004), and the fact that the efficacy of more recent training interventions on health and social care staff is expanding in institutional settings (Surr *et al.*, 2016; Surr and Gates, 2017), what proportion of the current workforce completed the training and more importantly what positive impact this training achieves on the lives and care of the people living in the community with dementia and their carers has yet to be shown.

However, it appears to be a good foundation for consistency and clarity across the health and social care workforce concerning levels of dementia competencies required to provide dementia care in hospitals and care homes, as well as at home. It further includes training topics such as ‘Person-centred dementia care’; ‘Living well with dementia and promoting independence’; ‘Equality, diversity and inclusion in dementia care and families’; and ‘Carers as partners in dementia care,’ which clearly indicates that after successful completion the workforce should be able to provide more sensitive, tailored and competent care for people with dementia and their informal carers. Finally, the Framework focuses on enhancing dementia capability, not only for the current workforce but also for the workforce of the future, by including the educational institutions where they have been trained.

Despite this strong focus on training frameworks for professionals, no such framework or even training needs assessment exists for informal carers. This is somewhat surprising since the presented data has shown that to date most of the care at home is conducted by informal carers.

2.6.3 Support Services for Informal Carers

Historically, the provision of services to support informal carers in their caring role has been criticised as highly variable and often inadequate, due to both personal circumstance and residential status (Keeley and Clarke, 2002; Maher and Green, 2002). Efforts to address this shortcoming were embodied in various government policy and legislative initiatives, which focused on the recognition of carers’ rights and obliged local authorities to provide services. Legislation included The Carers Recognition and Service Act 1995, and subsequent legislative acts in 2000 and 2004 (UK GOV, 1995, 2000, 2004). Most recently the Care Act, 2014 placed a duty on local authorities to provide assessments for individuals who might need care and support (UK GOV, 1995, 2014).

The Care Act 2014 recognised that carers of people with dementia have their own individual needs and thus should be assessed independently of the person cared for. Although such assessments were previously introduced in the Carers Recognition and Services Act 1995, this was the first-time it became a carer's right to have an assessment separate from the person for whom they care. Such an assessment aims to look at the impact of the carer's caring role on all aspects of the individual's life and identify relevant needs (UK GOV, 1995). This would include assessing the carer's ability to continue to provide support to the individual for whom they care.

2.6.4 Carer Assessments

There is general acceptance that a 'carer assessment' is the initial step to defining the nature of assistance provided to carers (National Institute for Health and Care Excellence, 2018b). Such assessments are promoted by a range of service organisations, including the NHS and such voluntary groups as the Alzheimer's Society, Carers UK, and Age UK and are called for in a variety of care contexts (e.g., financial evaluation, care adaptation of a home, or the need for a brief respite in care).   For example, the consumer website, Which, provides important content on how individuals can prepare for an assessment (Which, 2020). Nonetheless, despite significant promotional messages that encourage carers to have an assessment as a 'right' of informal carers, the uptake has been slow. A report published in 2019 reported that in England only 27% of carers had a carers assessment in the previous 12 months, and this was a reduction from 31% in 2016 (Carers UK, 2019). It was further reported that amongst carers aged 65 and over, 30% had received a carers assessment in the previous 12 months, but 1 in 5 of these individuals had waited longer than six months for the assessment to be carried out. The report concluded that implementation of this element of the Care Act is variable and is failing to achieve the intended outcome for carers. Only one-third of carers surveyed felt that their own needs were thoroughly considered in their assessment (Carers UK, 2019). This indicates that the availability of carers assessments remains inconsistent and perhaps used as a tool of 'rationed care' for carers 'at the end of their tether' (Arksey, 2002, p. 88).

Carers' assessments are intended to focus on the carer's needs. There are, however, two sets of needs that are likely to need consideration—those of the persons being cared for and those of the carers—and these sets are often distinct and do not overlap (Triantafillou *et al.*, 2010). A survey carried out by the Dementia Action Alliance confirmed these notions of differentiated needs; respondents felt the National Dementia Strategy had 'got it right' for people with dementia but not for the carers. For example, people with dementia were much less positive about the support provided to those caring for them (Dementia Action Alliance, 2014). Despite such uneven results, the Care Act 2014 has elevated the debate and created a gateway for informal carers to seek support by having an established right to a carer's assessment.

2.6.5 Support for Informal Dementia Carers

Support needs and interventions for dementia carers are often interlinked with the person being cared for, as suggested. Such support includes access to information, including how to get a carers' assessment, tangible assistance, e.g. to access carers allowance if eligible, respite care, access to peer-support, training-education to enhance resilience, coping strategies and reduce caring burden. To determine what works to support carers, over the years, and despite a number interventions being systematically reviewed, there is as yet no conclusive agreement. Training and educational intervention focusing on enhancing resilience for carers such as the START intervention (STrAtegies for RelaTives) intervention used therapy based training or education programs that aimed to enhance dementia carers coping strategies (Livingston *et al.*, 2013, 2019) . Dementia specialist nurses known as 'Admiral Nurses' also promoted good practice in dementia care by providing education, training, advice, and guidance to other staff working with people with dementia and their families including carers (Thompson and Devenny, 2007). Volunteer-led befriending and peer support offers carers of people with dementia emotional and social support, potentially reducing breakdowns in the mental and physical health of carers and enables them to cope better with challenges and to continue to provide care (Smith *et al.*, 2018). Examples of positive effects of such interventions are reduced depression, anxiety and stress levels and improved relationships and family functioning (McKechnie, Barker and Stott, 2014a).

The Prime Minister's Challenge strategy aimed to further such initiatives, by focusing on enhancing informal carers' resilience in and positive experiences of caring. The strategy expressed its commitment to carers of people with dementia through the provision of compassionate and person-centred care from health and social care staff trained in dementia, as well as offering knowledge of and opportunities for respite, education, training, emotional and psychological support (Department of Health, 2015, p. 10).

While a number of reviews reported some effectiveness of certain interventions such as professional self-management support and information, cognitive behavioural therapy and support, volunteer led peer support to reduce caring burden and depression and loneliness and to increase carers resilience (Pillemer and Suitor, 2002; Pinquart and Sörensen, 2003; Boots *et al.*, 2014; Chappell *et al.*, 2017), effectiveness of some others are not yet evident. Furthermore, one of the relatively commonly offered types of support is respite care by admitting the person with dementia into a care home for a short break. However, if the person returns home distressed and upset as a consequence of the change in routines, this can actually increase stress for the carer rather than the reduction that is intended from such a break in care provision for the carer (McKechnie, Barker and Stott, 2014b).

Access to information about dementia care is evidently one of the most common, yet vital aspects of support for informal carers in dementia. Various websites have been developed, including the UK Government site and those of the NHS, as well as various charities, including those focusing exclusively on helping people with dementia and their carers (e.g. Alzheimer's Society, Dementia UK); some sites even have dedicated pages of advice and information for carers and later life care. Such conscious efforts to inform dementia carers deserve closer attention in order to explore the content of the information provided to carers. 'Information' for carers includes a number of items in common, representing the range of provision to support the carer. This will typically include information about carers' rights to a 'carer's assessment', advice to check 'eligibility for benefits,' and to register with a GP as a carer (NHS, 2020b). In addition, some other commonly found types of information support offered to carers will include assistance with home adaptation, assistive technology and respite care. Social prescription is another form of support which links informal carers to a local support group such as a dementia café (The Kings Fund, 2020).

As dementia is a progressive condition, the carer's support needs are likely to vary and change over time as the person cared for deteriorates. With dementia transition points, needs for regular assessments taking into account any changes in the needs for information, coping skills, support and service have been suggested by Novais (Novais *et al.*, 2017). However, Mansfield et al (2016) highlight that such measures to assess the unmet needs of dementia carers are very limited (Mansfield *et al.*, 2016). Within the literature on carers, another important feature is the focus of research on caring as it relates to tasks or activities. However this does not always take into account that such tasks are, rather, a dimension of, and embedded in, a dyadic relationship, often of long-standing (Larkin, Henwood and Milne, 2019).

2.6.6 Challenges in Getting Appropriate Support

The extent to which the dementia carers needs can be met is largely dependent on the availability of resources, including social networks and support services (Downs and Bowers, 2014). There is no standardised or universally agreed delivery for provision of information and support to dementia carers in the UK, a fact which makes even understanding of their effectiveness nearly impossible (Miles *et al.*, 2020). While intervention to support carers starts with a carers assessment as a first step, what is on offer following an assessment remains variable, with some services not widely available. Further, evidence about actual outcomes and the impact of services on dementia carers is yet to be fully established. For instance, social prescription, a relatively recent support item for carers, is not found across all areas and is in variable stages of development, according to a CQC report (CQC, 2019).

Additionally, an earlier systematic review presented little evidence of either benefits or adverse effects of using respite care for people with dementia and their carers, with a cautious explanation of the lack of high-quality research in this area (Maayan, Soares-Weiser and Lee, 2014).

What constitutes ‘support’ for informal carers in dementia is, in reality, quite poorly defined and relatively untested. Where some local services are available to promote the health and wellbeing of older people and their carers in the community, there is a lack of widespread knowledge about them or access is too complicated and confusing to allow people to use them easily (CQC, 2018c). Furthermore, professionals working in this area were not always sufficiently knowledgeable about the services available in order to successfully make referrals on behalf of individuals to the right services in a timely manner (CQC, 2018a, p. 23). Whilst increasingly informal carers are expected to provide care at home, often alone, there are no clear steps apparent to either understand carers’ levels of ability, e.g. the know-how of caring for someone with dementia, or for the provision of any dementia care training and education for (informal) carers. Although NHS information pages about support for carers advises carers to check training opportunities locally, there is no live link or signposting to follow (NHS, 2020a). Other websites, such as those run by charities, offer leaflets with information, but it is not readily apparent what training courses might be available for informal carers and how these could be accessed at local level. Evidence suggests, however, that by increasing informal carers’ knowledge of dementia, both biological and attitudinal, the quality and management of care can be improved (Taylor *et al.*, 2009). A further report suggests that there is little appetite amongst informal carers to deepen their knowledge (ARUK, 2020); however, within this report no potential explanation is offered as to why that might be the case.

In summary, the policy response to dementia care in the community has focused on developing a dementia friendly community in which the person with dementia and their carer can live without stigma, and amongst a better understanding of the condition and it’s trajectory from the community. In addition, it has focused on developing and upskilling the health and social care workforce in order to better understand dementia and dementia care requirements, thus enabling better care provision for both people with dementia and their carers. This can have both direct and indirect benefits on informal carers experiences while living in the community and caring for someone with dementia.

Finally, it is important to look at the carers recognition of the provision of support available to them as informal dementia carer(s). The degree of actual support for dementia carers at home appears far lower. The carers assessment, as a tool to access any services or interventions, appears to have become an intervention itself. The actual effectiveness of other available instruments, such as respite care in the context of dementia care, is yet to be fully established. Current support mechanisms do not appear to include efforts to comprehend informal carers' own knowledge and understanding of what constitutes caring for someone with dementia and to provide any interventions to enhance such knowledge.

2.7 Informal Care

Over the past decade the definition of 'informal care' has been based on the work of Triantafillou et al. (2010) which is now widely used. Within this definition unpaid care is that which is provided to older and dependent persons by a person with whom they have a social relationship, such as a spouse, parent, child, other relative, neighbour, friend or other non-kin (Triantafillou *et al.*, 2010). The distinction here is the unpaid nature and social relationship of the carer to the person cared for. I use this definition for the purposes of my thesis.

There are an estimated 1.4 million informal carers in the UK providing, on average, over 50 hours of care per week, with 1 in 5 of the carers aged over 65 (Local Government Association, 2018). Unpaid/ informal carers are regarded as a 'critical and valuable part of a high-quality health and social care system' (CQC, 2018b), and the replacement cost of informal carers with paid carers is estimated to be £57 billion per year (Office for National Statistics, 2017).

People aged over 65 are the majority of users of the NHS, especially for acute care in hospitals (Bynum *et al.*, 2004). In the year 2000, whilst the population of over 65 year olds made up just 16 per cent of the total hospital population, they occupied almost two-thirds of general and acute medical beds (Department of Health, 2000). On average, an elderly person admitted as an emergency patient stayed in hospital more than 50 per cent longer than the average length of stay for all adults and, when admitted as a planned admission, more than 150 percent longer (Department of Health 2000; Harper & Shahani 2002). Today, the situation is even graver, particularly if media reporting is to be believed. Often older people cannot be discharged because there is no one to 'keep an eye on' (i.e. supervise / monitor) them whilst they are still recovering from a medical intervention; thus, they remain in hospital despite needing no further medical attention, contributing to a phenomenon known as 'bed blocking.' Although there is relatively little research carried out on what contribution informal carers make to reducing such hospital overstays, it is likely to be significant (Banerjee *et al.*, 2003).

2.7.1 Impacts of Informal Caring

Despite the invaluable contributions provided by informal carers, the impact of informal care on carers has been associated with a number of social, economic and mental health difficulties (Savage and Bailey, 2004). Theoretical concepts frequently focus on the 'outcomes' of informal caring e.g. carer burden and issues relating to health and wellbeing (Pearlin *et al.*, 1990; Bastawrous, 2013). Research has frequently found that carers of older relatives are more likely to have low immunity to and a high incidence of physical illnesses (Kiecolt-Glaser *et al.*, 1996). Research also shows that carers can become overwhelmed by the care burden and be prone to psychological and mental conditions such as anger, anxiety and/or depression (Ory *et al.*, 2000; D'Aoust, Brewster and Rowe, 2015). The research evidence highlights such negative outcomes and appears to focus rather narrowly on the health outcomes for carers. Health and social care provision appear to be premised on the assumption that carers feel burdened and are waiting for an inevitable breaking point. Therefore, a breaking point for carers remains a trigger for interventions such as a referral to social care services or specialist dementia facilities. Predictors of such points therefore determine the outcomes and subsequent interventions.

Although not as frequently discussed, there are positive outcomes from caregiving too. Rapp and Chao (2000) suggest that positive appraisal plays an important and under-recognized role in caring, different to that of negative appraisal; the predictors here are viewed as more significant in dictating outcomes (Rapp and Chao, 2000). Beach et al (2000) correlated better caregiving involvement with better mental health outcomes, together with reductions in anxiety and depression for older carers (Beach *et al.*, 2000), and in particular for women as carers (Yee and Schulz, 2000). By providing care for someone who needs care, carers can gain a sense of purpose and satisfaction (Sanders, 2005). Kramer (1997) claims this satisfaction represents perceived subjective gain and rewards which lead to personal growth. Furthermore, the carer's gender and the carer / care recipient relationship also affect the carer's sense of satisfaction (Lawton *et al.*, 1991; Kramer, 1997; Carbonneau, Caron and Desrosiers, 2010). For spouses/partners who are carers, satisfaction with caring appears more closely related to the carer's emotional wellbeing rather than to the care recipient's symptoms, the amount of time spent together or even their own physical health (Kramer, 1997). Satisfaction in or rewards derived from caregiving are suggested to be rooted in the interpersonal lives of individuals, reflecting particular value positions and closely held personal convictions which can 'co-exist' with the stresses and strains of caring (Grant and Nolan, 1993, p. 156). This view has been shared by others as caring could be simultaneously negative with demands on personal time and positive with a sense of personal satisfaction (Pratesi, 2011). Whilst there are some positives in forms of carers sense of satisfactions, the inevitable stress and negative impact of informal caring is well established. Despite this, informal care remains an integral part of the care of older people, which requires further exploration concerning the reasons that influence such informal care arrangements.

2.7.2 Reasons for Informal Care

The reasons behind the provision of informal care are complex and involve several different factors. In recent years, in recognition of the future inevitable involvement of informal carers in care of older people, academics have developed the Informal Care Model (ICM) that provides a framework for understanding (Marjolein, Broese and Alice, 2016). The ICM model is a behavioural model constituted of three key elements: the existence of someone in the social network in need of care; an individual with the intention to provide care; and an external context that either enables or restricts the intention to care from materialising (Marjolein, Broese and Alice, 2016). The ICM model makes a theoretical connection of these three aspects of informal care in which the provision of informal care is a process, whereby both the care recipient and caregiver are intertwined not only by the need for care but also by the normative belief system and quality of their relationship. In this type of model social relationships once again emerge as a prominent factor in informal caring.

The definition of informal care developed by Triantafillou et al (2010) confirms that informal care is mainly provided by either a family member, close relatives, friends or neighbours, and is one in which a pre-existing reciprocal social relationship is evident. Carers perform a wide range of tasks, which would otherwise be performed by formal carers and which would have to be paid for in the absence of informal carers. These informal carers, however, are non-professionals who are neither trained to provide care nor have contracts regarding care responsibilities, and in addition, have essentially no limits on the time spent on providing care (Triantafillou *et al.*, 2010). Effectively, this presents a form of self-determined individual responsibility that arises from a pre-existing social relationship, or a sense of obligation, which some explain as social capital.

Social capital is a type of resource generated through social relationships, which can benefit individuals greatly in times of need. The value and significance of social relationships in the formation of social capital has been widely discussed and agreed (Coleman, 1988; Putnam, 1995; Field, 2008). Social capital in the form of social relationships can be at both individual and community levels, involving more than one person but also applying to individual relationships. More recent research claims that social capital affects the health of older people more, and therefore carries more significance in the health and care of older people (Muckenhuber, Stronegger and Freidl, 2012). Both Colman and Putnam have identified that key components for social capital are reciprocity and a sense of obligation (Coleman, 1988; Putnam, 1995). These are also very applicable to cases of informal care, derived from social relations.

There may be no better example of a form of social capital than informal care, where a deep sense of obligation compels a family member or friend to commit to care. This is not because they have to (in a legal sense, at least in the UK context), but because they wish to, as someone close to them is in need of care. The ICM model is therefore followed via external and contextual factors, which may well also include the availability of formal care and assistance.

2.7.3 Informal Care in Dementia

Increasingly, informal carers have become inextricably linked with long-term elder care, and especially within dementia care (Norton, 2015a). The extent and magnitude of informal carers' contributions in dementia care is now simply too large to ignore. A report commissioned by Alzheimer's Disease International (ADI) published in 2018 estimated that the global number of informal care hours provided to people with dementia per year in 2015 was some eighty-two billion, which is equivalent to more than 40 million full time workers, of which women contribute 71% of the global hours worked by informal carers (Wimo, Gauthier and Prince, 2018). With the continuing rise in incidence of dementia, this figure is also set to rise, with the highest proportion of increase likely to occur in low-income countries. However, the same trend in terms of increasing numbers is also seen in the UK.

Informal carers' roles in and contributions to dementia care are highly significant. Over 2 million people in the UK today have a friend or family member living with dementia, and well over 700,000 people care for an affected family member or friend as an informal carer (Dowrick and Southern, 2014). A total of 36% of these people provide in excess of 100 hours of care per week (Office of National Statistics, 2017). Furthermore, two thirds of people with dementia live at home and most are supported by informal carers (ARUK, 2020). Additionally, over 1.4 million older people, many with dementia, live with unmet needs, such as not having access to the care and support they need (CQC, 2018c). This indicates a situation in which it is likely that many older informal carers are living and caring for someone with dementia with little or no formal support from social care services. The inevitable reality is that the health and social care services would simply not be able to function without these informal carers (Knapp *et al.*, 2014). Anecdotal evidence (Banerjee *et al.*, 2003; Kassianos *et al.*, 2015; Pickens *et al.*, 2017) further suggests that appropriate support from informal caregivers allows people with dementia to remain at home longer with fewer hospital admissions and with later admission to residential and nursing care homes.

Informal care in dementia is neither an easy endeavour nor one without profound consequences. But positive emotional impacts may also result within the context of informal care in dementia. A qualitative study carried out by the Alzheimer’s Society explored the feelings of the carers who were caring for someone with dementia, finding that the role changes family relationships, leaves people feeling socially isolated, affects mental and physical health, and creates financial difficulties (Norton, 2015b). On the other hand, some carers are positive about their responsibilities and appear to be comforted by knowing they have provided the best possible care for their loved ones (Norton, 2015a). There is clear evidence that appropriate support for carers can be very effective in improving carers’ experiences and outcomes whilst these outcomes are judged according to two key indicators. These are carer stress and delay in the need for people to go into institutional care (care homes or equivalent) (Pickard, 2004). If carers are appropriately supported, then positive outcomes can be achieved for people with dementia who need care.

One of the objectives of this research is to locate the informal dementia care role within the context of a broader integrated care system, which promotes well-coordinated, person-centred care services delivery. Although the integrated care model acknowledges supporting carers, the actual value of the informal care itself has generally not been sufficiently taken into account and nor do informal carers appear to be included as partners in care within an integrated system. There continues to be an urgent need for holistic and horizontal thinking about dementia care, which is cost effective, sustainable and delivered in the community. To meet this need, a better understanding of the integrated care model is necessary.

2.8 Integrated Care

The concept of integration in health and care services dates back to the 1980s but has grown in prominence as its benefits in quality and efficiency have become more apparent. The World Health Organisation's (WHO) working definition of integrated health care services is: *"The organization and management of health services so that people get the care they need, when they need it, in ways that are user friendly, achieve the desired results and provide value for money"* (World Health Organisation, 2008, p. 1).

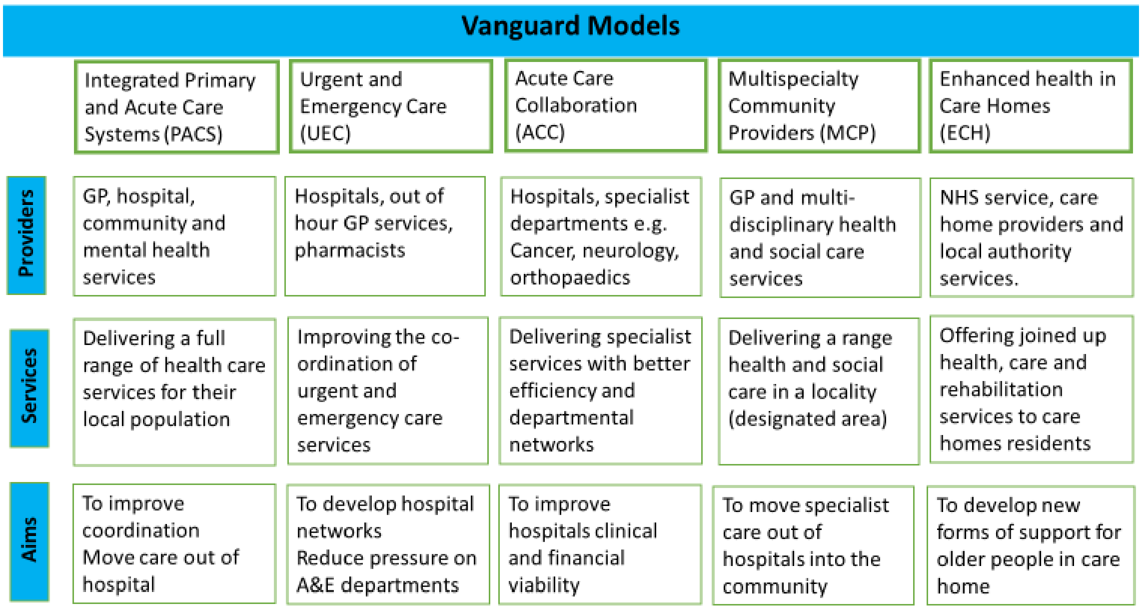
Integrated health care for older patients has become widespread as in Germany, Belgium, Canada, and the United States (Kodner and Kyriacou, 2000; Anaert, Van Den Heuvel and Windey, 2005; Amelung, Hildebrandt and Wolf, 2012; Heckman *et al.*, 2013; Taflinger *et al.*, 2016). Similarly, faced with the challenge of an ageing population with a range of health and care needs, a closer integration of health and social care has been a priority policy goal for the UK government for decades and this has been coordinated by NHS (Department of Health, 2013).

Over the years various models of integrated care have been developed, piloted and evaluated. Such models seek to horizontally integrate the range of different health care *services* such as primary and community health care, outpatient, inpatient, and rehabilitation, but also to integrate health with other care providers, such as social care services and housing (Minkman, Ligthart and Huijsman, 2009; Mountford, 2012; Heckman *et al.*, 2013). While some models target specific groups or types of diseases, others targets the whole population (World Health Organisation, 2016). However, it aims to deliver well-coordinated, personalised healthcare by addressing the existing longstanding traditional divides among various parts of health services e.g. primary care, community services, and hospitals (NHS England, 2016).

2.8.1 NHS Integrated Care Models - Vanguards

The NHS flagship program for better integrated health and care of new care models, known as the ‘vanguards,’ was allocated about £389 million and covered around 5 million people to run from 2015-18 (NHS England, 2016). Vanguards started in 50 sites to develop various new care models in five different categories of new integrated care models being developed, piloted, and with some being evaluated. The primary focus of these new models was to reduce pressure on hospital bed by moving specialist care out of hospital into community and/or into care homes through improved coordination between service providers to make care flexible and responsive to the needs of local population and care home residents. Three of these models are acute health care centred that focus on reducing hospital pressures and enhance clinical and financial viability. The other two models had a focus on moving specialist care out of hospital and into the community and enhances health and care for care home residents.

Figure 2.2 A diagram presenting five key Vanguard models



Vanguard Models

	Integrated Primary and Acute Care Systems (PACS)	Urgent and Emergency Care (UEC)	Acute Care Collaboration (ACC)	Multispecialty Community Providers (MCP)	Enhanced health in Care Homes (ECH)
Providers	GP, hospital, community and mental health services	Hospitals, out of hour GP services, pharmacists	Hospitals, specialist departments e.g. Cancer, neurology, orthopaedics	GP and multi-disciplinary health and social care services	NHS service, care home providers and local authority services.
Services	Delivering a full range of health care services for their local population	Improving the co-ordination of urgent and emergency care services	Delivering specialist services with better efficiency and departmental networks	Delivering a range health and social care in a locality (designated area)	Offering joined up health, care and rehabilitation services to care homes residents
Aims	To improve coordination Move care out of hospital	To develop hospital networks Reduce pressure on A&E departments	To improve hospitals clinical and financial viability	To move specialist care out of hospitals into the community	To develop new forms of support for older people in care home

Based on NHS England, 2016 and Naylor and Charles, 2018

The vanguards were closely monitored, audited and evaluated for efficacy, efficiency and replicability, as a key rationale for these new models. While the methodological challenges in evaluating such complex vanguards programme were recognised (Fowler Davis, Hinde and Ariss, 2020), there was no shortage of attempts. The National audits of these new care models reported neither any financial savings nor any reduction in hospital admissions (National Audit Office, 2018)**.** The evaluation that compared the efficacy of different vanguard models specifically in reducing hospital utilisation, (e.g. the population-based and care home site) found that vanguard sites had increased hospital utilisation in terms of emergency hospital admission and there was no significant reduction in the hospital bed-days used (Naylor and Charles, 2018; Morciano *et al.*, 2020).

Although the evaluation of the first vanguard programmes shows it has fallen short of intended aims, there has been a widespread consensus about the wider unintended benefits of such integration. Potential benefits include non-monetary, intangible aspects such as greater collaboration, recognition of common priorities, and equitable access to high quality well-coordinated care (Stocker *et al.*, 2018). The efficacy of a pre-determined organisational model of integrated care has also been questioned. It is suggested that any integrated model development is strongly contextually-bound, nearly impossible to replicate and can only be successful if it accounts for the unique needs and characteristics of the targeted population (Goodwin *et al.*, 2014). Subsequently, the long term plan of NHS commits to expanding integrated care vanguard models across England, with an initial focus on care home residents with personalised care plans (Winter, 2019). Whilst such a commitment indicates there will be further efforts to establish integrated care in the NHS, it also raises questions about how to gain greater effectiveness in delivering integrated services for people living at home with dementia.

2.8.2 Integrated Model and Dementia Care at Home

Four out of five vanguard models are focused on care at institutions (e.g. hospital and care homes). Apart from the Multi-speciality Community Providers (MCP) vanguard model, which aimed to deliver better integrated care in the community at a locality, there is no other piloted vanguard model that focuses on people who are living at home and living with dementia. The intention was to reduce hospital usage by moving specialist care out of hospital and into the community and providing better coordination of health and care service providers (Naylor and Charles, 2018). In such integrated care horizontally integrated models of dementia care that link the ‘medical treatment’ (the health care providers who address a medical condition) and the ‘care’ (other care providers who address the wider social care needs) promises to improve the overall effectiveness of care and the quality of life of the service user. However, the role of informal carers in achieving such outcome is yet to be recognised in existing piloted vanguards.

2.8.3 Integrated Model and Informal Carers

Kodner and Spreeuwenberg (2002) presented two overlapping but different concepts of the integrated care – one hierarchical ‘top down’ and the other patient-centred ‘bottom-up’ (Kodner and Spreeuwenberg, 2002, p. 5). While the former is more process driven and generalises organisational demands for perfection and optimisation, the latter focuses on the characteristics and needs of specific groups of patients and how they fit within existing systems. Such approaches influence care and determine what, how, and where the integration takes place. In this context, the NHS-led integrated vanguard models represent a top-down optimisation approach designed at the institutional service delivery level. While this approach enhances holistic care assessment, care planning, better care coordination and single point of entry, it does not always capture individual experience derived from the bottom-up perspective. Evaluations suggest that the success of integrated care is more likely where there is a specific focus invested in promoting self-management with individuals and informal carers (Goodwin *et al.*, 2014).

Despite considerable efforts in developing new models of integrated care in vanguards, there is less attention given to the ‘integration’ among formal, public providers, and the informal, unpaid care provider, often a family member, neighbour, or member of the immediate community. The contribution of the informal care provider, who bridges both the medical and the social care components, is considered to be significant, but is not seen explicitly as a part of the current integrated model.

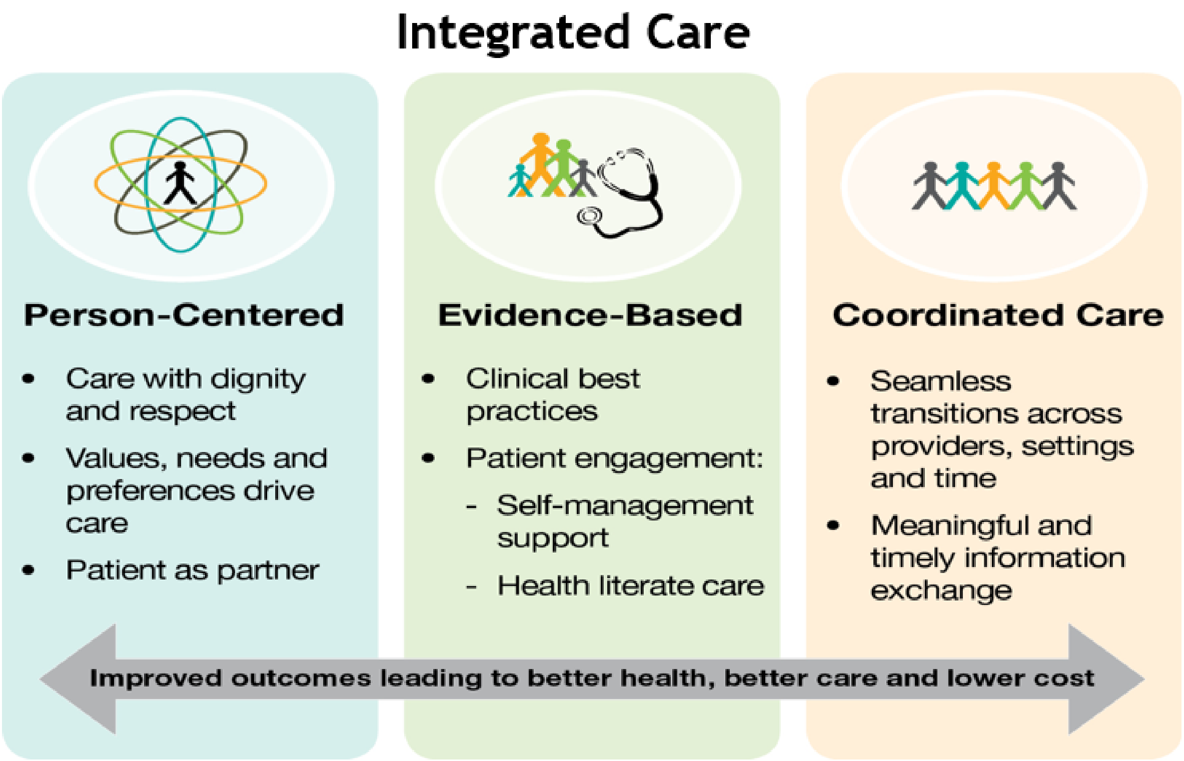
Studies such as (McConaghy and Caltabiano, 2005; D'Aoust, Brewster and Rowe, 2015) argue that there are many complex issues surrounding the role of the informal caregiver, such as time demands and the capacity of those involved in such care provision. The goal of dementia care is to maintain the functioning of the individual and reduce the need for institutionalisation. Therefore, it is particularly important that the critical role of the informal carer, who often lives with the person with dementia is understood and is considered as an active partner in service delivery for people living with dementia in the community.

2.8.4 Integrated Person-Centred Care in Dementia

The UK Government's integrated health and social care services has introduced a widely adopted vision of more coordinated and person-centred care (see Table 2.2). The intent of this vision is to provide a better patient experience, particularly for those with long term conditions, by reducing the relentless increase in long term demand on hospital services (Parkin, 2019). However, the process of integration has admittedly been complex and time consuming, and one Think Tank report suggests patients are yet to benefit from the proposed advantages of integrated care (The Nuffield Trust, 2019).

According to reports (The Nuffield Trust, 2019) that a number of key areas have either not improved or indeed have worsened, such as people not feeling supported to manage their long-term conditions, or people not being involved in decisions about their care, making potentially avoidable emergency hospital admissions and timely discharges from hospital to care difficult to achieve. Informal carers themselves reported a deteriorated quality of life (The Nuffield Trust, 2019). Perceptions of support varied depending upon their condition. People living with dementia felt less supported than people living with cancer or heart disease but felt more supported than those with other mental health related and neurological conditions such as epilepsy (The Nuffield Trust, 2019).

Figure 2.3: A diagram presenting key aspects of Integrated Care (by Sutter Health/ Sutter Care at Home



Source: Sutter Health/ Sutter Care at Home - 2017

While integrated care service delivery is yet to produce evidence of ‘value for money’ for UK taxpayers by reversing trends in some of the indicators reported above, there is evidence that demonstrates the value of person-centred care in dementia. Person-centred care is highly valued by people with dementia themselves and their families and it can reduce agitation in people with dementia (Chenoweth *et al.*, 2009; Edvardsson, Fetherstonhaugh and Nay, 2010). Although these studies focused on residents or respite care users of care homes and dementia, they certainly show the value of person-centred care in dementia. Although arguably all care for people with dementia and their caregivers should be provided on a person-centred basis in order to achieve the most effective outcomes for individuals, this is not entirely synonymous with integrated care (not all conceptions of integrated care are always wholly person-centred).

Given the ageing population and the increased incidence of dementia, there has been a call for an ‘integrated approach’ to dementia care, where the different providers of health and social care services would work within a collaborative model focused on the multiple and varied needs of the person living with dementia. While dementia cannot be cured as yet, care could be improved to a level whereby someone with dementia is enabled to live well with the condition. This requires providing ‘person-centred’ care and support focused on that person and their individual needs and preferences (Ballard and Aarsland, 2009; Behuniak, 2010; Telban and Milavec Kapun, 2013; de Witt and Ploeg, 2014; Edwards, Voss and Iliffe, 2014). Person-centred integrated care is considered to be crucial for people regardless of where they live. The model does not just apply for people in institutional care settings but also for people living with dementia at home.

2.9 Need for this study

This review of relevant literature has focused on the increase in dementia care needs, the stress on current health and social care resources, and the critical role that informal carers provide in dementia care. Health and social care services are at a crisis point due to the demands of an increasingly older population and overall resource constraints. As such, there is little doubt that a more integrated model of providing dementia care will be critical. To achieve such integration, the essential role of informal carers and their needs will have to be fully addressed. Relatively little is known or done to formally recognise informal carers and create effective policy responses to sustain this under-appreciated asset, which currently accounts for £11.6bn per year. Without informal care, the health and social care systems simply cannot survive. Moreover, the financial contributions made by informal carers do not include the emotional benefits and costs that accrue to both those being cared for and those providing the care.

National guidance emphasises the importance of care at home, and there is a strong exhortation to look after people with dementia in the community, where informal care is taken as the norm, but may not always be available. Various policy strategies, such as local authority carer assessments (UK GOV, 2014) and NHS general practitioners and the Quality and Outcome Framework (2006) aim to address aspects that enable people with dementia and their carers to stay at home for longer. However, there is little clarity on what dementia care at home entails, how confident current carers are in providing care, and how effective the mechanisms of support in an integrated person-centred approach are.

Despite questions about the potential negative impact on caregivers, informal care has become a reality inseparable from elder care, most significantly in relation to dementia. As there is neither the availability nor the resources to replace this with formal care services, this shortage of provision is likely to persist in the future, where carers may be faced with perhaps even stricter rationed care allocations (Arksey, 2002).

It is important to state that dementia care is a specialised task that requires appropriate training and education. Workforce development in dementia care in institutional settings has come a long way from the days where having “a kind heart and common sense” was all that was necessary to work in residential care (Doyle and Ward, 1998, p. 589). Currently, whoever is in the dementia care workforce in the health and social care sector is expected to complete training at an appropriate level and to a satisfactory standard (Health Education England and Skills for Care, 2018). However, informal carers are not part of the formal workforce and as such are excluded from these training requirements and opportunities. A potentially dangerous assumption seems to exist that someone who is willing to care already knows all there is to be known about dementia and its care.

Even if a well-trained formal workforce is available, the cost of social care may remain out of reach for many individuals, leaving people with dementia reliant on informal care. Appropriate support for informal carers includes not only incentives but also education and training. However, such support is extremely limited, and how best to balance the interests of both the carers and the cared for requires careful scrutiny and further research.

My research aims to profile the nature of informal dementia care at home, including the characteristics of informal carers and their needs. The research then situates this informal care within a context of community care and institutionally provided formal care. This study will explore ways of including informal care within the integrated care model in order to improve dementia care service delivery in the community. It intends to assess their relationship with the broader health and care delivery system as well as the perceived barriers to sustain care in their own home. Overall, this study seeks to provide pathways for improving care in the community and in the broader health and social care delivery system as a means of sustaining dementia care at home.

2.10 Research Aim and Questions

The overall aim of this study is to enhance the understanding of informal dementia care at home. As established in the literature, informal care is an inevitable reality for those living with dementia at home. Nonetheless, there remains a lack of clarity about what dementia care at home entails and on the skill levels and support mechanisms needed to sustain informal care at home. As such, this research directly addresses the integrated person-centred approach that currently seeks to improve the quality of dementia care at home.

This research seeks to explore the existing knowledge gaps in dementia care at home as expressed in the following four key questions:

1. Who are the informal carers in dementia and how prepared are they to care at home?
2. What constitutes dementia care at home in the community setting?
3. What is the carer’s experience and assessment of integrated person-centred care services?
4. What kinds of support do informal carers need to sustain dementia care at home?

Chapter Three: Methodology and Methods

3.0 Introduction

This chapter presents the methodological approaches adopted to address my central research questions regarding dementia caregiving at home. It describes the overall research design and the pragmatic approach that provided the philosophical and theoretical basis for the research. The chapter then presents the conceptual framework underpinning the research design and outlines the suite of research methods used in the data collection. As the conceptual framework indicates, this mixed methods design was implemented in different but interrelated-sequential stages, including qualitative in-depth interviews with informal dementia carers and service providers, a quantitative online survey of informal carers, and a focus group discussion with informal carers and service providers. The chapter lays out the sequence of data gathering and analysis at each stage, the process of interpretation and integration of results, and the final analytical approach. It also identifies and addresses the ethical considerations related to the study.

3.1 Research Design

This research explores the management of dementia care and care provided by informal carers for people living with advanced dementia at home and the relationship with an integrated care system. Informal care is highly heterogeneous with regard to carer characteristics and abilities. Availability of formal care services provision is also variable depending on where people live. Thus, it was necessary to design a research methodology that could identify important patterns of the informal care in the community and, at the same time, situate the challenges of informal care at home within the broader integrated system of formal care for people living with advanced dementia.

As argued in the previous chapter, the existing literature presents a contrasting picture of the role, value, and impact(s) of informal caregiving for dementia. Much of the medical and health sciences literature suggests an array of negative impacts associated with family caregiving, with a particular focus on the long-term psycho-physical condition of family carers. From this perspective, family caring can become a burden that generates long term physical and mental health problems. In contrast to this argument, there is evidence of carers' personal satisfaction leading to positive physical and mental health outcomes, therefore making informal caregiving a mixture of positive and negative experiences, as presented in the previous chapter. It is, however, widely accepted that the informal, home-based care contribution to dementia care is a major factor in the quality and availability of person-centred care and is highly significant in (informal) monetary terms. This research addresses this debate and gathers evidence on the role and position of the informal family carers as the frontline workforce in dementia care and as an essential part of overall dementia care in the community.

The study thus documents the wide-ranging experiences and perspectives of family carers and service providers, analyses the experience and needs of the informal caregiver, and explores strategies for improving care at home in the community. Presented below is the rationale for the choice of pragmatism as a guiding philosophical approach and the choice of a sequential mixed methods design. A consideration of the 'researcher's positionality' is also discussed.

3.1.1 Finding an Appropriate Worldview for this Research

A philosophical worldview is presented as a basic 'set of beliefs' that guide action (Guba, 1990, p. 17). To inform the research questions of this study, a range of ontological and epistemological approaches were carefully reviewed (Biesta, 2010; Evans, Coon and Ume, 2011; Morgan, 2014a; Patton, 2015) in order to identify a philosophical foundation that informs real world action.

Four main worldviews or research paradigms—the positivist (and post-positivist), constructivist, participatory and pragmatist—were carefully considered (Creswell, 2009).

The first two perspectives are widely held in research, traditionally seen in polarised research paradigms, as incompatible, guarded from binary positions and subject to differing assumptions and methods (Tashakkori and Teddlie, 1998), although others hold views that in practice, they are more permeable (Crotty, 1998). The philosophical under-pinning of positivism views the existence of one true reality, which can be researched without influencing it by researcher-held values, and is assessed objectively, utilising statistics or empirical/quantitative methods (Crotty, 1998). The reworking of positivism, post-positivism, acknowledges that the goal of an absolute truth is unobtainable while studying human experience and behaviours, but still prioritises reductionism and theory verifications (Creswell, 2009). The constructivist paradigm, on the other hand, asserts the existence of multiple participant meanings and understands that “truth” is interpreted through social and historical constructions (Sarantakos, 2005; Creswell, 2009). Such a perspective is generally best explored using qualitative methods capable of collecting rich personal data and then subjectively analysed by researchers (Mason, 2006) toward an objective of theory generation (Creswell, 2009). Since the purpose of this research was neither the generation nor verification of theory, these approaches were considered to be unlikely to be appropriate in order to fulfil the aims of the study.

The participatory worldview was considered for its focus on positive change through collaboration. The participatory worldview is driven by the need to improve our society and prioritises such issues as empowerment, marginalisation, and patriarchy. The methodological approach situates researchers in collaboration with individuals who experience such injustices (Creswell and Clark, 2011). While collaboration and change are instinctively attractive, this perspective did not appear able to provide the right approach for this research. Having rejected three of the contrasting approaches as inappropriate, the researcher considered the pragmatist worldview. The pragmatist approach is associated with mixed methods research and has a focus on consequences of the research evident in real world life and practice associated with this (Creswell and Clark, 2011). After careful consideration, pragmatism was therefore selected as the most promising to inform my research.

3.1.2 Pragmatism and its Value for this Research

Pragmatism originated in the United States in the late 19th century with the work of philosophers William James, John Dewey, and Charles Sanders Pierce. Pragmatism derives from the Greek word (*pragma*) for ‘action’ or ‘deed’ and is etymologically linked to the common meanings of practice and practical. The fundamental axiom of pragmatism is that a phenomenon is best known through its effects or impacts, and the philosophy promotes an emphasis on action-based change that can be measured and evaluated (Morgan, 2014a). The decision to incorporate this methodological approach into my study was guided by three key factors.

First, this research seeks to achieve an understanding of an integrated dementia care system that highlights the existing role of informal carers. Its purpose is to improve both the management and practice of dementia care. From a pragmatist perspective, reality is not a constant but rather an ever-active flux of change; change that occurs as a direct result of action. Needless to say, the landscape of health and social care in the UK at the current time is under constant change. This research does not aim to generate new theory through inductive empiricism or to test a hypothesis in a deductive manner. It assumes, along with the pragmatists, that reality is dynamic, constantly negotiated, debated and interpreted. The conceptual tools for understanding a changing reality and for solving problems related to that reality should be equally flexible and adaptable, as well as action-oriented. Thus, my research employed a wide range of tools designed to capture the varying realities of a wide range of actors and stakeholders. The end goal is to identify, through this multi-faceted process, some practical solutions to improve integrated person-centred dementia care at home for people living with advanced levels of dementia in which informal carers and formal service providers work in partnership. The pragmatic approach is preferred by its proponents for its suitability in ‘having an impact on real people’ - an action-oriented inquisition, which can be identified in this research.

Second, I considered that the best way to conduct this research was to embrace a wide range of views and experiences. It is widely recognized that the value of action research depends on stakeholder engagement and co-production. In order to fully understand a phenomenon like dementia care, it is necessary to access multiple perspectives and multiple actors. The pragmatic approach, with its focus on the actions of multiple actors, favours a mixed methods design (Onwuegbuzie, 2004; Onwuegbuzie and Leech, 2005). The utilisation of mixed methods is perceived to be the 'best practice' in health science research (Creswell, 2009; Creswell and Clark, 2011). Given the wide range of views and experiences that constitute the objective of the research, the use of a mixed methods design seems an essential component.

Finally, the connection between the research and the researcher is itself a critical element of any research. Dewey's 'model of experience' in Morgan (2014) reminds us about the process of experience and the connections between our chosen belief and chosen action and presented a model to demonstrate interconnection between these two, situating human experience in an historical and cultural context (Morgan, 2014b, p. 3). As I was a family dementia carer myself, I was conscious that my own experience could provide valuable insights, but if not managed carefully, that experience might adversely affect the quality of my research. A pragmatic approach to manage the researcher's positionality is critical. With this approach, I wanted to ensure the inclusion of wider experiences from informal carers, key stakeholders, and professionals to develop a 'collective experience' in relation to informal care in dementia and the integrated care system.

3.1.3 Conceptual Framework

The conceptual framework for my research derives from two well-known conceptual models – Sen's capabilities approach (Sen, 1982, 1993) and the sustainable livelihood framework (DFID, 1999). Sen's capabilities theory centres on the wellbeing of individuals. Its conceptual building blocks are the states of "being and doing" called *functionings*, in which people have "reason to value", such as being healthy, having a job, being emotionally satisfied, and so forth. Capabilities are thought of as packages of *functionings* that individuals choose to value. For elderly people, especially those that struggle with some stage of dementia, these *functionings* might include cognition, mobility, nourishment, and good health as some of the key elements that define their quality of life (Sen, 1993). Grewal et al. have identified quality of life attributes as activities, relationships, health, wealth and surroundings. They also assert that loss of ability to pursue these attributes leads to a poorer quality of life for older people (Grewal *et al.*, 2006). Thus, research on dementia care can be seen as an effort to enable the *functionings* desired by the affected person. At the same time, the focus on the informal caregiver highlights the significance of the wider context of family, household, and community, where resources are available to achieve the desired *functionings*. It is in this context of larger social systems that the sustainable livelihood framework becomes relevant.

The Sustainable Livelihood Framework (SLF) is a heuristic analytical tool that organises empirical reality into conceptual categories that are systematically interrelated. Its usefulness as an analytical framework is to provide a comparative perspective that identifies problem-solving options (Mazibuko, 2013). SLF focuses on 'holistic contexts' within which individuals operate to achieve their 'functioning' and 'good quality of life'. SLF is one of the most widely used conceptual frameworks in poverty alleviation within sustainable development research. The UK Department of International Development (DFID) was a pioneer in introducing the SLF approach into its worldwide programming. Within the SLF, individuals are not isolated entities but integral members of households and communities, engaged in a system of activities. Households are diverse and complex units with variable levels of needs. In this approach, Sen's *functionings* are seen as livelihood 'outcomes' or welfares. To achieve desired outcomes, households mobilise and allocate packages of resources known as "capitals," commonly referred to as human capital, physical capital, natural capital, financial capital, and social capital. In response to any shocks or stressful events, in the case of my research, a shock could be a diagnosis of dementia, a household draws upon collections of capitals to increase their resilience and maintain their functioning.

As a combination of the capabilities approach and the SLF framework, my conceptual framework enabled me to ground and guide my research. A diagnosis of dementia, and the sequential progression of dementia through different stages, from mild to moderate and severe, presents two key elements of the SLF approach – a diminishing human capital for the person diagnosed with dementia and an accumulation of levels of shock for a household. Affected individuals and households, however, have different combinations of capitals (resources) with which they may counter or deal with the shock(s). Someone may not have a significant level of financial capital to purchase 24- hour care, however, non-financial social capital can be mobilised to achieve a desired level of care. A household's ability to utilise and draw upon different forms of resources, including social capital in the form of informal caring arrangements, contributes to the way individuals with dementia are cared for. Consequently, this will have implications on the broader health and social care services as well as the health, care and quality of life of the person with dementia and the wider family.

Informal care is neither universal nor available to every household, or to every individual. It may be perceived as a form of social capital that has been accumulated through various mechanisms over the individual's life course - including relations of kinship, successful family ties, friendship, a history of reciprocity, and so forth. It is not by random chance that some people may have informal care available to them and others may not; rather it is often the history of an individual's social investment that creates a social capital stock which is manifest in informal care arrangements. A utilisation process of social capital in the form of informal care is carefully studied in this research and is of key relevance to the topic of interest.

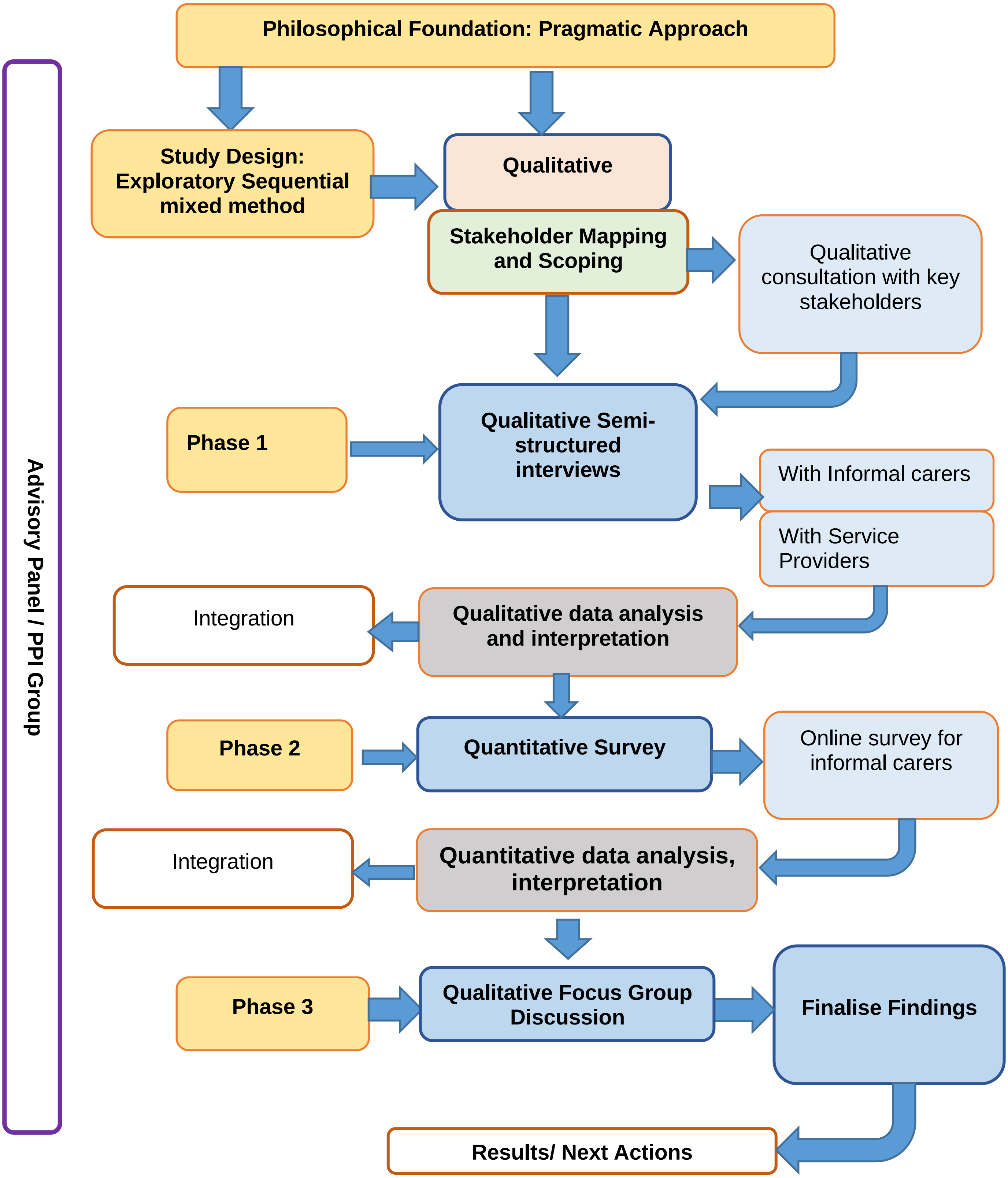
The conceptual contributions of pragmatism, Sen's capabilities approach, and SLF significantly influenced this study. At this point I should admit that I arrived at this somewhat unconventional combination inspired by my own personal and professional experiences. On the one hand, as an informal carer myself, I was committed to enhance knowledge in a way that could have practical application in improving dementia care at home. On the other hand, my previous professional experience as an international development practitioner and researcher exposed me to the capabilities approach as well as the practical applications of SLF approach. Sen's capabilities approach guided this study in terms of the way that dementia care is approached as a tool to achieve or maintain human functioning. Dementia itself is not viewed as a non-curable medical disease that people may eventually die from, but a human condition that people may live with for some time, which often affects an individual's functioning to achieve and maintain good quality of life. The SLF approach influenced the context of dementia care arrangements at home effectively and considered the management of various forms of capitals in a household. In this context, the individual with dementia is living with gradually diminishing human capital, and the informal carer is a type of social capital that the person with dementia is able to mobilise. In effect, the care providing household manages all available types of capital to sustain functioning, in the context of a declining health condition - in this case dementia. Where the SLF offers a systems perspective of the household that is holistic, resource-based and solution-focused, it is aptly complementary to the pragmatic worldview where knowledge is evaluated in terms of consequences and outcomes. Taken together, these complementary approaches favoured a mixed method exploratory study design in order to explore the realities of dementia care.

3.1.4 Exploratory Sequential Mixed Method Design

I employed an exploratory sequential mixed methods approach in my research (Ivankova, Creswell and Stick, 2006; Creswell and Clark, 2011; Morse, 2016). This is a desired and complementary match for research based on the pragmatic philosophical foundation. Therefore, I chose to employ both quantitative and qualitative methodologies in logical sequences, whilst adapting a strong participatory research strategy based on the use of participatory tools. The mixed methods design values both objective and subjective knowledge, and draws upon diverse methods (Morgan, 2014b; Pluye and Hong, 2014). It provides an opportunity for multiple methods and their philosophical traditions to generate new knowledge through dialectical discovery and practice. Mertens (2009) posits that mixed methods research favours a transformative perspective that permeates the entire research process, from the problem to the conclusions, and the use (including dissemination) of results (Mertens, 2009).

The exploratory mixed method research was designed in three sequential phases, as presented in the schematic overview in Figure 3.1. The purpose of Phase One was to collect and analyse qualitative data from semi-structured, in-depth interviews with informal carers and service providers in dementia care. This phase documented the perspectives of both informal carers and formal service providers and provided the basis for classifying different care tasks, identifying rewarding and challenging factors in informal caring, together with accounts of experience in person-centred integrated care and working together (e.g. health and care services and informal carers). It also explored possible actionable ideas that could help carers and sustain care at home for longer. In Phase Two, an online survey was designed on the basis of the qualitative findings and was administered to a sample of informal carers for the purpose of estimating a sense of frequency of care tasks, carers self-reported confidence and care training, their experience in integrated care and the assessment of care needs. The third Phase was based on a focus group discussion with both informal carers and service providers to finalise findings by scrutinising key findings, further exploring connections within findings, seeking insights into the nature of informal care and integrated care and also mapping out potential future directions.

Figure 3.1 An overview of the exploratory Sequential Mixed Method Research design



3.1.5 Ethical Considerations

It is a requirement of the university ethics policy (UEA, 2017) that all research with human participants must have ethical approval before being undertaken. With this specific study, there were a number of key ethical concerns, primarily in relation to the sample of caregivers. Such related to informed consents, risk assessment, potential distress for caregivers during interviews and how to manage these, confidentiality, and protection (in terms of safeguarding and data protection and storage). In line with the UEA research ethics policy, the research was reviewed and approved by the University of East Anglia/ Faculty of Medicine and Health Sciences Ethics Committee (**Project Reference: 2016-2017 – 88**) (Annex 3). An amendment to the original approval was sought and approved in relation to conducting the online survey, which followed the qualitative interviews.

There were multiple ethical considerations at each stage of the research. The sensitive interview dynamic with carers and the potential emotional state of some of the carers who took part in interviews meant that a number of important factors were considered before, during, and after the interview process. I remained mindful and sensitive to the possible effects that my requests might have and maintained communication with empathetic standards to ensure minimisation of any distress.

Participation in this study was on a complete voluntary basis. Before confirming potential participation in interviews, participants were given Participant Information Sheets (PIS) and any questions were answered before an informed decision about taking part in the study was made. In relation to the interviews, if participants who consented to take part in the research decided to withdraw at any point, they were able to do so without any reason or justification needed. Potential participants were informed about this in the PIS information provided. In the event, none of the interviewees exercised this option. For participants in the online survey, information was provided on the first page, including their right to withdraw up until the point of submitting the survey and individuals were asked to confirm consent to participation prior to starting the survey proper. Once completed and responses had been submitted it was not possible to retract or withdraw answers because there was nothing identifiable to locate any individual's responses and enable them to be deleted. This was made clear to all respondents in the initial information provided.

All interview transcripts were anonymised, were kept confidential, and kept in secure and coded storage. All personal data (for example, names as provided on consent forms) was assigned a study number in order to maintain anonymity. Data was stored in line with standards of good clinical research practice and in keeping with the Data Protection Act 1988 and Data Protection Act 2018 (for survey data). All electronic data were stored on secure servers and managed using databases encrypted with industry standard cryptographic methods and protected by passwords. Interview transcript recordings and hard copies of the transcripts were stored in a locked cabinet in a locked room, to which only I had access.

Throughout the data collection, my priority was the wellbeing of the carers and the person with dementia they cared for as well as the participant service providers. I always followed the preferred time and place that carers chose and allowed plenty of time to be able to allow some flexibility with arrangements. As indicated, the majority of interviews took place at the carers' homes, and this required flexibility around the routine of both the person with dementia and the carers. In some cases, I had to reschedule on arrival, due to unforeseen circumstances, which I did. Participants were informed in advance (via the PIS) about my responsibility in case of identification of any potential safeguarding concerns (identified through either observation or any disclosure); fortunately, there was no such occurrence during the course of the study. During the interviews, if carers became emotional, interviews were stopped as and when necessary and resumed at a point when the participant felt able to continue, often following a break. As many of the interviews took place at participants' homes in accordance with their preferences, so additional time was added, as needed. For the service provider interviews, these took place at the location of participant's choice, either at their workplace, home or even at the university. Fortunately, all participants also agreed to have their interviews digitally recorded.

3.1.6 Lay Advisory Group/ Patient and Public Involvement

Involvement of patients and the public in research refers to active partnership of service users and lay individuals with researchers at every stage of the research process. This has been the ethos of participatory development in disciplines including social development for several decades (National Institute for Health Research, 2013). Since 2006, the National Institute of Health Research (NIHR) has promoted such initiatives as good practice within research and increasingly involvement is becoming an essential element of health-related research in the UK (NIHR 2014). The UK government Select Committee on Health carried out an evaluation of public and patient engagement in the NHS and encouraged the need to improve effectiveness by public involvement 'at the heart of what is done' (House of Commons Health Committee 2007 p.7). This was also seen as including involvement in research.

My study had a strong Patient and Public Involvement (PPI) element throughout, from stakeholder consultation at an early stage to formulate and develop my research questions, to formation of an advisory panel for advice, support and general oversight of the research. At an early stage of my research I formed a PPI advisory group consisting of five members. Further information on the background of PPI advisory group members is presented in Annex 4.

3.2 Research Stages

As stated earlier in this chapter, I employed an exploratory sequential mixed methods approach in my research. The research flow diagram presented earlier in this chapter shows my sequence of different stages and application of different methods. Here I present the different stages with the purpose and expected outcomes in tabular form, (see Table 3.1) and will explain these specific steps in the subsequent sections.

Table 3.1: Research plan outlining stages, methods, purposes and expected outcomes

Stages/ method	Data collection	Purpose	Expected Outcomes
Qualitative	Stakeholder mapping	To map the field of dementia care To identify key stakeholders To identify potential PPI advisory group members	Inform/ finalise research protocol & questions PPI group formation
Qualitative	Semi-structured Interviews (carers and service providers)	To explore carers lived experience and views about integrated care and dementia To explore service provider experiences in dementia care in the community and views about informal carers roles in integrated care	Find themes and patterns to answers to the research questions Integration of themes and draft findings
Quantitative	Survey (carers)	To explore extent of the themes and patterns from qualitative interviews	Semi-finalise answer to the research questions
Qualitative	Focus group discussions (mixed – stakeholders, carers and service providers)	To explore explanation and finalise answer to the research questions To explore/map out possible next steps	Finalise – research questions answered

3.2.1 Stakeholder Mapping

The first stage of the research involved stakeholder consultation and mapping as a practical and worthwhile starting point. Stakeholder mapping is a commonly used tool in the area of social science and development studies and particularly in action research, that addresses policy and practice. The popularity of stakeholder consultation and mapping is due to its usefulness in gaining a rapid understanding of situations and contexts by drawing a matrix of different players in a given field, their relative influence, and to gain some understanding of their alignment and direction of travel. The purpose of my use of this technique as the first step of research was to gain a quick understanding of existing contemporary initiatives in Norfolk in relation to dementia care and carers. Most importantly, I needed to be as certain as possible that no other similar research was in progress or in the pipeline that I was about to venture into and to try and ascertain that there was a need for the work that I was about to undertake.

Stakeholder consultation started with a brain-storming session with my academic advisory team followed by a meeting with a few potential contacts, both individuals and organisations. Initial meetings were conducted with the local Dementia Alliance members and professionals from the local mental health trust, the Norfolk and Suffolk Foundation trust (NSFT). The consultation involved a brief discussion about the research ideas and questions and sought to identify current initiatives regarding dementia and integrated care. A strategy of snowballing was used to build a cadre of contacts. During this process an invitation to be part of a PPI advisory group was made and the group was formed. A subsequent meeting was conducted with group members individually and also as an advisory group at certain points during the research.

These initial consultations with stakeholders and PPI members were very useful in clarifying the research questions and to help work out a research plan which was realistic and achievable. Some of the key elements that became clear at this stage were the initiatives that were focused on creating an integrated dementia pathway, and post-diagnosis support. There were three main beneficial factors in carrying out this somewhat rapid stakeholder consultation and mapping, as below.

In all, this first stage achieved a satisfactory level of clarity on key existing services and of the perspectives of certain shareholders. For instance, Norfolk Suffolk Foundation Trust (NSFT) was in the process of carrying out a service mapping for current and future dementia and post diagnosis support. The Dementia Alliance had also drawn up a map of Who’s Who in dementia care. By reviewing this in the light of my research problem and questions I quickly benefitted from gaining clearer perceptions of the dementia landscape in Norfolk and Suffolk.

Second, I identified a number of key individuals with relevant experience and expertise who demonstrated a strong commitment to improve dementia care. This has been hugely beneficial to me to shape my research and provide dementia-related advice from time to time.

Finally, the process helped me to develop a working definition of ‘dementia’ for this study. It was very reassuring to find that within the integrated collaboration and strategic direction, dementia was not only limited to a clinical definition but had a wider meaning. I defined dementia quite broadly, as follows: Dementia is not a mental illness. It is a condition that creates and aggravates physical, mental and social difficulties in people’s lives.

3.2.2 Qualitative In-depth Interviews

Being guided by Morse and Field (1995, p65) and their two key principles of qualitative research, that is ‘appropriateness’ and ‘adequacy’, this study first recruited informal carers for people with dementia. At this stage the focus of the study was to only include co-resident carers (Morse and Field, 1995).

3.2.2.1 Carer Recruitment

Initially I made contacts and visited dementia cafés in Norfolk to inform them about the research and seek potential interest from informal carers. During these visits I left flyers that were designed to provide information about the study and to recruit potential participants. I also talked about my study where/whenever I was asked to do so. This resulted in generating some initial interest from carers to participate. I followed such interest up by sending individuals participant information sheets either by post or through further visits to meet them at one of the cafés.

With repeat visits to cafés I was able to not only to build rapport with the attendees and organisers but also observe activities and conversations amongst the attendees. Initial interest by individual carers was followed up with telephone contacts to confirm interest in participation and to provide relevant follow-up arrangements i.e. determine a place and time for interview. During this time potential participants' eligibility was also checked and confirmed. The inclusion and exclusion criteria and associated rationale is presented in Table 3.2 below.

Table 3.2 Inclusion and exclusion criteria with rationale for potential informal carer participants

Inclusion criteria	Exclusion criteria	Rationale
• Adult carers – age 18–90, male or female • Relationship to cared-for person - partners, relatives or friends • Co-resident with the person • Providing care for someone who is living at home with a confirmed diagnosis of moderate or severe stage(s) of dementia • Providing a minimum 7 hours per week of care/ help which ordinarily would have to be paid for (if it was unavailable from the carer) • Able to communicate in English as either first or second language	• Paid carers • Provides irregular, one off or occasional care/help • Carers who do not live in the same home • Providing unpaid care on behalf of a voluntary sector organisation • Carers who also have a diagnosis of dementia	A large number of informal carers for older people are partners and spouses, who are older themselves. Living arrangements and level of severity of the condition are important factors in my research as it can have significant impact on maintaining care in the community.

After confirming eligibility, a date and location for the interviews was set.

3.2.2.2 Carer Interviews

Twelve carer interviews were conducted at a place of the participant's choice. The interview was arranged well in advance as stated earlier, and before commencing I followed the informed consent protocol and reiterated the process of withdrawal at any point without having to provide any reason and with no effect on the individual or any care they received. Most of the interviews were conducted in the participant's home; however, a small number were conducted at the premises of the dementia café because carers were happier to take part in the knowledge that the person they cared for was being engaged in some activity with dementia café volunteers.

The interview was semi-structured, conversational in nature and used a topic guide to provide some structure to the flow of the dialogue (Annex 5). The interviews were exploratory, and participants were encouraged to discuss whatever they felt to be important. Whenever interviews extended beyond an hour, individuals were reminded about the time and a check was made that the interview could continue. In a number of instances, participants needed to have breaks and at times individuals became very emotional. Careful consideration, compassion and empathy were fundamental to these interviews and breaks were taken as and when felt needed. A small number of interviews were conducted over two visits. All interviews were audio recorded after obtaining participants' permission for recordings to be made as part of the consent process.

The first three interviews focused on the services that the carers and the person they cared for accessed and used. The participatory tool, the 'Venn diagram', was used to visualise and discuss the different services that were used by the carers and their relative closeness or intensity of their interventions. Subsequently, a draft list was drawn up that included the named services that were in existence and used by carers. This list was checked with the later carer interviewees and any additional suggestions were added to the list. This list of service providers provided a resource to identify services from which provider professionals were selected and contacted for a further set of interviews, as explained and discussed in the following section.

3.2.2.3 Service Provider Recruitment

A purposive and opportunistic sampling technique was used to recruit service providers. A range of strategies was applied for such recruitment. A list of agencies was drawn up when stakeholders were consulted initially at the initial stage of the study. The carer interviews provided further insights as to which agencies had been frequently mentioned by carers. These organisations were then contacted and invited to participate in the study. Many expressed an encouraging level of interest, and the number of selected service providers represented a wide range of different perspectives.

Relevant inclusion criteria for recruitment of service providers were:

- Working for a statutory, voluntary community, community organisation or private sector organisation providing dementia care in the community
- At least 3 years of experience in delivering dementia services in community settings

3.2.2.4 Service Provider Interviews

Thirteen interviews were completed with dementia care service providers, including statutory health and social care organisations (5 respondents), voluntary (2 respondents), private sector agencies (4 respondents) and community organisations (2 respondents). The Interviews took place at a place and time of participants' preferences. These interviews were similar in nature to those with informal carers, being conversational and semi-structured in nature. A topic guide was developed and used to provide some structure, whilst encouraging discussion to be as open and frank as possible. Interview questions focused on the individuals' role(s) in the overall service provision and delivery map, and different aspects of integrated care delivery in the community. This included views about the involvement of informal carers and perceived barriers and opportunities of including informal carers in the integrated care delivery system.

3.2.3 Qualitative Data Analysis

In an effort to achieve study rigor, all recorded interviews were transcribed (Robson, 2002; Feilzer, 2010). The anonymity of the interview participants was protected using a coding system involving unique letters and numbers. The letters IC represented the informal carer while SP denoted service providers. Numbers were allocated according to the sequence of interviews and transcription.

The analysis of the qualitative data adopted the *Framework Approach (FA)* because of its analytical transparency and robustness. Developed by social policy researchers, Ritchie and Spencer (2002), the FA has gained increasing prominence and application in qualitative data analysis in multiple research fields. Its use has been particularly widespread in health care research (Ritchie and Spencer, 2002; Ward *et al.*, 2013), including qualitative studies of dementia (Smith and Firth, 2011).

Despite the extensive popularity of FA, some experts have remarked that prior experience in qualitative research is an essential pre-requisite for its effective use (Gale *et al.*, 2013). My significant experience in qualitative research has involved several tools of data analysis, including thematic analysis, which helped prepare me to apply this approach.

The FA consists of a five-step process for analysis: familiarisation, identification of a thematic framework, indexing, charting and mapping interpretation (Ritchie and Spencer, 2002). The first step in the approach focuses on the researcher becoming immersed in the data. This is usually achieved by 'reading and re-reading' the interview transcripts in an active way. In addition to conducting all the interviews myself, I transcribed all of the interviews, using a computer programme called 'scribe'. This programme allows flexibility in listening, through use of a foot pedal that enables the transcriber to stop and start as needed, and to go back and forward in the recording as necessary. Although it was a time-consuming task for me to learn and carry out all the transcriptions, this proved immensely helpful for the 'familiarisation' process.

Use of such an approach provided an opportunity to become immersed in the data, to annotate transcripts to highlight areas of interest related to the research questions and to make notes around themes that were appearing from the data. This annotation and highlighting proved useful for the next step of the FA, identification of thematic categories.

Following familiarisation, initial themes were identified based on the objectives of the study, the research questions, and recurrent patterns that emerged during the familiarisation process. I closely reviewed 6 interview transcripts in two stages, which represents a quarter of the total numbers interviewed, to finalise the thematic categories. First, twelve informal carer transcripts were put into three piles following the sequence of the interviews and randomly one was selected from each pile. These three carers interview transcripts were then carefully reviewed to help to develop an overall framework of recurrent themes. Similar techniques were applied to select three service provider interview transcripts, and these were also carefully reviewed. While some common themes across the two participant groups emerged, some themes emerged as specific to either carers or the service providers. At the end of this process a thematic framework was ready to encompass the other transcripts for indexing purposes.

Although the computer programme NVivo was considered at this stage to gain speed, particularly in the analysis process, indexing and the strength of deeper personal engagement with the data was too great to lose. Therefore, the investment of time seemed a better option as it allowed me to form and undertake the interpretative process with greater insights. Indexing and charting was completed almost in parallel, although this started in a sequence as intended. Finally, the mapping and interpretation process, which is described as pulling together key characteristics of qualitative data to map and then interpret the whole data set was undertaken (Ritchie and Spencer, 1994).

The FA was instrumental in creating the domains of dementia care which are central to this study. These domains, presented in Chapters Four and Eight, were constructed on the analysis of the care tasks discussed throughout the qualitative interviews with both the carers and service providers. The common patterns of response allowed the generation of recurrent themes which were analysed and interpreted as care domains. Once these domains were established in the qualitative data set, they were used as key variables in the subsequent quantitative survey design and analysis.

3.2.4 Quantitative – Online Survey

The survey was carried out to validate the findings from the qualitative interviews. The qualitative interview analysis provided some answers which needed to be explored further. For example, the interview included only co-resident carers in dementia, however, it became apparent from these interviews that there were often other carers on the periphery who were not co-residents but who provided vital care that enabled both carer and the person with dementia to remain and be cared for at home. Therefore, this element was included in the survey.

The development of survey questions was designed and presented in four key sections. The demographic profile obtained included respondents' residential status, frequency of dementia caring tasks and the levels of confidence and training carers had received, and carers' knowledge and experience with the current integrated care system. To ensure quality and accessibility a pilot was conducted. After reviewing the feedback from pilot participants, the survey was amended and issued as a live/open process. Unlike active efforts in qualitative participant recruitment, there were no efforts to encourage any carers to participate. However, the survey link was placed on various websites. Initially, the response rate was slow to take off, but once it started to gain interest, this was substantial, and a number of potential participants and gatekeepers made contact to seek alternative forms, such as paper copies of the survey.

3.2.4.1 Survey Questions Development and Design

The development of survey questions was designed and presented in four key sections. The first was to capture the demographic profile of the carer and the persons they were caring for as well as the amount of care they provided. Secondly, the survey documents the frequency of dementia caring tasks and levels of confidence carers had in their caring abilities. It also focuses on the training carers may have received, with regard to both the dementia tasks, e.g. 'know-how', as well as the commonly available dementia training that may be accessible to informal carers. The fourth and final part of the survey assesses the carers' knowledge and experience of the current integrated care system.

To ensure quality assurance of the research process and clarity of the survey questions, a pilot was conducted. Five purposively selected respondents were requested to complete the survey and to provide feedback. These five pilot participants included one PPIE advisory group member, one professional academic with care experience and three members of the community. This was extremely useful in ensuring the clarity of the questions and online accessibility and ease of navigation. Following this, the online survey questions were revised and finalised before making it 'live' and accessible to all. Below is an image of its appearance.

Figure 3.2: Image of the online survey appearance with link

https://uea.onlinesurveys.ac.uk/dementia-informal-carers-survey

Dementia Informal Carers Survey - uea.onlinesurveys.ac.uk

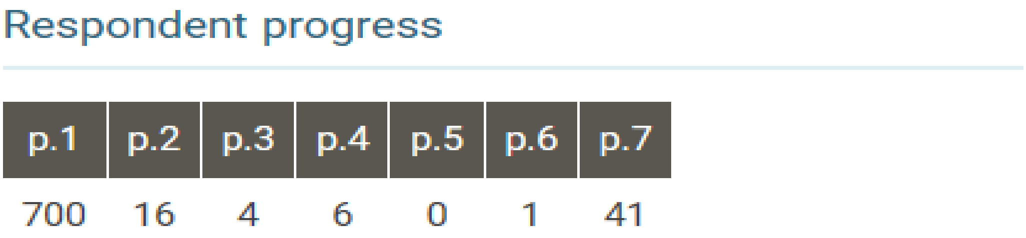
uea.onlinesurveys.ac.uk

Thank you for your interest in this survey. Before you decide whether to take part or not, it is important for you to understand why this study is being done and what it involves.

3.2.4.2 Responses and Analysis

At the time the survey data analysis was carried out there were a total of 41 respondents who completed the survey. Although there were 700 visits to the first page of the survey and 68 of them went through a number of pages, a total of 41 actually completed all questions and submitted.

Figure 3.3: Image of the survey respondents progress through pages



Respondent progress

p.1	p.2	p.3	p.4	p.5	p.6	p.7
700	16	4	6	0	1	41

A total of 41 carers participated in the survey, with a higher proportion of co-resident carers (n=28, 68%) than non-co-resident respondents (n=13, 32%). Basic demographic data was collected, including gender, age (in years) of the respondent, their relationship to the person cared for as well as their employment status. Residency status data, such as whether they were living with the person they cared for or not, was important for understanding differences or similarities between these two groups in some areas. In the interviews, co-resident carers often mentioned others who helped them and carried out some of the care tasks. Therefore, it was important to capture the residency status of the people who self-identified as informal carers of someone living with dementia. Although it may be the case that for some carers there was more than one informal carer available, for others there might be none.

Survey data was analysed using statistical programme SPSS : V25 and Microsoft Excel, mostly using descriptive analysis. The survey results are presented in Chapter seven.

3.2.5 Qualitative – Focus Group Discussion

The discovery process in the pragmatic approach is continuous and cumulative. An ongoing and iterative analysis in three distinct phases enabled this research to gain enriched knowledge. The third and final exploratory phase consisted of a focus group discussion. This was arranged in order to bring together carers and service providers to review the key findings from the qualitative interviews and survey, in order to finalise the study findings and also to act as an initial form of restitution.

The strengths and value of focus group discussions (FGD) in mixed method research has long been promoted for its suitability to examine how knowledge and ideas are developed and operationalised within a given context (Morgan and Spanish, 1984; Kitzinger, 1995; Morgan, 2012). The added value of focus group discussions lies not only in open communication between researcher and participants, but also between and amongst the participants' themselves (Morgan, 1997). Furthermore, focus group discussion (FGD) as a method holds great value in complementing other methods, especially in triangulation of both qualitative or quantitative validity checking (Morgan, 1997, 1998). Therefore, with the method considered to be valuable and integral to the study, the group and the focus of discussion had to be determined.

The FGD participants were recruited using purposive sampling. While a prescribed number of participants for a FGD does not exist, an ideal group size for a successful FGD is thought to be between four and eight (Kitzinger, 1994, 1995), or six and ten people (Morgan, 1997). A mixed group of nine participants were invited, including informal carers and service providers of dementia care. The service provider participants were considered from two categories: strategic level staff (e.g. members of a county level statutory strategic committee, who could potentially influence local policy and resources), and operational level staff (e.g. staff directly delivering dementia care services). There was one service provider and one informal carer participant included in the group discussion who had previously participated in an in-depth interview. As most of the FGD participants did not know each other, an initial period of informal interaction with refreshments upon arrival generated an effective synergy within the group. The group discussion was held in a neutral location at the University campus, which promoted cordial hospitality and set participants at ease.

The group discussion was divided into two parts: firstly, to present the key initial findings with discussion and reflection of the FGD participants' own experiences, and secondly, to explore additional issues and future directions. The focus group discussion was conducted using a checklist and topical guideline, included in Annex 8. While I conducted the group discussion, I sought the assistance of a notetaker who is a research colleague, for taking detailed notes of the group discussion.

In addition, a number of visual tools were utilised such as flip charts with sticky post-it notes to emphasise commonly held views or experiences among participants. Discussion and debate between participants were encouraged, as it was a mixed group, and the facilitation needed to be carefully organised to ensure equitable opportunities and in order to allow the expression of diverse views. At the end of the session, the tentatively identified issues were presented to participants for confirmation and any clarifications to maximise clarity of the outcomes sought, as suggested by Kidd and Parshall (Kidd and Parshall, 2000). Detailed observation and reflective notes were also made and added to the discussion notes immediately after the session. Together these notes and flipchart information formed the qualitative focus group discussion data for analysis.

3.2.5.1 Focus Group Data Analysis

The focus group discussion generated a rich dynamic of discussion and reflection within the group. Just like the planning and conducting of the focus group discussions, there is no universally agreed way to best analyse data generated from the FGD. While some suggest using individuals or a group as the focus of analysis (Kidd and Parshall, 2000), others suggest the whole group as an unit of analysis (Morgan, 2012). The importance of the interaction between participants in a group is also promoted as an essential aspect of FGD data analysis (Kitzinger, 1994). Given the mixed composition of the group, both individual and collective interactions were given careful consideration and attention within the analysis.

The FGD data analysis was guided by a 'classical content analysis' (Onwuegbuzie *et al.*, 2009, p. 6), which is based upon Morgan's three step coding framework (Morgan, 1997). Such analysis starts with the coding of transcripts, of either individual participants or groups. Sections of transcripts are then allocated to these codes according to similarities in content and meaning, and are then developed into themes (Onwuegbuzie *et al.*, 2009). For this study, FGD notes were reviewed and coded by type of participants (e.g. SS – Strategic level staff, OS – Operational level staff and ICFG – for Informal Carers). Recurrent themes were then identified and compared to previously identified themes which arose from the in-depth interview analysis. Similar themes were identified and collated, and additional themes were added. Finally, the content analysis was performed on the observation and reflection notes. This step-by-step analytical process was in tune with the previous two phases of the methodology and completed the final stage of the exploration. Key findings from the FGD are presented in Chapter Eight.

Chapter Four: Informal Dementia Carers

4.0 Introduction

This chapter describes findings relating to the informal dementia carers who provide and manage care at home for someone with dementia. It uses information from qualitative in-depth interviews with twelve informal carers and thirteen dementia service providers and creates profiles of dementia carers from the moment of diagnosis through the process of adjustment into the caring role for the loved family member. It examines the key reasons and motivations for continued care at home, as well as the level of knowledge, attitudes, and skills required to provide dementia care in the home environment. Finally, it focuses on the complex process that motivates the willingness of those who take care of loved ones and who adopt the self-identity as a carer. For clarity, verbatim quotes that will be used from the interview transcripts will be denoted as either IC (informal carer) or SP (service provider); the number that appears denotes the relevant interviewee.

4.1 Informal Carer Profiles

In the qualitative sample of interviews, the majority of the informal carers were women and most were themselves older. Many were in long-term spousal relationships; others, who were caring for their parents were a single child, often the only single living child of the person in need of care. Most of the respondents reported to have provided care for between 4-5 years with the exception of one case of someone caring for 2 years and another for 7 years.

The sample included two daughters, who for some time had managed the care of their widowed mothers from a distance and then decided to move them into their own homes. These were both the only remaining living child of their parent.

Table 4.1: Distribution of informal carer respondents by gender, age, relationship, age of PWD and care years.

Gender	Age	Relationship with PWD	Age of PWD	Caring for (in years)
F	69	Wife	74	5
F	84	Wife	86	5
M	80	Husband	82	5
M	76	Husband	74	5
F	83	Wife	87	7
F	85	Wife	87	3
F	55	Daughter	78	3
F	78	Wife	80	5
F	60	Wife	62	3
F	75	Wife	78	3
F	65	Wife	69	4
F	62	Daughter	89	2

The carers came from a wide range of working backgrounds, but all except one were now retired. Backgrounds ranged across healthcare, social care, education, military, business, salaried skilled worker, manual labour, and homemaking. One third of the spousal carers were in their second marriages, and in several cases, both spouses suffered from some level of (other) health problems unrelated to dementia.

4.2 Obtaining a Diagnosis

The process of accepting and acknowledging the existence of dementia in a loved one varied but was often painful and difficult for individuals. Prior to a formal diagnosis, some carers reported that they had come to recognize initial signs of dementia in their partners and parents as they had previously either observed or heard of someone else having dementia within their close social network. Even though their suspicions were strong, the confirmed formal clinical diagnosis brought shock and emotional disquiet.

Over two third of carers responded (nine out of twelve) that the process of seeking and receiving a dementia diagnosis was confusing and not well-explained. In one carer’s words:

> *“ .. so we went to the doctors, and had the referral, and then we went to see the clinical psychologist, we did have a test, you know the standard test, and some things he could not do, nothing was final, some of the questions they asked like can you pick up this piece of paper. That is some insult to your intelligence really and another thing is like can you count down from 100 in 7s, now I have to think about it. You know like 93 and so on. he just could not do that. Clock-face, is another question, he struggled, you know pin-pointing numbers, so they did various tests, of course they could not comment on it, and he scored certain level and then you see so many different people, but then they obviously decided it is good to have a scan, I did actually find the scan result, and it said ‘cognitive impairment’ and suggested that he had Alzheimer’s.. That was like in black and white. You got the diagnosis, and you think where do we go from here…?”* (IC_10).

Another carer explained the context of receiving a diagnosis:

> *“ .. oh she (the PWD) was told at the memory clinic by the consultant who just blurted straight out the diagnosis and my sister (who died a few months later) was very angry, because she thought it was done in a very insensitive way. Because neither of them was expecting it, not like that, I mean in retrospect I don’t know why we did not suspect it, but it was just blurted out, there was no sort of softly- softly, he said well you have vascular dementia. And my mother burst into tears...”* (IC_12)

Whatever the circumstances of the diagnosis, whether predicted or not, it arrived with shock and dismay. Following the diagnosis, the respondents reported that they had come to the realisation that someone they lived with or cared about had now been diagnosed with dementia, which does not have any effective treatment as yet and that person would need increasing amounts of care over time. At the time of diagnosis, despite some amount of referral to other services, there was no reported in-clinic discussion of the dementia condition, what caring for someone with dementia might entail, and how dementia is a progressive condition requiring increasingly intensive attention. Thus unprepared, and some more than others, the carers faced the post-diagnosis adjustment process.

4.3 Post-Diagnostic Adjustment

For carers who had lived together with their spouse for a considerable number of years, the adjustment to dementia care might be quite slow and difficult, perhaps requiring some practical changes to the daily routine. Such changes primarily focused on living arrangements and the suitability of the home for existing and likely future needs. For example, some couples decided to downsize their dwellings or even relocate to live nearer to their children or other close family members. Sometimes the option of relocation might have been considered for some time and then the dementia diagnosis played a catalytic role in making it happen. In the anxious context of a progressive condition for which there is often no treatment and that over time can only get worse, couples often resorted to reduce physical distance from sources of potential support such as children, and wherever possible to perhaps access additional help and support if needed. Such decisions appeared to be made with extended family members being involved, too. Almost all (eleven respondents in total of twelve) reported their extended family and friends also provided some support after diagnosis, while the adjustment to the diagnosis advanced. As one of the carers explained:

> *“.. I bought a ground floor flat, moved from our bigger house, that might be the best decision I have ever made. Its perfect, no stairs, there is a wet room, and my brother and son live close by, I can feel confident for caring for him/her...” (IC_03)*

However, two respondents reported that the situation of an older parent living alone brought greater challenges. To move a parent with dementia from their own home to that of an adult child was often filled with difficulties and dilemmas. Usually, the parent with dementia did not want to leave the familiarity and comfort of their own home. On the other hand, the parent might persistently and easily get lost or face other safety risks if they stayed in their own home. In such situations where significant personal risks repeatedly occurred for the person with dementia, the options open to family members became rather limited-- either relocation or institutionalization e.g. care home admission. One such carer sought professional advice for this difficult decision:

> *" My mother's adjoining neighbour wrote me, saying that they felt vulnerable, they felt she was not in control, that there might be a fire, and although they sympathised with the situation, they felt her health condition and problems arising from it impacted directly on them, and basically warning me, that I was put on notice, and that I had to do something about it meaning I have to move my mother from her own home … My mother of course wants to be at home, I did not know what to do really…… But I think sometimes you need someone from outside to tell you.. mother's doctor, she said, …. you need to take control of the situation. So, its that's the thing…I decided to bring her over with me...*" (IC_07).

The mental and emotional adjustment to such a decision could take a long time for everyone involved. One carer explained his/her emotional turmoil whilst adjusting to such changes thus:

> *"I found it really hard in the beginning… I was resentful actually I really felt I was pushed into a corner, not by anybody, but by circumstances. And I did not, having being used to a career, and being so active and stimulated I supposed, and suddenly you find the treachery of daily caring every day, every day, into the same routine. I found it so difficult …….. And I was relieved to see that people have the same kind of feelings kind of dichotomy between feeling that you want to do best for your mother or father, and at the same time your whole life is just one long hard grind and how sometimes you think things that you really feel bad about.. I absolutely care about my mother and I would like to be here for her, but there is that balance between subjecting your entire life to what you do as a carer and no break for any of the things you want to do. And you fall into it unwittingly, totally unprepared." (IC_12)*

The interviews consistently touched on the difficulties engendered by moving from a family home and also moving a parent into an adult child's home. In all instances, such moves created further confusion for the person already at least somewhat confused with dementia. Furthermore, generally the parent did not want to leave their own home. Whatever the relationship between the carer and the person they decided to care for, such decisions came with a great deal of anxiety and adjustment, and such a move created substantial burdens on the (usually) inexperienced carer. At this point, several carers (six out of twelve) had already learned about the possibility of a care home admission when they felt unable to cope with care, but no one amongst the interviewed carers ever considered this as a viable option. For various reasons they had decided to care for their older family member with dementia at home, perhaps due to feelings of being obliged to do so and they continued to provide care for a number of years. Therefore, it is important to understand the motivation behind such decisions. To do this, it is necessary to explore and understand what the key factors were that shaped such self-burdening decisions and the subsequent perseverance to continue to provide care at home.

4.4 Key Factors Influencing Care Decision

The decision to move a relative to a care home can be agonizing. For some the decision was made soon after the diagnosis, when the full enormity of the care burden was realised. For others, it was not the diagnosis itself, but rather a first major safety incident like a fall, that led to a hospital admission and then a subsequent move to a care home. Usually, however, for most people, care home admission was perceived as absolutely a last resort and not the main choice. Many carers could not even comprehend allowing their loved ones to be placed in a care home and would determinedly continue to carry on caring as long as possible. However, this variability in decisions about care home deserves further examination.

Two key factors were identified from the carer interviews. The first was that some families held very strong multi-generational bonds and a sense of strong elderly care values through which the younger generation would provide care for the older and spouses would remain together until death. For these carers, care was simply an accepted aspect of family life, given and received over generations. Some (seven out of twelve) of the carers recalled their earlier lives or even childhoods, when their grandparents were looked after by their parents residing at the same house; they expected the care culture to continue. As one carer observed:

> *"my grandmother lived with my mum, my grandmother had Alzheimer's too, and my mum most certainly had some ideas, she referred herself to the GP, she was having memory problem and thought I better check it out… so yes, I had to move her here with me,.. because I am the only child and my mum was living on her own." (IC_07)*

Another carer explained her multi-generational care history thus:

> *"when my grandma passed away, my dad brought my granddad to our house, and we lived with granddad, and he told us all the stories about Africa (laughter), to me that's what family is, look out for each other.. trouble is lots of my family is now gone, it's only me and my brother. My brother and his wife, came round Friday round to ours, she looked after (name), for the day, while we went fishing. She does that occasionally, which is very good of her really. Because she used to be a carer, yah, so it is very good of her that is." (IC_03)*

Such care values were grounded in a sense of filial (and familial) gratitude and obligation, nurtured over a long period of time. It was simply assumed that the child(ren) and their partners would step up to take care of a parent as necessary and would do so with love and determination. Carers who held such values extended them to their spouses, and many carers expressed views that their determination to care derived not only from their family values but also their love and gratitude towards their long-term spouses.

As one carer put it:

> *" ..I owe her so much. It's as simple as that., it is really a two-way street, we look after each other, it is not just looking after P (name), you must not get that impression. She is still doing the washing, and the rest of it. You know so, I know*

> *people do complain a lot but you have got to look at it, for the pluses, not the minus…. and that is what it's about, it is about not being selfish. You can't be selfish …. I would look after P no matter what." (IC_03)*

Carer perseverance was often presented as consisting of a 'one day at a time' principle, as the following suggests:

> *"we have been together for so long, that I just want to do all that I can do for her…as long as I can, taking one day at a time really.." (IC_02)*

Elderly carers of partners were quietly aware of not being able to continue to provide care forever, but the deep bonds and commitment towards the other influenced the determination to remain caring. It was upsetting to such carers to ever consider placing their spouse in a care home:

> *"I know it can happen, I am not thinking about it, sometimes it is taken out of your hands. Anyway, you don't have any choice of the matter. But I am not thinking about it, oh this will break my heart." (IC_08)*

Several respondents (four out of twelve) took the view that it was their duty to care for their elderly spouse, and some attempted to spin a positive outlook by comparing this with someone else who was in a worse situation than they might be, as seen in the following statement:

> *"There are lot of people far worse off than we are, I often try to tell myself.. What some other people have to do for their loved ones, some don't even recognise them, they have to put up with that. Touch wood, I am lucky, I can still look after him, I know it is going to get worse, but if I can keep coping like I am now, we are going to be all right." (IC_04)*

A sense of gratitude was prominent across carers, but also the ability to care for a loved one at a time of need provided great satisfaction to carers, despite it being a life changing adjustment for some. As one carer put it:

> *"I mean I am glad I am able to help my mum, obviously I would not do it, if I did not love my mum, so, but sometimes are better than others."* (IC_07)

Among the families where a strong multi-generational family value of care across generations existed, care appeared to be a group effort. Although one key person was primarily responsible, there were generally others who assisted if and when needed. In such contexts, to provide care was perceived as a 'success' and it was an 'achievement' to be able to care for a loved one at home. Carers who fulfilled this role not only felt a sense of achievement but also indicated that they gained some respect from others.

In addition to the family values and emotional bonding, there was another common factor which influenced the decision to continue caring at home. The financial burden of institutionalised care was a commonly stated factor, especially for older couples who were retired and had limited income and/ or savings. Even those carers whose burden of stress had led them to seek outside assistance found that the financial constraints were often too great. The costs of care played a very significant role in decisions about seeking help with care and delaying care home admission, particularly for people who would have to pay the full care cost themselves.

In addition, the costs of care were consistently cited (by nine respondents out of twelve) as the reason that carers were disinclined to seek day care, or to have a care worker to provide help with personal care at home, or to seek short-term admission for respite in a care home. For most of the interviewed retired couples, there was a great deal of uncertainty and anxiety not only about being able to afford the costs of care for the person with dementia but also for the remaining partner being able to afford to continue to live at home with half the income. When two people live on one pension, they could comfortably manage, but if one entered a care home, the household income was halved, and the remaining spouse might well not be able to cover the expenses of the home. As one of the carers stated:

> *"I have not got much of a pension at all, you know I think mine is £84/wk, so if anything happens to K, yah, I don't know where I would be living. I mean you can have £23000 each, but I think, that is going to be a struggle before long, especially if he has to go to a care home." (IC_09)*

The cost was seen as serving as a deterrent from institutionalised care:

> *"if he went to (a) nursing home, it is very expensive, you know for basic care and basic home about £400 to £700. If you wanted a good one with full works of 24 hours of nursing care, it is £1200 a week, they are probably nice with all sorts of lovely things… I don't know what we have to pay, ..but anyway, they said I could have him at home you see; although he is not very good, he is ok." (IC_04)*

Facing the need for care, some parents (three out of twelve) considered paying an adult child to move in with them, since this was much less expensive than a care home:

> *"My daughter had said if at some time things were very bad she will come, live with us and she will go home for the weekend. When we were talking about finding somewhere, she went to look at some of the care homes. She said 'Mum do you know how much it is there? It is £1000/ wk. and if it is dementia it will be more'. She said if you needed you will have to pay me, but I will come home and look after you both. So, I have that option, if it comes to that I have that option." (IC_05)*

Informal dementia caring at home is often a highly complex decision that family members make over other care alternative such as care home admission. Two major interconnected factors that contribute to this decision are the family values and the sense of duty, on the one hand, and the financial reality of paying for care, on the other. These are often stark choices; thus the decision to be an informal carer requires more attention, as follows.

4.5 Becoming a Dementia Carer

It is intriguing that few of the carer respondents actually considered themselves to be "carers," even after years of living with and caring for their loved ones. Even in the interviews, when questions referred to the respondent as a "carer," the frequent response was: *"I am not really a carer…he/she is my spouse and I am just looking after him/her." (IC-01,IC_02, IC_03, IC_05, IC_07, IC_09)* Even for the adult children who had made the decision to move the parent into their homes as the condition worsened, the term "carer" appeared either inaccurate or inappropriate. To these co-resident carers, the term itself referred to the "paid care worker" and not to themselves.

To become the informal carer of a person with dementia is a complex and progressive process that usually becomes more and more structured and demanding. Initially, the informal carer might see himself/herself "looking after" a loved one as nothing remarkable, and certainly not a "caring" type of relationship. Over time, however, as the nature of the tasks became more complex, the notion of "carer" as a unique relationship gradually became more accepted.

Those who regard themselves as carers for their loved ones followed a clear trajectory for this:

> *".. I did not see myself as a carer when it started but now I do, yes definitely, I do now.. started.. when .ahh.. at the beginning of the incontinence, well when we got there really I realise I have to look after him, he cannot do anything for himself anymore..."(IC_01)*
>
> *".. I became his carer not from the start.. probably not in the first few years, but I think probably since I have to do everything for him, bathing, shaving, washing, it's the personal care .. that is it..." (IC_08)*

Another carer said:

> *".. I think I started to think I am a carer when I realised I had to be making all those decisions. for both of us. It comes on slowly but I know very well, it is not going to get any better, it is going to get worse, I do understand that.. and I am the one who has to make every decision..." (IC_06)*

This self-perception as a carer was not related to the length of care or the number of years that an individual had had dementia. Rather, the transformation to the identity of "carer" was more determined by the type of activities such care required, such as dealing with personal care and incontinence or making all of the household decisions. This evolution to assume the identity of carer was often not conscious, but was recognized only after some reflection during the interviews. In the end, perhaps, the self-perception mattered less than the degree of assistance needed to address the various needs, as presented in the previous chapter. The increasing demands upon the informal carer, whether he/she considered himself/herself a carer or not, raises the issue of the readiness of the informal carers to take up these roles with an adequate level of knowledge, awareness, and skills.

4.6 Carer Readiness

At the point that a person is diagnosed with dementia, a series of more formal steps were undertaken, such as various assessments which are outlined in the next chapter. From the carer interviews, it appeared that none of the agencies involved, however, actually focused on an evaluation of the skills, knowledge levels, and preparedness of the potential (informal) carer for this role. The bottom line is that caregiving in dementia is a skilled task that requires specialised knowledge and skills on the part of the carer. The readiness or preparedness of individuals to provide such care simply remains unknown at this early point in the process.

Whether a family member identified themselves as a carer or simply a family member who was looking after someone they love, dementia care requires a set of skills with specialised knowledge and attitudes in order to achieve appropriate readiness for caregiving.

4.7 Carers' Knowledge, Attitudes and Skills

The level of knowledge, attitudes and skills of carers about dementia care could indicate some measure of their readiness to care for someone with dementia at home. In the absence of any available system to assess or enhance these qualities, the carers described their learning process as pretty much "learning on the job." It appeared to be up to them to acquire necessary knowledge and skills through their own effort and initiatives, from wherever they could. All carers recognised this process and accepted it as normal, and as one of the carers put it: *"I suppose you learn as you go along... "(IC_01)*

While most carers (ten respondents out of twelve) had some idea of some of the effects of dementia over time, these were all learnt from someone else, a friend, family member who lived with and /or died from the condition and who had been cared for at home or in a care home. Such independent learning efforts could be very beneficial and effective, however these are not without possible limitations of negative interpretation, reinforcing incorrect perceptions and even misinformation, because each case of dementia could be different and each person's living experience is equally likely to be unique. As a result, there was a wide range of experiences; deep understanding, misunderstanding and frustration were all evident in the interviews. Some examples of these are presented in the section(s) below.

4.7.1 Basic Communication in Dementia

A common aspect of someone living with dementia is poor short-term memory, which manifests itself in repetition and asking the same question again and again. During interviews, from a total of twelve respondents, nine provided examples of conversations they had on a regular basis with the person they cared for, and a wide disparity of responses was demonstrated in these testimonies:

> *"Her memory is terrible, but I never tell her that she has dementia, it might upset her, I just say she has got very bad memory, she is now remembering that she has a bad memory, and she would say herself voluntarily now, but it took a long time to for her to even admit that." (IC_12)*

> *" I get frustrated with her repetition, oh with silly little things, might be washing up, drying dishes and she constantly be asking do I take it here, do I take it there, because you know it did not ought to happen, but it does, she would ask – how long*

> *we have been married several times every day and so on, I get tired as well, as the day goes on.. but she knows I am here and I know she need to be reminded of different things you normally expect her to know.so there we are...” (IC_02)*
>
> *“..he changed; I have to tell him what to do now. Because he can’t think, he looks at the calendar, I put days on there, he would say - what is the day today. I would say- read the calendar, I make him do it, I make him read.., I think if I keep telling him he is not going to use his head…. we will sit there and he goes - what are we doing today.. we going out today aren’t we? I say - I don’t know, did you read the calendar, I say try, try and remember D (name)... you have got dementia, as they say if you don’t use you will lose it. Use it D try, I do sound a bit strong.. but if I pussy foot him he will be 10 times worse I think.“ (IC_11)*

4.7.2 Dealing with Sleep in Dementia

Changes in sleep patterns is another known symptom for a person living with dementia. Once again there were different levels of understanding and attitudes displayed by six out of twelve respondents during the interviews, as evidenced here:

> *“He sleeps very erratically… but sometimes he said to me, now he does not want to move him about, so I let him sleep.. he sits in there (pointing a chair) and then he sleeps a lot, he sleeps, during the day, he sleeps until lunch-time but he can’t tell the time, when he wakes up, he does not know whether it’s morning or noon.. sometimes we go to see a friend, he goes to sleep there, goes there and goes to sleep (laughter).. . when we come home, he likes to sleep a lot sit in his chair… I don’t say anything.. he probably needs it.. I have to keep an eye on him though because when he is sleeping, he goes down sometime in his sleep from the chair...” (IC_04)*
>
> *“He tries to help me with housework, but he falls asleep, he sleeps a lot, he will sleep on the chair, 9 o’clock in the morning he will be asleep, we will sit down to watch something together on TV, he is gone - will be sleeping.. (laughter).“ (IC_05)*

> *"He loves photography, he loves birds, and he can't work out how to use his camera any more, which is such a shame. Umm but all those books are around him and but he does not seem to have the interest any more, he just goes to sleep. And it is such a shame. If I take him in the car to somewhere, because he always wants me to take him out, he just go to sleep in the car, …. I understand it is quite normal, unfortunately, for me, I get very frustrated, and I feel like a bit angry…" (IC_06)*
>
> *"I struggle when he sits down and goes to sleep, it is 11 in the morning. Why would you go to sleep like that, you had 10 hours in bed, you had a little walk, you are sitting there and doing nothing, I do struggle with that." (IC_10)*

These testimonies exemplify a wide range of reactions from carers to some of the common and expected phenomena in dementia such as changes in sleeping patterns. The range of emotions extended from compassion and acceptance with a sense of humour, through to frustration and anger, which indicates that some carers may have a profound lack of understanding or misunderstanding of the condition.

4.7.3 Misunderstanding Leading to Frustration

Misunderstanding of behavioural patterns associated with dementia can create emotional stress and affect the well-being of both the carer and the person with dementia. Almost half (five out of twelve) of the carers reported being able to accept deviations from "normal" or "expected" behaviour (*IC_01, IC_03, IC_04, IC07, IC_12)*, while others struggled to understand why their loved one acted in such a way. Dementia often presents no obvious signs of physical change, and the motives behind behavioural aberrations could be misinterpreted as "intentional." Such misunderstanding of the condition could therefore lead to increasing frustration. In the words of one carer:

> *"he does not listen to me, things that frustrate most is I would give him some advice for his own benefits, but he would not do it. He won't take it. He would just carry on*

> *doing what he is doing. .. it is difficult to understand, why he can't remember what I am saying..." (IC_06)*

Or as another participant stated:

> *"I think he just wants to wind me up, in the morning, I think the hour is going to go quickly. And it is not there, and in the lunch time, he would sleep, he sleeps different hour. And then it would be getting up to lunchtime." (IC_09)*

Some carers (three out of twelve) showed great difficulties in accepting, let alone dealing with, some of the dementia symptoms. One of the carers indicated:

> *"It is very hard for me to think he has got dementia, I want to think he is just putting it on, but I know he is not, because he has got brain scan to prove it … but I can't believe he can't remember little day to day things…. that is where it gets hard for me because he don't realise, he got dementia…" (IC_11)*

Another carer compared people with dementia and public perceptions of short-term memory problems:

> *"thing about the dementia, is that, people think they are stupid, they are not. No way.. her short-term memory ain't good, but she can still remember our first phone number we ever had, I could not remember it. ……So you see, what I am saying. she remembers our first post code. Her long-term memory is still ok, it's not like my brother and his wife, she does not sometimes know where she is, that would be very hurtful." (IC_03)*

This widespread spectrum of awareness between carers demonstrates that being 'willing' to care for loved ones, does not always ensure being 'able' to care for them. This is more evident as the condition worsens and in situations where the person with dementia shows signs of aggression, poor hygiene and incontinence as well as poor memory and erratic sleeping patterns.

4.7.4 Knowledge Vs Know-How

Family carers who have good levels of understanding of dementia are more likely to accept the most common features that are expected. Among the carers interviewed, some (three out of twelves) were retired health and social care professionals and had knowledge about dementia. However, their knowledge did not seem to confer any advantages in terms of 'know-how' and practical skills in dealing with dementia, at this phase in their lives. Carer knowledge about some of the common characteristics of dementia was evident, such as in the case of hallucinations or delusions, but often participants said that they did not know how best to deal with the person when displaying these. One carer expressed frustration from being unsure how best to deal with episodes of delusional behaviour and what to do:

> *"She actually said that the other day. Oh, birds song it is so peaceful, but it is all the chat, chat, chat, I get very worn down by it. Because it is very innocuous chat as well you know. Some of it is completely… the other day it was oh look there is a dog up on the tree. I said there is no dog up on the tree, nothing there.. you know, probably totally opposite to say than what I should have said. I don't know, maybe I should have said oh how nice, that is then or something. The next day it was tiger, and sheep she sees on the tree. Or she would see some sort of object. That sort of things she sees all sort of funny things that I don't see, and I don't know what to say..." (IC_12)*

Carers repeatedly discussed (ten respondents out of twelve) how they felt challenged simply because they didn't know how to deal with emotional outbursts, suspicion, hyperactivity, and managing continence. They reported to have known that these challenging aspects of daily life might be attributed to dementia, but they were helpless in knowing how to deal with such situations. Service providers carried out various assessments of informal carers, but they seldom assessed what carers did or did not know and what they could or could not do in relation to dementia care. Thus, the following section addresses how formal service providers perceived and assessed informal dementia care.

4.8 Service Provider Accounts

Interviews with service providers offered some insights into the complex relationships between family carers and care recipients, the skill levels of informal carers, and strategies to provide assistance to the informal carer. Service providers sometimes faced particular challenges from the informal carers that neither recognised the need for, nor accepted professional help in dealing with a loved one. For some family carers, receiving help from a formal service provider, apart from health care, was almost a sign of defeat, and service providers initial encounters with carers were not always positive. Service providers were at times given a strong message that carers were doing their best as they always had done for their loved ones, and that should be enough without any need for external assistance.

Given that informal carers often did not see themselves as 'carers', the service providers' first challenge was often about forming (or transforming) a family member's perception of their role and to assume an important role in helping to establish such a carer identity:

> *"... being carers, it is really an alien concept to some, because they often caring for years but in carer's mind, it might be they are their spouse, their siblings, family member, and it is part of a normal relationship. And it has not realised or tipped to anything else. Just part of an existing relationship. For some, it is just to do with 'till death do us apart', and It has not gone beyond that.. and so sometimes we have to help them to identify themselves that they are actually 'carers'. (SP_01)*

Interviewed professionals (seven out of thirteen) consistently noted knowledge gaps in how informal carers understood their role in dementia care; and acknowledged that some found professional intervention to be an intrusion on their privacy. On the other hand, these professionals perceived certain opportunities with informal care. In an overall care strategy, the informal carer provided access to information on behalf of the person living with dementia. The professional was able to introduce certain interventions such as assistive technology equipment that minimised safety risks in the homes where an informal carer was present. Some professionals appreciated the invaluable role that informal carers play and talked positively of being able to support informal carers in their roles. As one of the service providers explained:

> *"Someone with dementia - can have quality and longevity of life with the right care, and the role of family carers is enormous, ... carers do things for the right motives, but not always with right understanding .. I worked with my colleague on a case, a lady has dementia with Parkinson's, and husband is caring for her. She lost a lot of communication.. she was allocated a pressure mat to put on the chair to sit on, she had them for pressure relief, and I think possibly the husband was having a few memory issues too, having been bombarded with piles of information, and he did not fully understand, he comprehended that he was making her comfortable, by putting her on the special seating, but his comprehension of it was more comfortable for her to use the cushion underneath. In the end it almost had to come to a point where it was potential safeguarding, because he insisted on going down a particular road, anyway, so me and my colleague went together.. We took him to one side and started a conversation, which then my colleague took further, she started to explain, with pictures, how pressure ulcers form and how you avoid it and how position is important, just basic facts which he needed the time to understand. Gave him some pics that backed what she was saying, helped his memory, and ultimately he is (aware) of the issue, but it took us some time, several visits, time consuming, but it was worth it..." (SP_08)*

While a small number of respondents (two out of thirteen) were able to invest time and effort to successfully impart important knowledge and skills to the carers, this was not widespread due to reported time constraints and other competing priorities. Professionals acknowledged the potentially harmful impact of knowledge gaps on the wellbeing of the person with dementia cared for at home. In some such situations, the more common practice was to make a safeguarding referral, which could even result in the person with dementia being moved to a care home. The alternative to such a referral was to improve the flow and appropriateness of information to the informal carer. Such information support was best delivered over time and not only at the time of diagnosis or crisis. The appropriate delivery of information took into account the educational level of the carer and the ability to absorb information through different channels.

4.9 Carer Coping Strategies

Despite being a diverse group of predominantly older people from different situations and backgrounds, the informal care community shared common sets of coping strategies. Such strategies helped them to learn as they go, to stay calm and patient, to take short respite breaks, and to call upon wider network supports when necessary.

4.9.1 Calm and Patience

Many carers (six out of twelve) adopted patience as a key strategy for interacting with persons with dementia. A strong level of patience and calm was a common response not only to the daily rigours of care but also in managing unusually difficult times. The person with dementia could become increasingly reluctant to perform common tasks as these became more difficult for them to undertake. There might also be episodic events of emotional outbursts, aggression, and insistent repetition that tested the carer's ability to keep calm and patient:

> *"..it's the constant asking…with her medication she has a same routine, we have a dose-box for 24 hours and she will bring those out and in the evening for the next 24 hours and she asks me, and I say you need one of those, and she has to ask sometimes, which one is it? But I said you come outside on to the next one and taken out before, that sort of thing, with anything like that you need a lot of patience, and you know, try not to rush, I try to keep calm, sometimes it is very difficult, in that respect, with my patience she does it quite well."* (IC_02)

Other provider participants asserted:

> *"There is only one word I could suggest, the carers got to have and that is 'patience'. You just accept, anything and everything as it comes and do what you can…" (IC_04)*

> *"Most important thing is about being patient, keeping patient and carrying on caring is heroic…" (IC_03)*

> *"Main thing is if I stay calm, patient, and don't get angry, don't get annoyed, it is much better, if I get angry he gets worse..." (IC_10)*

Carers considered patience to be the most important aspect of caring for a loved one who is living with dementia, and they sometimes observed that it is a quality lacking in paid care workers. They often cited the difficulties in adjusting to an increasingly slower pace that their loved ones were comfortable with and discussed how the demands of patience can lead to emotional stress and breakdown:

> *"If I am watching him, he says, I know you are watching me, I know it takes a lot of adjusting to not be criticising, not questioning things. I know, I must not confront, must not speak in a certain way, it is really hard though, it's my patience level. I think, I mean 4 years of this and sometimes it is awful and sometimes I go really silent. and he does not want to talk to me at all, he is in denial, sometimes he is so unreasonable, I say I don't want to be like that, don't want to push you away, my head is full of frustration and anger and things like that. sometimes I can't keep my patience, I get emotional (quiet.. and crying)." (IC_10)*

When the limits of carers' patience are exceeded, it was common for them to employ other forms of coping strategies, such as calling on an extended support network.

4.9.2 Extended Support Networks

Access to an extended support network is another major coping mechanism for carers. The elderly carer often relies upon adult children to carry out some practical tasks to run the household, including such tasks as changing light bulbs, tending the garden, and checking paperwork. The use of an extended family and friends network often went beyond household work. It was indeed part of the wider caring strategy, without which a single older carer might be unable to continue to provide care at home.

As stated above, living arrangements often changed after a diagnosis, as an older couple anticipated and required help and support from adult children or other family members living nearby. The interviews revealed significant evidence of such support provided by extended family members on a regular basis, and the carers repeatedly acknowledged the importance of this help. Carers discussed the value of this support as follows:

> *“..I have been supported by my family, my children, my sons, and supported by the neighbour. I can’t complain .. I am very lucky…(laughter)” (IC_01)*
>
> *“So, I think they (sons) are my support network. And my sons actually are very good at listening and sympathising, and actually good at practical help too.” (IC_07)*
>
> *“I have got a boy lives round the corner, my son is round the corner, and you know I have got a backup, if I need it…If I go fishing or something he is going to cover for us, he is going to come round and sit with his mum for a few hours, I won’t leave her on her own… so I suppose I am too careful, yah, it is just one of those things, I treasure her so much, that I can’t put her at risk, as simple as that, I am not saying she would be at risk, but I just ring up my son he comes round and sits with his Mum for a couple of hours.” (IC_03)*
>
> *“Having my family around makes a difference, my daughter lives in T (name of the place), on Sundays, she takes us up to T and gives us a lovely roast dinner and it is so nice, they pick us up and bring us back.” (IC_04)*

Beyond everyday household management, the extended family could step in in the case of illness or other forms of crisis. One carer stated that they had a formal social care service plan in place in case of any sudden health urgencies which might affect the elderly carer and the plan was to receive some urgent care for the person with dementia. But when the carer fell ill, that plan failed to work and there was no formal support available at short notice. Here, the family played a role:

> *“ My neighbour called my son, he came quickly and stayed overnight that night and on the next day my other son from (name of the place) came over and he stayed with his mother for the next two days and nights and until I came out of the hospital and came back home.” (IC_02)*

A number of crises might result from a health episode, for example, when the person with dementia became agitated, which may often be associated with an episode of UTI or delirium. In these instances, carers could experience great stress and resort to extended family members:

> *“I think he will hurt himself when he is like that, he lifted the table up when he was in a mood, I said be careful!!! But could not stop him, everything was going through the wall, that is when I called my son, I think he realised that he is doing it but he can’t stop it. It is really very hard, I think people don’t really understand, the full contents of when you go further down the journey and how it affects individuals, no, I could not manage it without my son...” (IC_08)*

In addition to practical assistance, others mentioned how their adult children provided emotional support at times of stress and anxiety. The larger family could also make decisions about the feasibility of care at home once the person with dementia started to show signs of aggression. Carers referred to the preparation of contingency plans in which adult children would move into the parents’ home if care was needed.

> *“My son said ‘oh mum!!’ please do something about it now, please don’t let it get any worse than it is. He is petrified that something will happen to me.” (IC_06)*

Almost all (eleven out of twelve) carers reported that they called upon family members and friends from time to time to take over some of the caring role so that the main carer could take a break. Some families considered use of a care home for short term respite, but on balance decided to use family and friends for such occasional short respite care instead of care home respite. As one carer explained:

> *"we did look for respite care in (name of the place) called (name)… just to see what it would be like to have her there for a week or two. The non-secure side of the home was perfectly reasonable, people looked slightly infirm but perfectly okay one could have enjoyed a conversation with them, and then we went to see the secure side, which was people who are really very far advanced, with Alzheimer, it was locked, door outwards were disguised, and so actually to go into a situation like that I don't think my (relation) would like that a bit. So we have tried to bring in our children to give us respite, organise other sort of part time respite, that kind of thing, and friends. Now this weekend, we go to (name of the place), and a friend will be helping out." (IC_06)*

The interviews showed that carers looked to extended family and friends for a variety of forms of assistance including respite from the burden of everyday care. However, other coping strategies included the search for respite care from other sources. Primarily, among these were the formal institutions that offer different types of respite care.

4.9.3 Respite Care

Respite care comes in many forms, ranging from a break of several hours provided by family members, to a day care centre that received a person with dementia during the day to a short term stay in a care home. Another respite option comes from dementia café provision, which is open to both the carer and the person with dementia.

4.9.3.1 Respite Provision in Day Care

Service providers noted that, in the past, a referral to a day care centre was common for older people when social services funding levels permitted such care. Day care is meant to provide a chance for social interaction and a break from the grinding routine of dementia care. Older people can have their hair done, have lunch, and enjoy activities with friends. A small number of day care centres are dementia friendly and accept persons living with dementia. However, in more recent years, day care facilities were decreasingly available to such lonely elderly people. Instead of combating loneliness centres had now become more of a 'holding facility' for people with high levels of health and care needs, where there was no alternative and the carer was reaching the breaking point.

According to some (four out of thirteen) of the service providers interviewed, at present, sometimes out of desperation, social workers placed people with advanced dementia in day care centres which were not designed for them. Such placement was common where social services would pay for the day care placement and were largely used at the point of carer breakdown. For many carers sending the loved ones to a day care centre on the basis of a specific one or two days per week was part of their planned care coping mechanism so they could have some time to themselves and carry out some essential household (or other) tasks, and the family often paid for the day care themselves.

While day care facilities effectively provided respite to fatigued carers, the cost of such a service was often seen as prohibitive. Day care centres tended to be managed by voluntary sector organisations, private owners, or social enterprise entities, which are usually the business arms of the local authority's social services.

The decline in social services referrals due to lack of social care resources had led to increased costs of placements at such facilities. One carer framed the cost issue as follows:

> *"On Mondays, he will go to the day care centre, so I can go out, that gives me a bit of a break, that is my day, I meet some friends and go to city and do other things, that I would not normally do .. but it is expensive, we pay £65 per day at the day centre. And he is picked up and I pay £10 for that one way. and then I have to come and pick him up. £75 for the day, when you think about it, it's very expensive, I know he gets a meal there, included, but occasionally he started to say it was horrible, and lately he has not always come out happier than he had gone..." (IC_08)*

Another carer pointed out the variability in both quality of and satisfaction about the day care experience for a person with dementia:

> *"In the day care, I think some days she has more enjoyable times than others, she finds people there are 'doolally', they are not quite right, some of them are ill, so she says.. it is a dementia special day centre, but I think that, there is so much misunderstanding of people with dementia, that when you get a whole lot of people with dementia together, they are unlikely to all get on well (laughter), .. but she gets on very well with the helpers, but her fellow attendees the other people, she finds them either 'doolally', or sharp or catty or something, not too keen all the time.. but she is definitely going because I could not cope with her otherwise, if I had it every day, a full burden of 24/7 care..." (IC_07)*

Another carer explained the challenges in finding a suitable day care facility:

> *"So I started with a day centre for her (PWD) one day a week. But after about 3 /4 months, suddenly, I had a phone call, which I missed and found a message on the answer machine, said 'hello we just wanted to inform you that we do not want you to bring your (relationship) here again', that is absolutely staggering, I was shocked, how could someone just leave the message like that, wouldn't you just try and ring again and speak face to face. So eventually I rang them back, and said what is going on? She said, 'because there was an incident' I said what incident!?, she (PWD) is not aggressive in the slightest! And it turned out that she was 'wandering'.. I said well she has dementia, you know she has dementia, they were not equipped for it though they say they are, any way that was the end of that day care …. but it was a blessing*

> *in the end, I found another (name), and the minute we walked in, I could tell my (relation) loved the environment, you could see they got it in 1940s/ 50s style, they got it all sorts of reminiscence stuff, she just liked the atmosphere there and she for the first time absolutely loved it there... sometime comes home with loaf of bread that they baked there (laughter). two days a week, I take her there, she loves it... I don't know what I would have done without it..." (IC_12)*

While respite in the form of day care provides a varied experience, especially for people living with dementia, the cost is also increasing. As fewer people benefit from social services referrals, assessments, and payments, those who do pay for the service had seen an increase in costs. In some day care centres where there was a waiting list of people wanting to attend with social services referrals and finances, there were now increasingly empty places that they cannot fill. In addition, such higher costs deter others who would pay for themselves, and in turn, the number of day care facilities has decreased to a point where many have closed. In parallel to this, dementia café provision has increasingly filled the short-term day care respite gap.

4.9.3.2 Respite Provision via Dementia Cafés

While quality and affordability are two major issues for carers in utilising day care centres, dementia café provision is usually free and can be accessed without any formal referral or professional assessments. A dementia café is a community organisation run by volunteers, the majority of whom are previously dementia carers themselves and who want to help others. These volunteers tend to be sensitive and skilled in communicating with people with dementia. The dementia café offers numerous activities for carers as well as people with dementia. Carers normally attend the café (also known as the club) together with the person they care for, and often a volunteer will engage the person with dementia in some leisure activity, leaving the carer the time and space to do something like dancing, sports, or a simple chat with others. In this way, carers have the opportunity to draw upon each other's experience and support. Unlike day care centres, 'affordability' is not an issue for access to the dementia café, however, availability is a major issue for many people, as they are not available everywhere.

Where a dementia café was accessible to a carer, it constituted an important coping mechanism in providing short term respite. Carers considered it a strong source of emotional support and greatly beneficial as seen in this statement:

> *“We look forward to go to the club (dementia café) on Mondays and Fridays, it is brilliant, lovely volunteers, always someone to talk to, play games with good laugh, very lucky to have it.” (IC_03)*

All the carers who attended dementia cafés remarked on the value of the café as a source of respite. With volunteers caring for their loved ones, the carers also enjoyed their time there. While the café provides a few hours of respite once or twice a week, temporary care home stays are also available for temporary respites that require a longer period, such as a week or more.

4.9.3.3 Respite in Care Home

Short term respite care in a care home for periods of one or two weeks was perceived to be one of the most important coping strategies by service providers and carers alike. The decision about care home respite was usually associated with signs of struggling with the burden of care. Normally, admission to a care home is preceded by an assessment of whether the person cared for by the carers is eligible for assistance with payments for a care place from social services; otherwise, the costs are borne by the carers themselves. Thus, carers with financial means were able to use respite regularly, but for those of modest income, the service was used only in the event of total desperation.

Such financial constraints were a source of great anxiety as seen in this testimony:

> *"Respite care is very expensive, and we have to pay £800/wk. Some of them are £1200/wk, as long as our saving lasts, other one we used was £600/ wk, but it was not, very nice. You know it was what you would expect from old people's home, smelt rank, this is a bit better, it is one of those cases where you get what you pay for…but even if he is in a care home, for respite I am not out of duty, I had a call from the care home - he tried to climb out the fence, well he could not get out it is totally secured, but he was trying to get out, to go home." (IC_09)*

Another carer expressed the ambiguous feelings about using care home respite:

> *"…it is you are in a constant dilemma, the honest thing is, and when she is sent to a respite care home for a week, I do nothing but think about her, all the time (laughter). ..it is like leaving your child at the school gate. It's hard for the first few days until that becomes a routine, even when she is in the respite, for a week, it is harder to get her back into her routine here. She is like she used to be, always going different and not understanding where she is. Once she has a routine, she is calmer again. I think that is probably rooted it. I think in dementia, that is seems to be the thing." (IC_12)*

Although short term respite care in a care home is one of the common coping mechanisms provided by services and utilized by family carers (eight respondents out of twelve), it can be rife with difficulties. There is first the financial burden, which can be constraining, but this option is further complicated in identifying which care home will accept a person with a particular level of dementia. Some care homes, based on their own assessments, simply will not accept someone who is potentially "*too difficult" (IC_06, IC_07, IC_11)* or their *"needs were too complex" (IC_09)*, or if they might be *"too destructive to other residents" (IC_07)*. There are numerous grounds on which a person with a moderate to severe level of dementia might not be accepted for short term respite care provision in a care home.

Even after a loved one was accepted and went to stay in a care home for respite, at times there could be difficulties in keeping the person safe. People with dementia were reported to have been very anxious in their unfamiliar surroundings and attempted to return home by all kind of means, including climbing fences, as seen in the example above. The care home usually informed carers about such incidents, which of course can affect their intended rest. It was reported as quite common for the person with dementia to reject the temporary respite care accommodation and to seek to return home by any means possible. The anxiety on the part of the loved one resulted in little rest for the carer. Moreover, when a person with dementia returned home after a temporary respite, he/she could struggle to readjust back, which elevated levels of carer stress. Nevertheless, interviewed professionals across the board highlighted respite care as being the single most important element of the available options to boost coping strategies for carers.

4.9.3.4 Service Providers' Accounts of Respite

The very meaning of respite differed among people. Some (two out of twelve respondents) interpreted respite as having a good night's sleep; others (four out of twelve respondents) to having a complete break from caring for a week or two. All professional service providers strongly encouraged respite as an important element of long-term care provision. A refreshing respite period was perceived as the key to continued care at home, as explained by one professional:

> *".. nearly everybody wants to continuing caring for their loved ones, that is a given I think, people don't like it, it is horrible having to place anybody, in residential care or nursing care. you know, bearing in mind, continuing to care for somebody you love, your husband, or your wife, your partner is the fundamental thing, system has to support that, but it all depends upon the availability of good regular respite care for a few days ... things like that, which support somebody keeping at home. Because everybody wants to keep, people I work with, nearly everybody wants to keep their husband or wife at home..." (SP_03).*

Another stated:

> *"…respite care, people tell me is very, very difficult to get. But often that can make a huge difference to family carers, the difference between being able to continue care at home or not, simple as that." (SP_09)*

Service providers also reported that they sometimes struggled to balance the well-being of the carer with that of the person with dementia. As one respondent put it:

> *"It is very difficult at times, …sometimes a carer would find it difficult to understand; for example, a carer would say 'I am desperate for a break, I really need a respite', we all understand that. However, if the person they are caring for with dementia still have the capacity and says I am not going anywhere, there is nothing we can do. The carers obviously find it very difficult to understand, no one can force that issue…. For somebody if they don't want to go, they don't want to go, but maybe, you could persuade the person with dementia for someone to live in the house, while their carer went away. If they gradually got introduced to them, I think that is the major burn-out for most, most of the carers I support that is the lack of regular and proper and sensible breaks, meaningful breaks from it, so even a day a week off, something like that. To give that carer, because if that carer gets burn out, they get exhausted they get angry, that is where it all starts to break down and they start to resent their loved one, and not everyone, by any means, but it can happen and it does happen quite regularly. And it happens regularly with dementia." (SP_02)*

The alternative—where the person with dementia stayed at home with appropriate support arrangements, while their carers go away—is a costly provision. As service providers repeatedly stated, *"... it's down to money" (SP_02, SP_04, SP_06, SP_13).* Four service providers out of a total thirteen also expressed frustration with apparent inequalities in health care access within dementia services by providing examples and comparing the cost of respite care in the case of dementia with other major diseases, as this example shows:

> *"Someone with cancer gets respite at the (name) hospice for example, it is medical, so they don't have to pay, but the next person up on the street go to respite go to a residential care home with severe dementia, they will have to pay. For the same respite. It just depends on the circumstance or the condition, how medical one person is and how un-medical the other person." (SP_01)*

Access to respite was also frequently highlighted as a major issue, especially considering the impact of the cost of such care:

> *"Caring for someone with dementia is a 24/7 job, and respite is the biggest issue, at least to the people I work with. Social workers are under pressure, so for somebody who just had a diagnosis, it can take 6/8/10 weeks or even longer for a social workers assessment for a respite care. I get frustrated when I am trying to help someone or doing something on behalf on somebody else, I think every care package, if it is a responsive one, must have respite in it where someone with dementia is concerned." (SP_05)*

Balancing the interests and welfare of carers and the person they cared for was a constant difficulty, especially in situations of dementia, because of the levels and intensity of care provided. Often, only by having regular respite were carers able to carry on, and the most common form of respite available was a 1-2 week stay at a care home for the loved one while the carer took a break. But this option is not without disadvantages, which raises the question of its benefit. One service provider expressed frustration as follows:

> *"It is even frustrating for us when someone says I need a break, which is understandable, and the person with dementia going into a respite, it is frustrating for us, because when people coming back after a few days away, they have always changed, but not for the better but for the worse, I suppose we don't know what goes on in the different care homes, I don't want to say that they are not very good, everyone is going to be slightly different. Some better than others. So it may well be, some people get good care some don't. But the main problem is that the person with*

> *dementia, that at least has short memory problems their familiarity of being at home and sort of know where things are, know where the toilet is, gets confused, coming back home, they are much worse than they went to respite.. it is frustrating." (SP_11)*

Nearly half (six out of thirteen) of the service provider interviews revealed that care home respite could aggravate the disorientation and confusion of the person living with dementia. As the person moved from their familiar surroundings at home to the unfamiliar care home environment, individuals could find themselves confused by not knowing where things are and even forget where things were when they returned home after respite. Such a disruption in routine might subsequently lead to a permanent care home admission, ironically defeating the very purpose of the respite care to be able to continue care at home. One service provider observed:

> *"Quite often someone will go into respite for a while, and then come back, it is clearly sad, and we see so much of it… so people going into respite and that is always a trigger, and they will come back and is harder, for them and for the carer, I suppose to take care at home. So that makes the family carer think maybe I should be looking for residential care now for good..." (SP_06)*

The carer and service provider interviews covered the range of diverse meanings and consequences associated with respite care. While respite remains the most significant and critical coping mechanism for carers, it appears to have unintended negative consequences for the person with dementia. Unfamiliarity and confusion in the person with dementia could lead to other difficulties, such as aggression, incontinence due to simply not being able to find the toilet, and further stress. In the absence of any form of dementia care education for family carers, respite could exacerbate an already fragile care arrangement, resulting in a subsequent total breakdown of care at home for the person and consequent admission into residential (or nursing) home care.

4.10 Value of Informal Carer Education

Both carers and service providers discussed the need for informal carer education on dementia care, which currently is extremely limited. Well-intended informal carers can fall short in their care efforts simply because they do not know how to undertake certain aspects, or specific tasks of dementia care. They make efforts to learn by simply carrying out the caring and learning from other carers wherever possible I order to fill the know-how gaps. To improve dementia care in the community, several informal carers suggested *“training”, “education really” (IC_04, IC_07, IC_12)* also indicating the need for appropriate training at the right times. Such access could not only enhance empathy and understanding about living with dementia, but also provide the day-to-day skills that carers could then utilise to improve their caregiving efforts.

Six professionals (from the total of thirteen) emphasised that advising informal carers was not part of regular care packages or planned interventions, thus it was hard to find the opportunity to do so. Some of them (four of the sample of thirteen) felt they did not have enough training themselves to tell carers how to deal with issues like aggression or delirium. They consistently stated that the support packages they could offer to carers were somewhat limited. While it might focus on finding financial resources from accessing carer’s allowance and so forth, they did not focus on finding out about the extent of the carers’ knowledge and skills necessary to provide dementia care at home. Yet with appropriate levels of knowledge and skills at least carers would feel confident to deal with day-to-day issues and challenges in caring for someone with dementia. As one of the service providers stated:

> *“People don’t need lot of resources, people need information, they need advice, they need to understand, need to be educated about their condition. …. There is no other disease process… terminal disease process, where we would diagnose someone and then do no follow ups, that is exactly what we do with people with dementia, it is like oh yes, you have got dementia and oh yes, it is over to you, to get on with the it, because you are the carer...” (SP_01)*

4.11 Chapter Summary

Informal dementia carers are a heterogeneous group of individuals that come from widely diverse socio-economic and cultural backgrounds. In the study sample, apart from being mostly older and retired, spouses most frequently assumed the role of a carer for a partner with dementia after a diagnosis was made. After the shock of a diagnosis, families realised the necessity of a readjustment of lifelong arrangements in care. Elderly spouses unassumingly found they had to take up additional responsibilities for running the household and looking after their partners. They sometimes felt compelled to move closer to extended family members where some additional help and support could help maintain the continuation of care at home for the loved one with dementia.

Key factors that influenced care decisions included intergenerational family values that carried expectations of care for close family members. Additionally, there are financial factors, which make institutional care impossible for some to afford. Although for some people caring for a family member was a regular part of family life, becoming a carer carried complex meanings and required a change in self-identity which emerges over time in the 'heat of battle' as it were. Formal service-providing professionals sometimes played a part in helping to form this identity in carers.

Becoming a carer does not imply a readiness to care and even the amount of time someone is cared for does not necessarily mean that a carer is 'ready' or prepared to care. There is often deep misunderstanding which manifests itself as frustration and depression in both carers and their loved ones, as they acutely realise that willingness does not always equate to ability. To continue to provide care, carers resorted to a number of coping strategies, such as patience, extended family support networks, and various forms of respite.

Respite care, one of the most common forms of support available for carers, is not without its own challenges. For example, the use of a care home placement for a person with dementia to provide a break for the carer, can deepen an already confused state of mind and undermine the person's ability to maintain a routine. Unintended consequences may become evident, with subsequent care home admission almost inevitable. Throughout the whole caring journey there are few efforts to upskill carers, although both carers and service providers considered dementia education to be an important aspect, which could make a huge difference in terms of the quality and length of care arrangements and provision at home.

4.12 Conclusion

This chapter has presented data about informal carers of dementia. For the most part, participants were fully committed and willing carers who showed deep love for and commitment. They continued to care at home as long as possible by drawing on help from extended support networks. However, the lack of skills and know-how affects the ability to continue to provide dementia care at home, and there was no systematic support available to allow carers to obtain these skills. What specifically constitutes care at home during the different stages of dementia is the focus of the next chapter.

Chapter Five: Dementia Care Domains

5.0 Introduction

Although some aspects of dementia care in institutional settings have been explored in previous research, dementia care at home is yet to be fully understood. This chapter uses information from qualitative in-depth interviews with twelve informal carers and thirteen dementia service providers to explore the nature of dementia care at home.

Overall, six interconnected domains of dementia care were identified from the qualitative interview data. In their entirety, these domains focus on the provision for the care needs for someone with dementia cohabiting with an informal carer at home. Four domains address different needs of the person whilst they are in a declining state due to the progression of dementia, one domain identifies the specific requirements to sustain the household, and the sixth domain describes the coordination and integration of formal and informal care arrangements. For analytical purposes, these domains are treated individually as if they were separate and independent; however, they are equally important and interconnected. A failure to achieve goals in any one of these domains could compromise the success of the others, a kind of domino effect. Successful management of all six care domains holds the key to sustain care at home, and informal carers are the linchpin for this type of care arrangement.

5.1 Domain One: Attending to Nutritional and Hydration Needs

5.1.1 Carer Accounts

5.1.1.1 Food Preparation

One of the most commonly experienced tasks for carers as reported by all twelve respondents is the preparation of meals and drinks. Some participants stated that they always had been involved in food preparation and continued to do so; others, regardless of their gender, only started to do this after their partners were diagnosed with dementia. In one case, a husband had started to cook and carry out housework when his wife was diagnosed with breast cancer a few years earlier, then continued to do this as his wife developed dementia. There were also homes in which the person with dementia previously did most of the cooking and food preparation and still attempted to carry out such activities; this could be a source of safety concerns for other family members. As one respondent described:

> *"… so I put some soup on a pan to warm and I said, you put the kettle on and we will have a cup of tea, when I came back minutes later to the kitchen she has put the soup from the pan into the kettle…. Another time she put raw bacon on the toast and was just about to eat.. So these days there is no raw meat in the fridge.. so if she helped herself to anything in the fridge at least it cannot do her any harm… when I leave her alone I make sure everything is turned off from the wall. Hob (cooker) is switched off, chopping boards are out of her sight, she complains, cooker does not work, well of course it does not because I turned it off for her safety..." (IC_07).*

Further, other carers reported that the person with dementia was unable to make *'even a cup of tea'* for, himself or herself although he/she had done it all his/her life *(IC_12, IC_02, IC_09)*. The person could not do anything *'without being disruptive',* having a tendency to '*just wander off in the middle of it', 'do something else'* or '*simply forget' (IC_12, IC_03, IC_07, IC_05) .*

Three respondent carers out of twelve who had to learn how to prepare food and drink for the first time tended to adopt strategies that could provide a regular and reasonable amount of food and drink without too much of a time burden. They bought food differently, relying on frozen meals, batch cooking, easy ready-made sauces, tinned fruit, and so forth. As one of the carers, a wife, put it:

"..well he was always the cook, and I never did anything, so what I do now is, I get frozen meals, they can be a little bit.. (makes gesture), you know, they are not very nice, but they are all right." (IC_04)

It was clear from the interviews with carers that they were able to assume the task of food preparation for the first time or adapt to the new situation by ensuring that certain safety measures were in place. Food preparation, however, is only one component in meeting nutritional needs. It is also necessary to assure proper and sufficient food consumption.

5.1.1.2 Food Consumption

The interviews with carers, eight respondents out of twelve emphasized the difficulties around food consumption experienced by people with dementia. Carers tended to eat together with the person needing assistance, but frustration emerged from a range of situations. For example, some care recipients did not want to get up for breakfast or eat when planned; some would sit in front of the food without eating, unless intermittently reminded to do so. A commonly reported aspect mentioned was that the person '*got stubborn*', or '*got more stubborn',* or *'won't listen'* to any suggestions regarding eating times *(IC_04, IC-09, IC_10, IC-11)*. In one case, the person would insist that he had eaten when he had not, leading to *'an argument sometimes' (IC-11)*. The interviews showed that carers adopted a range of strategies to manage any mealtime issues, from '*being regimental about when and what we eat' (IC_02)* to an acceptance of "*just go with it, when he is ready*" *(IC_10)*.

Another consumption issue experienced was the ability to use cutlery appropriately. How carers laid out knives and forks sometimes caused confusion for the person with dementia, and it could take a long time to work out what to do with which utensil and also ensure that food was cut up into small bite-sized portions. As one 75- year- old female spouse said:

> *"I cut his food up now, and don't put out the knife anymore, because otherwise he either tries to eat with his knife or chases food out of the plate with it. If I put something on his spoon, he will say 'I don't need feeding!', he will feed himself… he does not want help, gets cross... he messes about for some time… but he does eat his food eventually.." (IC_09)*

Or, from another:

> *".. I sometimes have to cut his food up for him (husband), because if it is a piece of meat or something, he can't seem to cut it anymore; he complains the knives aren't sharp enough. But actually they are fine… so I cut his meat up for him." (IC_06)*

Carers also mentioned difficulties with *'swallowing problems'*, '*regurgitation issues*', being '*sick while eating due to difficulties of swallowing' (IC_05, IC_06, IC_01).*

5.1.1.3 Social and Environmental Aspects of Food Consumption

During the interview responses, it became apparent the environment where the food is consumed is of critical significance, as demonstrated in two ways. Seven carers out of twelve talked of the value of meals together with friends and family as a tool for social interaction and to combat social isolation. The importance of sharing meals and observing a special meal like lunches on Sundays was often cited. Such opportunities often diminished, however, as the dementia became worse, and carers decided not to accept invitations from family or friends, often from a sense of embarrassment: '*there is no conversation'*, '*feel everyone is looking at him with pity and unsure about what to say*' *(IC-01, IC_10)*. One carer stopped going out to eat altogether following an incident where her husband *'brought up his food, everyone was looking, it was so embarrassing' (IC_09)*. The decision to stop eating with others intensified the sense of social isolation.

The second environmental factor is the significance of where the person with dementia consumes his/her food. In unfamiliar surroundings outside the home, such as in a hospital, people with dementia can have difficulty achieving nutritional and hydration needs because of timing regimens and lack of individual assistance. Hospitals have made an effort to become dementia friendly and to provide assistance with food, but it is often difficult without a carer present. One wife spoke of her husband's reduced food intake after he was hospitalized following a fall and broken hip:

> *".. in the hospital, he was losing weight fast, I asked if he was eating, one of the staff said he was refusing food …. While I was with him, someone came around with a*

> *drink cart and offered him a drink, he said he did not want anything.. . I asked afterwards why didn't he want a cup of tea or something, and he said he did not have his purse with him to pay for anything…. … you can't expect him to take food or drink without paying for it first, so he is not eating because he can't pay, I did not know whether to laugh or cry .. so he kept asking me ' how much is it costing? ' how is our pot of money doing? Have you spent everything yet, this place (hospital) must be costing a lot? … he was hallucinating, he does not know why he was there (in hospital)..'' (IC_04)*

This example shows the totally individualistic nature of the causes that can affect food intake of people with dementia. Financial anxiety, or fear of not having the means to pay for food as the cause for not taking food and drink may never surface, since the person with dementia does not state it in those terms, and professionals may never think to ask. Although this hospital example involved a person who was reported by their carer as hallucinating due to staying in unfamiliar surroundings with unknown people, there might be many other important reasons why achieving nutritional and hydrational needs is difficult for someone with dementia.

5.1.2 Service Provider Accounts

Service providers also discussed the challenges of nutrition and hydration for those with dementia. They raised issues around safety in meal preparation due to forgetfulness and the challenges in food consumption as the condition advanced, especially reinforcing the problem of social isolation and withdrawing from eating somewhere outside the home due to embarrassment.

Safety in food preparation was a concern for service providers. Dementia symptoms such as '*getting disruptive'* and '*forgetfulness*' *(SP_03, SP_04, SP_08, SP_12)* could make tasks like food preparation risky and dangerous. One example provided by a respondent was:

> *".. someone (with dementia) might be cooking a meal and they think, right, I will go and run my bath ready for when I had my tea, and then I will just have a quick bath,*

> *and by then actually forgot that they left the cooker and its burning… by the time they have gone through to the bathroom they have forgotten that they have left the cooker on". (SP_04)*

Several respondents (six out of twelve) described care tasks which were performed and provided for people at different stages of dementia. For example, to maintain independence at the person's own home, support workers/paid care workers would carry out tasks like *'taking out for shopping' , 'help preparing meal', supporting with meal'(SP_01, SP_04, SP_05, SP_09, SP_11)*. For individuals with severe stages of dementia who had very limited communication, the situation was different and could involve total dependence on the carer: *"… she sits on a chair, she would never ask for food or drink, because she can't, not anymore, if no-one was to help her she would just sit there, dehydrated and die"(SP_02).* The importance of food and drink, including the possible need for pureed food and drinks thickened with an additive was also mentioned for people with advanced dementia who developed difficulties in swallowing.

Service providers (five out of twelve) also confirmed the importance of the social aspects of food. As it becomes more difficult to eat independently and in public, carers might simply stop going out for a meal or drink. Causes of embarrassment included *'spilling food (in public) while eating, 'saying funny (inappropriate) things* and *'repeating themselves'*, and so forth *(SP_02, SP_01, SP_10, SP_12)*.

One dementia specialist participant opined that social care support to help with food and drink might not be achieved without someone to guide and watch over the person with dementia. The following account provides further detail on hydrational needs.

> *".. in my point of view, what care is required is not available. So, for example, that would be somebody actually won't eat or drink without prompting, very common in people with dementia. So it's ok to have a paid care worker coming in for 4 times a day, giving that person cups of tea, leaving drinks and food and snacks around the property... but that does not mean the person with dementia actually have any of that. Care worker may write food drink given 4 times a day. But, if there is nobody to*

> *see that person physically eating that food or taking that drink, then they might be only having very little of it, and that's reduced down to not drinking enough fluids - obviously potential to have increase infection and other health complications. So I would say, what is needed here is the need to be guided in what the person with dementia is doing throughout the day, and not just food preparation. (SP_05)*

5.1.3 Section Summary: Nutrition and Hydration

This first dementia care domain addresses the nutritional and hydrational needs of the person living with dementia from the early stage of the condition up to the end of their lives. This domain includes three key aspects: food and drink preparation, assisting and ensuring safe consumption and monitoring, and addressing any changes that might affect the person's unwillingness or inability to eat or drink. While food preparation is often perceived to be the easiest of the tasks, making sure the prepared food is effectively consumed can be challenging, especially for someone with dementia with severe cognitive difficulties. An individual's unwillingness to take food can be complex and may require more personalised understanding of both the causes and possible interventions. The presence of an existing informal carer makes this easier to manage.

5.2 Domain Two: Maintaining Appropriate Hygiene

Another common task for carer involvement is to ensure that appropriate levels of personal hygiene are maintained for an individual. As dementia progresses, the lifetime habits of personal hygiene often seem to falter, causing frustration and anxiety for carers as well as potentially serious health consequences for people with dementia themselves. Carers frequently mentioned that emotional states of the person with dementia, such as, apathy, anger, and frustration, can all affect personal hygiene. They also mentioned the ways in which aspects like incontinence affect emotional states. These are discussed further below.

5.2.1 Carer Accounts

5.2.1.1 Apathy and Personal Hygiene

All twelve carer participants interviewed stressed the difficulties of assisting individuals to maintain personal hygiene and how they increasingly had to assume more tasks because the person was simply unable or unwilling to do these for themselves. In one carer's words:

> *"I am having to step in and do more and more for him, washing, dressing, because otherwise everything is back to front, inside out or upside down, he just can't get it right. .not anymore ". (IC_08).*

One of the commonly reported (nine out of twelve carers) issues was apathy and the ways that this manifests itself in behaviour that also compromised personal hygiene. Apathy amongst people with dementia is well-known, and is a major source of frustration among carers, as this account demonstrates:

> *"For me the most challenging are the morning and the night-time routines, he does not want to get out of bed, wash, shower, toilet, just does not want to do it.. I keep telling him to do these things, again and again, and he will have a wash, but I am the enemy because I am asking him to do these things… . He does not want to change his clothes or wash, nothing. Getting him ready for bed is also very hard, quite often he would put his clothes on top of his PJs, go to bed fully clothed … it's just time, the time it takes, he has no concept of time any more, he used to be very punctual you know, but now, it is push.. push.. push.., like pushing an elephant up a hill, it just won't move. It is just so difficult". (IC_09).*

While a person with dementia was still able to carry out the majority of their personal hygiene tasks, carers were still likely to need to provide some assistance and keep an eye on individuals, albeit these are performed independently. For instance, making sure clean undergarments and clothes were in place. One of the carers talked about the need for a ‘lot of organisation’ to explain this situation:

> *“… I mean, a lot of organisation is needed for her to be able to do that. Usually, she will wear the same clothes all the time, her hygiene standards are still quite high, but certain things she would have never done like just small things, she thinks it is ok to wear a pair of pants for days, I have to make sure she is wearing clean pants every day, and things like that, it was never like that before.” (IC_12)*

5.2.1.2 Safety Aids and Hygiene

Whilst during the early stage of the condition carers can manage an individual’s hygiene by using prompts, organising, and ensuring cleanliness and hygiene, the intensity of assistance increases over time as the condition worsens. Assistive aids and equipment at this stage can play a crucial role for carers and were reported as widely used. Equipment such as the ‘bath bench seat across the bath’, which provides easier access to the bath, the ‘raised toilet’ and ‘grab rail on the bathroom wall’ which prevent falls, were greatly appreciated. *(IC_01, IC_02. IC_05)*

As one of the carers put it:

> *“ .. I can give (name) a bath, and good old wash, we have got grab rail on the wall (near bath) so s/he feels safe, I can ask (name) to stand holding the rail and s/he gets a good top to toe, wash.. I wash him/her hair once a week, feels safer.. (IC_02)*

The need for such aids is identified by Occupational Therapists (OTs) and funded by health or social services and/or rarely, by voluntary organisations. All of the carers reported having some form of safety aids at home which helped them to provide assistance with personal hygiene as the person became frailer. In addition, continence-related products became increasingly crucial in managing personal hygiene, for both accidental episodes and regular reoccurrence.

5.2.1.3 Continence Care and Management

The most frequently reported challenge in caring for someone with dementia was dealing with incontinence (ten respondents out of twelve). The difficulty lay not only in the practical handling of incontinence occurrences, but also in managing the emotional and psychological consequences. This is particularly true when the person with dementia became doubly incontinent, especially with early episodes of incontinence.

In almost all the interviews, carers stated that they managed continence for the person they cared for. For some this meant dealing with occasional accidents; for others, it was a common task. Regardless of the frequency of incidents, most carers thought that when the person became doubly incontinent, that is both urinary and faecal incontinence, it would be the time to seek institutional care. However, the carers of the people who were actually doubly incontinent (four out of twelve), although expressing the frequent exhaustion it entailed, did not consider this factor on its own to be a trigger for seeking care home residence.

The type of tasks that carers reported that they carried out to manage continence included: *reminding* and *accompanying to the toilet*, *handing out continence pads, checking and making sure they are correctly put on, clearing and cleaning of accidents, and* carrying out *an awful lot of washing every day. (IC_01, IC_03, IC_04, IC_05, IC_08, IC_11)*

Examples of accidents included: *not being able to reach the toilet on time*, *confusing the location of the toilet* and *urinating on a sofa or on a carpet in a corner of a room. (IC_01, IC_04, IC_08)*

Although such incidents were mentioned with a sense of frustration and exhaustion, carers reported managing them effectively and demonstrated a certain degree of resilience. As one carer put it:

> *“.. well he had a couple of accidents, he got up in the night and it was dark and he stood and weed all over the carpet. … I can’t get rid of the smell, I can’t, I keep spraying and spraying, but hey, you just have to get on with it.” (IC_09)*

In another carer’s words:

> *“..sometimes she leaves it too late, she had an accident recently.. during the night, I think she did not have a device (incontinent pad) on, she goes to toilet 3-4 times during the night, she is quite often awake, neither of us sleep very well, and I ask do you need to go, she often goes then, I leave the lights on, and when I ask she would say yes..” (IC_02)*

While urinary incontinence in both men and women were not reported to cause any major psychological distress for individuals, faecal incontinence, particularly in men, was stated to show serious emotional and psychological effects. These induced forms of behavioural changes, aggression and depression, especially in early episodes of faecal incontinence. On their own, both aggressive behaviour and incontinence are often associated with dementia. These are known to be common features and may be virtually inevitable at some point in the condition. Moreover, these two traits are the most common motivations to end dementia care at home.

There appear to be intriguing connections between these two traits, e.g., the first few episodes of faecal incontinence and first displaying out-of-character physical aggression among men, and this was often explored in the interviews. One carer explained:

> *“ .. I have noticed a change in his character, my husband, he is a very placid man, always the same, he would not say boo to a goose… but I have noticed he has got aggressive, recently, that is when he had a sort of tummy problem, you know, he lost control over his bowels, it was going everywhere .. I was trying to clean him up, and told him to stand still, and he sort of pushed me out, quite sort of forcefully… So that was the only time I ever… so I was very surprised. . so I said, oh no just hold on, sort*

> *of things like that… but, anyway, when we sat down afterwards.. he looked at me, suddenly burst into tears and said, what is happening to me….”(IC_04)*

Another carer described her experience:

> *“.. my husband, he is lovely, so loving… we had a little problem recently when I was trying to help him, and he hit me under my eyes, and he went, ahhh.. I was shocked, and he was so sorry and he wanted to kiss me better and was so sorry.. he is really lovely. Before dementia he always paid me compliments and always says thank you thank you.. still does, but this one time.. …when I am helping him to put his pad on, he goes no no no no no .. when he says no, I think he says that because he is depressed..” (IC_01)*

Continence care and management were by far the most significant challenges reported by carers. It was frequently perceived and explained as *‘the beginning of the end’ (IC_08),* for provision of care at home. Carers also often treated dementia and incontinence separately. They associated dementia with simple forgetfulness that could be managed somehow and saw incontinence as being the *‘real challenge’* and *‘worse than dementia’ (IC_06)*, rather than being part of the condition.

Interviews with carers explored the tasks carers carry out and the difficulties they faced to maintain appropriate levels of personal hygiene for the person they cared for. The interconnection between psychological aspects of dementia and personal hygiene were evident in their accounts. On the one hand, apathy contributed to a lessening of appropriate hygienic behaviour, but on the other hand episodes of incontinence led to behavioural outbursts, particularly in men. The significance of providing personal hygiene is a critical care domain and has consequences on the decision as to whether dementia care at home can be continued. The perspective of professionals in relation to the challenges and impacts of appropriate personal hygiene were further explored in the interviews with dementia service providers.

5.2.2 Service Provider Accounts

The interviews with service providers further confirmed the types and importance of the tasks that carers carry out to maintain appropriate hygiene, especially in the home environment. These interviews highlighted three key issues that affect the achievement of this care domain at home. First, the professionals’ understanding (or lack of it) and oversight to seek causes of incontinence among dementia patients; second, the superficial nature of incontinence assessment that might fail to address the magnitude of its impact, and lastly, the ways these could lead to a carer’s psychological breakdown which then results in the person’s admission to a care home.

5.2.2.1 Professional Oversight of Incontinence in Patients with Dementia

There is an inherent challenge for professionals working with individuals with dementia, especially when the cognitive decline is severe and communication becomes increasingly limited, in understanding the causes of the illness. Such is the case with incontinence as a linked element of the condition. At times, professionals may attribute incontinence in a dementia patient solely to the condition of dementia itself, without exploring other possible underlying causes. Some of my research participants in the service provider cohort were specialised in dementia care, and their reflections on working with other non-specialised professionals were very insightful. This research could not ascertain how widespread, or regular, oversight in healthcare practice might be; however, it is of critical significance even if it occurs only on rare occasions. One specialised professional described an experience with a female patient with dementia having incontinence:

> *“.. she has been seen by the continence team and she has been seen by her GP and they all put it (incontinence) down to ‘dementia’, it is her dementia, it is her dementia, her dementia... and I talked to her, looked at her chart and looked at other things and thought it is actually not her dementia, so many other things are going on*

> *with this lady... she has got gynaecological problems, in terms of her functioning of her bladder, she is very aware that she is incontinent and does not feel comfortable with the pads, but they (continence services) were refusing to prescribe her with pull ups and/or to investigate further... So, I had to write a long assessment about all of the things I thought were going on... the effects of her not having the right medication, and also her mood, how her incontinence impacts on her and her dignity and her family's perception of her... just to get her prescribed for some pull up pants…and if I could make them see beyond her dementia... for me it is incredibly sad, that incontinence is often avoidable, it causes so much distress, to someone at that point, and it is very sad." (SP_01)*

It was clear from the service provider interviews (six out of thirteen) that when someone with dementia fails to maintain their personal hygiene independently, it generally triggered a need for social care intervention. This could include someone having a care worker assist with the person's routine hygiene. Examples provided include: '*assisting with wash and dress' (SP_05)*, or '*to make sure the person is washing and dressing*' (*SP_10)*, and *'to help keeping their personal hygiene' (SP_09)* when the person is no longer able to perform such tasks unprompted or independently or responds better to a professional carer's instruction and assistance rather than to their family carers. Such needs were commonly labelled as the person '*can no longer care for themselves' (SP_03, SP_04, SP_10);* therefore, it initiated a care package. As the condition worsened and events of incontinence occurred, a more specialised incontinence assessment took place and other incontinence products were often prescribed.

According to some respondents (three out of thirteen), such incontinence assessments focus only narrowly on determining the allocation of the type and number of incontinent pads required for the person concerned. Continence care for a person with dementia is a complex undertaking and requires far more than mere pad allocation. As one respondent stated:

> *".. No one actually ever sits them (carers) down, and discusses different mechanisms for preventing incontinence, … why their loved ones may need more prompting to go to toilet, why they should hydrate their loved ones because if not it could cause UTI, what is UTI, and how it could trigger incontinence and other complications… incontinence would be seen as an isolated situation often rather than looking at the bigger context of how to manage it. The bigger picture. Both socially and emotionally." (SP_01)*

The wider process and effectiveness of various types of assessments to access care for the person with dementia and their carers will be discussed in a Chapter Six. However, in the interviews the superficial nature of the incontinence assessment was explored, as well as implications for carers' ability to manage the incontinence effectively.

5.2.2.2 Care Home Admission

In the service provider interviews, the management of incontinence and aggressive behaviour was the most frequently cited (by eight out of thirteen) reason for ending care at home. The perspectives of service providers mirrored those of carers at home in that incontinence was considered one of the main triggers for seeking care home admissions. In some instances, it could even be just one incident that caused the carer to make this decision. As one respondent put it:

> *".. incontinence, an unmanageable incontinence, I think, you know, especially if you have got an elderly carer, even with a maximum care package in place, there is only 4 visits per day, so, if there is one diarrhoea problem, that could be it, move to care home.. it is very difficult for them". (SP_08)*

Another respondent connected these two key aspects:

> *".. well everyone says the challenging behaviour, or behaviour that challenges people to put their loved one in care, I don't agree with that. ..from my practice, I have seen, 9 times out of 10, it's the management of incontinence. That tends to be*

> *the tipping point, rather than challenging behaviour… having said that, arguably, incontinence itself is a behaviour that challenges carers..”. (SP_01)*

5.2.3 Section summary: Hygiene

Both the carers’ and the service providers’ interviews highlighted the crucial significance of appropriate management of the hygiene of the person with dementia. They explored the interconnection between some of the behavioural issues associated with dementia and their causal relationship with behaviour surrounding personal hygiene. They reported the role of safety equipment that enabled carers to continue to provide personal care at home. They further presented the critical significance of professional attitudes to incontinence and dementia and the apparent narrow outlook towards understanding incontinence as a whole. Overall, unmanaged incontinence, which represents a breakdown in the management of hygiene at home, was reported as the most significant trigger for care home admission. Whilst the significance of related tasks associated with maintaining appropriate hygiene was established, as will be seen, the later quantitative survey helped to understand the frequency of such tasks for carers (see Chapter Seven).

The ability to maintain appropriate hygiene at different stages of dementia is one of the most important factors determining whether persons with dementia can remain and be cared for at home. Both the qualitative and quantitative data indicate that personal hygiene care needs, including effective management of continence for someone with dementia, is a complex matter and requires a wider understanding of its causes and consequences. Apathy and depression, in addition to actual physical ability, could contribute to someone with dementia not being able to achieve appropriate levels of personal hygiene. Some professionals may also fail to address the root causes of factors such as incontinence and too quickly attribute these solely to dementia.

An inability to manage appropriate hygiene, especially incontinence, also contributed to some challenging behavioural issues, such as a first-time display of aggression in men, and could have negative impacts on both themselves and their carers. Service providers needed to understand the wider impact of hygiene-related issues in order to provide appropriate help. Currently, according to the research participants, the mechanism to understand and deal with such issues appears to be narrowly focused, and largely did not reach beyond the number of care worker visits or the amount of incontinence pad allocation per person.

Safety equipment enables people with dementia and their carers to assist with personal hygiene tasks. Incontinence, in particular faecal incontinence, was reported as creating the greatest anxiety for carers. It is interesting that carers' perceptions of the consequences of incontinence appear to depend on how prevalent the condition is. Where either type of incontinence is yet to appear or presents itself as a rare accident, carers reported fear of an increase in regularity and saw this as a motive/reason for ending arrangements at home. In contrast, carer participants with more experience with both forms of incontinence at home, did not consider this as a prime reason for care home admission.

Nevertheless, incontinence and its associated behaviours, like emotional outbursts or displays of aggression, were two key triggers predicted by respondents for ending care arrangements at home and seeking care home admission. Although often viewed as two distinctly separate issues, incontinence and challenging behaviour in dementia are perhaps more closely interlinked than commonly perceived. In combination, these factors have a cumulative effect which can threaten the continuation of care at home. A deeper understanding of these connections and their management could not only delay institutional care admission but also improve the quality of personal care provision at home. These factors are also interlinked with other care domains, for example hygiene, which could contribute to the development of other health issues such as UTIs, and associated safety issues, which will be discussed in the following section.

5.3 Domain Three: Assuring Safety

The third dementia care domain is keeping someone with dementia safe. These safety measures encompass two different contexts - one is continuous and the other is intensive. With dementia, issues such as sight loss, mobility and balance, impulsiveness, lack of judgement and understanding of risks tend to worsen over time and required continuous appraisal of safety and led to adoption of safety measures. In addition, the person may become hyperactive and increasingly prone to risky behaviour due to an underlying health issue such as a Urinary Tract Infection (UTI) or delirium.

Carers assumed a range of safety related tasks that ranged from just keeping an eye on someone and aiding their mobility to safely moving and handling someone and stopping the person from carrying out tasks that elevated risk of falls or injury. Carers adopted a range of strategies to fulfil the safety needs of the person they cared for; but, often, safety failure (e.g., falls or near misses) became a trigger for ending care arrangements at home and seeking admission to a care facility. This is due to the fact that safety failure often brings the person with dementia as well as their carers into contact with formal services like primary or emergency healthcare. Services like police or fire may also get involved, which can lead to major changes for the person with dementia and their carers/ families. In fact, a diagnosis of dementia often stemmed from the family's attempts to explore the causes of diminished safety perceptions that led to accidents and near misses. Safety issues remained a crucial aspect of dementia care, a reason for diagnosis, an ongoing challenge for care management and a major reason for admission to a care home as presented below.

5.3.1 Carer Accounts

5.3.1.1 Safety Triggers for Diagnosis

Carers (eight out of twelve) frequently reported either an accident or a near miss incident which triggered the dementia diagnosis. In many cases, prior to diagnosis, the carer developed a sense as something not quite right with the person, such as a tendency to risk-taking behaviour. Unsure of the causes, they suspect it could be something serious. Often some carers shared their fears with close family members, but do not confront the person in question in order to avoid undue upsets. Eventually such suspicions often come to a head with an incident such as a fire in the kitchen, a fall, or a traffic accident. This brought the person into contact with an emergency service, such as the fire service, the ambulance or the police, followed by a hospital admission or a GP visit, and a subsequent diagnosis.

5.3.1.2 Driving and Dementia Diagnosis

Concerns around driving were presented as one of the most common safety issues that led to a diagnosis, especially for men. In such cases, the most common patterns were changes in the driving style and quality which became worrying for their spouse and other family. Here are some examples from carers:

> *".. he was always a very good driver, but it was his driving, he was clipping the kerb at the roundabout, and was doing things he would not usually do, we parked at Lidl in Norwich and he got into the car and it's an automatic. He got the pedals muddled up, and he pressed the reverse, instead of going forward, and put full force on the accelerator and shot backwards and crashed into a man's brand-new car". (IC_07)*

> *.". he was getting so lost... he did not understand the roads sort of thing…say to come off the roundabout, he would go round and round. I would say, if you indicate, oh no he said, no, someone behind me... indicate it, but no way he would want to go, I was a passenger then... I would say indicate now, you have got the pass, I said this is getting bad you know. We would be driving into Norwich, and he would be looking ahead instead of the car just in front." (IC_09)*

> *".. we noticed it was the driving, it was getting a little bit precarious, my daughter noticed and I think they got in touch with the doctor..."(IC_04)*

Sometimes a driving incident was combined with the person going missing following an emotional outburst or simply losing his/her way, becoming confused and unable to remember the way back home. As one carer states:

> *"He went missing (again).. we called the police and explained to them, by then they (police) have got a record of him, because he had disappeared couple of times before and had not come back. Anyway, eventually they managed to track him down, he was going the wrong way round the roundabout in Norwich and ran out of petrol. They brought him back, and they said that they will recommend DVLA revoke his licence. He must not drive any more. He was just shell shocked with the whole thing… He thought that the police had it in for him. It took a long time for him to accept that it was not against him, it was the fact that it was not safe for him to drive. Luckily, he was not hurt, car was not damaged." (IC_10)*

5.3.1.3 Falls and Dementia Diagnosis

Another commonly stated factor that led to a dementia diagnosis were incidents of falling (six responses out of twelve). The causes of some falls were attributed to changes in medication for some other health condition and seen as an explainable accident. The concerns arose where falls were avoidable and a clear lack of judgement, risk awareness and management were becoming apparent. In such instances, it was not just the fall itself but also the person's perception, their memory of falls and impulsive behaviours which led to falls that caused concern. Although carers could not explain the reasons for such risky behaviour, they were convinced that something might have been wrong and sought medical explanation. As one carer put it:

> *".. something was not quite correct… Umm what sort of brought it to a head was her fall. We have a greenhouse, there is nothing in it, just garden furniture, and few tools, I left the door open and it was raining that particular day. I suppose I said something, and she wanted to go at that minute to do it, I said you can't go there it's pouring with rain.. anyway, when I am out of the room, and I then heard a call. She fell outside, but managed to get back inside, she shrugged it all off as if nothing*

> *happened, but we took her to the A&E, she actually broke the 2, 3 and 4 metatarsals on her right foot."(IC_02)*

Another carer said:

> *"..first he had a couple of falls in the bathroom, which was not too bad, so we had a wet room with shower … .., he had yet another fall in the kitchen but he did not hurt himself, had a little bruise, and he fell again from the kitchen into the garage, and he was telling people that he hit his head so he can't remember things clearly.. and he was asking me if he fell off the stairs, we actually live in a bungalow (laughter).. then he again fell in the lounge from his chair trying to do his shoes, this was bad, we thought he broke his neck." (IC_06)*

Although a diagnosis of dementia provided an explanation of the risks associated with previous falls, prevention of subsequent falls posed an ongoing challenge for carers. These included effectively managing causes of falls and other safety concerns.

5.3.2 Managing Safety in Dementia

As stated earlier, safety management at home is characterized as continuous or intensive. As the person's cognition declines, his/her sense of risk and judgement for risk minimisation can become increasingly impaired, resulting sometimes in accidents. As previously discussed, someone with dementia might think they are able to prepare food and drink, dress or carry out hygiene-related tasks independently, but without a carer's supervision and some assistance, serious accidents can occur. While the person with dementia can move around the house with mobility aids, he/she will likely need assistance from carers to use such aids. This sort of supervision and assistance constitutes the continuous type of safety management to keep someone safe, which all twelve carers reported that they undertook on an ongoing basis.

Over time, as the condition progresses, the person may become physically unable to prepare meals or get around with safety aids. Such a condition would require assistance with movement, e.g., safely turning the person in bed and/or moving the person from bed to a chair. In such cases more specialised safety equipment is likely to be in place, such as a hoist and/or specialised beds and chairs. The carers' safety tasks at this point were reported as involving turning the person in bed to prevent pressure ulcers and moving the person to and from bed using a hoist or some other safety equipment. Such care is likely at the point of an advanced stage of dementia.

Intensive safety efforts are required when the person at any stage of dementia suffers from an episode of UTI or delirium, which can occur commonly. Carers reported that most cases of major accidents, like falls that lead to a hospital admission, were later explained to them as a consequence of UTI or delirium. Although preventing falls is not the only safety requirement in dementia care, it was the most common reason why a person required hospitalization and subsequent care home admission. Therefore, understanding the causes and consequences of falls and how to prevent them effectively is an important factor to which we now turn.

5.3.3 Falls Prevention in Dementia Care

Prevention of falls requires an understanding of the most common causes and consequences of falls in dementia, as well as current prevention strategies. Carers (eight out of twelve) frequently attributed causes of severe falls or consecutive falls to a UTI or a phase of delirium. Assistive technology (AT) and occupational therapy (OT) equipment was mentioned as being currently widely used to prevent falls. A fall was sometimes perceived as an indication of major safety failure at home and at times became a source of tension between carers and service providers. It could be perceived as a potential display of adult neglect and to protect the person a legal imposition such as a deprivation of liberty might be used. This is explained further below.

5.3.3.1 Delirium, UTI and Falls in Dementia

In the carer narratives, the cause of falls was often attributed to delirium or a UTI (five out of twelve). Sometimes carers interpreted a fall as evidence of a stroke. As one of the carers explained:

> *"… when he fell over before, because he could not move at all, he was stuck to the floor, and I had to call for help, I thought, he had a stroke. And he fell over, again recently, I thought again he may have had another stroke, but they told me it was not, it turned out to be urine infection." (IC_04)*

Another carer's account of the event of his/her mother's fall:

> *".. I rang her and there was no answer, so I rang again, and no answer, I started to get worried, and the 3rd time, she answered the phone. She had fallen down the stairs and smashed her head into the wall, but still managed to get to the phone to tell me that she fallen down the stairs… she does everything very fast, always very impatient…, I got her neighbour to go check on her… she ran down the stairs, and tripped, she hit her face and got a fractured cheek, it was awful…the neighbour said my mother insisted that she make her a cup of tea and leave her alone… , of course my mother had delirium." (IC_12)*

Another carer attributed falls to a urinary infection:

> *".. urine infection, he had a couple of them recently, it plays havoc. That really does affect him. He has fallen over several times, did not hurt too badly and I had to call for help, because I could not move him.. he is too heavy.. we have got one of those red buttons, had to call for help." (IC_06)*

Carers (five out of twelve) commonly stated the causes of falls to be delirium or UTI. They also mentioned the use of various safety equipment not only to prevent falls but also access help, and monitoring movement in and out of the house, as presented below.

5.3.3.2 Safety Equipment in Dementia Care

In the world of dementia care, a range of safety equipment has been designed to keep people safe at home. Such equipment includes various types of alarms and safety devices used to indicate danger, such as heat alarms, carbon monoxide alarms, fire alarms, and tracking devices. These are often connected to a central call centre. Also widely used are walking frames and grab rails offering mobility and steadying support.

Although some people purchased safety equipment on their own, most safety equipment was reported by interviewees as being provided by either healthcare or social services. It is assumed that the person with dementia would use these, but the equipment was issued only in the presence of a carer. This will be further explained in the service providers accounts of safety equipment.

However, people with dementia were not always able to make use of such safety equipment because they could forget or prefer not to use certain equipment and sometimes simply took the alarm off the neck or wrist, as the following accounts show:

> *"… he fell over one day, and he had not got it (*red button, alarm*) on, he had taken it off, he can't use it on his own... it helps me to get help for him…" (IC_06)*
>
> *"… before his fall, he was very unsteady on his feet. And I used to have to help him… we have such a lot of help, someone came to our house, and had a look all round, and we got handles on the front door, and keysafe, and had a wet room, see he also fell off the bath a couple of times. I noticed he would try to get out of the door… You see, he is very stubborn, he has a walking stick and walking frame, but he would not use the walking frame.." (IC_03)*

Regardless of the person's willingness or ability to use any of the safety devices, this equipment was greatly appreciated by the carers themselves. It provided peace of mind and reassurance that if and when something went wrong, they would be able to seek and get help quickly. Many of the older carers also themselves qualified for such safety equipment as they are older and have some health conditions; some carers wore an alarm on behalf of their spouse, because the person with dementia was confused at times and took the alarm off. As one of the carers stated:

> *“..I am wearing the alarm, it is on my wrist, I can’t rely on* (spouse’s name)… *I have arranged now to have this pendant on my wrist and am on for getting a key safe, because touch wood.. hopefully it won’t be needed, but prevention is better than cure.” (IC_02)*

Some carers (two out of twelve) used a tracking device, which was readily obtainable from online shops. Carers used these specially for people who were mobile but tended to wander out of the home and get lost. One of the carers explained how s/he obtained and used the device:

> *“..we have xxx (name of the device), …. I bought it from e-bay, .. it’s a little thing with the GPS and tracker. It’s not a wrist band, because she would take it off, but it works like that, it has a large orange button, if she is lost and pressed it, I get alerted on my phone… but I think she forgets all about it., but it tells me where she is. It also alerts me if she goes out of certain radius of her home… her friends came to visit from Scotland. I had just come out of the shower and my phone went off, she was going out of the radius range, she wanted to take her friends into the village but had taken them in completely the opposite direction, but I was able to see, they were walking by a very busy road, so without taking the towel off my head I jumped in the car and was able to go and I knew exactly where they were, which was great, they were very relieved, and so was she, so that was, it’s a good piece of kit, it is a bit like a criminal tag, but it is really for the safety..” (IC_07)*

Several types of equipment helped carers to supervise the person in the home. Alarms were used that went off when someone was trying to go out, or was outside of a certain fixed radius, which was deemed to be unsafe. Despite every effort to keep someone safe at times this could fail and that might lead to an accident and /or a serious consequence for the carers, as further explained below.

5.3.4 Safety and Deprivation of Liberty

Carers (three out of twelve) expressed frustration about when their relatives had gone out, forgotten the way home and hurt themselves. Whilst this caused a huge sense of guilt and anxiety to the carers, it also brought the carer's ability to keep the person safe into question and therefore about whether the person could remain at home. As one carer stated:

> *".. I had a call from the police saying they found my mother, she was in A&E, the A&E department said the police had picked her up wandering about in her nightie, in the street… so I drove, as soon as I could ...and she looked dreadful. She had a huge swollen face, I could hardly recognise my mother. She had delirium, so she was quite upbeat about the whole thing, anyway, to cut a long story short, she had a deprivation of liberty order placed on her, and I then realised, once you get into the system, how tricky it is... to advocate not to have your mother suddenly be taken into care, just like that…she was in hospital two weeks, I went every day, talked to the doctor and they said there will be a case conference, the only person that stuck up on my side was the social worker. The rest said my mother needed to go to a care home. I said look this is the first fall, she has had, you don't know really what she is like. OK she had delirium, you can't equate her behaviour initially, to be how she is going to be at home… And eventually they reluctantly let her come back with me, I thought it was shocking, it was so, just one fall and the next thing is they are all ganging up. I felt like that, and I worked in the health service myself. It is not like I am ignorant about the whole thing. Anyway, they did discharge her." (IC_12).*

It was evident how easy a lapse of safety could be and regardless of whether it had been caused by a UTI and/or delirium, some carers might simply lose all control and the person could be placed in a care home against their wishes.

5.3.5 Safety Failure and Care Home Admission

The continuation of care at home often becomes compromised with the inability to assure safety either as a continuous or intensive process. The decision to end care at home as a result of a safety concern was not always a decision shared between the person with dementia, the carers and the service providers. Sometimes carers felt they were simply unable to provide sufficient long-term and intensive supervision to keep someone safe. Carers did ask for help and assistance at such times, although this might not be readily available to them, as it involved complex assessment processes such as those which will be described in Chapter five. At other times, such decisions were made for the person with dementia with little or no say from the carer. This is also a point where conflict between carers and service providers could come to a head.

5.3.6 Service Provider Accounts

The narratives of service providers were consistent with those of carers. They highlighted the importance of safety in dementia care, the use of safety equipment, cost issues in providing safety at home, and consequences of safety failure. Participants also described the tension that safety failure can cause in relationships both with and between carers and families.

5.3.6.1 Importance of Safety in Dementia Care

The word ‘safety’ came into provider conversations by all thirteen service providers time and time again to explain the context in which any service provider intervenes. To keep the person safe is a constant priority whether it is when someone has been diagnosed and is getting lost or at points when returning from a hospital admission where there can be a need to ascertain whether it would be safe for the person to return home.

5.3.6.2 Allocation of Safety Equipment in Dementia Care

Service providers reported a wide use of safety and security equipment in dementia care. The equipment is presented in two separate categories – AT equipment and OT equipment. Assistive Technology (AT) equipment is largely provided by social services, occasionally by voluntary organisations, or is sometimes sourced by carers themselves, as discussed earlier. The AT equipment focuses on keeping individuals safe while they are struggling with their memory but physically able to do some activities and get around, mostly at an early stage of dementia. Such equipment includes reminders and tracking devices.

Sometimes AT equipment is provided at the point of the diagnosis or even prior to the diagnosis, when a concerned family member makes contact with the social services seeking advice, or when someone is being discharged from hospital.

> *“.. lot of the AT equipment provided to people who have dementia. But obviously people do change and what is out there (AT equipment) also changes as well. … these are aimed for people with learning disability, physical disability and memory loss. Some of the clients actually might be in the process of having that diagnosis and have not been diagnosed or may have been already have Alzheimer or dementia. … sometimes they may have benefited from certain equipment like memory aids being in place, earlier... but at the end stages they are not so much, end stages it is more to do with care and safety.” (SP_04)*

Usage of AT devices is widespread and appears to be one of the most common interventions for older people when diagnosed with dementia. These help to maintain the person’s independence so they can still make meals with less risk and be easily found if wandering and unable to return home safely. According to the service providers, effective usage of AT equipment depended upon the presence of a carer, as stated below:

> *“..if someone is still able to go out shopping, there can be concerns about the fact that they can lose their way, and may not be able to express where they live, but*

> *they're still quite safe to go out walking, so something like a tracking device would be good, but that is where you would need the backup person whoever that is,… there is always a bit of a trade-off, because the equipment can work, can be really effective, but there usually has to be somebody in the background supporting that. And it is very difficult if there is not somebody." (SP_05)*

AT equipment is considered effective at an early stage of dementia and when there is someone (e.g., a carer) there to use it with the person, make use of it, or respond to calls when needed. On the other hand, occupational therapy (OT) equipment is used in dementia care throughout different stages of dementia. It may be provided by both social services and health care services. Both types of services in different settings recruit their own occupational therapists as it is an important intervention in dementia care. There are broadly two types of OT equipment used in dementia care. One addresses simple safety needs and includes grab rails in and around the house, bath/ shower aids, and mobility aids like a walking frame which aim to provide safe mobility for the person when used either independently or with assistance. These are relatively low in cost. The other type includes more complex safety aids, such as lifting hoists and specialised beds which are aimed at people with more advanced levels of dementia and higher levels of need. It is not accurate to say that this type of OT equipment is used *by* the person with dementia, as they may no longer be able to do so, but is used *for* the person by carers or paid care workers to ensure the safety of the person. This relatively expensive equipment is often provided by health services with no cost to the recipient themselves. The high costs involved in safe operation of such specialised equipment, for example where two people might be needed to use a hoist, may lead to a care home admission.

5.3.6.3 Cost of Safety at Home and Care home Admission

Reflecting upon his/her experience one of the service providers highlighted the importance of safety in care in the context of care home admission decisions that might be made for the person with dementia.

> *" … in my experience, carers and the person they care for nine times out of ten are very resistant to going into residential care, so we need to reach the point where they are taken away for safety reasons." (SP_02)*

Regardless of the reluctance of both the people with dementia - while they were still able to express their preferences - as well as that of the carer, the care home admission decision may be made by professionals on the grounds of safety. During the service provider interviews it became apparent that the real meaning of the term 'safety' equated to the 'cost of providing safety'. At a later stage in dementia, safety equipment such as a lifting hoist and specialised beds are often thought to be required. While such equipment might be paid for and provided by health services, the cost of its ongoing usage falls to social care and is therefore paid for by social services or the family themselves. The safe use of such safety equipment relies mostly upon paid care workers and care agencies. Where social services pay for the care workers, the balance between respecting the persons' wishes and those of their carers with the cost of delivering safety at home or at a care home can create a dilemma. Subsequently, the balance may tip towards the most cost-effective or cheaper option to place someone in a care home with an arguable reason that it provides better 'value for money'.

Providing safe care at home in the later stages of dementia was fraught with complications such as cost effectiveness and monetary value, safe handling and movement and the inflexibility of policies as well as business and profit motivation. As one of the respondents explained:

> *"… there is a lot of resistance from care agencies because first we are looking at single handed care and equipment, and a lot of staff are new (due to high turnover), the techniques are new, and there is this old fashioned perception that legally you have to have two people to hoist, which is not actually the case at all. It means if you risk-assess, and people can be moved and handled quite safely with single assisted care, with the right equipment, right techniques, umm but there is a lot of resistance, lot of resistance at many levels, so you have got care workers stuck in their place,*

> *they think it is illegal, and policies are written for care agencies, to accommodate that, so it is most risk averse…. I mean yes you have got those things, then you have got resistance from the business end, because in the end care agencies are businesses. And the way they set up their rotas are often prohibitive, because you have a double up round, (laughter) umm, it makes it harder to be flexible… and the cost of double up rounds are very high…so in the end it is cheaper to place someone in the care home than to provide double up rounds." (SP_08)*

The extent to which the cost of providing safety at home became the predominant factor to place a person with advanced dementia in a care home was not sufficiently explored as it was not within the purview of this research. However, it was intriguing to find the significance of safety as a key dementia care domain and the relationship between the cost of continuation of home care at advanced stages and interestingly, among the carer respondents. Although they widely used AT and simpler forms of OT equipment, more complex OT equipment was not used by them. This may provide an explanation of the fact that once the need to use such complex equipment arises, most people are moved to a care home. As will be seen later, in Chapter seven, the patterns of safety tasks in different stages of dementia were further tested in the carer survey.

5.3.7 Section Summary: Safety

For carers, keeping someone living with dementia safe was one of the top priorities. This presented a considerable challenge for carers from a very early stage right up to the very end as the needs and nature of tasks change over time. An individual's perception and management of safety often resulted in a dementia diagnosis. A failure in safety was also a top trigger for ending care at home and seeking admission for someone to residential care, with or without considering the person's and their carer's full preferences.

To assure safety, and as the condition worsens, carers assumed more and more safety-related tasks - from keeping an eye on someone and assisting with mobility to safe moving and handling. These tasks were a constant effort, sometimes requiring elevation as the people with dementia suffer from an episode of UTI or delirium, causing hyperactivity and the person to become even more accident prone. At any point, a major safety incident may well be enough for carers and the person they care for to lose control over the care arrangements, as an imposed deprivation of liberty might be applied and a decision about residential home admission could be decided for them.

A range of safety devices and equipment is used to assure safety in dementia care. The NHS and social services, as well as some voluntary organisations, provide safety devices and equipment of different types. Assistive technology devices are provided by social services in the early stages of dementia. Simpler occupational therapy aids, such as grab rails and walking aids, are provided by either health or social care following OT assessments. These were greatly appreciated and very widely used. The more complex OT equipment, such as lift/truck hoists, are provided by health services; however, the associated costs of utilising this type of aid may prohibit its usage as it often requires two trained and paid care workers. The cost of safety assurance for people with advanced dementia is, at times, a deciding factor in care home admission, especially when care costs are met by social services.

Safety issues and concerns are closely interlinked with other care domains such as nutrition, hydration and hygiene, and without safety assurance these cannot be achieved, as discussed in earlier sections of this chapter. Safety also has profound emotional consequences, not only for people living with dementia but also for their carers. Incidents such as having a fall or being involved in a traffic accident affect people and their confidence levels deeply. The emotional consequences of something like losing a driving licence causes additional distress and upset which the carers have to deal with by providing the appropriate type and level of emotional support. This will be presented in the next section under the fourth care domain.

5.4 Domain Four: Emotional Support

The fourth dementia care domain is emotional support, which is provided from the moment of diagnosis through the entire course of the condition. As explained earlier, the realisation that one can no longer carry out tasks that were handled during a lifetime incurs a significant emotional cost. The causes of emotional stress may be either physical, such as losing control of one's bowel function, or practical, such as a revoked driving licence for someone who had treasured his/her car all their lives. People with dementia encountered these struggles with their emotional states and displayed their emotions in a range of ways. This included excessive attachment towards their carers, or contrarily, being suspicious and accusatory towards them and others, or even engaging in physical aggression and angry outbursts. Failure to effectively manage such emotional vulnerabilities could result in safety concerns such as someone wandering alone out of the house after an outburst and later finding themselves unable to return home safely. Carers managed this on a regular basis but not without a profound impact on their own emotional well-being.

Family carers or informal carers were mostly individuals with an enduring and intensive emotional connection to the people they care for. As explained in a previous chapter, the social capital has been built up over time between these two individuals. Therefore, emotional support was not only a vital catalyst to achieve the three previous care domains but was also dynamically intertwined with the carer's own emotional well-being. To provide emotional support as well as being able to make emotional connections at times is one of the most challenging but also most rewarding aspects of dementia care according to the carers. These delicate interconnections are explored and presented below.

5.4.1 Carer Accounts

5.4.1.1 Emotional Impacts of Losses in Dementia

Dementia was presented by ten carers out of twelve as consisting of unexpected episodes and events that delivered losses. While accounting for such events, from either prior to, or the very early days of the diagnosis, up until the time the interviews were conducted, the emotional impacts of such losses were at times quite visible. Some examples have been provided in the previous sections of incidents where the person with dementia had lost physical control, such as incontinence, and was showing emotional outbursts. In this section, the profound emotional impact of some practical losses such as loss of a driving licence is explained further. It was frequently reported that especially among men, the loss of a driving licence came as a devastating and traumatic blow, adversely affecting their emotional wellbeing.

As one carer said:

> *"… so he was told not to drive, he came back and of course the car went, so he could not, you know on that particular day, and it was so quick, and so sudden, you see, he knew, that it was not him, it was the other people you see, on the road, and it was due for an MOT, and due for the TAX and it was like a bereavement, he has never got over it. It was a bereavement." (IC_03)*

Another carer stated:

> *"One of the most upsetting things for him is not being able to drive, he is not allowed to drive, my daughter- in-law has got the key. Like today, I have been out to surgery, usually he will say 'I will take you, and 'why am I not to drive.. who told you I am not supposed to drive..?' but it has been a little bit better, it's been frustrating."* (IC_05)

Such a sense of frustration and deep sense of loss sometimes heightened peoples' emotional demands from their carers, which at times resulted in too close an attachment which carers had to manage.

5.4.1.2 Managing Excessive Attachment

One carer captured the relationship between a sense of loss and heightened attachment in dementia in this way:

> *"…it's a funny sort of set up, it's a funny world in dementia, you have lost something, but you try to hang on to what you have got, I think that is the easiest way to put it.." (IC_04)*

This was a commonly reported pattern (six out of twelve) in dementia between the person with dementia and his/her carer regardless of their gender. Whether it arose out of anxiety or was just an effort to hang on to what they have still got, the person with dementia often became excessively attached to their carers. As one of the respondents stated:

> *"..He wants me to be right here, I am like his blanket. You know, he does not want me to move anywhere without him, yah, if I say to him, I am just going out in the garden… he says, ' I will come and help you'." (IC_09)*

As another carer put it:

> *" ..We have been so close for so long that, you know, if anything, the condition (dementia) made her more sort of clingier, 'come and talk' 'where are you going?' Of course you can try to explain, you could try to explain where you are going.. I have explained a lot before but of course it's gone...asking the same question again, … answer again and again, that is the best way to deal with it." (IC_02)*

And another stated:

> *".. if I go out for more than 10 mins, she is calling me or she is wandering off… it is that constant needing to be with me…"* (IC_12)

Carers commonly mentioned the issue of '*monotony*', '*repetition*' and '*clinginess' (IC_01, IC_02, IC_03, IC_06, IC_07, IC_10, IC_12) to* be amongst the more challenging aspects of dementia care as it made them feel stuck, frustrated and emotional at times. This affected the emotional well-being of the person with dementia as well as that of the carers in a downward spiral, to ultimately reach a point where they could no longer continue with the emotional burden of care. As one of the carers explained:

> *"… I know it takes a lot of adjusting, to not criticise, not question things. I know I should not confront him, should not speak in a certain way, but it is really hard*

> *though, it's my patience level. I think, four years of this, unreasonable, monotonous, denials.. sometimes it's just awful and sometimes I go really silent. My head is full of frustration and anger and things like that. Sometimes I get emotional… he says he can manage; he does not need me... That hurts…. (goes quiet and starts crying)." (IC_10)*

Sometimes excessive attachment could manifest itself in emotional outbursts and anger. In this case, the emotional storm prevented getting whatever little help was available to carers from their informal social network, such as from a willing friend or kind neighbour. The following extract provides one such incident, as stated by a carer:

> *"… so my friend came to help me a bit, she knows my mum, and mum knows her very well, so, she can keep an eye on my mother… one day I went out for an hour, I just went up to the supermarket, and I had to go and get some things, and I thought it will be quicker, if I go…. And I got a phone call from my friend, saying 'are you on your way'? … because my mother had gone mad, she had gone out, she wanted to know where I was, she was rude to my friend. She stormed off upstairs, she was packing her bag and leaving. My poor friend did not know how to cope with it. I thought 'Gosh, this is not going very well, can't ask her again'..". (*IC_12)

Several carers (three out of twelve) reported that they sometimes felt stuck as they managed excessive levels of attachment, which left them no time for themselves. They felt reluctant to call for help when the person with dementia was prone to making accusations and unfounded suspicions about the helper as well as the carers themselves. Some of these are presented in the section below.

5.4.1.3 Management of Suspicion and Accusations

A key emotional effect of a person with dementia was to display deep suspicions, as reported by seven out of twelve carers. This sometimes occurred during an episode of delirium and/or hallucination, where the person with dementia would see someone who was not there, did not recognise their carer and became suspicious about the unknown people around them. For others, it was a common occurrence and constant state of mind. According to carers, one of the major challenges in dementia care for them was to manage suspicion and accusations made by the person they cared for. Such suspicions caused great stress and frustration for the carers. As one carer said:

> *"..The worst is his wallet, he hides it and he does not know where it is and he forgets he has his wallet, I said you don't need it you can put it in the drawer.. he hides it and he is anxious someone has taken his money."* (IC_05)

Another carer expressed his/her feelings of being accused by the person s/he cared for:

> *"..well.. I am grateful, that I am able to do it (caring for mum), I am able bodied, and you know, fortunate, to have the space, and comfortable enough to organise other people to help. I mean there are good times, and good days, and those are fun, but you know when her mood changes, suddenly I am a thief, I find that ..sort of thing a bit too much. That really is the worst, that really gets me down. It was so obvious to me that she put her money away somewhere to keep it safe and forgot about where it was, but to be the first person to be accused of theft, not very nice at all… It is very hurtful."* (IC_06)

This carer went on to state the reasons behind feeling reluctant to find care workers to help, based upon both their own and their friend's experience of being accused, and their fear of what would happen if care workers were recruited and then accused:

> *"..My friend's mother, she moved down in the southwest somewhere and they organised live-in carers, but they went through several agencies, because they refused to come back to her mother who had Alzheimer's and would say all those things, mainly that they were stealing things, and in the end she locked carers out of the house and would not let them in!... the way my mother is presenting, clear to me, .. carers who might possibly be coming to help would be, thieves, rapists, whatever else, it would not have been any good for the carers although people who care for*

> *people with Alzheimer's are used to being accused of various things, but I would not be able to cope with that…" (IC_06)*

Although some carers reported to have adopted a strategy of *'keeping quiet'*, '*taking time out' (IC_01, IC_02, IC_04, IC_05, IC_10)* to manage suspicion and accusation, others stated that this was one of the major reasons for some occasional arguments and emotional outbursts between carers and the cared for. Of course, emotional outbursts could result in the person with dementia leaving the house which heightened anxiety about the personal safety of the person.

5.4.1.4 Emotional Outburst and Personal Safety

Among the people still physically able to wander away, the trigger for such behaviours was often an emotional outburst. Emotional support constituted a large part of caring for someone with dementia and required enormous amounts of 'patience'. When, however, carers were struggling with their own emotions and may have engaged in an argument, this could lead the person with dementia to leave the situation, as seen in several carer accounts:

> *"… I know people with dementia wander, but this word 'wandering' is not the right word. My mum now, if there is any tension, or we had a little bit of a spat, because she had done something dangerous and I have been sharp with her, that's it! she is packing her bags, she is off now, she is going to see her mother, who is dead of course. And that is the thing I find quite challenging. This constant threatening, she is going to leave, sometimes she's actually gone to the gate, I've found mum trying to open the padlock on the gate." (IC_12).*

Another carer stated:

> *".. we had a little argument, and he went out, said he needs to get his head clear, and it was getting late. He went off really angry, and ended up in xxx (name of the place, several miles away from home) at a friend's house. Walked all the way there, I*

> *started to ring people, and actually rang her, he used to work with her, they were good friends and she said 'Yes, he has just turned up, he is here'. She brought him home. (IC_10).*

The emotional support for both carers and the person with dementia by friends was a prominent feature mentioned throughout the interviews by all twelve respondents. At times of distress and emotional outbursts both the person with dementia and their carers tended to turn to friends. The existence of such a social network, providing advice and sympathetic listeners, played an invaluable part in providing support to the carers, which effectively helped them to carry on caring for longer.

Despite the fact that managing negative emotions was commonly stated as one of the major challenges in dementia care, for many carers being able to make positive emotional connections was also a source of satisfaction. The power of positive emotion was quite significant. The small nuggets of happiness and sense of reward gained from making connections, shared companionship and togetherness, as was mentioned time and time again by carers, was very important to the carers for continuing to provide care.

5.4.1.5 Power of Positive Emotion in Dementia Care

One of the most common responses from carers (nine out of twelve) regarding the rewards of caring was being able to make an emotional connection. Carers' reported abilities to help their long-term spouse or partner or their parent, who was now living with dementia, being able to share laughter together, see the person with dementia being happy, or to enjoy together a leisurely activity or hobby like gardening, baking or even singing together made the constant companionship positive and rewarding. It was clear from responses that the power of positive emotion was vital to the carer's resilience which enabled them to continue caring for someone they loved despite all the difficulties and challenges.

Especially, long term spouses felt some kind of gratitude to be able to reciprocate the years of happy moments. In one carer's words:

> *".. I am so grateful I have got her, you know, we have been together since she was 15, and she is now 74. and she has been brilliant to me, all my life you know.." (IC_03)*

Another carer expressed their emotional connection, how they shared laughter, and how it made her feel rewarded:

> *".., as long as he is happy I am happy… the worst is when he is anxious and grumpy and starts being negative or having a meltdown, it upsets me. But, luckily it is only sometimes… and if he is happy, that makes me happy, I know I am doing something right anyway.. … He was a very sociable and very intelligent man, can turn his hand to anything, he still likes to act sometimes. I like to see him laugh, it is his giggles that makes it rewarding for me, it is nice to see him laugh, .. we do have a laugh together sometimes, if he gets in a muddle or something at times, we laugh. You know... I am not laughing at him, I am laughing with him, you have to, otherwise.. it will be impossible.." (IC_08)*

Another carer echoed the power of laughter together in his/her words:

> "*..I think when we have nice days, it's like we get on well, and we are laughing at the same things, .. when we can do nice things together and are relaxing, enjoying each other's company. Not necessarily talking all the time, just feeling being there together...(IC_10)*

Another carer further described these positive emotions:

> *" my mother is very vivacious, and when she smiles and her face lights up, she has got a good sense of humour. I love seeing her cracking jokes, the other thing I have learnt that she is Welsh. All her life she told us she did not know any Welsh, and since she had dementia, she can sing a song all in Welsh, I never knew that she could do that … so I have sort of learnt the tune now, and we sometimes sing together. And*

> *that tickles her, she did not sing much when she was well, but now she throws herself into everything with great gusto." (IC_12)*

When the positive connection was hard to reach for whatever reason, carers sought positive emotional support from friends at places such as a dementia café. In one carer's words:

> *" The reward is probably to go somewhere like Friday club (a dementia café), well mixing with other people, because people there understand, that is the hardest thing, someone to understand.. (IC_09)*

As presented, the power of positive emotion, sharing laughter, was repeatedly reported by carers, and things that helped them to achieve such emotion were mentioned. The intertwined nature of emotional dependency between the family carers and the people they cared for was important in providing emotional support in dementia care and sustaining care at home. It was clear, despite huge challenges and difficulties, that carers carried on caring until they reached the point of emotional exhaustion, when making emotional connection with the person cared for proved impossible. Close friends within the wider social network and places such as dementia cafés played an important role in offering emotional support. Although the role of a dementia café will be discussed later in Chapter Five, it is important to briefly present here how carers valued the emotional support received from such places.

5.4.1.6 The Dementia Café - A Source of Emotional Support

The majority of the respondents (carers) were recruited from dementia cafés, so they tended to see the cafes as an important source of support. The cafés are informally constituted and have a range of neutral names that do not reveal their purpose, such as: 'Friday club', 'Monday club', 'Luncheon club', 'the café', and the 'Pabulum café' *(IC_01, IC_03, IC_04, IC_05, IC_07, IC_08)*. Dementia cafés do not exist in all areas, and not all dementia carers attend them. Nonetheless, where there is a well-operating café with good attendance, carers found the experience very useful, and they were stated to provide a major source of emotional support for the carers and the persons they care for.

Some carers reported that they became highly reliant on the café:

> *“.. we look forward to go to the club (a dementia café) on Mondays and Fridays, that place is brilliant, because when we go there, we meet someone else, who might be sort of in the same boat, we will tell each other what problems we might have. Um, and you know, we don’t really solve anything.. but we have a good laugh together, we play bendy dominos, it’s a great crack out, it really is..” (IC_03)*

The welcoming and non-judgemental nature of the place was very important to carers as well as the help of the volunteers. As another carer explained his/her experience:

> *“..They (the volunteers) are lovely... they just have such a lovely way with people who have dementia, they really know how to make them feel good about themselves, I mean, and they are completely bomb proof (laughter)… one time I went with X , and a guy there called XX (name of the volunteer) came in and said ‘oh hello X how are you? Can I get you a drink?’, and s/he said I will have half of lager.. we all laughed, but he did not laugh, you know, in a situation like that you might be judged, as an alcoholic, asking for lager at 10 in the morning, s/he is not an alcoholic, , it’s the social norms that people expect, the norms that are not there in people with dementia. They (volunteers) are very sympathetic, clued up…” (IC_07)*

Various leisure activities organised by the dementia café were reported as being very useful to both the carers and the person they care for. Although not all carers were uniformly happy, most felt that the volunteers in the dementia café were very attentive to individual interests. They tried hard to find something that each and every individual liked doing and like-minded people to do it with. The personalised nature of leisure activities for individuals with dementia was greatly valued by carers. As one respondent explained:

> *“.. they sometimes bring in an animal, some people like it. … of course, my husband, he is not interested in any animal, or talking about football, but he likes playing*

> *chess, someone plays chess with him and he loves it… he has a great time.. of course he is very good, one advantage of chess is you don’t need a memory but you need to think what’s coming.. …. he was a master bridge player, but of course you have got to remember what cards you have, so he had to give that up, I used to say I was a ‘bridge-widow’, you know, it was so important to him. He was a pianist, he played grand piano, and he never looked back, he is not a person who talks about the past. If you mention to him his piano, he does not get upset, but he can’t play because he shakes..” (IC_01)*

It was apparent from the carers reports that great benefits could derive from a well-run dementia café or from other similar support groups. The emotional support gained through engaging in appropriate leisure activities and being able to talk to people in a similar situation who often have prior or current experience of dementia provided a sense of common experience. It was very clear that the social interaction in a non-judgemental and safe environment with peer support enormously helped the carers to continue caring for their loved ones. While places like dementia cafés are important to those who can and do attend, for some it may not be an option for various reasons, which were further explored in service provider interviews.

5.4.2 Service Provider Accounts

Interviews with service providers confirmed the significance and importance of appropriate emotional support that carers provided for the people they cared for as well as that which they received themselves. It became apparent from these interviews that the emotional components and associated tasks were crucial in dementia care. It is critical to recognize that while carers provide emotional support to the person they care for, their own emotional well-being remains closely interconnected. To achieve emotional support for the person with dementia it is therefore important to understand and support the emotional well-being of the carers. The service provider interviews highlighted three key issues that affected the achievement of this care domain: (1) the understanding and ability of professionals to manage emotional relationships between dementia patients and their informal carers; (2) the profound force of emotional connection in spousal or partner care where carers might be reluctant to seek or receive formal care and the risk of carer emotional breakdown; and (3) the importance of social interaction in managing good emotional well-being that prevents carer breakdown and sustains continued care at home.

5.4.2.1 Managing Emotional Relationships in Dementia

Service provider interviews mirrored the carer reflections, in that when someone with dementia displays emotional stress or outbursts, it affects the carer's own emotional state. In such a situation, the carer often turns to a doctor for help. Apart from prescribing anti-depressants, (the case for several respondents), there are limited options available to help this situation. GPs sometimes made referrals to specialist services to explore support options for carers. According to the interviewees, there was limited expertise to provide emotional support within the general health care system. One respondent explained what a better understanding of dementia could potentially achieve:

> *".. generally speaking, GPs (generalist practitioners) are not all experts in dementia, and we are not all experts in managing the emotional relationship issues in dementia. Later stages of dementia, when a carer presents that they feel they are struggling, in any aspect of dementia, they are sometimes forwarded to an admiral nursing… and that emotional support backing carers is so important, umm … people are more able to cope and continuing to care for longer, if they know that if their loved one is saying horrible things, that is not to wind them up, or to hurt them, but it is part of their disease progression. It's very much how we can help someone to distance themselves from that powerful emotional relationship, challenging behaviour, sudden outburst, removing from the situation becomes part of the family's understanding of the disease progression, and once they understand it, it is less stressful for them. (SP_01)*

According to some professionals, carers' acceptance that their loved one did have a progressive condition which is likely to worsen, and for them then to seek other help, but is not a failure, could be a challenge to manage.

5.4.2.2 Emotional Liability and Carer Breakdown

From the perspective of the service providers, some carers considered their role an 'emotional liability' *(SP_01, SP_02, SP_08)*, especially among older persons providing care to long term spouses. Some spouses refused to accept that their husband/wife had dementia and some simply referred to this as '*s/he is just a bit woolly, just vague' (SP_05, SP_08)*. Such an attitude frustrated service providers at times, especially when people could afford to purchase additional help from care workers but refused to do so. Professionals dealt with this in one of two different ways.

The first adopted a rather heavy-handed proactive approach, with a view to impose additional help before the carer reached a breaking point and the care arrangement collapsed. As one of the service provider respondents stated:

> *".. with dementia care there are two sides to that, so I think, practical monetary side, but also the emotional side. If the person living with dementia is unable to express their own wishes and their own needs, then the carers you listen to, you have to be a bit cautious of course, because the carers may know best but whose interest are they putting first?…, you have to be careful because I have people in the past where it was evident.. .. we had to remove a gentleman under the deprivation of liberty, we had to put in a safeguarding referral because his wife was refusing to pay for his care. They had got a lot of money, and he was well down his journey with dementia, clearly struggling. but she was refusing to pay for her husband's care…… so you have to be careful, but it is not so common, and carers should be listened to. They should be also listened to about their own health and wellbeing. Not just about the person they cared for. There should be an absolute understanding, and respect for the work that they do, and if one goes under the other one would too.." (SP_02)*

The second was a more reactive approach, which is more commonly practiced, according to the respondents. In such cases, the service providers might wait until carers admitted to having reached or being close to reaching breaking point and seeking assistance, at which point service providers attempted to find some sort of support for the carers. '*Carer breakdown' (SP_01, SP_03, SP_06, SP_11, SP_12, SP_13)* was one of the most commonly used terms across service providers to explain when they intervened or felt the need to. Each potential referral to health and/ or social service was a possible carer breakdown. As one of the respondents put it:

> *".. they (the carers) struggle on and on, and then reach a point, where they call the GP and someone has to pursue them [as] they need to have some help… tell them that.. you can't sustain this. And then social services get a referral… someone speaks to the carer, and asks them if they want to put in some care to support carers, and if they say, 'no, don't want carers (care workers)', we will say, 'how can we support you then. Would you like a carer's assessment?' We offer a carer's assessment, and one of our team will go out and do a carer's assessment. We offer them a voluntary service called Carers Matter. And they can go out and can do a lot of emotional support for carers…or if they want any respite.." (SP_10)*

The need for emotional support for carers was prominently featured across service providers' interviews, due to the isolated nature of the task of caring. The value of social interaction was also highlighted.

5.4.2.3 Social Interaction and Emotional Well-being

The sentiment that caring is by nature a lonely task was prominent in the interviews. The need to provide constant companionship to someone who may or may not always respond in the same way, made for a difficult caring task. As mentioned earlier, some carers might have places they could go to for some social interaction such as a dementia café or visits to / from friends who provided emotional support. Many carers, however, were constrained by their own physical mobility. For them, any contact with service providers offered an opportunity for social interaction. The value of such contacts was explored in the interviews; as one of the provider respondents explained his/her encounter with an older carer:

> *“.. I went to see a lady who has dementia and her husband cares for her, he is doing a good job looking after her.. so when I finish with her, I looked at him and said, .. ‘and how are you doing?’ .. and to my surprise, the gentleman sat down and he cried and he said he needed some help and he is a proud man, and I sat with him for nearly two hours, just listening.. and I will never forget it, because afterwards he just had his hand on my shoulder and said ‘you have just given me a holiday.. Because you sat with me and you listened, no one has done that for four years…’. and for me that was just huge… we go to people’s homes, they trust us, we ask about the person’s dementia, put in services, ask about their emotion and behaviour, but often forget the carers, they are still a person there with emotion…” (SP_13)*

Both carer and service provider interviews confirmed, regardless of the emotional state of the carers themselves, that they carried out a range of tasks to provide emotional support for those they cared for. As will be seen in Chapter Seven, the frequency of these tasks was tested further in the quantitative survey.

5.4.3 Section Summary: Emotional Support

Emotional support is an important dementia care domain that involves a range of tasks that carers undertake. To most carers, emotional support represented one of the most challenging aspects in dementia care and at the same time it could be one of the most rewarding elements.

As dementia progressed, individuals experienced personal losses of various types that affect their emotion, at times manifesting themselves in emotional outbursts that compromise personal safety. Other common emotions reported as experienced by people with dementia, such as excessive attachment, suspicion and accusation towards carers and others at times caused hurt, frustration and upset for carers. Family carers and those who they cared for often had close emotional bonds, and at times this became an emotional tug of war having significant impacts upon both.

While carers carried out a range of tasks regularly to provide emotional support such as companionship and managing outbursts and anger, the power of positive emotion in dementia care cannot be underestimated. Being able to share laughter, enjoy leisure activities, have someone to talk with, all helped carers to maintain their own emotional well-being which in turn helped them to support their loved ones for longer. Carer breakdown was one of the most common reasons for families to seek help from health and social services and to end care arrangements at home.

To sustain dementia care at home it is crucial to understand the emotional needs of the person and their carers, which are often inter-connected. Carers' positive emotion is vital to help maintain resilience, which could be nurtured when they have access to a good social network from which they can obtain emotional support. In order to sustain carers' ability to continue care, it is also important to explore changes in household management as happens when a household member is diagnosed with dementia. This will be explored in the next care domain.

5.5 Domain Five: Household Management

The fifth dementia care domain involves smooth management of the premises where the person with dementia is being cared for and resides with their family carer - the home. It is widely assumed that most people wish to remain at home as long as possible, a preferable option shared by carers as well the service providers. However, a prerequisite of remaining and being cared for at home demands a well-managed household where the business of the household could go on uninterrupted despite the presence of dementia.

The running of a household involves a range of tasks and activities some of which are performed individually, others together or collectively. Over time, most households adapt either consciously or unconsciously, a 'division of labour' arrangement, where individuals living within the household accept some responsibility for certain aspects and tasks for running the household. When dementia affects one member of a household, and their ability diminishes, this longstanding arrangement is disturbed and certain adjustments are needed. Often this led to the carers increasingly assuming responsibilities alone which once were shared between couples.

In the process of such adjustment household members adopted strategies involving planning, such as putting in place powers of attorney permitting other family members to intervene when decisions had to be made on their behalf. In the management of a household where a person with dementia resided, the extended social network, such as other family members, friends and neighbours played vital roles. These are explored in this section along with different tasks that were involved in management of the household and performed by carers, however, this list is not exhaustive.

5.5.1 Carers Accounts

5.5.1.1. Practical Tasks in and out of the House

Most carers (seven out of twelve) in a spousal relationship reported that the diagnosis and subsequent progression of the condition resulted in their partners not being able to carry out practical tasks that they had used to do for their household. Some described in great detail who did what previously, as well as how they had acquired new skills even in their advanced years. As one of the carers described that household's labour distribution prior to the dementia:

> *"..He did all the cooking, all the decorating, and gardening.. before his dementia he was normal, and everything was fine, he was a gardener, DIY, he was like the gardener Percy Thrower and the cook I can't remember his name, in one, he made*

> *bread every day, by hand.. he was really ideal, he had all the attributes… he left me to look after all the finances... I did the paperwork and finances for us….” (IC_04)*

Some carers, both male and female had learnt to cook for the first time after their spouse's diagnosis. Several of the strategies carers adopted in relation to their food preparation and consumption were presented earlier in this chapter under the first care domain. A number of carers continued to use their extended family for advice, whilst feeling confident in carrying out such tasks they had had to learn beyond what they did prior to their partner's diagnosis. As one carer stated:

> *“ … I can almost cook anything now, if I do get stack, I call my brother, how do you cook so and so, and he clues me on that… So cooking is no problem. washing up is not difficult, you know and she (wife with dementia) still always dries up…” (IC_03)*

Another carer put simply the gradual increase in a carer's workload thus:

> *“..it creeps up on you… gradually you need to do just a bit more than you did last year… so I suppose you learn as you go along.”. (IC_01)*

Although most of the carers accepted and adapted to an ever-increasing workload, occasionally it also led to an element of resentment and emotional stress for carers, as one carer respondent stated:

> *“..I don't really want to feel he is a burden or a nuisance, but sometimes I wish he had done more, when I am so busy, I struggle with him doing nothing. How can you sit there doing nothing.. when I am doing everything!? ”(IC-10)*

The significance of family transport and the ability to drive in carrying out practical household tasks outside the home was repeatedly mentioned. Where both spouses held driving licences, although driving long distances to visit family and friends was no longer preferable or feasible for them, getting practical tasks done was still possible. As one of the carer respondents indicated:

> *“.. since he lost his driving licence I have been driving ever since… it is a good job that I drive, I am not very good at navigating, he was always very good at navigating… I could not go on a long distance drive.. on my own, I will be absolutely petrified, because there is so much traffic on the road…”(IC_06)*

Carers reported that when they did not drive, they were dependent upon their family or friends to take them shopping, which worked out well for them. While practical tasks in and out of the house were managed by carers with some assistance from their extended family and friends, other tasks, such as dealing with paperwork, sometimes needed external assistance.

5.5.1.2 Dealing with Paperwork

Carers (five out of twelve) reported to have been managing their household administrative tasks with occasional assistance from family members, and some also said that they had made contingency arrangements by putting in place a Power of Attorney should it be needed. As one carer reports:

> *“.. as long as I am here, I can do anything, cope with anything, that needs doing, you know, financially, insurance, in an administrative way, um, should the worst happen it is better to have these things in place… we made arrangements… our two sons have POA for both of us …If anything happens to either of us..” (IC-02).*

Ten out of twelve carers reported that after the diagnosis, a need to deal with a range of paperwork had emerged, either having to complete it on behalf of the person with dementia or for themselves. The majority of such paperwork included filling in forms to try and access various financial assistance, such as pension credit, attendance allowance, carers allowance and so forth. Throughout the interviews, carers repeatedly brought up the fact they had accessed someone to fill in forms for them. This was greatly appreciated and acknowledged.

As one carer said:

> *“. .a very nice lady from XX (name of a voluntary organisation) came and helped us filling in the forms, we are allowed to have attendance allowance.” (IC_07)*

Another stated:

> *“.. Someone from xxx (name of a Voluntary organisation), came and filled in forms. They sorted our pension credit, … that was very helpful what they did for us, we would have struggled and not get any help, that helped..” (IC-11)*

At times, carers did not remember where such people came from but did remember their help and how the assistance in filling in paperwork had assisted them. Their knowledge and experience in the ways the forms were supposed to be completed helped carers. As one of the respondents put it:

> *“.. a woman came and sat there (pointing at a chair) and wrote it all out for me. She asked me questions and wrote answers, and you know now I have the full attendance allowance, she sent it off for me, and I was just amazed. They are very long forms! I probably err on the side of caution oh yes she (PwD) can do that sometimes, and she would then probe and say, oh, ok would she wear the same clothes all the time? And I might not have known things like that..” (IC-12)*

The help with filling in forms was frequently reported to have assisted carers to achieve access to some financial assistance. This was greatly appreciated, as often a diagnosis of dementia resulted in carers having to manage household finances with extra demands at times to pay for additional paid care.

5.5.1.3 Management of Household Finances

While some carers who had managed household finances for years continued to do so, some others had had to take over this role for the first time. Carers managed by prioritising and monitoring their income and outgoings closely. As one of the carers explained:

> *"I have got a system, believe it or not.. I keep a check of all my bills and I keep a check on all my direct debits, everything that goes out, when it goes out it gets a tick. .. I have my gas and electrics, water, telephone all those things, regular things to go out. I keep an eye on those, and my priority is to pay my bills first… then food, upkeeps, run the car, and it is a very old car, I keep it maintained, which I want to keep doing… I need it, to take him out. That sort of thing.."* (IC_06)

Carer respondents came from a wide range of economic backgrounds, some being financially comfortable and others admitting to struggling financially. Regardless of how economically comfortable (or not) the household was, the cost of institutional dementia care such as respite or a care home placement, or even help at home or a live-in carer, was at the forefront of all twelves carers' minds. It was reported in interviews that this surfaced frequently as a form of anxiety for the carers, not only how they would afford such high costs but also what this provision would likely mean for household finances for the elderly carers themselves as their income could be reduced.

For most carers interviewed, being subject to a 'financial assessment' *(IC_01, IC_02, IC_04, IC_05, IC_06, IC_07, IC_09, IC_10, IC_11)* was reported to be a common occurrence. This was aimed at determining whether or not the person in need of care was eligible for public funding should they need a paid carer at home or require some respite care. While that was being determined, it remained unclear to carers with limited means what the financial consequences for the household might be, should the person with dementia have to move to a care home. Further details on assessments will be discussed in Chapter five.

As carers managed their household and performed associated tasks with variable degrees of confidence and adaptation, while continuing to care for the person with dementia, their family, friends and neighbours, where available, also played a vital role in sustaining this.

5.5.1.4 Extended Support Network

Carer respondents repeatedly mentioned the existence of people within their support network who were either family member(s), friends or neighbours, who provided them with the practical support and confidence to care at home. Whilst family members assisted periodically in doing their shopping, or taking them out shopping, to the doctors, or other appointments, and made regular visits to make sure everything was running well at the household, the close proximity of willing neighbours also boosted confidence. According to carers, neighbours with their own experiences of dementia showed greater fellowship towards these carers. As one carer described her support network, which included neighbours:

> *".. I can manage.. because I am headstrong (laughter), I can manage. My daughter comes in every few months,.. my daughter in law takes us shopping, weekly. I don't have many friends here but I have got good neighbours.. We don't go in and out of one another's all the time, but if needed they are there. My neighbour understands because her mother had dementia and she says, 'I understand, my mother had it'. It makes a lot of difference for us, to know if I want something, I can ring and she will be round." (IC_05)*

Another carer stated:

> *"… to carry on caring….I think it helps to have neighbours, although you can't really organise that. Good neighbours, who are aware of your situation, who are sweet and kind enough to be caring and if you've got people like that, it makes a big difference..." (IC_01)*

5.5.2 Service Providers accounts

Service providers interviewed mentioned two key aspects that mirrored carers accounts, the transport difficulties experienced by people in rural areas causing isolation, and their efforts to assist carers and the household in accessing financial assistance.

Regarding the first, respondents stated that one of the challenges they often observed was for female carers residing in rural areas with limited public transport who quickly become very isolated as a result of their husbands losing their driving licence. This became a huge challenge for them then to continue caring as the management of the household could become too difficult. Rural coastal areas are very desirable places for many people to retire to, however, when dementia affected the household, very soon people became isolated and providing services became challenging for service providers. Some providers explained how they helped the carers with paperwork to either obtain or to retain a 'blue badge' (parking permit) that enabled them to drive the person with dementia to doctors' appointments or to a hairdresser and to carry out practical tasks outside the house.

In relation to the second aspect, respondents stated how they either facilitated or helped families to fill in complicated forms to access different financial assistances. Statutory organisations might suggest such benefits to carers, however they would not have time to complete these lengthy forms, so could sometimes request a voluntary organisation to help to complete such paperwork. As one such respondent stated:

> *"…working with charitable services is good, we work very effectively with XX (name of the voluntary organisation), they are doing a lots of benefit checks. Filling in forms. Things I won't have time to do." (SP-13)*

Another respondent described having different options for places that they could turn to for filling in forms, and how they might prioritise this:

> *"...so I have three different places where I can go to get somebody to go out there (carer's home) and do the forms. Get them the benefits they need…. I can either put them through someone in XX (named a district council department), I can go through XX (named a voluntary sector organisation), if they are over certain age (65), or social services welfare department in-house in XX (name of the place), I can put them through any of them. So I check through which one is going to be the quickest. To get these forms filled...and get them their". (SP_10)*

One respondent who carried out such activities described the way they filtered demands and decided who they could provide support to:

> *"we get a lot of referrals.. . via advice line… other organisations. of course, there is logistical issue, time and hours available, the amount of carers we can support – sensibly and reasonably. Because if the carers want to... have a big issue, say continuing health care or attendance allowance forms, that is a lot of work, so we have to be logistically canny with referrals we receive and sometimes pass onto others". (SP_02)*

One of the service providers also explained the reason for prioritising 'filling in forms' as a service for dementia carers, by stating:

> *".. carers, some of them, getting older themselves, they have to cope with financial pressures, housing pressures, medication, looking after the person they are looking after, filling in forms on top of all of that just a nightmare… " (SP_04)*

It became apparent from both sets of interviews that dementia carers carried out a range of tasks to run the household involving practical tasks inside and outside the house, dealing with paperwork and managing finances. The frequency with which carers performed such tasks is reported on in the results of quantitative survey in Chapter Seven.

5.5.3 Section Summary: Household Management

Dementia results in an increased workload for carers, as what was once shared to run a household, increasingly becomes a single-handed operation. Sometimes new responsibility came with having to learn new skills. which carers acquired by perseverance and help and advice from family and friends. Carers bore such loads and their ability to do so generally enabled the person with dementia to be cared for at home for longer.

Carers received assistance from various organisations assisting paperwork, mainly completing forms to access financial assistance, such as carer's allowance, attendance allowance, pension credit and so forth. Service providers, in both statutory and voluntary sectors were involved in facilitating and providing practical assistance for this and were often successful in doing so, which carers appreciated greatly. Nevertheless, management of finances was often also clouded by carers' anxieties about paying for institutional care or other paid care for the person they cared for and how they might still manage to meet their household expenses for themselves.

Carers were able to draw on help from their neighbours, friends and relatives for practical assistance. Where it was available, kind and willing neighbours were perceived by carers to be a great source of comfort and help due to their closer physical proximity. This informal support network is important to help carers to manage their household, provide appropriate care and deal with formal care arrangements. Where the household meets the services, there is another set of tasks in dementia care around coordinating care for the person living at home with a progressive condition.

5.6 Domain Six: Care Coordination

The sixth and final domain in dementia care at home involves efficient coordination and management of various health, social and other care interventions. These can include medication management, or carrying out practical health care tasks, such as changing dressings as well as arranging and coordinating various sorts of formal care.

5.6.1 Carers Accounts

5.6.1.1 Managing Medication

Almost all of the carers (eleven out of twelve) reported that one of the tasks they did every day was either giving and reminding about medication. Mostly these were linked to some other health condition that the person had had for some time and for which they were having to take regular medication. Carers mentioned the forgetfulness, a result of dementia, of the person they care for, requiring the carer to have to remind them, and at times to watch that the tablets handed to the person, were actually taken. Although infrequent, some carers also mentioned administering some new medication for dementia for the first time alongside other health conditions, which sometimes resulted in severe side effects which carers then had to manage by seeking urgent GP consultation and intensive monitoring. While medication management included ensuring its intake, some carers also carried out other types of practical health care related tasks.

5.6.1.2 Practical Healthcare Tasks

Other practical healthcare tasks involved giving injections if needed, bandaging wounds, administering a catheter etc, most of which would usually need a trained clinician. Although carers reported such activities were administered at home, only on rare occasions, and a very small minority, had ever attempted to do such tasks themselves. Despite the fact there were carers who were once clinicians and health care professionals themselves and who stated they could potentially do some of these if required, carers reported these to be a task for the community health care professional, which they sometimes arranged and coordinated.

5.6.1.3 Arranging and Coordinating Care

In addition to all the tasks within each of the domains presented above, carers also had to arrange and coordinate care for the person they cared for. This could include organising home visits by different professionals to carry out various assessments, organising attendance at day care centres or other support groups, organising and arranging respite care places, arranging and coordinating visits from paid domiciliary care workers, and other health and social care professional home visits.

Whilst some carers were very appreciative of some of the interventions such as help in filling in forms (presented earlier), specialist nurses for timely advice, or home visits by a professional who understood them, and whilst some of these led to carers being able to access some assistance and feel reassured, some carers were not so positive about their experiences of dealing with different professionals. They presented a range of issues that concerned them including the cost and quality of domiciliary care workers, repetition in assessments, and at times they felt they were subject to suspicion from professionals. This occasionally led to a complete breakdown of trust between carers and some service providers. Furthermore, when carers were starting to find appropriate help, they felt they had to go door to door from one disinterested professional to another. As one of the carer respondents described his/her experience:

> *".. after some considerable battle with hospital, I got my mother home, but they said 'ok, you have to adapt the house to make it safe for her.. So they send an OT, she came and she was not interested in anything at all, just suggesting where the handrails will be fitted. My mother came down the stairs, and said 'I don't want a banister here, that will ruin the look'! My demented mother had fallen down and been in the hospital for 3 weeks and did not want handrail... and the OT said "Okay then", turned round and left. I thought she is so disinterested, I was really quite surprised, so then I rang up the social services to see what I was supposed to be doing about this. And the first thing they asked was what my mother's assets were. It was all about the money. Nothing about what services there were, what she needs, how could she be safe and in the end she basically she told me 'oh well….' I found it so demoralising, and then I found a voluntary agency.. who I called for help.." (IC_12),*

It was not only knowing what to do and where to go for appropriate services for people with dementia in order to care for them at home, but sometimes the cost and quality of care delivered at home also worried carers; as one of the carers said about the costs:

> *" well, I looked into these people who do home care, they come out but charge an awful lot. I looked for some help so I can go out once in a while, and it was £30/hr. And that is supposed to be 'helping old people', £30 an hour!! I could not afford it, you could not go out for couple of hours, or 3 hours and you are talking about nearly £100!." (IC_06)*

Another carer described her varied experience with different domiciliary care workers:

> *“.. my husband does not want them, sometimes he would not let them get close to him,.. no… you have to be a special type of person to do the care work, there was one or two who was good, he got on ok with them but others, no, not saying others were bad but he would not let them shower him.. and one time they sent a young woman, she was not trained for dementia and she was young and pregnant.. there was my husband kicking off, fortunately he did not get up and she had to go and find someone else... thank goodness, she was not hurt.. when she came later to see him, and I realised she was pregnant.. I thought my goodness what could have happened!.. she said ‘I want to train for dementia, but they have not called me yet.’… things like that..”(IC_01)*

Some of these challenging aspects of care arrangements at home were also shared by the service providers interviewed, as presented below.

5.6.2 Service Provider Accounts

Service provider respondents also raised issues such as the availability of domiciliary carers, costs of care and payment responsibility, and at times their frustration about a carer’s ability to keep someone safe and convincing them to seek and pay for support. They further confirmed the crucial central role that informal carers held in organising and delivering dementia care at home and suggested that the formal support structure is often required to sustain this care for longer.

Acute shortages in domiciliary care workers who are well trained and have sufficient experience in caring for people with dementia were mentioned time and time again by providers. The demanding nature of such care work, especially in caring for someone with dementia, was also noted at times. As one of the respondents explained:

> *“..we are struggling .. finding carers, a carer’s agency, they can’t take them that is the problem we have, when councils decided, what we call is the old home care, we used to take 70% and give 30% to the private sector, they stopped that, and it all went privatised, to agencies, and there is no care. We get so many people with unmet needs, and not getting the care they need. .. acute shortage of carers, so you can still pay the carers agencies but there is not enough people to do the job..”. (SP-10)*

Another service provider respondent accounted for his/her encounter to explain the emotional challenges that care workers at times face in caring for someone with dementia:

> *“.. so I was with this person when his/her care worker came in. and this person (with dementia) goes, “oh here comes the fat lump”, you know, it is really tricky for the care staff, she responded well with humour, but they aren’t well educated, aren’t well trained, aren’t supported either sometimes you know, I just hope that she was able to talk with her team about it, but I doubt they do, I think sometimes care workers had to internalise a lot of very awkward feelings and awkward situations.. and that is not easy..”. (SP_09)*

In addition to challenges in providing domiciliary care services, respondents also mentioned that some family carers’ ability to care, their attitudes towards service providers and a reluctance to pay for care at times became an obstacle to continue to provide care at home. Some service provider respondents also felt at times they had not been treated very well by carers, and they reported some difficulty in agreeing with a carer about what was best for the person with dementia. As one respondent put it:

> *“.. if you can manage to help someone, it can be very rewarding but also can be very difficult at times, some carers are quite hostile, not because they don’t care about the person they care for but, either themselves or the person they care for do not want to have any kind of support. They don’t want anyone in the house, they don’t want to talk to anyone.. Also risks in and around the house and leaving the property in an unsafe manner.. but you can’t help..” (SP_02)*

Establishing and explaining who was responsible to pay for care was also a challenge for many providers. This issue was presented earlier, and further details are provided in Chapter Six.

It was commonly stated and agreed by provider respondents (ten out of twelve) that family carers, where available, hold the key to sustaining dementia care at home. Carers could not do this alone however, especially as many such carers are also themselves older and had their own share of health problems. But they were still regarded as key to a coordinated effort to provide the person with dementia good quality care at home with appropriate, flexible and constant support. As one of the service provider respondents stated:

> *"..the key is the level of support available to the carer… because that is crucial, I know from people we talk to, they carried on and would want to carry on caring, if they had some support, you know. And by that I mean practical, physical hands on support… Which might be in the house, or might be through external respite care… Maybe domiciliary type of service.. I don't know of any specialist home care service for instance, or sitting services, so having some kind of well-trained domiciliary support network, which can go in, sleep in maybe, 1 day, 2 days, whatever. Respite means different things to different people. Somebody might just need a good night's rest. that kind of thing, where people had disturbed nights night after night." (SP_03)*

5.6.3 Section Summary: Care Coordination

Care coordination is an important aspect of arranging, delivering and sustaining dementia care at home. Carers assumed a range of tasks in order to coordinate care at home, from reminders about medication to dealing with professional carers and negotiating with and overseeing various care interventions by health, social care, voluntary and private sector providers.

While the family carer’s ability to manage this coordination effectively could ensure the sustainability of dementia care at home, a positive and trusting working relationship between family carers and various service providers is essential. Failure in this could well lead to a breakdown of the care arrangements at home and the person with dementia being placed at risk.

5.7 Chapter Summary

Whereas past studies have identified the kinds of needs people with dementia have, this research shifts the focus to the care needs at home provided by informal carers. Based on the accounts of informal carers and dementia service providers, six dementia care domains have been presented in this chapter. There are four domains addressing nutrition and hydrational needs, hygiene, ensuring safety and providing emotional support to the person living with dementia at home. The other two care domains concern the actual running of the household in which the person resides and is cared for, and coordination of the care arrangements.

Dementia care domains are delicately interlinked and need careful balancing at all times in order to secure, as well as sustain, the overall care needs of the person living with dementia at home. Failure to effectively manage one domain could have a domino effect on others, which in turn could have a serious impact on the close connection between the person with dementia and their carers.

The care of older people is a skilled task and with dementia it becomes a yet more specialised enterprise. Not everyone is likely to have a family carer with the determination, willingness and emotional connection to continue providing care at home, but for those lucky enough to have such a carer (or carers), those qualities alone may not be enough, and some further skills need to be acquired. In the case of dementia care being provided at home, the household itself effectively becomes the care delivery hub, where the family carers are in charge, not only by carrying out a wide range of care tasks themselves, but also mobilising and coordinating services and care that is provided by formal services. In terms of delivering dementia care in the community, e.g., at home, the household is the frontline operational unit, where person-centred care can be delivered in an integrated manner with both informal carers and formal care services working together as a team around the person with dementia.

5.8 Conclusion

While someone with dementia resides and is cared for at home, the house becomes the delivery hub for integrated care in which carers play the most significant role. Sustaining dementia care at home is entirely reliant upon not only the carer's ability to perform caring tasks themselves, but also to mobilise and pay for additional help and assistance. Sustained dementia care at home demands much more than just a family carer's sense of emotional liability, duty or simply the sheer determination to continue. It involves carers being able to acquire appropriate knowledge and skills which will enable them to continue care at home with enhanced confidence. This will be explored further in the next chapter.

Chapter Six: Integrated Care

6.0 Introduction

In the two preceding chapters, the role of informal carers and aspects that constitute in-home dementia care were analysed with the data provided by the qualitative interviews. This chapter shifts the focus to the informal care interaction and interface with formal services and in particular integrated care. Throughout the dementia trajectory, the person with dementia and their informal carers pass through stages that are often triggered by health or safety incidents and concerns. The informal carers underwent various types of assessments in order to gain access to formal services by these service providers. These assessments were frequently experienced as repetitive and episodic, and the results tended not to be shared systematically across agencies and service providers.

This chapter examines the nature of integrated care based on interviews with both informal carers and the professional service providers who work with individuals with dementia and interact directly with in-home informal carers. In this context, the goal of integrated care is to foster a cohesive person-centred approach to dementia care at home that promotes the coordination of health and social care services.

6.1 Service Provider Profiles

The service providers included in this study were identified by informal carers as persons with whom they had interacted during the course of their experiences with dementia care. Not all carers remembered who and when a professional provider came into their lives, but some kept very detailed records of each interaction and intervention and were able to provide contact information, such as business cards. There were also services that had been engaged at some point but were no longer available for one reason or another.

Two thirds of the service providers interviewed were representatives of some of the services and providers that had been mentioned by carers, many by names or type of professions e.g., Admiral Nurse, care support workers. An attempt was made to be as inclusive and as broad as possible by including service providers from statutory health and social care services, voluntary organisations that work with carers and older people, community organisations including dementia cafés and dementia carer support groups, the private sector and social enterprise. All of the service provider respondents provided services for people living at home with dementia and their carers.

One intriguing observation was that the individuals who had become community service providers, and successfully created and ran the community organisations at the time of the interviews, had previously worked for health or social care organisations. For many, following retirement they had decided to do something useful for the community by volunteering, and subsequently initiated, formed and ran community organisations such as dementia cafés and dementia support groups. These backgrounds provided the community groups with the benefit of relevant and usually substantial experience relating to older people, caregiving and dementia care.

Table 6.1: Service provider respondents by employment sector, profession, gender, years in service and care qualification

Employing Care sector	Profession Type	Gender	Years in Dementia Services	Care Qualification
Statutory – Health	Dementia Specialist	Female	15	Mental Health Nursing
Statutory – Health	Community Health	Female	6	Adult Nursing
Statutory – Social Care	Assistive Technology – Specialist	Female	10	General Nursing
Statutory – Social Care	Adult Social Care	Female	5	Occupational Therapist
Statutory – Social Care	Adult Social Care	Female	15	Care in Learning Difficulties
Voluntary – For Carer	Carers support work	Female	10	Social Care
Voluntary – For Older People	Day Care Centre Management	Female	10	Social Care
Community Organisation	Dementia Café Management	Male	9	Social Work
Community Organisation	Dementia Support Group Management	Female	5	Mental Health Nursing
Private – Social Enterprise	Day Care Centre Management	Male	10	Care Management (Dementia and Learning Disabilities)
Private – Social Enterprise	Day Care Support Work	Female	6	Teaching
Private – Social Enterprise	Home Care Support Work	Female	12	Social Care
Private – Independent	Live-in Carer	Male	5	Social Care

6.2 Dementia Care Services

Overall, the available dementia care services were largely the same services available to older people and people with mental health needs. Although not all service providers had a service pathway for dementia care, local mental health services do have dementia care specific dementia care pathways, which are elaborated in Annex 6. These pathways did not seem to mirror either carers' or service providers' experiences detailed in the interviews. The reported informal carer trajectory that emerged from the data appeared to be somewhat different, as is presented in the next section. Nevertheless, it is worthwhile to describe the formal services provided to people with dementia and their carers.

Dementia care services can be classified into four types—statutory, voluntary, community-based, and private sector services. Statutory services are commonly provided by local government and National Health Services; these are available to all including people with dementia and their carers. The specialist community nurses known as 'Admiral Nurses' have specialised dementia knowledge, however, the full extent of their availability at local level is uncertain.

The voluntary sector organisations usually offered two distinct type of services. On the one hand, they engaged in respite-related activities, such as day care facilities or care homes for older people with dementia, both of which provide short term respite care. The other set of services supported carers and people with dementia by sharing information and working directly with informal carers. They also sometimes assisted the local authority social care services, carrying out such tasks as assessments. One such provider explained:

> *".. we are called 'carer connectors'… basically we run a carers advice line so what happens is a majority of the time professionals or carers themselves, call in to our advice line, and say umm , I have got X, Y or Z… that problem. ..Sometimes the advice line can just answer the question and other times carers have some deep complex difficult issues, and are upset or in distress and they will ask if they would like to see a face to face worker.. .. we do a lot of development work, at hospitals, talking to the carers of people with neurological disorder, Parkinson's and MS, stuff like that.. so we ourselves, distribute information in places like GP surgery, social care offices, libraries… and we do assessments. .so for example, GP might make a referral to social services because carers may be eligible for a carer's assessment, sometimes that takes a long time, and NCC might ask us to do one, So we are not a formal NCC carer's assessment, but we do our own assessment which they (NCC) have approved, because they fund some of our activities, and it is very similar.. you know you can't*

> *spot the difference other than it does not have the NCC logo on the top, to be honest." (SP_02)*

The available community groups were comprised mostly of volunteers who support people with dementia and their carers. Their activities focused on peer support and short respite for the carers. They also provided a link to other professional services, for example by inviting an Admiral Nurse to come and discuss aspects of care with individuals or groups. These community groups were not consistently available and were not all run with equal rigour and dynamism. The success of these groups appeared to depend upon the experience and perseverance of the organisers and the availability and quality of the volunteers. Wherever a well-run group existed, carers found these an extremely valuable source of support. In addition to the benefits of the dementia cafés or other groups, the community group created an environment where carers could develop friendships that extended beyond the café itself. As one of the organiser respondents stated;

> *"I don't do anything, I listen to carers, I listen, where we developed certain things, inevitably that comes from a conversation with a carer or a group of carers… so it came out of the conversation, when we talked to carers we talked to their lives, so you pick up the family history, their life stories.. like we learnt G (name of attendee with dementia) loves paying table tennis, and we bought a table tennis table. So we did, then we bought a snooker table and now the sports room is that is the much part of what we do. So it's listening, I have not got any kind of magic formula, it's listening to people. And at the end of the day what we do is what a very good social environment provides. Except we are a kind of safety within that environment. We also have 70 independent volunteers, they all receive training, we have set training and annual training, in terms of safeguarding and confidentiality, health and safety, essential things, and dementia awareness. And some volunteers have opted to go on to advanced training, which if it is appropriate, we help them fund." (SP_03)*

Some community groups identified themselves as voluntary sector organisations with independence. This distinction is relevant to this research since a voluntary sector organization is eligible to request public funding for delivering services. Community organizations, on the other hand, do not seek public resources and in the absence of contractual obligations have more room for creativity and responsiveness to specific needs. There are no systematic referral systems for these services where they are available. Carers sometimes simply found them by random publicity such as information obtained in a library or supermarket, as one carer explained:

> *"I was not made aware the 'Friday club' (dementia café), I found it accidently, I was in Waitrose, shopping, and you know they give you a little green token and you have to decide which charity you wish to support for them to donate, when I saw name of the 'Dementia support group', I thought they are definitely getting my green token, I looked them up on the internet when I got home and made contact." (IC_07)*

The private sector organisations provided a range of services. These included personal care at home, day centres and care homes providing respite for the people living at home with dementia. The interviews revealed two types of private sector organisations. One was a social enterprise that operated as the local authority's business arm, and shared revenue. The second was a totally private sector enterprise providing domiciliary care.

Following the increasing demand for more complex services, the informal carer was likely to meet a range of professionals who provided needed assistance. Whilst every individual experience dementia in a unique way, the interface with various professional care services often follows a common pattern and pathway.

6.3 Informal Carer Patterns of Interaction with Formal Services

The interaction with the formal care system appeared to occur in a more or less common trajectory often starting with emergency services involvement. In most cases, a significant incident triggered a referral and a subsequent diagnosis of dementia. Such situations often included a kitchen fire, the person becoming lost and subsequently being found by police, the person being involved in a traffic accident, or a fall sustained at home. All of these incidents led to the involvement of emergency services, such as fire, police, or ambulance, and almost always a hospital admission or at least an appointment to see the GP. The subsequent diagnosis of dementia was usually based on specialised mental health tests, a brain scan, and other formal tests, delivered by the specialist mental health services.

With a confirmed diagnosis of dementia, the mental health service generally referred the patient back to primary care services, mainly the GP, who then subsequently referred the patient to other sector services. Most carers reported this to be a busy time with multiple professional contacts at home. Numerous assessments were conducted, many of which the carers did not specifically remember, but only recalled a stream of people knocking on the door. After the initial rush of professional visits and related activities, formal staff gradually disappeared and the person with dementia and their carers were often simply left alone. For example, if a safety issue raised an alarm, a professional assessed safety needs and measures were taken, for example to adapt a bathroom, install guard rails, and/or introduce assistive technology equipment. Once this had happened, however, the carer was then left alone with little follow up.

It appeared to be a common practice for the GP to conduct an annual dementia review, but there were rarely other contacts unless some other emergency situation developed. This cycle of crises sparked by an emergency incident and followed by social service interventions often contained a strong financial dimension. An assessment determined who was responsible to pay for any care provision and what sorts of services a carer might be able to purchase and whether the full cost of any service would remain with social services. These numerous contacts with professional service providers were usually made independently. Even if the same organisation visited the family on a second occasion, with a new referral, they simply started again, with little or no use made of the person’s history or any previous information that had been provided. Therefore, every referral appeared to trigger yet another cycle of repetitive assessment questioning and so on.

6.3.1 Access to Formal Services

Access to any of the formal services that offered assistance to people living with dementia and their carers in this study mostly started with a referral from the GP. Service provider interviews repeatedly asserted that the combination of referrals directly depended upon how much the GP knew about existing services. Some providers mentioned initiatives to disseminate information on available services to people with dementia and to distribute relevant information leaflets to GP surgeries. Even social services referrals often came from GPs, who also referred individuals and/or carers on to other health care services such as community health and specialised mental health services.

Social services provided by local authorities often made referrals to their own internal departments and to external service providers, including voluntary organisations, for information and support for individuals. These referrals to community organisations were reported as mainly arriving via word of mouth.

Despite the numerous referrals that directed carers and their care recipients to diverse service providers, it appeared that not much information was shared. The lack of information exchange was reported as both inefficient and frustrating to the carers who found themselves describing the same situation over and over again. This apparent flaw in the system was mentioned by both carers and service providers:

> *".. because time and time again, families are told, it is not us (this service) it's another service. And they (carers) have to make another call and tell their story all over again and again. Until they hit the right bit of the department or provider, if there is one at all.. (SP_01)*

6.4 Assessments

Access to services for people with dementia begins with a provider assessment. As already indicated earlier, throughout the dementia trajectory there are numerous and often repeated (and repetitive) assessment moments. Comparing across the many different assessments, interview respondents highlighted that there were three important factors that were dealt with in such processes.

The first common feature reported by eight respondents out of thirteen was that most assessments sought to establish eligibility for financial support from statutory sources such as the benefits section of the Department for Work and Pensions (DWP). These financial benefits can include attendance allowance, carers allowance, council tax discounts, and disability allowances. In relation to these benefits, often a voluntary sector support worker performed this assessment soon after the diagnosis of dementia. In some cases, carers reported no knowledge that such financial support existed and was available. Carers stated that they greatly appreciated such assistance, especially when someone invested time to physically visit their houses, sit with them, and facilitate completion of the necessary applications. Often during these visits, the support worker handed out additional information leaflets about day care services and resources such as dementia cafés.

The second assessment step reported by six respondents out of thirteen was a review of home safety and recommendations about appropriate home interventions, such as assistive technology or home adaptation. This type of assessment could be carried out by diverse service providers, such as occupational therapists or assistive technology staff.

The third and most frequently reported by ten respondents out of thirteen focus for assessments was to assess needs vs finance, to establish who would pay for any care that might be needed, including domiciliary care at home, or short-term respite care at a day care centre or a care home. Such assessments were carried out by social services staff, and if the financial assessment revealed that someone was responsible to pay for their own care costs, it could become difficult for them to get any practical help from social services, even in relation to putting in some small safety items such as a grab rail. As one of the respondents stated:

> *"… they (social services) came once and checked the house was suitable (safe).. and there was a bit of a problem with the shower, not as it should be, and told me you need this and that, but, we are not eligible for any social services assistance, so I am at the bottom of the queue, and that's that…. Even to put in grab handles… Well I asked my son to put some handles.. outside the door.. it is not much of expense but needed someone to put it. and there is a step to get out, my son did it too. If I needed something like that then I can wait for him to do it, because it is not,.. you know takes too long, and you know they (Social Services) have too many people needing help.." (IC_01)*

6.4.1 Types of Assessment

Every service provider interviewed reported that they had carried out assessments to determine the suitability of services for certain individuals, appropriateness of the equipment, and eligibility for any of the services which might be on offer. While service providers received referrals from other agencies, the referrals tended not to contain sufficient information about the person with dementia, their carer and/or the issues of concern in order to make a full assessment about any intervention. As one of the service providers explained:

> *".. from a referral we don't know enough about what the main issues are.. because we might get a referral from a GP which will say 'this family is very distressed, they are looking after someone with dementia', and that does not really tell you much, then you phone them and they would say 'oh yes we are trying to move because our house is not appropriate', so actually the dementia has nothing to do with the problem but the housing is.. so you see, you say, so how are you coping with the caring? And they would say 'oh no that's fine. We just need to move... so again you*

> *might just make sure that the person gets to the right service. Umm that might be the first function of our assessment.. .. So might be the carers phone up and say..'' I can't do this anymore… you know I have had enough', it could be try to unpick what it is that has changed, umm can we rescue that situation, by supporting them to think about, themselves, and own needs and some respite and whether they need some education about on managing relationships or some practical help, so that assessment is about gauging what is the most detrimental thing that is happening at the moment. Can we manage it? And can we make a difference? " (SP_01)*

Social services have a statutory duty and are required to conduct two types of assessments for persons with dementia and their carer. These are the person's needs / financial assessment and a carer's assessment; both of which were consistently mentioned by both service providers and the carers during interviews. In effect, these two critical assessments determined the suite of services that would be recommended for that particular person and either the ability of the household or family to cover the financial costs or their eligibility for either free or subsidised services. Data from the interviews on these two types of assessments are presented below.

6.4.1.1 Assessment of the Person with Dementia – Needs and Finances

A needs assessment aims to determine the ability of a person with dementia to carry out certain tasks independently, such as self-feeding, dressing independently, and so forth. If the person is unable to carry out these tasks, this is registered as a 'care need', likely to be addressed by provision of a domiciliary carer to help if the carer at home is not able to do so. Together with this needs assessment, and often reported in the interviews as of greater concern, is the associated financial assessment.

The financial assessment is undertaken to determine whether the person with dementia is over or under a 'financial threshold', i.e. has a level of financial resources available to them (e.g. the person in need of care along with their spouses), to pay for their proposed plan of care in terms of any service provision. In the view of respondents, financial assessments seemed to take precedence over other concerns since this established who would pay for care. When the person with dementia had resources above the financial asset threshold, he/she was classified as a 'self-funding client' and they would simply be provided with information about types of care available and associated payment methods. No other significant assistance apart from information leaflets appeared to be available for such individuals. As one of the service provider respondents explained:

> *"..So if someone is classed as self-funding, which is if you have over £23,500 in the bank, they are coming into a category as self-funding, and then for those they are having to look for their own care. So if you are looking after your loved one, and then you need to have someone to care for them as well, because you are struggling, but you class yourself as self-funding, then social services send out a directory, with a printed sheet out of care home and things. When you are trying to look after a loved one with dementia, and sort out care packages, it is really difficult, but the 2014 Care Act says everybody is entitled to a financial assessment. ..it is a financial assessment, and there is a needs assessment, each person is entitled to that too. But if you have over £23,500 you will be told to look in the care directory, and when you're under that and below 16K or 14K, then you know social services will pay for your care, some people are waiting 20 or more weeks for an assessment…(SP_13)*

One reported concern was that the result of the financial assessment was neither prompt nor quickly communicated back to the family. The delay in arriving at an assessment outcome could lead to anxiety for the carer who has to wait for some weeks for a determination of what support is needed and how it will be obtained and paid for. Also indicated as disconcerting to the carer was that numerous assessments could have been conducted at different stages of the dementia trajectory. In the words of one carer:

> *"I have had a financial assessment.. a while ago, and I had a letter saying you will be liable to pay so much money, for respite. So much money for permanent residential care. Well that's all changed, as far as I know, because I had to have another*

> *financial assessment recently, I don't know the outcome. I am still waiting, and my head just gets full up with things…. In this sort of situation it needs to be a bit clearer, so that the person caring knows exactly what the situation is. …At the moment I don't know what I am going to end up with or if anything at all. Whether I can manage or whether I can get some more help…. There is no dignity in this sort of thing (financial assessment), because they want to know everything. Right down to your last penny. I don't know if they want to do another one, before long if R(name) goes into a care home. … ..one of the many pieces of paper I have got it tells you to look at the care home before you decide, but I can't, can I, if I don't know who they are… I don't know because you accumulate so many pieces of paper that you in the end do not know where you are." (IC_06)*

A lack of accurate record-keeping within a household was also stated as being likely to become a major obstacle for a helpful assessment. It was common among the families of respondents that one of the partners took responsibility for the finances. If, in fact, that person was becoming confused as a result of dementia, the other partner often had little experience to be able to inform the social services assessors about their finances. Such a challenge also occurred when a carer was dealing with their parents' finances, as they were not necessarily likely to have access to records. One carer in such a situation explained:

> *" ..well the first thing I was asked was what my mother's assets were', it was all about the money…. my mother she is on a very small pension, and the problem is my mother never told me what assets she has other than her house, not because she is preventing, and does not want me to know, she has never written them down, she told my sister before she had dementia, that she was going to do it, but she never did, so I see all her mail now and I think what's this, oh she has got a savings account there, and something here, and shares, and I am gradually piecing a bit of a picture, because ultimately I need to look at what her total assets are, you know, but that's not easy…. I was put off right in the very beginning, with the talk of my assets, my*

> *mother's assets, I thought, that's it then, I would just not bother, with any support, other than what I can find myself. (IC_12)*

The timing of financial assessments was also reported to have an impact on care. If it was conducted soon after diagnosis, the focus on highly private and sensitive financial information could create a reluctance to seek further assistance or served to undermine confidence in the service providers. Many respondents thought it was not useful:

> *"I had a visit from social services, for assessment, once, oh several years ago. And I am afraid I was not very impressed. It was all about money you have, and then have this leaflet and that leaflet, oh a total waste of time, I don't know, I can't even remember what her (person carried our assessment) name was (laughter), I did not bother anymore after that.." (IC_08)*

The unintended consequences of carers being put off by the assessment process may have led to them becoming reluctant to seek help until it reached a crisis point. Some service providers understood that an assessment for someone with dementia that combined individual care needs and household finances hindered the forging of a trusting relationship between the service provider and the care recipient family, as well as making it more difficult to achieve an adequate understanding of the person's actual (and likely future) care needs. The other most common form of assessment involved that of the carers themselves.

6.4.1.2 The Assessment of the Carer

All the respondent carers had experienced some kind of assessment with the person they cared for, and some reported they had had a specific 'carers assessment' completed by social services staff. The carers' experience of assessment varied widely, with some reporting it very useful and others with the opposite view. It can be frustrating for a carer when their loved one is unable to participate and provide reliable information during an assessment process. It is often difficult for a carer to distinguish between a carer's assessment, which is a statutory right, and other assessments in which they are asked to participate. Carers agreed that the most useful assessments also involved completing paperwork to facilitate access to benefits, such as carer's allowance, attendance allowance, council tax reduction, or disability benefits. These assessments often took place quite early on following diagnosis, or after an episode requiring crisis mitigation. Such assessments do not require family financial details as they are generally accessible to all regardless of the financial assets available at their disposal.

During interviews, some carers recalled the different assessments they had undergone, whereas others did not. This appeared to depend on the carer's ability to manage paperwork and communicate with formal services. For example:

> *"I am almost sure I had a carer's assessment, sometime back, it might have been through Alzheimer people, they are very helpful, it was J (name of the worker) who is the dementia support worker, who told me about council tax rebate for people who have dementia, got us attendance allowance, I thought we were not entitled to anything.   But she said 'you are', so she did the forms." (IC_10)*

Another carer recalled:

> *"Yes. We had assessment, me as a carer, and (name of spouse) as for disability, (name) gets disability, he has got a blue badge, because he could not walk very far, and he could get near to the places, where he had to be, yes, and also we got the alarm button, the security button… it was in the beginning, we had one of the Admiral nurses, and another lady, she was ever so sweet, called (name) somebody from N (name of the place). She was another worker, we have not got anyone now like that, that would be nice.." (IC_04)*

Some carers were unsure about whether a carer's assessment had taken place or about the value of having one. As one carer explained:

> "*I did not know there are such things as carer's assessments, again somebody I got to know, said she had had a carer's assessment, I said I did not know there is such a thing. ….I don't know what you get after that, so whether it Is worth having or not, I am sure it is probably a piece of paper that needs filling in.. I never had one. I did not*

> *know whether I was supposed to have one or not. So I basically just carried on, I think after the first encounter I had with social services, when all they were interested in was our assets, I think I was so alienated, I thought I can't be bothered with this anymore.." (IC_12)*

It was interesting to note that some service providers valued their own assessment tools but were relieved that a carer's assessment was not their responsibility but that of the social worker from social services. As one of the service provider respondents expressed it:

> *"This is when I am glad I am not a social worker (laughter). I don't know the answer to that to be honest. No because obviously, there is the carer assessment, and somebody can have a carer assessment, potentially could be assessed, but who do you assess, there might be a 85 year old spouse thinks they are doing fine, there are other family members, they are either working or have family of their own or carers have health issues all of their own, and I think informal carers sometimes are amazing.. But I don't know how you can formalise carer assessment, or recognise the carers.. sometimes people are a little bit unaware about the onus they are putting onto themselves to care for somebody, and not necessarily they are being brave or mean but they just can't see it for what it is (laughter).." (SP_05)*

Another provider indicated the unease attached to financial assessment as a part of the carer assessment as follows:

> *"a lot of the carer's assessments are done by the social workers, and the information is given in a rounded view about what is available and what is out there, I suppose, some people may benefit from having a more direct connection with the social services, that's potentially because some of us are better at it than others. Like for example I do lots of assessments but asking a dementia patient and their carers about their personal finances for me will be an absolute no-no.." (SP_02)*

While some providers expressed relief at not having to carry out the carer assessment and explore household finances, they also acknowledged that social workers could take a long time to complete this step due to their high caseloads and potential waiting lists. Such a delay could potentially affect the whole care package, including the non-social services elements. As one service provider stated:

> *" I think they (carers) struggle on and on, and then they reach a point where they call the GP and someone has to pursue them - they need to have some help. You know, you can't sustain this. And then I get the referral, I speak to the carer, and I will ask them, say we can help, .. how can we support you then? Would you like a carer's assessment? We could offer a carer's assessment, but one of the social worker team will go out and do carer's assessment. We can offer them voluntary services assistance; a support worker can go out and can do some emotional support for carers. We can offer some AT, then we talk about respite. Have they thought about having a break? Put their loved one into respite for a week or so that they can have a break, we will arrange that, I can put emergency respite care through one of our departments, if that is a carer's breakdown. Because at that point, we can't wait for a social worker to go out and see them because they could be on the waiting list for quite a little while. (SP_10)*

Although obtaining an assessment for access to services was not always straightforward or easy, all respondents reported that they had been assessed during their time as a carer. Whilst they did not necessarily distinguish between assessment for carers or the person cared for, they were quite clear on their feelings about the limitations of the assessments that they had had.

6.4.2 Assessment Limitations

Respondents reported several limitations in the assessment process and provided examples of the failure of assessments to fully address the needs of both individuals and their carers.

6.4.2.1 Episodic and Inflexible

The process by which individuals with dementia and their carers attempted to access services was experienced as only episodic. It almost always started with an episode relating to a health or safety issue, or when carers reached breaking point. The wheels of the system then started turning, and referrals led to assessments followed by further referrals or even a closed referral. According to respondents, at each stage of the process a new referral was generally initiated without referral to any previous history or making use of assessments by any other organisation or even the same one. Subsequently, families in need of help or care received multiple assessments. With diminishing resources in social services, the focus has increasingly shifted to the resources the family might have and how they should pay for their own care. Although, the emphasis on contributing towards the cost of care really developed subsequent to the introduction of the NHS and Community Care Act 1990 (GOV 2020), the past decade of austerity and cuts to services has accelerated the shift to the apparent maximisation of individual and/or familial contributions.

Four carer participants out of twelve indicated that another problem with the system concerned the care plan that emerged from a (carer) assessment and/or a needs assessment of the person with dementia, and many respondents considered the care plan to be potentially useless when an urgent need appeared. Some of the carers mentioned being able to use services such as Night Owls, and Swifts (unplanned rapid response workers, who dealt with personal care) when they needed them. Others stated that their care plan did not 'hold water' when needed. As one of the carers explained:

> *" ...I have got a box of leaflets and all sorts of things, I have a care plan in place which failed in crisis and family had to help. Nothing is available at short notice, I had a care plan and registered with the (local authority), for in case anything happens to me, there will be some help for (name). I have a carer card in my pocket, but when I had a fall and had to go into hospital, it's difficult to get immediate quick help, I said to my son to call them, and they said you have to have an assessment (laughter).. I thought I already had! So nobody at hospital knows sort of things… social services need to do*

> *yet another assessment, they could not give any emergency help or immediate help at all, no.” (IC_02)*

For participants, each referral appeared to be triggered by a specific incident and once the incident was addressed, the case was closed. But respondents felt that this approach did not take into consideration the regular need for assistance. As one carer reflected:

> *“Sometimes I feel sometimes you get the impression ..they (social services) can’t help indefinitely, sometimes, you see so many different people.. .. like I had recently, she (service provider) said you would not need to see us anymore .. so she said we will close your referral down. Because everything is all right, well it depends how you define ‘all right’ I suppose.” (IC_10)*

6.4.2.2 Narrow Focus

The interview data indicated that most assessments disproportionately concentrated on establishing who would be paying for whatever care or support was needed. As one of the carers stated: *‘it is pretty much all about money’ (IC_09).* While documenting the financial resources of the carer and the person cared for might be necessary, it clearly does not provide a holistic picture of the range of resources that might be available to the family as they seek to fulfil the person’s needs. Finances alone do not in any way ensure that the person with dementia and their carer would acquire what they considered was needed. Skills in caring are perhaps even more important than financial resources, but the assessment of skills appeared to participants to be notably absent from most assessments.

For carer participants, often the care plan appeared to be determined by what was available in terms of services, or what was believed to be necessary when in fact the context actually dictated something else. So, for instance, safety equipment was sometimes set up in a house but not used by the person with dementia and their carers because, as one service provider respondent said: *‘they are not familiar with it and can’t work it out’(SP_05)* . The offer of respite care was another example, as whenever a carer had shown signs of distress and being overwhelmed, the automatic response from providers was a short respite in a care home. This involved the person with dementia going away for one to two weeks and staying in a care home while the carer had a much-needed rest. Whether this was useful and appropriate for a person with dementia, depended on how confused the person already was, and the stage of dementia they were living with. In many cases reported by interviewees, the respite was detrimental and negatively affected both the person with dementia and the carer, resulting in elevated levels of anxiety and confusion when the person returned back home. Difficulties relating to how a person with dementia was affected by their (dis)placement and how the subsequent adjustment affected carers was cited time and again by participants.

It is clear from the interviews that a one-off ‘snapshot’ of a person’s inabilities was often misleading, yet it seemed that that is how individuals’ needs were assessed. With a condition such as dementia, a person’s abilities are not in a constant state and can vary, depending on many other factors. A person with dementia may think that they are able to do something safely such as preparing a meal, and sometimes they indeed can, but they may not be able to do so all the time, and at times such actions are clearly not safe. Alternatively, someone who might not be able to speak for themselves on one day might be perfectly able to do so on another day, as reported by several respondents.

6.4.2.3 Assessment Fatigue

Since assessments were episodic and repetitive in terms of process, fatigue for both carers and service providers was stated as occurring relatively often. Some service providers (three out of thirteen) were simply dissatisfied with the quality of the assessments, considering them to be superficial or even copied from a previous assessment. As one of the service providers stated:

> *“ a lot of it (assessment/ reassessment) is just text copied forward, I think it is appalling, because people change, when they have a neurological condition, and acquire other co- morbid health problems like type 2 diabetes, and that has*

> *implications on their medication and care and just copy forward texts from an old assessment is just inaccurate. (SP_08)*

Six out of twelve carers indicated that they became equally frustrated by the repetitive nature of the assessments undertaken by various agencies and even by the same agencies, having to repeat the same information time and time again. Carers stated that this could result in a loss of respect for and confidence in the professionals' way of working. As one carer put it:

> *".. they (professionals) are probably, say, scatty, well you don't know. Some don't seem to know anything about what the others are doing, ..you have to repeat yourself a lot, time and time again, somebody you have given a lot of information to, and I don't think they really communicate with each other. And it then becomes very boring and unnecessary... , if you need any help, you have got to wait. Have yet another assessment... I have already given you this information, and they are asking for that again. It is just the same... and that is putting more and more strain on me. Because you don't know what is happening. (IC_06)*

From the participants' perspectives, the success of any relevant intervention plan depended upon a good quality assessment. Whilst resources in social services are limited, the assessment process has become, according to the experience of some respondents, a tool to keep people out of the system, instead of being to gain a deeper understanding of an individual's situation and to intervene accordingly. Although an assessment should be a means to an end, in the case of dementia care it appeared to participants to be an end in itself. More often than not the assessment itself was stated as being the 'intervention' offered by support services.

6.4.2.4 Assessment of Carer's Ability

As reported in the interviews, a critical aspect missing from all assessments was an understanding of a carer's ability to care for someone with dementia. As stated previously, dementia care is a specialised task that requires a good level of understanding of the condition, as well as a great deal of skill in how to deal with certain aspects of such a challenging condition. Whilst over half of the interviewed carers had had a carer's assessment and others indicated that they had had partial assessments, not one of the assessors had asked about the carer's understanding of the condition of dementia and/ or what was involved in providing dementia care. There appeared to be a blind assumption that because someone was willing to take care of their loved one with dementia, they were capable of doing it.

The lack of understanding of the condition by carers was at times evident to some service providers and reported in interviews. As one interviewee put it:

> *".. the most pressing thing is for them (carer), and a lot of what we see, is around lack of understanding about the condition (dementia) because pathways locally are so dispersed, so people will be diagnosed, discharged and more or less they are on their own, they might have medication appropriate, or might not, they might be seen by a memory clinic for 3 months, once a month to try to take the medication up, but after that it will be seen as non-complex and discharged back to GP. ..So the carer doesn't really have a chance to learn about the condition, what the person's need is.. not grasp what the main issues are, and what is likely to happen in the future... (SP_01)*

It was clear from the interviews that some carers had experienced doubts about how to respond to certain situations. Some mentioned that soon after the diagnosis they received some information from a range of providers, such as Admiral Nurses, volunteers from the Alzheimer's Society and Age UK; but they did not have any consistent contact with anyone they could turn to if they had any 'know-how' related questions. As time went on in providing care for someone with dementia, such questions often arose for participants, and remained unaddressed, which suggests that the need for additional information and skills to continue dementia care at home is both long-term and regular. What emerged from service providers' perspectives was a view that when the carer reached a 'breaking point', it appeared to be assumed that they were having to do too much (e.g., the amount of care) and not that they were desperately lacking knowledge, understanding and skills in dementia care as well as appropriate support.

Limitations and challenges in the assessment process were not just presented by respondents as being the province of a single service provider either internally or externally. Some limitations such as information sharing across agencies not only affected one service provider but also provider agencies working together in an integrated manner to support someone living at home with dementia with a family carer present.

6.5 Integrated Care

The experiences of carers with integrated care systems are a foundational component of this research. Thus, a consistent research lens focused on the level of informal carers' knowledge of integrated care, their perceptions and experience of it, and the benefits that person-centred integrated care conferred on both carers and the people they (had) cared for. At the same time, the research sought to explore service providers' knowledge and experience in organising and delivering such services, and the impacts on households with dementia. The findings from this chapter suggest that integrated care is not yet a fully operationalised approach within dementia care, and much confusion concerning its meaning and application was reported by interview participants.

6.5.1 Integrated Care – Carer Knowledge and Experience

> *"Integrated care? I have not heard about it.. can you tell me? Does anyone you know have experience of it? Integrated care.. it sounds like it is still on the back of an envelope, who is organising it? County Council?" (IC_07)*

This was the reaction of one informal carer when asked about integrated care and similar views were shared among most of the other people interviewed. Only those people who had retired following work in the health or social care sectors and were now themselves informal carers for a family member with dementia showed any familiarity with the concept of integrated care, as seen in this extract below:

> *“ I think, in theory, not based on my own experience, but in theory it is an absolute nonsense that we have not got an integrated health and social services having talked about it for 30 years. And you know – these are partial, some areas of the country are better than others, but as everyone says it is the individuals (with dementia) or a carer - they don’t care where they (service provider) are coming from, they want someone who knows and orients them or gives them that service or facilitate access to that service… I absolutely agree that integration is the way forward, and something like a case worker for every person, somebody with whom you can link with, I think it will be very helpful. At the moment, it is an absolutely confusing system, that you have to travel, and you face with.. oh that is social services, oh no that’s health.. , I have sympathy for health service and social services, I really do. I think the expectations are very high, and I know it is very hard for them. But in a carer’s shoes it is just impossible to navigate your way through the current system. (IC_12)*

Another carer expressed his/her attempt to work through various services as follows:

> *“I have got this card and that card (of service providers), I keep them carefully. But I feel there are too many people and it all gets too confusing, it is down to me to organise things (care for spouse). But how can you organise? There is no joined-up anywhere. Like when I talk to people, I feel I don’t really remember things, or they don’t really listen. It is like the realisation that something is not right. Everything is a muddle for us. (IC_10)*

The difficulty carers experienced in navigating health and social care service provision was a strong indication of the very non-integrated nature of dementia care. Consequently, integrated care was very much an alien notion to carers, despite them generally expressing an openness to new care options.

6.5.2 Integrated Care – Service Providers' Perceptions

All service providers were well aware of the value of integrated care and the benefits of better cooperation between health and social care. Service providers with many years of experience recalled the longstanding efforts of integrated care services as well as inherent difficulties in its operationalisation. Reported obstacles included the lack of information sharing between health and social care and establishing what care came under the responsibility of health and what came under social care because of cost implications. For example, a piece of safety equipment might be provided free of charge to a person living with dementia by health care services, but the same equipment offered by social services required a financial assessment to determine whether the social services or the recipient was liable to pay. Although all service provider participants agreed that integrated care is the 'way forward', as a systematic approach to improve care in the community, it was reported as only currently operating in some places and this appeared to be often due to the effort of an individual member of the workforce not the system itself. As one service provider explained:

> *"well before I retired, integrated care was a buzz word as well, merging health and social care. And it never happened, I think, in terms of statutory services, it has to happen. It has not happened because of the people, you know, the institutions like the local authorities and NHS are very protective of their professional status, their institution is incredibly driven by process.. people fall between…. I don't think IC exists at the moment, it is fragmented, there is some excellent practice, where there are good.., it is people like a nurse, social workers.. if there was an Integrated Care strategy that would enable hopefully, one professional to manage all aspects of the care needed, be it the social care, domiciliary services, access to NHS facilities, and so on.. At the moment there are so many gateways that one has to pass through to get each of these." (SP_03)*

Although there has been development of integrated care strategies at Government and strategic levels, it was clear that for some service provider respondents they were seemingly unaware of these at their operational levels.

Service providers strongly supported integrated care as the way forward:

> *“ I think it is a way forward, I mean to do integrated model, and integrated pathways, so you know it is not like you have to jump over one to get to the other ones, it is almost transitional in whatever you need, the resource at that time, and I think it has got to be more efficient and I think it is also going to need a better skill mix, because rather than people having separate components , they are going to have to take broader responsibility, a health and social care system to cope with it needs, I think, it needs careful management, it needs appropriate supervision, it also needs where people don’t become too generalist. So we all know lots about lots of things, but no one is specialist about any of it. But I think the principle of integration has got to be the way forward.. in dementia care, because it cuts through so many other elements. I think it happens in pockets, but at the moment it’s the individuals that make it happen and not the systems, and you see some fantastic practices, and because the people on the ground decided that’s the way they are going to work, but actually that is not the way they are commissioned or managed, in terms of strategically.” (SP_01)*

The friction between the health and social care charging structure was repeatedly highlighted by provider participants as being one of the key barriers preventing an integrated care system from developing, as seen in this extract:.

> *“well Integrated care, I always thought it was like health care and social care were working together. That is where it is coming from… it should work but I am sure the part of the reason it does not work is that battle about the money again. Is it social care, is it health care and not social care? Then who pays? Do we pay, do we not pay? (SP_02)*

In the view of this service provider, their experience did not include the establishment or implementation of pooled budgets between health and social care as a key part of integrated care. In addition, the gap between funding sources from care services and individuals who self-fund their care did not appear to be fully recognised.

Service providers, especially from health care organisations, considered the Multi-Disciplinary Team (MDT), as synonymous with integrated care, as it appeared to be the operational aspect of integrated care in the healthcare sector. Respondents highlighted how effective 'co-location' was for some when teams were located in the same building and were in regular contact with professionals from other disciplines, sharing information about patients and developing shared perspectives. However, health professionals placed in a social care setting reported finding it difficult to share information in a way that achieved effective care integration. As several of the provider respondents stated:

> *"we get so caught up in the data protection, this is like what'd you do with it? If you are in a person's home, they give you permission, look at the discharge summary, its information, it's current, at the moment, whereas if I ask for a GP to send information, I spend a couple of months finding a fax, that I can fax people safely, every photocopy you go to, in social services offices (name of the place), notices be aware to turn this off, if you leave anything in the photocopier, it is a breach of data protection, everything that comes through the Integrated care team, at the bottom there is a huge thing, saying don't forget any loss of data incurs a £500,000 penalty, so it's a huge issue. You know, and still the systems don't talk to each other, I can't even send an email securely, without specialised email, which for some reason I have been denied having. So I have to write in a way, like 'Mr. X, as our mutual client, etc.. as vague as I possibly can be so there is no possibility that this information could escape'.. So I am fully supportive of care integration, I would be really happy working in an MDT, I work that way, that is me, but it has difficulties.. In a practical sense, information sharing, communication between my computer and another, and the things and hoops you have to jump through to get any information.." (SP_08)*
>
> *You know, in some respects, the non-compliance, if someone has dementia you have to build a rapport with them, you have to acknowledge who they are, the person as an individual, it is not a case , when you work in the community, it is not a criticism, but services have got busier, and become more 'task oriented', When you go to see a person with dementia, task orientation is taken away. Because you can't just go and*

> *have a task orientated view. You have to go and know the patient first. And that actually takes time… and there's still a huge gap. I just feel that there is a need for services to work more closely together, we have a lot of services but they work in silos, work separately and don't bring together. We have got a lot of services that guard what they do, because it is their own service.. we have to work together. (SP_13)*

6.5.3 Integrated Care – Past, Present and Future

Amongst this sample of informal carers and service providers, those who had had a former affiliation with the workforce in health or social services understood the value of integrated care systems. Some had been part of the effort to develop integrated approaches but remained frustrated by an apparent lack of progress. On the other hand, those family carers without previous knowledge of integrated care appeared to be oblivious to the concept, yet raised issues directly relevant to integrated care provision, such as closer cooperation and better information sharing between organisations. However, none of the participants directly raised points relating to the involvement of carers as part of the integrated care systems, including any sense of co-production of care.

The apparent sources of frustration among service providers, most of whom supported integrated care, were related to the perceived systemic barriers, such as incompatible computer systems, among agencies. Information management, and the fear of regulatory breaches of data protection was reported to almost paralyse some providers, and instead of sharing information they simply resorted to not sharing in order to avoid any potential breach. Health and social care coordination worked most effectively at a personal level where individual professionals were able to forge personal connections and share information. Where integrated care coordinators were being recruited by the health services to work with the social services, they reported as being mandated with extremely narrow objectives, such as *'to reduce care packages' (SP_04, SP_08)* or '*to fast track social care assessment for health service clients' (SP_13),* which unfortunately further limited the possibility of integrated care provision in a person-centred, individualised and person-focused way.

According to these accounts from carers and service providers, the future of integrated care within dementia is yet to emerge, but there were some noteworthy opportunities which have already been identified. Truly person-centred integrated care in dementia should not and could not flourish without full buy-in from and involvement of the family carers. The assessment and re-assessment process would likely need to be re-thought in order to make it more person-centred and person-owned and would then be produced once but be used multiple times, albeit with some updating, as necessary. This would help gain better trust between informal caring and formal services in order to enable dementia care to be maintained at home. These aspects will be further discussed in the final chapter of the thesis (Chapter Nine).

6.6 Chapter Summary

Informal carer and service providers experience (of lack of it) in integrated care, as well as ways formal services to interface with informal carers and people living with dementia have been presented in this chapter. Dementia care services were being offered by four categories of service providers: statutory, voluntary, community groups and private (for-profit) sector organisations. People with dementia and family carers often followed a trajectory of formal care service which started with a statutory, often emergency, services, and which then led on to other non-statutory service provision.

Various forms of assessments were carried out in order to access these services. While all providers undertook some form of assessment relating to suitability and eligibility for their services, the two most significant assessments were completed by social services, including assessment of the needs and financial situation of the person with dementia and a carer’s assessment for carers. In the experience of the participants, assessments were generally episodic and repetitive in nature, which frustrated carers as well as some of the service providers. It was also reported to affect levels of trust in the relationship between informal carers and formal service providers, and ultimately the person living with dementia at home.

Although integrated care was intended to be a way forward for greater working together between health and social care services and the delivery of more person-centred care for people living with dementia, most carers in this sample had never heard of it. Their experience of navigating care services also confirmed that until now it had not been operationalised in the area covered by this qualitative study. Service providers knew about integrated care and their responsibility to implement this; however, they reported that they were unable to progress this effectively due to systematic barriers such as the production and sharing of personal information securely across health and social care sectors.

6.7 Conclusion

From the accounts obtained, the role of informal carers in delivering and sustaining dementia care at home in the community is clearly a critical one. The ways in which informal care interfaces with formal dementia care services deserves much more clarity and strengthening. Integrated care offers an opportunity for improved systems of care and support, although from this research it appears yet to manifest itself through tangible benefits for people living with dementia and their carers at home.

Although for care to be ‘integrated’ there needs to be higher levels of collaboration and coordination, fully integrated care requires more than just high-level collaboration and coordination. Despite the existence of various pilot projects across the country to test out different elements of integrated care, this is not yet likely to be experienced by the majority of carers and was certainly not the case for the participants of this study, including service providers.

Chapter Seven: Informal Carer Survey

7.1 Introduction

This chapter detailing the findings of this phase of the study focuses on an online survey of informal carers. The purpose of the survey was to build upon the results of the qualitative analysis discussed in the previous three chapters and to develop further understanding about the variability of the key elements of informal care identified in the qualitative phase. This chapter presents the survey objectives and then discusses the findings from the survey.

7.2 Survey Objectives

One key purpose of this study is to (find ways to) explore the role of informal carers and their experience with integrated care while caring for someone living at home with dementia. This aims to improve dementia care at home through an enhanced understanding of informal caring. The qualitative interviews reported in earlier chapters explored a number of different aspects - including what constitutes care tasks in dementia care at home, who the carers are and what their perceptions about their role are, together with carers' experiences in integrated care, including access to and utilisation of services. This will enable us to deepen understanding of care that is specific to people living with dementia, informal caring, and the people who carry out these care tasks and their connection to existing formal services.

The survey was carried out to validate the findings from the qualitative interviews and further explore informal carers experiences. While only co-resident carers were included in the interview phase of the study, it became apparent from this stage that there are other carers on the periphery who were not co-resident, but, nevertheless, provide vital care that enabled both carer and the person with dementia to remain and for care to be provided at home. Therefore, the inclusion criteria for participants were widened for the survey.

The primary objective for carrying out the online survey as part of the mixed method research design was thus to gain data that would validate the results from the qualitative findings rather more widely. The three key aspects in the survey included:

- Who the self-identified informal dementia carers were, and who they were caring for, as well as how much care they provided
- Whether carers undertook dementia specific care tasks, and if so, whether they felt confident to carry out these tasks and what level of training they had to carry out tasks in any aspect of dementia care
- What services carers used (including the mechanism(s) used to access services), and what level of knowledge, understanding and involvement dementia carers had within integrated care efforts.

The findings from the survey are presented in the sections that follow.

7.3 Profiles of the Carers and the Cared For

This section presents the profile of informal carers, as respondents to the survey self-selected and identified themselves as informal carers providing care at home for someone with dementia. It further presents the profile of the person with dementia being cared for, and the amount of care provided. The availability and amount of additional informal care available to these respondents, as reported in the survey is also presented.

Table 7.1: Distribution of informal carers by gender, age, relationship, employment and resident status

	Informal Carers Profile					
	Co-resident		**Non-resident**		**Total**	
	Count	%	Count	%	Count	%
Gender						
Male	9	33%	3	23%	12	30%
Female	18	67%	10	77%	28	70%
Total	27	100%	13	100%	40	100%
Age	Years		Years		Years	
Mean (Sd)	68 (10.5)		51 (16.3)		63.1 (14.98)	
Median (range)	72 (40)		53 (54)		66 (67)	
Minimum	46		19		19	
Maximum	86		73		86	
Age range						
under 39	0	0%	3	23%	3	7%
40-49	1	4%	1	8%	2	5%
50-59	6	21%	4	31%	10	24%
60-69	6	21%	4	31%	10	24%
over 70	15	**54%**	1	8%	16	39%
Total	28	100%	13	100%	41	100%
Relationship of cared-for to carer						
Partner / spouse	21	**75%**	1	8%	22	54%
Grandparents	0	0%	3	23%	3	7%
Parents /(in-law)	7	25%	7	54%	14	34%
Other	0	0%	2	15%	2	5%
Total	28	100%	13	100%	41	100%
Employment status						
Work full time	3	11%	7	**54%**	10	24%
Work part time	4	14%	2	15%	6	15%
Retired	20	**71%**	3	23%	23	56%
Self-employed	1	4%	1	8%	2	5%
Total	28	100%	13	100%	41	100%

The profile presented in Table 7.1 confirms that female carers, both co-resident and non-resident, were twice as common as male carers in this sample, similar to the qualitative phase of the study. The co-resident carers tended to be older with a mean age of 68 years, with half over 70 years, while the non-resident carer group had a mean age of around 50 years, and half were less than 53 years of age. Within the co-resident group of carers, the vast majority was a co-habitant spouse, while for the non-resident carers, there was a preponderance of cross-generational care provided by adult children or in-laws. For those who lived with the person cared for, the carer tended to be the spouse (75%) or an adult child or in-law (25%), whilst for the non-resident carer group, over half the carers were adult children/in-laws and nearly a quarter were adult grandchildren.

Another major characteristic explored was the carers' employment status. This is important as the negative financial impact of caregiving on carers is in general well documented. Most co-resident dementia carer respondents were spouses and older themselves and were therefore among the retired population (71%). For non-resident care, amongst which carers were mostly adult children, over half (54%) worked full time and a further 15% were in part-time work.

7.3.1 Additional Informal Carers

As also seen from the findings of the qualitative interviews, carers often relied upon additional support from family members, friends or neighbours. Table 7.2 shows that over half the carers (54%) reported the availability of an additional informal carer. The assistance of an additional informal carer was markedly more common among the non-resident carer group, likely due to the fact that there was another co-resident carer present and /or constraints of time for people who tended to be fully employed. Such additional care was not episodic but rather contributed significantly to overall care in sustaining someone living with dementia at home. The survey revealed that over 90% of these additional carers provided assistance at least once a week, and half contributed daily assistance. It is likely that the reliance on additional carers increases with the severity of the condition. Again, the pattern was more pronounced in the non-resident carer group.

Table 7.2: Distribution of additional informal carers by care frequency resident status

		Co-resident		Non-resident		Total	
		N	%	N	%	N	%
Additional IC availability	Yes	11	39.3	11	84.6	22	53.7
	No	17	60.7	2	15.4	19	46.3
	Total	28	100	13	100	41	100
Additional IC frequency	Every day	4	36.4	7	63.6	11	50
	Every 2-3 days	1	9.1	1	9.1	2	9.1
	Twice a week	3	27.3	0	0	3	13.6
	Once a week	3	27.3	1	9.1	4	18.2
	Once in two weeks	0	0	1	9.1	1	4.5
	Once a month	0	0	1	9.1	1	4.5
	Total	11	100	11	100	22	100

The prevalence of additional care provides a clearer picture of the patterns of informal caring in dementia care provided at home. For those who are co-resident carers and who tended to be elderly themselves, the frequent assistance of an additional carer can be critical. This favoured around 40% of the co-resident group. For the non-resident group, the contribution of additional assistance was more apparent and likely reflects an effort to balance employment responsibilities with the care of older parents or in-laws. This presents a broader picture in which those respondents who are retired and elderly themselves and are looking after their spouses, tend to receive additional assistance from other informal carers, likely to be adult children and/or their partners. This may be seen as somewhat reassuring, as many older carers are likely to have some health conditions themselves and having additional informal care from extended family and friends could serve to make the caring arrangement more sustainable.

7.3.2 Profile of the Person with Dementia

There is significant variability with regard to the severity and duration of the disease for people with dementia reported in the survey. As the severity worsens and the duration of the condition extends over an increasing number of years, it poses greater challenges for carers, both co-resident and non-resident. The type of dementia presented in Table 7.3 follows the trend of the UK national epidemiological data, as the greatest frequency in the survey sample is for those suffering from Alzheimer’s Disease (37%), followed by Vascular Dementia (22%). It is of relevance that around 15% of carers could not identify the type of dementia that the person cared for had, particularly among co-resident carers, which may be an indication that the differentiation of types does not carry much significance for some carers, or perhaps that such information is not provided at the time of diagnosis.

Table 7.3: Distribution of person with dementia by stage, type and duration of the condition and by residence status

	Person with Dementia Profile					
	Co-resident		Non-resident		Total	
	N	%	N	%	N	%
Dementia Stages						
Mild	2	7%	1	8%	3	7%
Moderate	14	50%	8	62%	22	54%
Severe	10	36%	4	31%	14	34%
Don't know	2	7%	0	0%	2	5%
Total	**28**	**100%**	**13**	**100%**	**41**	**100%**
Diagnosis Duration (in years)						
Between 6 and 12 months	3	11%	1	8%	4	10%
1-2 years	2	7%	1	8%	3	7%
2 - 3 years	2	7%	1	8%	3	7%
3 - 4 years	4	14%	5	38%	9	22%
4 - 5 years	2	7%	1	8%	3	7%
5 - 6 years	5	18%	0	0%	5	12%
6 - 7 years	3	11%	1	8%	4	10%
7 - 8 years	1	4%	1	8%	2	5%
8 - 9 years	2	7%	1	8%	3	7%
9 - 10 years	2	7%	1	8%	3	7%
Over 10 years	2	7%	0	0%	2	5%
Total	**28**	**100%**	**13**	**100%**	**41**	**100%**
Dementia Type						
Mild-cognitive impairment (MCI)	1	4%	1	8%	2	5%
Alzheimer's disease	10	36%	5	38%	15	37%
Vascular Dementia	6	21%	3	23%	9	22%
Mixed Dementia	2	7%	1	8%	3	7%
Dementia with Lewy Bodies (DLB)	0	0%	1	8%	1	2%
Frontotemporal Dementia (FTD)	2	7%	1	8%	3	7%
Parkinson's Disease with Dementia	2	7%	0	0%	2	5%
Don't know	5	18%	1	8%	6	15%
Total	**28**	**100%**	**13**	**100%**	**41**	**100%**

As we know, dementia is a progressive disease that worsens in terms of severity over time. The survey findings revealed that approximately half the persons cared for lived with moderate stages of dementia, while about one third were in more severe stages. There was no difference between those receiving co-resident care or non-resident care. For both types of carer, the individual recipient's diagnosis of dementia was made six years previously or less; however, for the non-resident carers, the most frequent duration post-diagnosis was four years. This pattern suggests that persons with dementia were diagnosed earlier and remained at home when a co-resident carer is present. In sum, the survey revealed that those people living with dementia and cared for at home with more severe stages of the disease and for longer periods of time since diagnosis, were more likely to have a co-resident informal carer with them.

7.3.3 Amount of Care Provided

The amount of care required for persons with dementia can vary with the level of disease severity, thus increasing different types of demand upon carers. Table 7.4 seeks to document the frequency and intensity of care between the two carer groups.

As expected, the co-resident carers provided care of the persons with dementia on a daily basis, virtually during the entire day (90 hours per week). Over half the non-resident carers were present on a daily basis, but around one-third reported caregiving twice or three times a week, suggesting that the person with dementia was either alone for a significant amount of time, living with earlier stages of dementia, or that these non-resident carers were providing additional care to the person in need of care. For this carer group the intensity of care was also less, and over half reported less than 20 hours a week of care; however, if such care is provided in situations where an elderly co-resident carer was present as well, it could be highly significant in sustaining care at home for longer.

Table 7.4: Distribution of amount of care provided by care frequency, hours per week, number of years and by residence status

	Amount of Care provided					
	Co-resident		Non-resident		Total	
	N	%	N	%	N	%
Care frequency						
Every day	28	100%	7	54%	35	85%
Every other day	0	0%	1	8%	1	2%
Every 2-3 days	0	0%	2	15%	2	5%
Twice a week	0	0%	2	15%	2	5%
Once a week	0	0%	1	8%	1	2%
Total	**28**	**100%**	**13**	**100%**	**41**	**100%**
Care hours per week						
6 hours or less	0	0%	2	15%	2	5%
7 – 19	2	7%	7	54%	9	22%
20 – 34	0	0%	2	15%	2	5%
35 – 49	5	18%	2	15%	7	17%
50 – 69	3	11%	0	0%	3	7%
70 – 89	2	7%	0	0%	2	5%
90 hours or more	16	57%	0	0%	16	39%
Total	**28**	**100%**	**13**	**100%**	**41**	**100%**
Years of Care						
1 - 2 years	3	11%	2	15%	5	12%
3 - 4 years	8	29%	4	31%	12	29%
5 - 6 years	10	36%	3	23%	13	32%
7 - 8 years	5	18%	2	15%	7	17%
9 - 10 years	1	4%	1	8%	2	5%
10 years or more	1	4%	1	8%	2	5%
Total	**28**	**100%**	**13**	**100%**	**41**	**100%**

Whether informal carers were resident or not does not show any significance in the number of years that someone has provided care. Over 60% of the respondents reported having been caring for between 3 to 6 years, whilst a quarter of the carers reported caring for 7 – 10 years or more.

7.4 Dementia Caring Tasks and Training

The qualitative phase of the research established the set of tasks that constitute informal care for someone with dementia. In Chapter four these tasks were presented under six interconnected yet distinctive care domains, specific to dementia care, that emerged from the data analysis. Although the care domains are wide-ranging, they do not provide an exhaustive list of dementia care tasks. These tasks, however, do represent the diverse activities performed by informal carers to meet the needs of the person progressing through different stages of dementia while living at home. Tasks within each domain mark the progression of the condition, especially in the first four domains. Thus, for example, to maintain appropriate nutrition and hydration for someone in the earlier stages of dementia, a carer may prepare meals and eat with the person. As the condition advances towards a more severe level, preparation of additional special meals (pureed food) and drinks (easily drinkable thickened drinks) and perhaps even feeding assistance may be necessary, especially at a point at which the person can no longer feed themselves.

The online survey phase of the study aimed to validate these qualitative findings by documenting how extensively such tasks were performed by informal carers more broadly. Since the care needs for dementia become ever more demanding for the informal carer, the survey sought to identify carer levels of confidence in performing specific tasks and, relatedly, if the carer had received any training in such care.

7.4.1 Dementia Care Tasks

In Table 7.5 the list of tasks are organized according to the relevant care domain established from analysis of the qualitative phase of the study, and to compare differences in task distribution between co-resident and non-resident carers.

Table 7.5: Frequency of care tasks of respondents by domains and residence status

		Co-resident carer					Non-resident carer				
Domain	**Tasks**	**Regularly**	**Some times**	**Rarely**	**Never**	**N/A**	**Regularly**	**Some times**	**Rarely**	**Never**	**N/A**
Nutrition and Hydration	Preparing meals	100%	-	-	-	-	62%	31%	-	-	8%
	Assisting with meals	54%	21%	18%	4%	4%	38%	23%	0%	23%	15%
	Preparing special meals and drinks	21%	14%	11%	25%	29%	31%	8%	15%	23%	23%
	Feeding	7%	18%	4%	32%	39%	15%	15%	8%	38%	23%
Hygiene	Assisting with Personal care	71%	21%	7%	-	-	54%	23%	15%	-	8%
	Carrying out personal care	68%	21%	7%	-	4%	38%	31%	8%	15%	8%
	Continence management and care	36%	21%	14%	21%	7%	23%	23%	31%	15%	8%
Safety	Supervision	100%	-	-	--		77%	23%	-	-	-
	Assisting with mobility	54%	18%	14%	4%	11%	46%	31%	-	8%	15%
	Dealing with episodes of confusion or hyperactivity	36%	25%	18%	11%	11%	38%	31%	23%	8%	-
	Assisting with movement	11%	11%	7%	36%	36%	8%	31%	15%	31%	15%
Emotional Support	Companionship	96%	4%	-	-	-	92%	8%	-	-	-
	Supporting social and leisure activities	71%	18%	4%	4%	4%	54%	23%	8%	8%	8%
	Providing emotional support	68%	25%	4%	4%	-	77%	23%	-	-	-
	Dealing with emotional outbursts	30%	30%	22%	11%	7%	23%	54%	8%	8%	8%
Household management	Practical housework	100%	-	-	-	-	54%	31%	15%	-	-
	Practical out of home work	89%	11%	-	-	-	77%	23%	-	-	-
	Dealing with paperwork	75%	14%	4%	4%	4%	77%	8%	-	8%	8%
	Dealing with financial matters	89%	4%	4%	4%	-	75%	17%	-	8%	-
Care Coordination	Reminding of medication	89%	11%	-	-	-	62%	15%	8%	-	15%
	Healthcare tasks (e.g. injections, dressings)	14%	11%	7%	36%	32%	8%	15%	15%	46%	15%
	Arranging/coordinating care	54%	4%	11%	14%	18%	54%	31%	8%	-	8%

As the table above shows, informal carers, regardless of their living arrangements, carried out care tasks in all of the domains, but the intensity of the care provided was different for the two groups. With regard to those tasks associated with nutrition and hygiene, supervision, companionship and practical household work, resident carers carried these out more frequently.

In relation to emotional support and certain aspects of household management, non-resident carers carried out relatively more tasks. Both co-resident and non-resident carers carried out varying degrees of dementia-caring tasks, regardless of their living arrangements. As would be expected, all of the co-resident carers carried out care tasks such as making meals, as well as practical housework, which may have once been shared but were now carried out alone. In addition, carers would have taken on the role of keeping an eye on the person with dementia to keep them safe, e.g. supervision and providing companionship and emotional support. Co-resident carers not only carried out proportionately some of the caring tasks more, but they did it with more time and intensity /frequency, as reported earlier in this chapter.

Generally, the more regularly undertaken care tasks, undertaken by both the co-resident and non-resident carers, are for those individuals in the mild to moderate stages of dementia. Those tasks that were carried out relatively less regularly, which both resident and non-resident carers answered they had ‘never’ done or were ‘not applicable’ to them, suggests that the need to carry out such tasks had not arisen as yet for those they were caring for, as these tasks are generally associated with someone living with severe levels of dementia. However, a smaller proportion of carers reported carrying out tasks associated with more severe stages of dementia such as feeding and managing continence. This corresponds with the sample distribution showing that one third of people cared for were living with a severe stage of dementia. Notably, all care tasks undertaken in all six care domains, by both resident and non-resident carers, were undertaken less often by the non-resident carers.

While a lower frequency of the same tasks might be a factor for the non-resident carers, in a few areas they were doing more than the resident carers. Examples of this include emotional support, which could apply not only to the person being cared for but also for a resident carer, as well as carrying out maintenance of paperwork as part of household management. This could mean that as resident carers were more likely to be elderly spouses, they relied upon their non-resident carer relatives for certain aspects of their care, including emotional support and completion of paperwork to maintain care at home. Non-resident carers were also doing more in the area of dealing with financial matters than resident carers.

To carry out paperwork tasks and dealing with finances on behalf of someone living with dementia generally requires a certain level of legal authority which is usually acquired by obtaining a Lasting Power of Attorney (LPA or PoA). One survey question was designed to ascertain whether informal carers had obtained such powers of attorney. Nearly three quarters of all respondents had obtained a power of attorney, this included 79% of co-resident and 61% non-resident carers. Therefore, regardless of the carers' residence status, they were legally able to carry out such tasks on behalf of the person cared for when this became necessary. This also indicates that the families' decision-making regarding the care of someone at home with dementia involved carers that may or may not live with them. Caring tasks can therefore involve not only the household but also the extended family network, as these individuals might also act as attorneys if appointed and registered to act on the individual's behalf.

From analysing the responses about which tasks carers carry out and with what frequency, it became clear that older co-resident carers carried out more care tasks and with more frequency in general, with some exceptions. As stated above, the performance of all six care domain tasks, especially as dementia progresses, requires skills and confidence in using those skills. The survey therefore also enquired about the respondents self-defined levels of confidence by domain and their participation in relevant training sessions.

7.4.2 Carers’ Confidence

Broadly, a diagnosis of dementia in a household suddenly imposes changes in the division of labour as well as a need to understand and manage changes as the person’s care needs change over time. Thus, a carer’s role increasingly involves undertaking caring tasks, as well as carrying out tasks to maintain a household that may originally have been shared between both individuals. For informal carers generally this shift represents learning new skills, understanding the health condition e.g. dementia regardless of its type, often with a considerable emotional burden for carers. In such cases, the carer’s confidence to increasingly undertake caring tasks becomes very important, as was reported in the qualitative interviews. The survey thus also aimed to establish carers’ self-assessed levels of confidence in carrying out their caring tasks.

Overall confidence levels were low across the tasks that carers need to undertake under each domain in order to continue dementia care at home. Moreover, confidence levels decreased as severity worsened. Although resident carers caried out care tasks with more intensity and for longer periods of time, this did not seem to affect their level of confidence as in some of the tasks non-resident carers had comparatively greater levels of confidence in tasks under one domain, e.g. household management. As the non-resident carers were among the younger aged people and those in employment, they might find it easier to deal with paperwork and financial management tasks. Providing caring tasks for longer did not lead to enhanced confidence levels for the resident carers, as seen in Table 7.6, below.

Table 7.6: Distribution of carers confidence in performing care tasks under six domains by residence status

		Co-resident			Non-resident		
Domain	**Tasks**	**Not Confident**	**Confident**	**N/A**	**Not Confident**	**Confident**	**N/A**
Nutrition and Hydration	Preparing meals	22%	79%	0%	16%	69%	15%
	Assisting with meals	11%	68%	21%	8%	61%	31%
	Preparing special meals and drinks	7%	39%	54%	8%	46%	46%
	Feeding	11%	30%	59%	23%	16%	62%
Hygiene	Assisting with Personal care	47%	43%	11%	46%	31%	23%
	Carrying out personal care	35%	53%	11%	54%	16%	31%
	Continence management and care	40%	36%	25%	31%	38%	31%
Safety	Supervision	46%	54%	0%	31%	69%	0%
	Assisting with mobility	36%	40%	25%	31%	31%	38%
	Dealing with episodes of confusion or hyperactivity	71%	11%	18%	46%	31%	23%
	Assisting with movement	18%	14%	68%	31%	8%	62%
Emotional Support	Companionship	64%	35%	0%	53%	46%	0%
	Supporting social and leisure activities	43%	47%	11%	53%	38%	8%
	Providing emotional support	57%	36%	7%	54%	46%	0%
	Dealing with emotional outbursts	53%	18%	29%	54%	38%	8%
Household management	Practical housework	30%	71%	0%	23%	69%	8%
	Practical out of home work	36%	61%	4%	38%	62%	-
	Dealing with paperwork	32%	60%	7%	31%	69%	0%
	Dealing with financial matters	47%	46%	7%	31%	61%	8%
Care Coordination	Reminding of medication	32%	64%	4%	38%	46%	15%
	Healthcare tasks (e.g. injections, dressings)	15%	25%	61%	16%	23%	62%
	Arranging/coordinating care	43%	39%	18%	61%	23%	15%

In light of reported confidence levels, the study examined the influence of training on carer confidence. The underlying assumption was that increased training builds the confidence levels of informal carers at home.

7.4.3 Dementia Training

Training is key to enhancing the knowledge and understanding of dementia, which increases both the skill set and confidence of the informal carer. The survey sought to assess the level of training among carers in two ways. This was, firstly, through recording whether carers had attended any training specific to performing dementia care tasks under six domains, as reported above; and secondly, whether they had attended any other dementia training courses available for health and carer staff and/or volunteers.

The survey first inquired about whether the informal carer had completed any kind of training related to the care tasks listed in each domain. The results indicated notably low training attendance across survey participants and this was more apparent amongst the resident carers, as shown in Table 7.7.

Most carers responding to the survey reported little or no training in any of the task domains. This is significant because common care tasks increase in complexity as the dementia progresses. For instance, cooking a meal is a routine daily event for most people; however, to meet the nutritional and hydration needs for someone living with dementia specialised knowledge and skills are required, especially when the condition worsens, and carers are likely to be required to make special meals which are both nutritional and easily swallowed. In effect, someone can confidently carry on preparing meals and drinks up until the time such needs arise; however, without appropriate training, there is a risk that confidence will falter and the carer will not be able to respond appropriately. This may then result in malnourishment and/or the person's inability to eat without choking. Such consequences as these can often lead to the end of care being provided at home.

Table 7.7: Distribution of carers training by care tasks under six domains and by residence status

		Co-resident			Non-resident		
Domain	**Tasks**	**No Training**	**Training**	**N/A**	**No Training**	**Training**	**N/A**
Nutrition and Hydration	Preparing meals	86%	4%	11%	77%	15%	8%
	Assisting with meals	71%	7%	21%	69%	23%	8%
	Preparing special meals and drinks	64%	4%	32%	69%	23%	8%
	Feeding	61%	4%	36%	62%	23%	15%
Hygiene	Assisting with Personal care	79%	7%	14%	69%	23%	8%
	Carrying out personal care	82%	4%	14%	77%	23%	0%
	Continence management and care	75%	7%	18%	77%	23%	0%
Safety	Supervision	100%	0%	0%	77%	15%	8%
	Assisting with mobility	64%	4%	32%	62%	23%	15%
	Dealing with episodes of confusion or hyperactivity	89%	0%	11%	77%	15%	8%
	Assisting with movement	57%	7%	36%	62%	23%	15%
Emotional Support	Companionship	96%	4%	0%	85%	15%	0%
	Supporting social and leisure activities	100%	0%	0%	85%	15%	0%
	Providing emotional support	89%	7%	4%	69%	23%	8%
	Dealing with emotional outbursts	86%	4%	11%	69%	31%	0%
Household management	Practical housework	79%	0%	21%	77%	15%	8%
	Practical out of home work	79%	0%	21%	77%	15%	8%
	Dealing with paperwork	83%	3%	14%	85%	15%	0%
	Dealing with financial matters	86%	4%	11%	85%	15%	0%
Care Coordination	Reminding of medication	93%	4%	4%	62%	23%	15%
	Healthcare tasks (e.g. injections, dressings)	64%	4%	32%	77%	15%	8%
	Arranging/coordinating care	89%	0%	11%	85%	15%	0%

Following the question on level of training received, the carer respondents were then presented with a list of available training courses (14 in all) to determine which of these types of training they had attended. A list of these potentially available formal training courses was drawn up, based on an online search and the in-depth interviews with service providers and carers and is presented in Table 7.8. Such courses were offered by different agencies and training providers and could potentially have been accessed by informal carers, although not all in all areas at all times.

Table 7.8: List of available dementia care training courses carers could potentially attend

List of dementia training courses	
Dementia awareness training / dementia friends	Skin care in advanced Dementia
Training about Assistive Technology	Health and hygiene in Dementia care
Safe moving and handling	Managing continence
Communication with people living with Dementia	Emotional support for persons with Dementia
Managing difficult behaviour in Dementia	Reminiscence in Dementia
Food, diet and nutritional needs in Dementia	Art and music in Dementia
Falls prevention in Dementia	Palliative care and end of life support
Others (please specify)	

It was hypothesized here that there is a correlation between training and the confidence level(s) of informal carers, whether task specific or generic dementia training. The number of training courses available to those who cared for persons with dementia and attended are summarized in Figure 7.1 and Table 7.9. Of the 12 carers (31%) who had received some training, only five (12%) had attended more than one course, and only 5 of the co-resident carers had participated in one or more courses.

Figure 7.1: A bar diagram presenting number of dementia training courses attended by carers by resident status

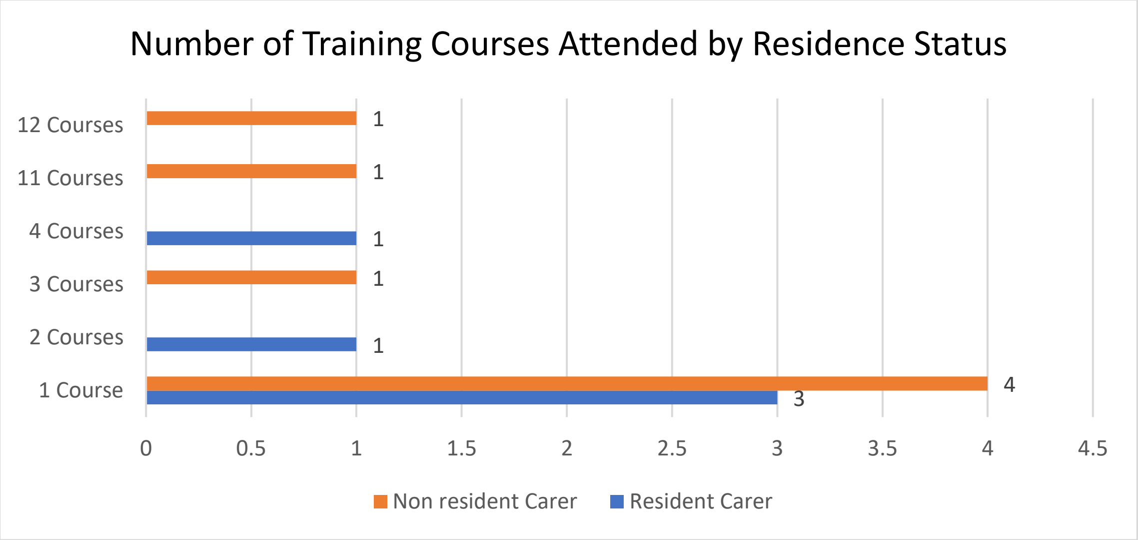


Table 7.9: Distribution of carers by attendance in dementia training by resident status

		Co-resident		Non-resident	
		N	%	N	%
Dementia training	Yes	5	**18**	8	**62**
	No	23	82	5	38
	Total	28	100	13	100

A majority of those respondents who had attended dementia training had only completed one type, which was the dementia awareness course (dementia friends), which aims to raise basic awareness about dementia. Co-resident carers had less training than the non-resident carers, which might be an indication of a working-age population that had more access to information and both the time and interest to attend. Two non-resident carers who attended 11 and 12 training courses were caring for a grandparent and another (unspecified) person. A majority of the co-resident carers (82%) who provided a high level of care had attended no dementia training, which could go some way towards explaining the low levels of confidence reported in performing the more specialised dementia care tasks.

7.4.4 Carer Confidence and Training

A key question is whether access to training opportunities enhanced carer confidence. The results of the survey suggest first of all that few carers had any relevant training. As shown above, some respondents reported that they had attended dementia awareness (dementia friends) training available to them as a member of the community. It did not appear that carers sought to undertake training in order to develop their skills and enhance knowledge about dementia care, or it may not have been available to them. This study attempted to assess the value of training in increasing confidence across the six care domains. A dummy confidence variable and a dummy training variable were created, and a Chi-squared analysis was performed to find out if there was a non-random association of values linking training and confidence. The analysis showed no overall statistical relationship between access to training and level of confidence in carer tasks. A 3-value variable in confidence (no confidence, confidence in 1-3 domains, and confidence in more than 3 domains) and a similar 3-value variable in training was then created. In a further review of the 10 carers who had undertaken training, 7 reported to have some domain confidence, whilst 3 did not. These results suggest that the basic dementia awareness (dementia friends) training *per se* played a very minimal role in informal care in dementia, but it hints at training as holding the potential to an increase in confidence in care domains.

A similar analysis was performed between the co-resident and non-resident carers. The data obtained broadly suggests that the non-resident carers tended to receive more training and to have more confidence, although once again the statistical relationship was not significant. While this is a small sample size, it is clear that task-specific dementia training is widely lacking and there is significant room to increase the task confidence. The current opportunities for training may not be adequate to meet this goal because of the lack of availability and/ or an insufficient outreach effort to include informal carers.

It is interesting that the non-resident carers were more likely to have had training and were relatively more confident in their skills/tasks. This tendency could be linked to the younger age of the non-resident carers or perhaps to more refined/developed self-identity as a carer. Overall, these results reveal a dearth of training for informal carers.

7.5 Services Used and Experience in Integrated Care

This section discusses levels of knowledge about integrated care on the part of informal carers as well as their use of formal services. Within the qualitative Interviews, carers reported that they periodically purchased or accessed a range of other forms of formal care services in addition to their own informal network. These forms included paying for domiciliary care workers, day care services, the use of different types of equipment and attending community support groups and dementia cafés. The types of formal services contained in the survey were compiled based on the qualitative interview responses. The interviews had further revealed that informal carers were well aware of the necessity of an assessment of the care situation as a means of obtaining access to the formal care services. The following section uses the survey data to describe the patterns of use of formal care services and their accessibility.

7.5.1 Carer's Assessment

Access by informal carers to any services within the integrated care system is based on an effective assessment of the needs of both the carer and the person cared for. Under the Care Act 2014 (Sub Section 10), every household is entitled, by right, to a 'carer's assessment' for the carers and a 'needs assessment' for the person cared for. While the carer's assessment seeks to ascertain what help and support an individual carer is entitled to, the qualitative interviews suggested that the intent and results of the assessment were not always clearly understood. The online survey was thus designed to measure the percentage of carers who had received an assessment and their perception of its usefulness.

Table 7:10 reveals that less than half (46.3%) of the carers had completed an assessment, even though about 90% of the sample had been caring for three years or more. Those carers who were co-resident were more likely (53.6%) to have had an assessment compared to the non-resident group.

Table 7:10 Distribution of respondents by carers assessment and residence status

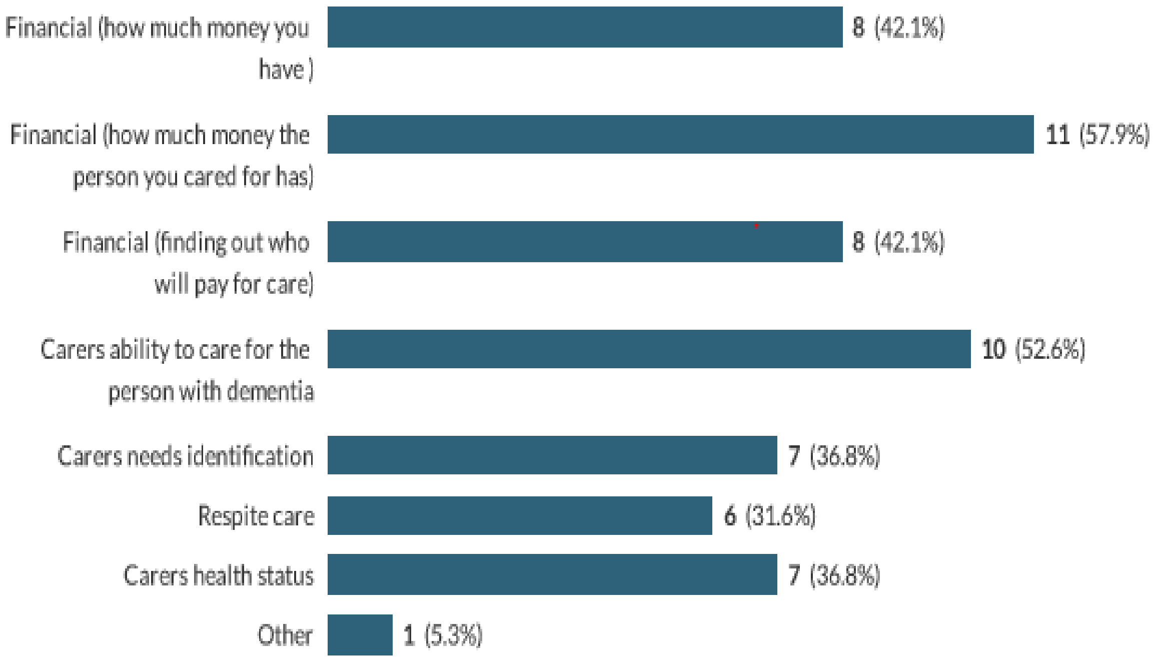
		Co-resident		Non-resident		Total	
		N	%	N	%	N	%
Carer Assessment	Yes	15	53.6%	4	30.8%	19	46.3%
	No	13	46.4%	9	69.2%	22	53.7%

7.5.1.1 Content of the Carer’s Assessment

According to this survey sample of informal carers, the type of information elicited in the assessment varied (presented in Figure 7.2 below). Out of the 19 carers who had had an assessment, most mentioned a dominant focus on the household’s financial means and the ability to finance care. Another frequent topic in the assessment that was reported was the carer’s ability to provide care and their related needs. A final area of inquiry within the assessment was the health status of carers themselves. In sum, assessment enquired into issues of financial ability to pay for care, the caregiving ability of the carers, and the general health of the carers.

Almost one third of respondents also reported that respite for the carer was another aspect covered in the carer’s assessment, although it appeared that the respite would mean the person with dementia would temporarily reside in a care home while the carer had a break from caring. Overall, the dominant factor in the carer’s assessment appeared to be the financial assessment and households’ ability to pay, which ranked in line with the qualitative interviews of carers’ experiences.

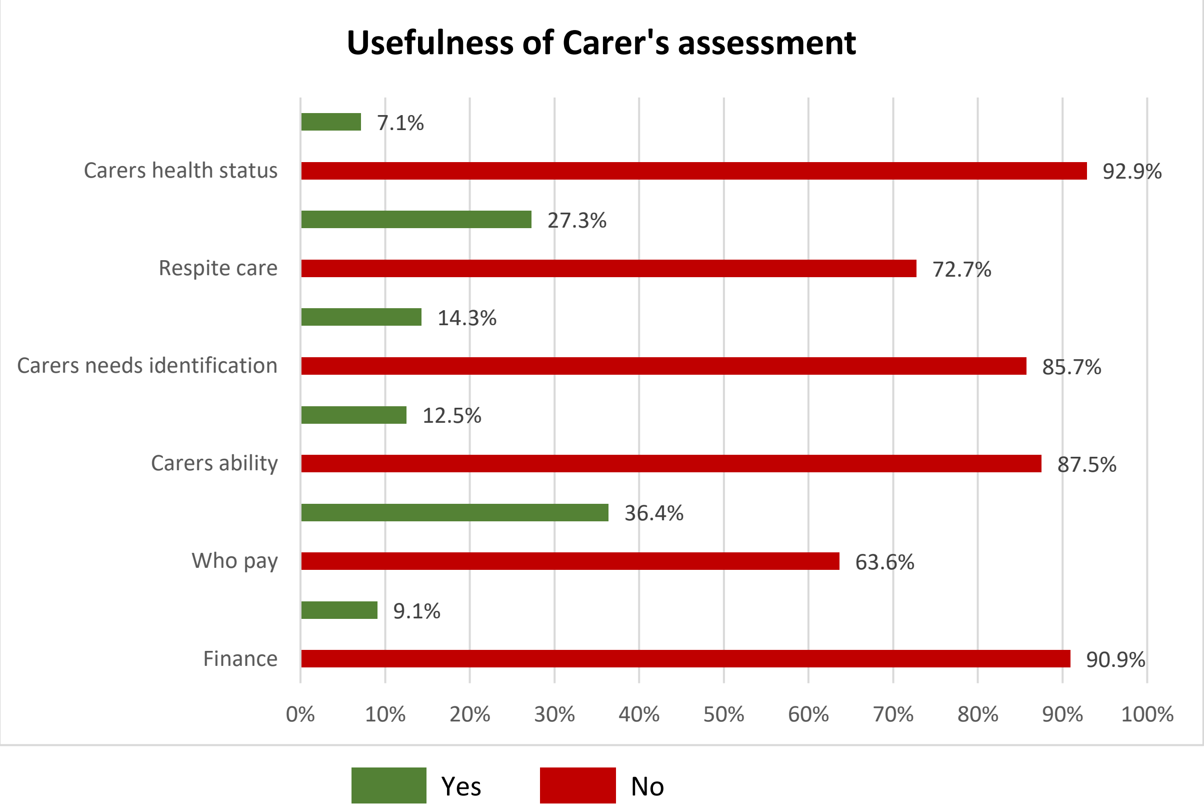
Figure 7.2: A bar diagram presenting types of information gathered in the carer's assessment with number and percentage



7.5.1.2 Utility of Carer's Assessment

It is not surprising that the informal carers, as a group, attributed little usefulness to the carer's assessment. Figure 7.3 presents that for those informal carers who had completed an assessment, the value of the information was viewed as uniformly limited. In fact, a large proportion of co-resident carers had not received a carer's assessment and even for those for whom it was conducted, it was perceived to be of little or no use to them. It is important to acknowledge that from this relatively small sample size it is not possible to generalise about the effectiveness of the carer's assessment, however, it gives a noteworthy indication of patterns and confirms the qualitative findings from the interviews.

Figure 7.3: A bar diagram presenting respondents' perceived usefulness of a carer's assessment



7.5.2 Formal Service Utilisation

A Carer's Assessment is one of the mechanisms to access formal services, although there are other avenues such as a needs assessment of the person with dementia that might result in service provision. Participants in the qualitative Interviews reported they had identified services using a referral process with specific assessments for such aspects as obtaining assistive technology (AT) equipment. Some carers also reported that they were able to obtain other services through information channels and without formal referral, as is the case with the dementia café.

Two thirds (65.9%) of the survey sample reported that they had sought out and used some form of available formal care service, as presented in Table 7.11. Most common among these were use of a domiciliary care service (59%), where a paid care worker assists the person with dementia by providing personal care. More than half the co-resident carers had also attended dementia cafes. Relatively fewer respondents, just under a third (31.6%), reported use of day care services. Just over a third (37%) of the respondents also reported they had made use of either mobility or AT equipment for the person with dementia. Nearly one in three (29.6%) respondents also reported that they had used respite care, whereby the person with dementia went away to a care home for a few days at a time while the carers had a break. Only one co-resident carer reported that they had been away for a period of respite whilst the person with dementia remained at home (with support).

Table 7.11: Distribution of respondents by their use of formal care services and by residence status

		Co-resident		**Non-resident**		Total	
		N	%	N	%	N	%
Purchase/ Access Formal Care	Yes	19	68	8	65	27	70
	No	9	32	5	39	14	34
Paid - personal care	No	8	42	3	38	11	41
	Yes	11	58	5	63	16	59
Paid – house help	No	16	84	7	88	23	85
	Yes	3	16	1	13	4	15
Day care	No	13	68	8	100	21	78
	Yes	6	32			6	22
Dem café	No	9	47	6	75	15	56
	Yes	10	53	2	25	12	44
AT equipment	No	14	74	8	100	22	82
	Yes	4	21			4	15
Mobility equipment	No	14	74	7	88	21	78
	Yes	5	26	1	13	6	22
Respite for PWD	No	14	74	5	63	19	70
	Yes	5	26	3	38	8	30
Respite for IC	No	18	95	8	100	26	96
	Yes	1	5	0	0	1	4

7.5.3 Experiences of Integrated Care

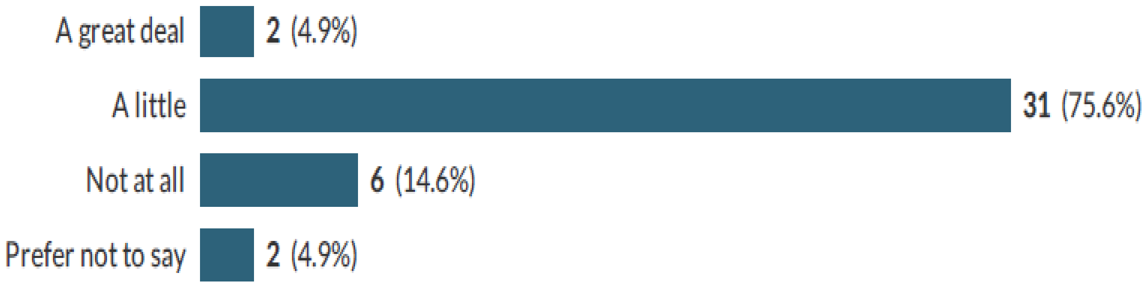
Although at the start of this research, it was assumed that integrated care is a common practice and informal carers would have gained experience within integrated service provision, the results of the qualitative interviews revealed that many informal carers were not aware of integrated care either in theory or practice. The repeated testimony from informal carers regarding the disjointed nature of services, repetitive assessments from different professionals, with concomitant needs, the need to tell the same story again and again confirmed that integrated care appeared to be more a policy rhetoric than an actual experience for carers. The survey of carers thus sought to explore the levels of knowledge and experience carers had of such provision, and to what extent they engaged in working with health and social care workers, as a measure of integrated care in practice.

Figure 7.4 Three bar diagrams showing respondents' knowledge, involvement and experience in integrated care

Knowledge about integrated care

Involvement in integrated care

Experience (working together) with health and social care professionals



The survey information presented in Figure 7.4 confirmed that the majority of informal carers reported little or no knowledge of integrated care systems. Similarly, the vast majority (over 86%) indicated either little or no involvement with integrated care or of working together with health and social care professionals (90%).

7.6 Complementarity of Qualitative and Quantitative Results

The mixed methods design in this study sought to enhance the findings that emerged from the qualitative interviews with the results of the quantitative online survey. The qualitative phase of this research identified through the interviews a range of care tasks involved in caring for someone at home through different stages of dementia. By systematic analysis of the qualitative data, it was possible to assemble multiple tasks into consistent categories labelled ‘care domains’. From the analysis, four care domains to address different needs of the person living with dementia at home e.g. nutrition and hydrational, hygiene, ensuring safety and providing emotional support were previously presented and two domains encompassing the running of the household in which the person resides and is cared for, and coordination of the formal and informal care arrangements were established. The qualitative analysis also revealed carers’ own evaluation of the difficulties with dementia care tasks associated with different domains. Within the online survey, the distribution of tasks and domains demonstrated important patterns across co-resident and non-resident carers, particularly with levels of confidence. Among co-residents, such confidence was shown to be relatively more limited. This result reinforces the qualitative finding that increased training and education are needed to support informal care at home. In comparison, non-resident carers tended to have more training and show relatively more confidence in general than resident carers, although the survey sample size does not allow a generalisation with a high level of confidence. However, these results confirm the qualitative results by showing a low level of care confidence among informal carers and an absence of associated training support.

The quantitative survey was able to describe the distribution of tasks across a sample of carers, comparing those who are co-resident with non-resident carers. The analysis of this distribution pointed out the patterns of carer confidence as related to access to training.

7.7 Chapter Summary

This chapter has presented the findings from an online survey of informal dementia carers, comprising both those who were co-resident with a person with dementia and those who were non-resident but provided regular care. Within this phase of the study, family members who looked after someone with dementia appeared more likely to self-identify as 'carer' when asked anonymously through the online survey as opposed to a question during a face-to- face, qualitative semi-structured interview. The results show that informal dementia carers were themselves predominantly older, co-resident spouses and retired from formal paid work. This group of carers spent significantly more time of the day and days of the week engaged in caring activities, and they tended to have done it for longer periods of time. Co-resident informal care is a huge commitment and a potential source of care burden on older people, many of whom have their own health needs. It is clear from the survey, however, that these carers tended to share any care burden with additional informal carers available to them. In contrast, whilst resident carers undertook relatively more of the tasks associated with the person cared for, non-resident carers assisted more with household management activities and provided emotional help to both the cared for and the carer (if resident and present). A majority also held a Power of Attorney to enable them to act on behalf of the person with dementia, which demonstrates a conscious and collective decision-making process within the household and potentially the wider family. Therefore, it was clear that informal care in dementia is a 'team effort'. However, this is a situation in which older spouses generally shoulder the majority of the burden, and although this will not be the case for everyone, it is highly significant for those for whom it is the case in relation to health and social consequences (and sequelae).

Sustaining dementia care at home totally depends not only on the carer's ability to confidently perform caring tasks themselves, but also to mobilise and coordinate additional informal and formal care support and assistance. A carer's assessment is one of the common mechanisms to access help and assistance, and indeed, a good proportion of carer survey respondents had received such an assessment; however, the utility of these assessments was not perceived to be high. Assessments were reported as being dominated by assessment of financial availability of the household and ability to pay for services. This heavily outweighed any focus on the carer's needs, health and/or their ability to provide, or to continue to provide care. Nevertheless, carers made use of a range of services to a variable degree. Respondent carers' knowledge and experience of integrated care remained very limited, and their own experience, in the sense of working together with other care providers, was also reported as virtually non-existent. This suggests that 'integrated care', although the aspiration of the service providers, remains at the level of a policy rhetoric which is yet to become a reality.

7.8 Conclusion

The online survey positively validated the findings from the qualitative phase of the study, as presented in this chapter. To further triangulate the combined findings of these two phases a focus group discussion was arranged with a mixed group of participants. Findings from this focus group discussion are presented and discussed in the next chapter.

Chapter Eight: Focus Group Discussion

8.0 Introduction

The preceding four chapters detailed the findings of the in-depth interviews with informal carers and dementia service providers as well as the online informal carers survey. This current chapter reports the outcomes of the focus group discussion carried out during the final stage of the research. The purpose of the focus group discussion was to provide an opportunity to analyse the qualitative and quantitative findings in order to explore further the key findings through critical reflection, to expand the range of explanations emergent from the findings, and to identify potential ideas for future plans from the study.

8.1 Focus Group Discussion Participants

Participants for the focus group discussion (FGD) were selected from three categories: staff working at strategic levels, staff working at operational levels, and informal dementia carers. Three participants from each category were invited; however, out of a total of nine invitations, seven participants attended the group discussion, as presented in table 8.1.

This mixed group of participants was carefully selected to represent different insights and viewpoints about dementia care at home. In effect, two previously interviewed participants were included in the FGD to share the findings and the subsequent analysis. The interaction amongst these three categories of participants provided the opportunity to enrich and triangulate the study findings from the interviews and survey.

Table 8.1: Distribution of Focus Group participants by category, gender and years of service/care in dementia.

Participant Category	Participant Code	Gender	Service / Caring for (in years)
Strategic level staff, member of a statutory committee, overseeing resource and policy in dementia care at county level	SSFG_01	F	4
Strategic level staff, member of a multi-agency monitoring group for dementia services	SSFG_02	F	6
Operational level staff – Statutory organisation	OSFG_01	F	6
Operational level staff – Community organisation	OSFG_02	M	9
Operational level staff – Private sector organisation	OSFG_03	F	8
Informal Dementia Carer	ICFG_01	F	5
Informal Dementia Carer	ICFG_02	M	7

8.2 Focus Group Discussion Findings

The FGD generated important insights into the research questions that made up this study. The session also determined the extent to which the findings and interpretations were consistent with the experiences of the participants, and it identified where additional clarifications were needed. The findings from the FGD are presented in four key areas below.

8.2.1 Informal Dementia Care

As reported in the previous chapters, a combination of qualitative interview data and the carers survey results indicated central features of informal dementia care. First, the carers who reside together with the person with dementia living at home are mostly elderly themselves, in a long-term spousal relationship, and retired. Other co-resident carers are adult children who relocated elderly parents into their home as a result of the dementia diagnosis. The second feature of informal care in dementia is it appears to be a group enterprise, and while there is a primary carer often identified by professionals carrying out some sort of assessment, others regularly play a significant role in providing and sustaining dementia care at home.

The focus group participants unanimously agreed with these findings, and all provided examples from their own respective experiences. Four out of five service providers were previously engaged in dementia care with someone close to them, but non-resident with them, including a long-term neighbour who had dementia. This raised an issue about the full picture of informal care, which may include not only family members but also friends and neighbours. The extent and quality of relationship plays a critical role in such care arrangements and beyond, in terms of availability and acceptance.
Insights from the FGD participants included:

> *"Once their loved one is labelled a dementia patient, the family members start to pull together, some family members step in, some seek help, some family members offer to help, but it all depends on the relationship." (OSFG_02)*

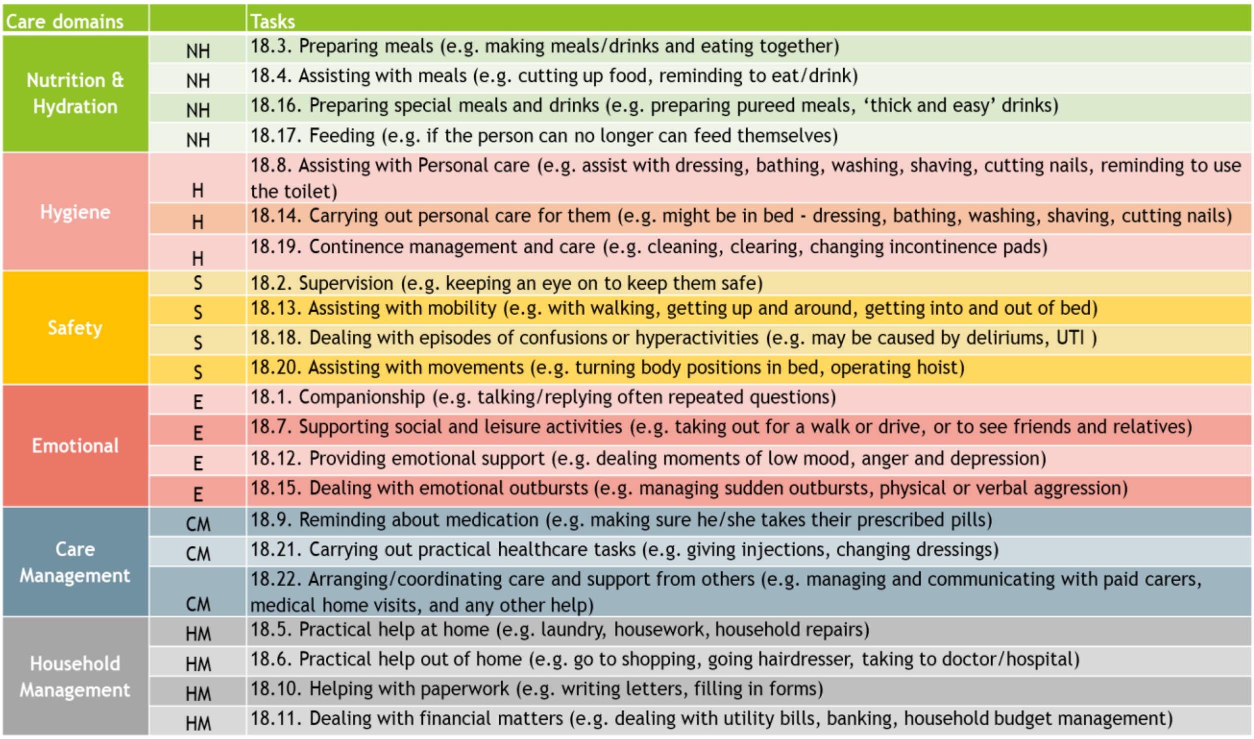
> *"It really depends on the individual with dementia agreeing to receive the assistance on offer, from a family member, friend or even from domiciliary carers; they may accept from one person but not from another, …. if someone with dementia does not want help, it is hard to help, and it is possible to have a genuine conversation only if there is a good relationship." (OSFG_03)*

The influence of the personal relationship in dementia care becomes clearly apparent, not only in terms of the acceptance of informal care but also in accessing formal care resources.

8.2.2 Dementia Care Domains

The qualitative interviews and survey data provided an understanding of what constitutes dementia care at home, specifically, the six interlinked care domains. The discussion worksheet (Table 8.1) was used to generate reflection and discussion. Participants were divided into three small sub-groups with strategic, operational and carer participant categories to review, which was followed by discussion of the whole group.

Table 8.2: Image of a Focus Group discussion worksheet on dementia care tasks and domains



Care domains		Tasks
Nutrition & Hydration	NH	18.3. Preparing meals (e.g. making meals/drinks and eating together)
	NH	18.4. Assisting with meals (e.g. cutting up food, reminding to eat/drink)
	NH	18.16. Preparing special meals and drinks (e.g. preparing pureed meals, 'thick and easy' drinks)
	NH	18.17. Feeding (e.g. if the person can no longer can feed themselves)
Hygiene	H	18.8. Assisting with Personal care (e.g. assist with dressing, bathing, washing, shaving, cutting nails, reminding to use the toilet)
	H	18.14. Carrying out personal care for them (e.g. might be in bed - dressing, bathing, washing, shaving, cutting nails)
	H	18.19. Continence management and care (e.g. cleaning, clearing, changing incontinence pads)
Safety	S	18.2. Supervision (e.g. keeping an eye on to keep them safe)
	S	18.13. Assisting with mobility (e.g. with walking, getting up and around, getting into and out of bed)
	S	18.18. Dealing with episodes of confusions or hyperactivities (e.g. may be caused by deliriums, UTI)
	S	18.20. Assisting with movements (e.g. turning body positions in bed, operating hoist)
Emotional	E	18.1. Companionship (e.g. talking/replying often repeated questions)
	E	18.7. Supporting social and leisure activities (e.g. taking out for a walk or drive, or to see friends and relatives)
	E	18.12. Providing emotional support (e.g. dealing moments of low mood, anger and depression)
	E	18.15. Dealing with emotional outbursts (e.g. managing sudden outbursts, physical or verbal aggression)
Care Management	CM	18.9. Reminding about medication (e.g. making sure he/she takes their prescribed pills)
	CM	18.21. Carrying out practical healthcare tasks (e.g. giving injections, changing dressings)
	CM	18.22. Arranging/coordinating care and support from others (e.g. managing and communicating with paid carers, medical home visits, and any other help)
Household Management	HM	18.5. Practical help at home (e.g. laundry, housework, household repairs)
	HM	18.6. Practical help out of home (e.g. go to shopping, going hairdresser, taking to doctor/hospital)
	HM	18.10. Helping with paperwork (e.g. writing letters, filling in forms)
	HM	18.11. Dealing with financial matters (e.g. dealing with utility bills, banking, household budget management)

The participants confirmed that this research effectively captured what constitutes dementia care at home, with such comments as: "*it was spot on,*" *(ICFG_01)* and how this *"birds-eye view of dementia care" (SSFG_01)* helped to define a clear picture of the different yet interconnected aspects of dementia care.

One key issue that the participants found to be missing was online safety of the person with dementia and their carers. The suggestion was that this should be added to the safety domain and task of supervision, as there is an increasing number of people able to make use of IT devices. On-line access offers an important benefit for some to keep in contact with their family and friends, which helps them to combat loneliness and seek emotional support; on the other hand, people could become vulnerable to online scams and other potentially criminal activities. This risk increases with degrees of cognitive decline. Another key issue raised by one of the carer participants was the need to communicate about safety with the person with dementia, which can often lead to emotional outbursts. This, once again, highlights the interconnectedness of different domains.

The group agreed on the innate complexity of dementia care tasks, especially recognizing that each case is in some way unique. Different people require different packages of care. Also, the tasks involved in achieving certain outcomes change over time and many of the tasks often overlap. For example, at an early stage, someone with dementia may only require a meal to be prepared, while after a deterioration in condition more assistance is required for nutritional intakes. Managing care at home, which requires effective navigation of care systems, was highlighted to be one of the most difficult issues in continuing to provide dementia care at home. The group also supported the domain approach to dementia care and suggested it offers a long term and holistic view of dementia care needs, thus helping prepare carers in advance to deal with such declines. It can also offer providers a broader foundation for an effective plan with and for the person with dementia and their carers.

8.2.3 Integrated Care in Dementia

Discussion of integrated care started with dementia care pathways which, from a carer's point of view, represents a cycle of assessments, hospitalisations, risk management, breaking points, re-referrals and re-assessments, and so forth. From the beginning of the dementia journey and throughout the period of decline, dementia care is explained in terms of episodic, disjointed interventions. Participants shared numerous examples of what they had witnessed:

> *".. people are not listened to at the beginning, pushed away, well you have a diagnosis of dementia, and you have to have assessment, many carers even struggle to have a proper assessment." (OSFG_01)*

> *".. well simple things like side effects of medication that the person can have, are not made clear to carers at times, it very much depends on what your GP is like, if you can get services or not." (ICFG_01)*

> *".. there is a lot put on the memory tests and the principal diagnosis is based on memory, but dementia is much more than memory, it is complicated and not always understood by professionals to the extent to help carers." (ICFG_02)*

On numerous issues, cares and service providers shared common insights. For example, the timeliness of interventions was described as follows:

> *".. it is when they need it, timing of giving information is very important, carers struggle to navigate systems and they don't know what they don't know, and giving information at one time is not useful, until something is relevant to them, there is no one size fits all.." (OSFG_02)*
> *"building carers' capacity is the key, capacity to cope and capacity to care" (OSFG_03)*
> *".. it is probably shortage of staff, nurse, OT, it takes too long to access any help.." (ICFG_02)*

The effectiveness of assessments was highlighted by participants, for its repetition and lack of clarity. One explained,

> *"we muddle financial and needs assessments, it's like.. we are cutting cloth according to availability, without considering the size of needs.. (laughter), so we make a dress according to what we have, but it does not fit the person.. we need to pay more attention to the person we're planning the care for.. " (SSFG_02)*

Integrated care in dementia according to the participants was more a buzzword than a reality. As stated by some participants:

> *" The majority of people don't know what it (integrated care) is, family and people working in the sector alike." (OSFG_02)*
>
> *".. sadly, complicated systems, information sharing, make integrated care difficult.." (SSFG_03)*

> *"It has become more of a political issue than health and social services working together in an integrated way to help people who need help." (OSFG_03)*
>
> *"…putting together time and energy for one set of assessments to understand the situation could be a first step for working together… it is exhausting to tell the same thing again and again. Filling in forms again and again.. " (ICFG_02)*

Difficulties in sharing data between agencies were highlighted as key barriers to better integration.

8.2.4 Future Actions

The final focus theme, consistent with research carried out from a pragmatist viewpoint, was, 'so what?' and 'what can be done?' The ensuing dialogue in the discussion yielded a number of ideas which informs the discussion and conclusion chapter of this study. Social aspects of food and drink in dementia care and the power of *'a cup of tea'* (compassion and empathy) in combating carers' loneliness and isolation were mentioned. Often professionals are not supposed to receive a drink while on home visits, for their own safety. At times, however, it can be a powerful source of trust-building between carers and service providers as well as enhancing rapport, leading to better and more integrated support for the person with dementia.

The carers' competence check and training was identified to be a critical aspect, which is currently absent. As one of the participants stated:

> *"Informal carers are our frontline defence really, and we don't check if they are up for it, and we don't give them any training to learn the job either.. training for informal carers is still not a priority for social services or anyone else…" (OSFG_02)*

Another point emphasised was the way that needs are assessed and understood by professionals, often focusing solely on the person's ability or inability to carry out certain tasks. With dementia it is more complex. Where there is an informal carer present the needs are more interdependent, and may even be interlinked, thus requiring a more holistic understanding to fully address the needs of people with dementia.

8.3 Chapter Summary

This chapter has presented the findings from the last and final phase of the study, the focus group discussion with service providers at strategic and operational levels and informal carers in dementia. This group discussion provided an opportunity to discuss combined findings from both the in-depth interviews and the online survey. It offered the participants an opportunity for scrutiny of the research process, critical reflection and some further analysis of the study findings. The discussion also enabled further exploration of ideas for future actions in research and practice, that could potentially improve and sustain dementia care at home where informal care is available.

The collective nature of informal care was confirmed, where, alongside an older partner/spouse resident carer, an informal care network remains in many cases, consisting of family members and friends. Nevertheless, the older spouses most commonly carry responsibility for the majority of the dementia care at home as co-residents, and their ability to continue to provide this is significantly dependent upon the informal care network that exists. The value and strength of the relationship between the person needing care and the people willing to provide it are critical elements of informal care arrangements. Also apparent was that dementia care at home constitutes a complex and wide range of variable tasks that change over time and which are often interlinked. Using a domain approach to describe and operationalise what is involved in dementia care can be an effective way to assist service providers and informal carers alike to explore, understand and address care needs and this may be particularly relevant over a long period of time.

An ability to access timely and appropriate services was confirmed to be another important aspect in relation to sustaining dementia care at home. However current assessment procedures to access such assistance appear to be neither agile nor effective. While it is widely accepted that person-centred integrated care is the best way forward, turning it into reality remains filled with systemic and systematic difficulties, among which are interagency communication, the sharing of information, the prioritization of dementia care, and finding effective ways to work together with informal carers.

Finally, informal dementia carers were perceived to be the frontline workforce and appropriate education and training to upskill carers is important. Informal carers' willingness and determination to care, if complemented with timely and appropriate practical dementia care training and appropriate support interventions from formal services, could hold the key to achieving improvement and sustainability in dementia care at home.

8.4 Conclusion

The focus group discussion positively supported the findings from the previous phases of the study, as presented in this chapter. The next chapter will present a discussion in relation to the four key research questions based on study findings and conclude with suggestions and recommendations for future directions in this area.

Chapter Nine: Discussion and Conclusion

9.0 Introduction

This chapter presents a discussion of the study findings in relation to the research questions in the context of the existing literature. It outlines the methodological strengths and limitations of the study and presents implications and recommendations for policy, practice, and future research.

9.1 Research Context, Aim and Questions

To reiterate the context and purpose of this research, it is apparent that both health and social care services face an impending crisis caused by the demands of an increasingly older population. To address this crisis, UK health and social care services will need to expand and support the role of informal carers within an integrated care strategy. Person-centred integrated care has been already accepted as one of the principal ways to achieve effectiveness and efficiency in the context of an ageing population, a reasonable proportion of whom live with complex health conditions such as dementia. The value of the informal care contribution in terms of dementia care costs is already estimated at over £11.6 bn annually (Alzheimer's Society, 2007; Knapp *et al.*, 2014) , and without it, the health and social care system would be likely to experience significant strain and potential collapse. Despite this importance, empirically-based research on the nature of informal care at home for people with dementia has been lacking. Relatively little is known about what dementia care at home entails, who and how well-equipped informal carers are, what support is needed to sustain dementia care at home to reduce and delay institutionalisation, and how informal home care is best integrated with formal health and social services.

The aim of this research has been to expand our understanding of informal dementia care at home. To achieve this aim, the research engaged the participation of informal carers and service providers to generate a systematic and detailed description of what dementia care at home entails. Findings from the study have proposed that informal dementia care consists of six domains, each comprised of an assortment of tasks. Furthermore, it has elicited from informal carers perceptions of their level(s) of confidence in performing these tasks as well as the support they have received or feel they need. At the same time, the inclusion of research interviews with service providers in dementia care enabled identification of the challenges of dementia care and how formal and informal care can be better integrated. And as importantly, this research has given voice to a group of people not often listened to. It has provided a markedly human face to reality of dementia and the difficult decisions that are made in the context of providing care at home.

Specifically, this aim of this research is summarized in the following research questions:

1. Who are the informal carers in dementia and how prepared are they to care at home?
2. What constitutes dementia care at home in the community setting?
3. What is the carer's experience and assessment of integrated person-centred care services?
4. What kinds of support do informal carers need to sustain dementia care at home?

In the course of this research, each of these questions was addressed, and the sections below provide the relevant findings and analytical insights.

9.2 Who are the informal carers in dementia and how prepared are they to care at home?

9.2.1 Informal Dementia Carers

Accurate age-disaggregated demographic data of informal dementia carers is, to my knowledge, not readily available. However, some facts and characteristics are well known. Two thirds of informal carers (nearly 4 million in 2000) in England provide care for people over 65 and more than a fifth of such carers who co-reside with the care recipient provide care for 100 or more hours a week (Beesley, 2006). The older generation supplies a disproportionate amount of care, one in five over 65-year-olds was a carer (Beesley, 2006), and older carers, e.g. aged 85 and over, are most likely to be a carer for someone with dementia (Parkinson *et al.*, 2017; Carers UK, 2019).

The findings of this study are consistent with such profiles. The majority of informal carers in dementia are themselves elderly, women, in long term spousal relations, retired, and many have significant health problems of their own whilst co-residing with the person they care for. Other co-resident carers are either a single child, or an only living child, caring for their parents, where 'co-residency' is by relocation of the person with dementia as a direct result of dementia progression.

Co-resident informal care is a huge commitment and care burden on older people, especially on many who have to deal with their own health issues. However, the interviews suggested that while such older spouses assume the 'primary' informal carer's role, they often share the burden of care with 'secondary' informal carers. These are often members of the extended family and friends. The survey further confirmed that 40% of the co-resident and 86% of non-resident carers had 'additional informal carers' sharing care tasks with the respondents. Therefore, it is clear that informal care in dementia is a 'team effort' whereby elderly spouses shoulder the majority of the burden, and although this will not be the case for everyone, it is highly significant for those for whom it is the case. This study proposes that informal caring is not just one person carrying out everything alone for someone with dementia but is often a group effort within which there is a principal provider, who is supported by extended members. This result must be interpreted with caution, however, as the extended network could be variable and not equally available to everyone however, and such additional care contributes significantly to overall care in sustaining someone living with dementia at home.

9.2.1.2 Being and Becoming the (Informal) Carer

One of the intriguing findings in this study was carers' perceptions of their own identity as carers. Most co-resident informal carers, regardless of their gender, whilst in face-to-face interaction during interviews, did not identify themselves as a "carer" even after years of "looking after" someone and referred to the term as "paid care worker" and not to themselves. However, when asked anonymously, regardless of their resident status or the amount of care provided, survey respondent carers identified themselves as carers by participating voluntarily in an online survey. This may indicate that carers accept themselves as being a carer individually or privately before socially expressing their role as an informal carer. Existing literature suggests that carers' identity is significant in care and it changes over time with important implications for intimacy and sexual relationships with their sick spouses, although not always in adverse ways (Hayes, Boylstein and Zimmerman, 2009). The importance of preserving a sense of 'identity' of the person with dementia is widespread, as well as dilemmas surrounding this while caring for someone in a close relationship (Orr and Teo, 2015). This study observed such dilemmas strongly existed in carers who are long-term spouses, and notes that some people may never assume a self-perception of the carer identity. However, for other carers there are individualistic, predicted perceived turning points, which are not uniform as they are in professionals having a 'caregiving career trajectory' (Ducharme *et al.*, 2011, p. 493).

From the study, the self-perception as carer is not related to the length of care or the years of living with a person with dementia. Rather the transformation to the identity of "carer" was more determined by the type of activities such care required, such as dealing with personal care and incontinence or having to make household decisions. This evolution into the identity of carer is often not conscious, or spontaneous, and was recognized only after some reflection. In the end, this self-perception only matters if it influences a carer's attitude towards dementia care, and about when and how further formal/ informal assistance should be sought.

9.2.2 Carer Preparedness

Carers’ preparedness constitutes two key aspects – the first is carer having the confidence to care, which is underpinned by appropriate dementia care knowledge, attitude and skills; the second is the existence of robust coping mechanisms. These aspects are often associated with care training.

9.2.2.1 Carers’ Training and Confidence

Carers’ confidence is central to providing good quality dementia care, regardless of where the care is delivered. Numerous researchers have presented the value of relevant training to enhance knowledge and skills and consequent confidence (Doyle and Ward, 1998; Featherstone *et al.*, 2004; Surr *et al.*, 2016; Livingston *et al.*, 2019). This study found from both interviews and survey, that overall carers’ confidence level is relatively low about continuing to provide dementia care at home and it drops even lower as dementia severity worsens. Although resident carers carry out care tasks with more intensity and for longer, it does not seem to affect their level of confidence, therefore ‘doing something’ for a long time does not equate to ‘enhancement of confidence’ or ‘doing with confidence’. Non-resident carers, although providing less volume of care, in some aspects showed higher levels of confidence, which coincides with survey findings that non-resident carers had attended relatively more training than co-resident carers.

Training has been a proven way to enhance knowledge and confidence as well as to change attitudes in dementia care, among hospital staff (Surr *et al.*, 2016; Surr and Gates, 2017; Elvish *et al.*, 2018), nursing staff workers at care homes (Scerri and Scerri, 2019) and care workers in care homes (Featherstone *et al.*, 2004; Hughes *et al.*, 2008) . Introduction of a dementia training standard framework (Department of Health and Social Care, 2015; Health Education England and Skills for Care, 2018) has mandated that all the health and social care workforce required to be dementia trained. This is without doubt an encouraging step towards enhancing the confidence of the formal workforce and the quality of care provided;

unfortunately, however, the dementia training framework has left the informal carers behind. Efficacy of dementia training is not only evident in the enhancement of knowledge, attitudes and confidence of health and social care staff in challenging aspects of dementia care, but is also apparent for informal carers. Although rather limited, research suggests that carer training improves carers' knowledge, skills and perception (Taylor *et al.*, 2009; Morris *et al.*, 2018), their communication strategies and skills with the person with dementia (Haberstroh *et al.*, 2011; Morris *et al.*, 2018) , their coping strategies (Livingston *et al.*, 2013) and managing behavioural problems and delaying institutionalisation (Teri, Larson and Reifler, 1988; Feast *et al.*, 2016).

This study found that while carers assume their dementia caring role, it is mostly done with a view that they will 'learn on the job'. As Upton (2005) put it 'grasping the nettle' e.g. by taking full responsibility for care (Upton and Reed, 2005). Currently, there is neither a requirement for basic understanding nor any mechanism to enhance carers' understanding of dementia care in order to assume or continue their caring role. Inevitably, a range of understanding and emotions was displayed by carers in this study, ranging from compassion and acceptance with a sense of humour to frustration and anger, and sadly, an indicative display of a profound lack of understanding and misunderstanding of the condition. Whilst some carers were able to accept deviations away from 'normal' or 'expected' behaviour as a result of dementia, others struggled to understand why their loved one acted in certain ways. Dementia presents no obvious signs of immediate physical change; therefore, the motives for behavioural aberrations can be misinterpreted as 'intentional'. Such misunderstanding leads to emotional stress for both the carer and the person with dementia, as they are often closely emotionally linked. In the study, family carers who had a good level of understanding of dementia were more likely to accept the common features that are expected, although their knowledge did not seem to confer any advantages in terms of 'know-how' and practical skills in dealing with dementia. This widespread spectrum of awareness and skills in carers demonstrates that being 'willing' to care for loved ones, does not always assure being 'able' to care for them with confidence and readiness.

Most carers in this research had little or no training that could enhance their readiness in performing care tasks confidently to meet the needs across the different care domains. This is significant because common care tasks increase in complexity as the condition progresses. For instance, cooking a meal for most is a routine daily event, however, to meet the nutritional and hydration needs for someone living with dementia requires special knowledge and skills, especially as the condition worsens, and carers are required to make special meals which are both nutritional and even pureed. In effect, someone can confidently carry-on preparing meals and drinks up until such needs arise, but without appropriate training there is the risk that confidence will then falter, resulting in malnourishment or choking. Such consequences as these can often lead to hospital or care home admission.

The only training that carers had attended appeared to be some basic dementia awareness training, and most had accessed this as a member of the community or part of the workforce, and not as a dementia carer. The value of and need for carer education about dementia care became apparent in this study, which is currently extremely limited. Well-intended carers can fall short in their care efforts simply because they do not know how to undertake certain aspects of dementia care. Participants made efforts to learn by doing and used peer sharing wherever possible to fill the gaps to acquire the know-how, however, if their source of learning had no training themselves, it could just become a dangerous cycle of misinformation about dementia care. Appropriate training at the right time could not only enhance empathy and understanding about living with dementia, but also provide day-to -day skills that carers can utilise to improve their efforts, which are essential for carers' readiness to care and the wellbeing of both themselves and the cared-for person.

9.2.3 Carers' Coping Strategies

An effective coping mechanism is a crucial part of carers' readiness. This study found that informal dementia carers utilise three key coping strategies to sustain and continue care at home. These were first, moderating self-behaviour by conscious efforts to stay calm and patient, second, by reaching out to a wider social network for help and support, and finally, taking brief periods of respite. Through adopting and enhancing 'patience' carers coped from an early stage of dementia when repetition of questions persisted, subsequent interactions as well as managing episodic difficult behaviours. When the limits of their patience were exceeded, it was common for carers to employ other forms of coping strategies, such as calling on an extended support network.

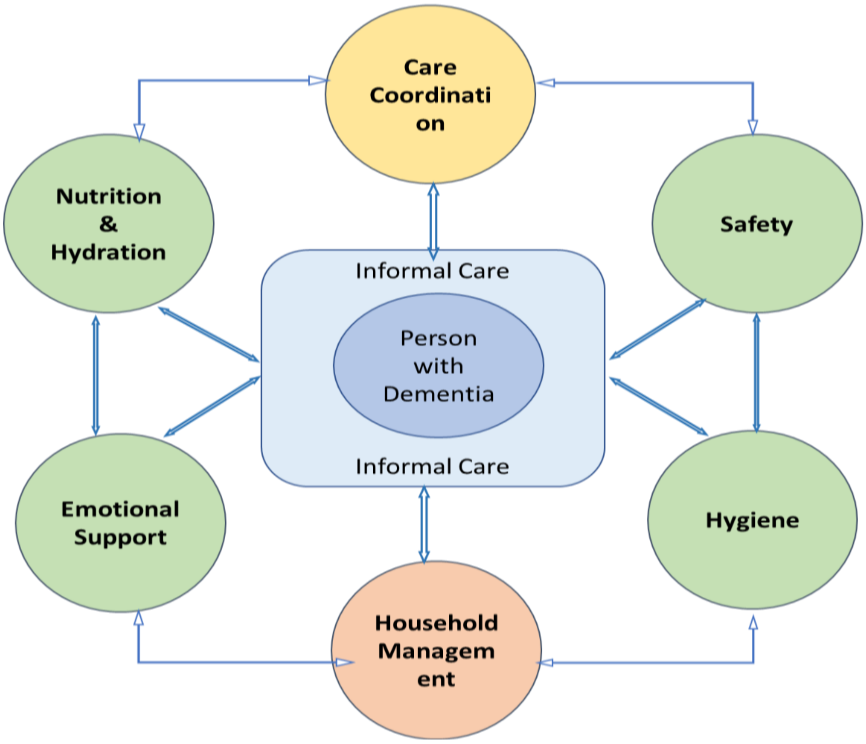
The current study found that the older carer, as part of their support network, often relied on adult children and longstanding friends. These forms of support involved help with carrying out practical care tasks to run the household, provision of emotional support and brief respite from everyday care where someone else would provide supervision. Most carers were also reliant on utilising formal respite from formal institutions that offer respite care.

9.3 What constitutes dementia care at home in the community settings?

9.3.1 Dementia Care Domains

Based on my results, I propose six dementia care domains essential for maintaining care at home for someone with dementia. Four of the domains identified here cover nutritional and hydrational needs, appropriate hygiene, safety, and emotional support for the person living with dementia at home. The other two involve the actual running of the household where the person resides and is cared for, and coordination of their care arrangements. The six dementia care domains are equally critical and are delicately interconnected, needing careful balancing at all times in order to achieve, as well as sustain, the overall care needs of the person living with dementia at home. Successful management of all six care domains holds the key to sustaining care at home, and informal carers are the linchpin for this care arrangement. There are myriad care tasks associated with each of the care domains and these are dependent on the type and stages of dementia with which someone is living.

Figure 9.1: Care Domains Relevant to Dementia Care at Home



9.3.1.1 Nutritional and Hydrational Needs

The first dementia care domain addresses the nutritional and hydrational needs of the person living with dementia from an early stage of the condition up to the end of their lives. The associated tasks within this domain could be broadly divided into three categories - food and drink preparation, assisting and ensuring consumption and monitoring as well as addressing any changes that might affect the person's unwillingness and/or inability to eat or drink. Dementia affects the ability to prepare and consume food and drink safely. People living with dementia are known to experience differing effects relating to eating behaviours, such as a change in food preference which develops in earlier stages, an increase in appetite and altered eating habits, and finally swallowing problems (Ikeda *et al.*, 2002). Some types of dementia are known to lead to changes in a sequential pattern and therefore can be somewhat predictable. For example, frontotemporal dementia presents such a pattern more clearly than Alzheimer's Disease (Ikeda *et al.*, 2002).

That achieving appropriate levels of nutrition and hydration for people with dementia in a care home or hospital presents a significant challenge is evident in numerous studies (Bryon, Gastmans and Dierckx de Casterlé, 2010; Abdelhamid *et al.*, 2016; Nell *et al.*, 2016). Use of oral nutritional supplements, food modification, dysphagia management, and assistance with eating are some of the common interventions that have been researched (Abdelhamid *et al.*, 2016). In addition to the practical aspects of feeding the person with dementia, meeting nutritional needs for people with advanced levels of dementia poses further ethical and legal dilemmas, including such challenges as food refusal in palliative care or intervention with artificial nutrition (Wasson, Tate and Hayes, 2001; Esther-Lee, Ofra and Goodman, 2016; Chen *et al.*, 2018).

Eating and drinking difficulties form an essential part of care needs by both professionals in health and social care institutions and by informal caregivers (Miranda-Castillo, Woods and Orrell, 2010, 2013; Abdelhamid *et al.*, 2016). Most intervention research, however, focuses on institutional health and care settings such as hospitals and care homes. Social care needs assessments tend to focus on individuals having access to or being able to prepare food and drink by themselves (Alzheimer's Society UK, 2020). While such assessments might appropriately identify the needs for someone without dementia, it might easily fail to capture the nutritional and hydrational needs of a person with dementia; in effect access to food does not equate to fulfilment of nutritional and hydrational requirements. Having a co-resident informal carer may ensure access to food and drink, however, further measures may be required to meet this need appropriately. Addressing the nutritional and hydrational needs of the person with dementia remains a crucial aspect of care that informal carers deal with on a daily basis.

9.3.1.2 Maintaining Appropriate Hygiene

The second domain is to maintain appropriate hygiene at different stages of dementia. Physical ability as well as apathy and depression contribute to someone with dementia not being able to achieve appropriate levels of personal hygiene. An inability to manage appropriate hygiene contributes to further behavioural problems. The interconnection between some of the behavioural issues and incontinence and poor hygiene has been reported before and was presented as one of the predictable characteristics in dementia (Teri, Larson and Reifler, 1988). This study found challenging behaviour and emotional outbursts, especially in men, to be closely connected to an early incidence of incontinence, especially faecal incontinence, which causes emotional stress to both people with dementia and their carers.

This combination of incontinence and challenging behaviour has been identified as a great stressor for carers, but not as a driver for seeking institutional care (Upton and Reed, 2005). This study's findings are consistent with that finding. Incontinence was the greatest anxiety for carers, and where either type of incontinence is yet to appear or presented itself as a rare accident, carers reported fear of an increase in regularity and saw this as a reason for ending care arrangements at home. In contrast, carers who were managing such situations gained more experience with both forms of incontinence at home and did not consider this as a prime reason for care home admission at all. It is, therefore, perhaps not the incontinence itself but the management of incontinence at home that was the key factor in determining whether to continue care at home. Previous research also shows that the stigma associated with incontinence at times results in carers being reluctant to seek help from health care providers until it reaches a crisis point (Drennan, Cole and Iliffe, 2011). The current study found professional attitudes to incontinence and dementia and the apparently narrow outlook towards understanding incontinence as a whole to be a significant barrier to addressing the issue.

Overall, unmanaged incontinence, which represents a breakdown in the management of hygiene at home, was reported as the most significant trigger for care home admission. Although often viewed as two distinctly separate issues, this research found 'incontinence' and 'emotional stress leading to challenging behaviour' in dementia, perhaps more closely interlinked than previously presented, and the cumulative effect of the combination can threaten the continuation of care at home. Inability to maintain appropriate hygiene causes emotional stress for carers as well as to the person with dementia, which at times is displayed as challenging behaviour resulting from loss of control over ones' body, leading to anger, sadness and frustration.

9.3.1.3 Ensuring Safety

The third dementia care domain is concerned with ensuring someone with dementia at home is safe. A failure in safety often results in a dementia diagnosis and is one of the top triggers for ending care at home and admission to residential care. This study found that safety measures at home encompass two different contexts that require differing amounts of care: 'continuous', and 'intensive'. With dementia, difficulties such as sight loss, mobility and balance, impulsiveness, lack of judgement and understanding of risks tend to worsen over time and require continuous safety measures. In addition, from time to time a more intensive level of care is required if the person becomes hyperactive and increasingly prone to risky behaviour due to an underlying health issue such as a urinary tract Infection (UTI) or delirium.

Safety at home and making the home safe appears as the topmost concern shared by health and social care professionals for someone living at home with dementia, and this is reflected in the vast amount of research and practical guidance in this area. Older people living at home are among the 'at risk' group for certain safety concerns, and dementia only serves to raise the magnitude of risk further. Among safety-related issues at home are incidents of falls and these risks are exacerbated with dementia (Shaw and Kenny, 1998; Kudo *et al.*, 2009; Petersen *et al.*, 2018), leaving home and getting lost, e.g. 'wandering' (Hope and Fairburn, 1990; Hope *et al.*, 1994; Klein *et al.*, 1999; Algase *et al.*, 2004), and an increase risk of fires and burns (Harvey *et al.*, 2016). In addition, not eating and drinking and self-administered medication errors are also perceived as safety concerns at home (Douglas, Letts and Richardson, 2011) as well as traffic accidents (Wang and Carr, 2004). This study found traffic incidents/ accidents (and near misses) were more common amongst men and were often evident before diagnosis, and even acted as a trigger to get the diagnosis.

Previous research has identified six safety concerns for informal carers at home. These are: injury from falls, injury from ingesting dangerous substances, wandering, injury to self or others from sharp objects, fires or burns and inability to respond rapidly to crisis situations (Gitlin *et al.*, 2001; Lach and Chang, 2007). This study found that as the condition worsens, carers assume more and more safety-related tasks to ensure safety – from supervision/ 'keeping an eye on someone' to assisting with mobility and safe moving and handling. This management of safety tasks is a constant effort, with periodic elevations as people with dementia suffer from an episode of UTI or delirium, which can cause hyperactivity and the person to become even more 'accident prone'. A range of safety devices and equipment is commonly offered by professionals and used to assure safety in dementia care. These broadly fall under two categories - Assistive Technology devices for people with early stages of dementia, and Occupational Therapy (OT) equipment and aids for all stages of dementia. However, for people with advanced stages of dementia, more complex OT equipment is required, such as lift/truck hoists which are currently associated with higher operational costs, such as requiring two trained and paid care workers to operate them. The cost of such safety assurance at times leads to a care home admission, especially when care costs are met by social services. At any point, a major safety incident is enough for carers and the person they care for to lose control over the care arrangements, as an imposed deprivation of liberty may be applied and a decision for residential home admission could be taken with or without full consideration of the person's and their carer's preferences.

9.3.1.4 Providing Emotional Support

The fourth care domain is to provide emotional support to the person with dementia, which represents one of the most challenging aspects of dementia care according to the carers, whilst at the same time can be one of the most rewarding. This is probably one of the most un- (or under-) recognised care needs in dementia. Previous research has recorded the significance of a dementia diagnosis and proposes it to be a social act and not just a medical process (Husband, 1999; Aminzadeh *et al.*, 2007). Aminzadeh et al. (2007) reported the emotional response to a dementia diagnosis for the patient as a grief reaction, a display of an emotional crisis related to the experience of actual or anticipated losses associated with dementia (Aminzadeh *et al.*, 2007). The current study found that such emotional despair does not disappear with the progression of the disease, but, if anything, perhaps becomes greater, even well into its progression, which is consistent with (Magai *et al.*, 1996; Magai and Cohen, 1998) who found fully intact and functional emotional systems present even at the last stages of dementia.

As dementia progresses, individuals experience personal losses of various types that affect their emotions, at times manifesting themselves in emotional outbursts that can compromise personal safety. Other common emotions experienced by people with dementia can include excessive attachment, suspicion and accusation towards the carers and others causing hurt, frustration and upset for carers. Family carers and those whom they care for often have close emotional bonds, and at times this becomes an emotional tug of war having significant impact upon both parties. This is often displayed as emotional breakdown in carers and behavioural challenges in the person with dementia, the two most commonly found issues in dementia care. Previous studies have focused on supportive communication with the person with dementia (Done and Thomas, 2001) and managing behavioural and psychological symptoms in dementia (Georges *et al.*, 2008; Ringer *et al.*, 2020). This current study proposes that one underlying cause of carers' emotional stress and behavioural outbursts of the person with dementia is rooted in unmet emotional support. This is in line with Kitwood's person-centred approach in which behaviour is perceived as an expression of emotion and needs (Kitwood, 1997).

While carers regularly carry out a range of tasks to provide emotional support such as companionship and managing outbursts or anger, the power of positive emotion in dementia care cannot be underestimated. Being able to share laughter, enjoy leisure activities or have someone to talk with, all help carers to maintain their own emotional well-being, which in turn helps them to support their loved ones for longer. To sustain dementia care at home it is crucial to understand the emotional needs of the person and those of their carers, and the degree to which these are interconnected. A carer's positive emotions are vital to help maintain their resilience and can be nurtured when they have access to a good social network from which they can access and obtain emotional support.

9.3.1.5 Household Management

The fifth dementia care domain involves uninterrupted and continuous management of the household, ‘the home’, e.g., ‘care premises’, where the person with dementia is being cared for and where they reside with their family carer. The running of a household involves a range of tasks and activities including practical tasks in and out of the house and dealing with paperwork and household finance management. This is another under-recognised aspect of care at home. Very limited research exists in this area, although looking after the home and money was explored as a significant need for people with dementia and their carers (Miranda-Castillo, Woods and Orrell, 2010). This current study found household management of much greater significance in sustaining dementia care at home than so far recorded.

Household management tasks fall broadly into three categories – carrying out practical tasks inside and outside the house, dealing with paperwork, and managing household finances. Over time, most households adapt a division of labour arrangement, where individuals living within the household accept some responsibility for certain aspects of running the household, some individually, some together with others, and some collectively. When dementia affects one member of a household and whose ability then diminishes, these longstanding arrangements become disturbed, and certain adjustments and rearrangements are necessary to maintain the smooth running of the household. Wider family or a friend network often step in and carry out tasks that were once performed by the affected person. If the alternative arrangements are not in place and the person with dementia carries out what they have done previously, such attempts can lead to falls and accidents leading to further physical and emotional decline. Management of finances also often comes with associated anxiety for carers about being able to pay for or contribute to institutional or other paid care whilst still having to maintain their own household expenses.

9.3.1.6 Care Coordination

The sixth and final domain in dementia care at home is the coordination of care e.g. health and social care delivered at home. This includes the arranging, delivering and sustaining of formal and additional informal care for the person living with dementia at home. Carers carry out a range of health care tasks themselves, including reminding about and the administering of medication. In addition, they deal with paid carers (where existing) and negotiate with and oversee various other care interventions by health, social care, voluntary and private sector providers. While the family carers' ability to manage this coordination effectively could ensure the sustainability of dementia care at home, a positive and trusting working relationship and collaboration between family carers and various service providers is essential. Failure to achieve this could be overwhelming for carers and lead to a breakdown of the care arrangements at home. Some carers are able to draw upon help from their neighbours, friends and relatives for practical assistance, and kind and willing neighbours were perceived by carers in the study to be a great source of comfort and help due to their closer physical proximity. This informal support network is important to help manage the household, provide appropriate care and also to help deal with formal care arrangements.

Management of medication for the person with dementia has been identified as a significant care domain (Travis, Kao and Acton, 2005) as it has potentially serious consequences. This study finds medication management forms only a part of the care coordination domain, which may be performed by the carers themselves or a qualified health care professional if that is more appropriate. Even if the medication management is not undertaken directly by the family carers, and is administered by the health service provider, carers are still required to arrange and monitor such activities. Access to any health and social care services also involves various assessments and reassessments which form part of this care domain.

9.3.2 Interconnection of Care Domains

These six dementia care domains are of equal importance and delicately interlinked, and failure to effectively manage any one of these domains could have a domino effect on others and could compromise their overall success.

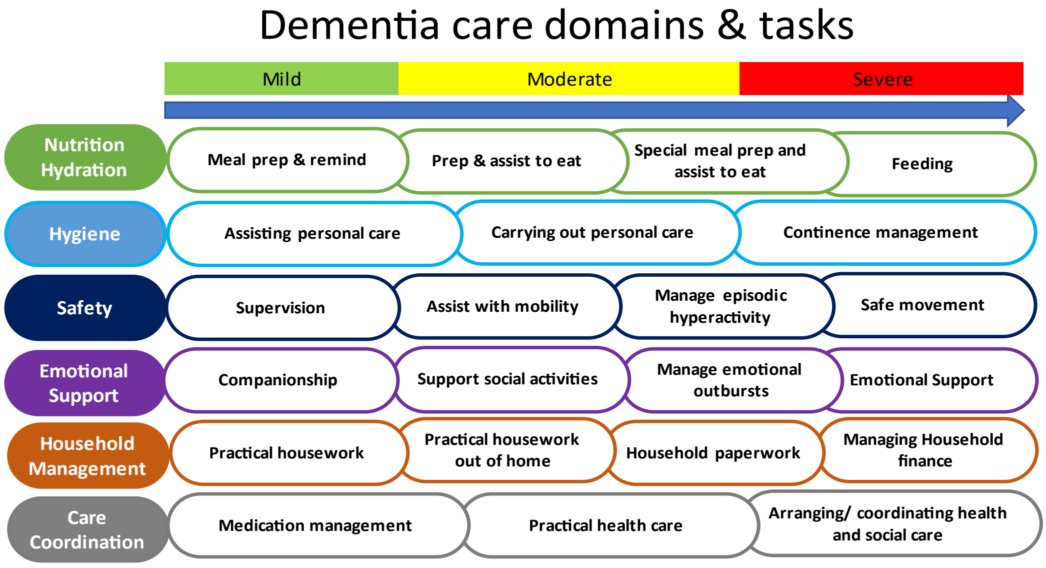
For instance, safety issues and concerns are closely interlinked with other care domains such as nutrition, hydration and hygiene, as food preparation is not without risk of fire and burns and consumption carries risks of choking or swallowing problems (Lach *et al.*, 1995). Poor hygiene could contribute to the development of other health issues such as skin-related problems, UTIs, and associated safety issues. Without safety assurance, nutrition, hydration and hygiene cannot be achieved. Safety also has profound emotional consequences, not only for people living with dementia but also for their carers. Incidents such as being involved in a traffic accident or having a fall can affect people and their confidence levels deeply. For example, the person with dementia could have a fall as a result of attempting a simple household management task, like changing a lightbulb that involved climbing a small ladder, which they have done all their lives. Further, the emotional consequences of something like losing a driving licence causes huge distress and upset on the person with dementia which carers have to deal with by providing the appropriate type and level of emotional support. A deeper understanding of these domains, their connectedness and their effective management could not only delay institutional care admission but also improve the quality of person-centred dementia care provision at home.

9.3.3 The Six Domain Model of Dementia Care Tasks

The six-domain model developed and presented in this research encompasses what constitutes dementia care at home settings where informal care is available. Two key features of this model are their interconnectedness and changeability over time. The domains are closely interconnected and have positive or negative effects upon each other, and tasks within each domain are changeable over time dependent upon the stages and abilities of the person living with dementia. This model has been developed based on the study findings, and while not a comprehensive list of tasks, it does document the critical tasks required to achieve positive outcomes in each of the key domains.

There are multiple care tasks associated with each of the care domains and these are dependent upon the type and stages of dementia with which someone is living. As someone progresses to more severe levels of dementia, the actual care tasks associated to achieve the same functioning outcomes change. The task sets that have been presented in this study (Figure 9.2) are not an exhaustive list of dementia care tasks, nevertheless they represent the diverse tasks informal carers carry out to meet the needs of the person progressing through different stages of dementia while residing at home. Tasks within the first four domains mark the progression of the condition. For instance, preparing meals and eating together may be enough to achieve nutritional and hydrational needs at an earlier stage of dementia. But as the condition advances towards more severe levels, preparation of additional special meals and drinks may be necessary and even feeding assistance may be required in the severe stage at a point when the person can no longer feed themselves independently.

Figure 9.2: Care Domains with Associated Tasks



Regardless of their living arrangements (either resident or non-resident), informal carers carry out these tasks, but the intensity of the care is different at different points in time resulting from the progression of the dementia. With regard to those tasks associated with nutrition and hygiene, supervision, companionship and practical household work, resident carers carry these out more frequently. With regard to emotional support and certain aspects of household management, non-resident carers carry out relatively more tasks. This could mean that as residential carers are more likely to be elderly spouses, they rely upon their non-residential carer relatives for certain aspects of the caregiving including emotional support and paperwork to sustain their care at home. Non-residential carers do more in the area of dealing with financial matters than residential carers. To deal with paperwork and finances on behalf of someone living with dementia, a certain level of legal authority is required which is usually obtained by a Power of Attorney. This study found three quarters of respondents had the Power of Attorney and were therefore able to carry out such tasks on behalf of the person cared for. This also indicates that the families' decision-making regarding the care of someone at home with dementia involves carers that may or may not live with them. Caring tasks therefore involve not only household members but also, importantly include the extended family network, where available.

In sum, the six-domain care model with associated tasks provides a basis upon which to assessment the needs of the person with dementia and their informal carers. It therefore informs the development of further assessment toolkits and contributes to a richer understanding of informal dementia care at home and in the community.

9.4 What is the carers' experience of integrated person-centred care dementia care services?

9.4.1 Carers Experiences of Integrated Care

To reiterate from Chapter two (literature review), the NHS England's definition of integrated care is "person-centred, coordinated, and tailored to the needs and preferences of the individual, their carers and family. It means moving away from episodic care to a more holistic approach to health care and support needs, that puts the needs and experience of people at the centre of how services are organised and delivered" (NHS England, 2020). For over forty years it has been the policy aspiration that integrated health and social care would offer three key benefits: better outcomes for service users and patients, make limited resources go further, and improve peoples' experience of health care and support (Humphries and Curry, 2011). This study focused on exploring the experience of the carers in relation to integrated care in dementia.

The 'Integrated care' model is accepted worldwide as a health care service that provides seamless, well-coordinated person-centred care delivery. This study, however, found the integrated care model wanting with regard to such coordination in the case of dementia care. There were frequent expressions of frustration by participants in relation to the current practices and a stated desire for a more holistic approach to health care, social care, and other support that is inclusive of the contributions of informal carers. My findings dovetail with a Government Select Committee report (2018) acknowledging that progress has been slow in achieving integrated care at local levels of health care (House of Commons Health and Social Care Committee, 2018). It is entirely possible that the study area was one of those where progress has been slow and therefore has not yet been felt by service users and carers. However, some of the service providers' perceptions of the narrow purpose of integrated care was concerning, as it also has an effect on carers' experiences of integrated care services.

9.4.2 Service Providers' Perceptions of Integrated Care

The understanding of integrated care demonstrated by provider participants was twofold. The non-statutory agencies providers perceptions of integrated care were, broadly, that they were an outsider to integrated care, akin to an onlooker. On the other hand, the perception of integrated care expressed by providers from the statutory agencies demonstrated an apparently singular focus on the financial savings that integrated care is supposed to deliver. Although limited in number, there was evidence of efforts to reduce care packages in delivering integrated care. ‘Cost efficiency’ is one of the perceived benefits that integrated care is supposed to deliver, although plenty of research evidence indicates that integrated care does not save money, at least not in the short term, and could even lead to a rise in cost in the delivery of person-centred integrated care (Nolte and Pitchforth, 2014; Parkin, 2019). Unfortunately, as ‘cost saving’ appeared to have gained prominence in providers’ assessment processes, this may be detrimental to determining appropriate needs for the people with dementia and their carers. Information management, and the fear of regulatory breaches of data protection was reported to almost paralyse some providers, and instead of sharing information they simply resorted to not sharing in order to avoid any potential breach and consequent consequences. Service providers, especially from health care organisations, considered a Multi-Disciplinary Team (MDT), as synonymous with integrated care, as it appeared to be the only operational aspect of integrated care in the healthcare sector. While ‘co-location’ was effective for some, it did not resolve apparent issues around sharing information about patients and developing shared perspectives with professionals from other disciplines. The friction between health and social care charging structures was repeatedly highlighted by provider participants as being one of the key barriers preventing an integrated care system from developing, and the gap between funding sources from care services and individuals who self-funded their own care did not appear to be fully recognised. The concept of ‘person-centred’- ness was also yet to be recognised in the service providers focus on delivering integrated care.

9.4.3 Carers’ Experiences of Assessments

The reported interactions with the formal care system presented a common trajectory which usually started with the involvement of emergency services. It appeared a common practice for the GP to conduct an annual dementia review, but there were often no further contacts unless some other emergency situation developed. This cycle of crises is typically sparked by an emergency incident leading to hospital admission or an ambulance call out, followed by social services intervention. Such encounters involved countless assessments, not only at the time of crisis and by the emergency agencies involved, but also subsequently by various other potential service providers as the person could be referred on to other services. Every service provider interviewed reported that they had carried out assessments to determine the suitability of services for certain individuals, appropriateness of equipment, and eligibility for any of the services which might be on offer. Nevertheless, health and social care services are the two main gateways to access any kind of services except ones provided by some community organisations, such as dementia cafes.

Carers in this study were clearly fatigued by their experiences of assessments. The assessments were faulted for being too repetitive and lacking, particularly in sufficient dignity being afforded to the person being assessed. Such repetitiveness might be a result of ineffective information sharing, both within and across agencies. The lack of information exchange was reported as both inefficient and frustrating for carers. This study finds that information sharing remains a challenge, a point also emphasised in the work of Mastellos and colleagues (Mastellos *et al.*, 2014).

Social services have a statutory duty to conduct two types of assessments for persons with dementia and their carer. These are the person's needs / financial assessment and a carer's assessment. The financial assessment is undertaken to determine whether the person with dementia is over or under a 'financial threshold' and to ascertain responsibility for and contribution(s) to any subsequent service provision. For carer participants, financial assessments seemed to take precedence over other concerns since this establishes who will pay for care.

Although obtaining an assessment for access to services was not always straightforward or easy, all respondents reported that they had been assessed during their time as a carer. While they did not necessarily distinguish between assessment for themselves as carers or the person cared for, they were quite clear on their feelings about the limitations of these assessments. These were reported as including their episodic and inflexible nature, the overly narrow financial focus, and sheer assessment fatigue commonly suffered by both carers and service providers. Although an assessment should be a means to an end, in the case of dementia care it appeared to participants to be an end in itself. More often than not the assessment was stated as being the main ‘intervention’ offered by support services.

9.4.4 Role of Holistic Assessment in Integrated Care

An effective long-term support plan may be crucial in providing and sustaining dementia care at home, and such plan development depends on effective and meaningful assessments. The reported current assessment and re-assessment processes were perceived as neither effective nor useful by most carers, and should be reviewed in order to make them more person-centred and person-owned. To establish person-centred care within everyday care is known to be challenging and requires attention to detail in the support plan while taking into account individual life stories and knowledge about health condition, social psychology and their personality (Rahman, 2017). An integrated holistic assessment for someone with dementia should involve the person with dementia themselves and their carers from the very onset of the diagnosis. This requires periodic reviewing over time but not a repeat assessment from the start each time. None of the participants in this study reported that they had received such an assessment

In such assessments, the person with dementia must remain at the heart of the plan and ideally co-produce the support plan while they are still able to. An overly-narrow focus on financial income and capital assessment appears to be counterproductive in assessing and understanding needs. The value of social capital is paramount in elderly care but does not currently appear to be acknowledged in any assessment. This study argues informal caring is a part of social capital that individuals in need of care have invested in over their lifetime and might now be in a position to draw upon. While it is extremely important to acknowledge that not everyone would have informal carers available to them, for those who do, the situation could be highly beneficial to the service providers. Most importantly, even where an informal carer exists there should be no reason to assume that they can simply provide dementia care at home because they appear both willing and feel obliged to.

9.4.5 Integration at Personal Level

Three different levels are identified where care could be integrated: the personal level, a service level and at an organisational level (House of Commons Health and Social Care Committee, 2018), and this study focussed closely on the personal level. One key element of this is the coordination of the services provided for the person living with dementia at home. This indeed is one the key dementia care domains undertaken by informal carers while someone is cared for at home. From the carer's viewpoint care coordination of dementia care involves four types of service provider agencies — statutory, voluntary, community-based, and private sector. Efforts to integrate care in dementia at other levels appears to really only involve part of the statutory services, e.g. health and social care. Other providers remain outside of the integrated care circle, and those service providers in this study, while recognizing the need for service integration, remained frustrated and unclear about how this could be achieved and how they might contribute.

There is less attention to 'integration', in terms of the relationship between formal, public providers and the informal, unpaid care provider, who is often a family member, neighbour, or member of the immediate community. The contribution of the informal care provider, who is effectively a bridge between both the medical and the social components, is considered to be significant, but is not seen explicitly as a part of the current integrated model, due to the complexity and the demands on carers' time. Informal dementia carers invest enormous amounts of care time and a well-coordinated and integrated service provision might indeed reduce the time burden by improved coordination.

9.4.6 Integrated Care in Dementia

'Integrated care' is mainly driven by the NHS, which is explained in simplistic terms as 'person-centred coordinated care' (Department of Health, 2013), to be experienced by both people with dementia and their carers. Person-centred integrated care confers benefits on both carers and service providers' knowledge and experience in both the organisation and delivery of such services. The findings from this study determined that integrated care is not as yet a fully operationalised approach to dementia care, and confusion concerning its meaning and application was widespread amongst the respondents. While there was total agreement among study participants that it is needed, it was reported as frustratingly absent.

Previous research called for integrated dementia care to be person-centred and holistic, inclusive of a multidisciplinary team of health and social care practitioners as well as the patient, the family and the wider community (Robertshaw and Cross, 2019). The findings of this study support this position and further suggest the inclusion of the voluntary and community service providers, as they often play a significant role in the person's life and care. This further supports Sixsmith and Woolrych's (2012) suggestion that to achieve benefits from integrated dementia care a shift in the structures of care delivery is required. This will encourage freedom and innovation amongst those delivering face-to-face care, ensuring that those living with dementia and their informal carers are effectively supported (Sixsmith and Woolrych, 2012). An early intervention supporting carers is known to be more effective (Ducharme *et al.*, 2011) than interventions only at breaking points. Therefore, with timely and appropriate innovative support, informal carers can sustain dementia care at home, and the person with dementia can stay and be cared for at home for as long as possible.

Kitwood (1997) taught us about person-centredness in dementia by stressing that the person with dementia deserves respect and must remain at the heart of any person-centred approach (Kitwood, 1997). There appears to be an almost blind assumption that because someone is willing to take care of the person with dementia, they are also capable of doing so. This is not only alarming as a care practice but may also impact negatively upon both carers and the person cared for. It is important to remember that care of older people is a skilled task and in relation to dementia it becomes a yet more specialised enterprise. Without appropriate training, education and support, informal carers can neither become nor remain effective carers.

9.5 What kind of support do informal carers need to sustain dementia care at home?

To determine what support mechanisms can help sustain care at home, it is necessary to understand what motivates people to assume a caring role and to continue to deliver care at home.

9.5.1 Reasons for continuing care at home

Continuing to provide care at home is often a complex decision that family members make over other alternatives such as institutional care in a care home or nursing home. This study found two factors that contribute to this decision. These are: family values together with gratitude and the sense of duty on one hand, and the financial reality of paid care on the other.

Not all, but some families have very strong multi-generational bonds and a sense of strong care values which are grounded in a sense of filial gratitude, nurtured over a long period of time. In such families the younger generation would help with care for older family members and spouses will remain together until death. For these carers, care is simply an accepted aspect of family life, given and received over generations. Some individuals have witnessed and experienced examples from their childhoods of when their grandparents were looked after by their parents residing in the same house, and the expectation is that such ‘care values and culture’ continues. It is simply assumed that children and their partners will step up to take care of the parent with love and perseverance. Carers who hold such values extend them to their spouses, and many carers expressed that their determination to care derives from their family values as well as their deep love and gratitude towards their long-term spouses. A sense of gratitude was also prominent across carers. Ability to care for a loved one at a time of need provided a great sense of satisfaction for the carers, despite it being a life-changing adjustment for some. The findings from this study confirmed previous work that explained caring being a burden as well as a source of satisfaction for carers (Grant and Nolan, 1993; Pratesi, 2011). Among families where a strong multi-generational family value of care across generations exists, a group effort for caring is also very prominent. In such cases, whilst one person is generally primarily responsible to care and co-resides, there are others who assist if and when needed. To provide care is perceived as a ‘success’ and it is seen as an ‘achievement’ to be able to care for a loved one at home. Carers who fulfil this not only felt a sense of achievement but also gained respect from others.

The second common factor which influences the decision to continue caring at home is the financial burden of institutionalised care, especially for older couples who are retired and have limited income. The cost of care plays a disincentive role in seeking help with care and contributes to delaying care home admission, particularly for those people who would have to pay the full care costs themselves. In addition, the cost of care is a key contributor affecting carers’ reluctance to seek day care, to have a care worker to provide help with personal care, and to use short-term admission for respite at a care home. For retired couples, there was a great deal of uncertainty and anxiety about not only being able to afford the cost(s) of care for the person with dementia but also the remaining partner being able to afford to continue to live at home with less income if their partner moved to a care setting. When two people receive a pension, they may well manage comfortably, but if one enters a care home, household income may be halved, and so the remaining spouse may not be able to cover home expenses.

9.5.2 Addressing Care Needs at Home

There is an ever-increasing body of research evidence and knowledge with respect to dementia care in institutional settings, both in hospitals and care/nursing homes (Surr and Gates, 2017). At the same time there is a significant lack of evidence to inform dementia care in home settings where an informal carer is present. As seen in this study, the specialised care needs of the person with dementia arise while they are living at home and clearly do not only exist when someone is placed in institutional care. Depending upon the type of dementia they are living with and its progression, these needs are likely to be unique, variable and to develop over time. Therefore, it is critical for carers to know how to address dementia care needs at home.

The management of carer stress, coping mechanisms and resilience has been a central part of the discussion about sustainability of dementia care at home. Addressing all the care needs of the person could have the potential to increase carers' stress levels, and appropriate coping strategies are crucial to maintain care at home (Livingston *et al.*, 2013; George and Steffen, 2015). The ability to manage care at home often appears to depend on having appropriate formal service provision for the person with dementia as well as for the carers themselves. While there are two distinctive assessment provisions in place, a needs assessment for the person with dementia and an assessment for the carers, these are often mingled and could contribute to an ineffective care package being put in place. However, in the absence of a comprehensive dementia care domain set which could provide a framework for understanding individual needs, it is impossible to fully assess the appropriate support strategy. Whilst all care needs may not be provided for or offered by formal service providers, it is important to explore how these might be met. For example, some of the practical tasks for household management may be performed by an extended family-friend network; however, even if a formal service package cannot address some of the needs, it is important to acknowledge that a real need (in that particular domain) exists.

A comprehensive needs assessment is a pre-requisite for identifying a fully appropriate support package. Moreover, it is critical to acknowledge that dementia care requires specialised assessment. In the dementia specific needs assessment, the questions to be asked may not be whether or not someone with dementia could or could not perform specific activities of daily living, such as food preparation, but the starting point to assess needs has to be how his/her nutritional and hydrational needs are to be met, safely and sustainably. This should be personalised and flexible over time to not only address increasing levels of needs but also to address carers' stress and sustain care at home. The six interconnected dementia care domains presented in this research offer an initial comprehensive framework for holistic needs assessment and care education to support carers and people with dementia in a proactive, person-centred way that sustains care at home.

9.5.3 Respite in Dementia Care

Respite care forms a critical part of informal carers' coping strategies and comes in many forms. This may include a brief break of several hours provided by someone within the informal network such as a family member or a friend, a day care centre that receives a person with dementia during the day, attending a dementia café together with the person with dementia, or placing the person with dementia in a care home for a short-term stay.

The study found that day care facilities regularly offered by social services, in combating loneliness in older people, had reportedly become more of a 'holding facility' according to the respondents, for people with high levels of health and care needs, particularly where there is no alternative available and the carer is (at risk of) reaching a breaking point. As fewer people benefit from social services referrals, assessment and support with payments, those who were liable to pay for the service have seen an increase in costs. In some day care centres, where there used to be a 'waiting list', increasingly there are now empty places. In addition, higher costs are deterring others who would have to pay for themselves. In turn, the number of day care facilities have decreased as many have closed their doors. In parallel however, the dementia café has increasingly filled the short-term daytime respite gap.

A dementia café is a community organisation mostly run by volunteers, free of cost and can be accessed without any formal referral or professional assessments. The dementia café offers numerous activities for carers as well as people with dementia. Carers normally attend the café (also known as a club) together with the person they care for, and often a volunteer will engage the person with dementia in some leisure activity, leaving the carer the time and space to do something for themselves. A dementia café offers carers the opportunity to draw upon each other's experience and support. Unlike a day care centre, ‘affordability’ is not an issue for access to the dementia cafe; however, availability and quality remain major issues as the resource is not widespread, and standards are variable.

Short term respite care in a care home for periods of one or two weeks is perceived by service providers and carers alike to be one of the most important coping strategies. The decision about use of a care home for respite purposes is usually associated with signs of carers reaching breaking point and mostly admission to a care home is preceded by a financial assessment to determine who is responsible for the payments. Although respite care in a care home is one of the most commonly used coping mechanisms offered and utilized by family carers, it is reported as beset with difficulties such as the cost, availability, and identifying which care home will accept a person at what stage of dementia and will be appropriate individual’s needs. Some care homes may not accept someone even after their own assessment determines the person’s suitability for a temporary respite admission. There are numerous grounds on which a person with moderate to severe level of dementia may not be accepted: they could be assessed as being potentially ‘too difficult’, a perception that their ‘needs are too complex’, the person might be considered ‘too destructive to other residents’ or they are ‘wanderers’. However, even once accepted, returning home after a week or two often causes readjustment difficulties, which at times can elevate the level of carer stress. The care home respite can aggravate the potential disorientation and confusion of the person living with dementia. As they move from their familiar surroundings at home to an unfamiliar care home environment, people can find themselves confused by not knowing where things are and may even forget where things are when they return home after respite. Such a disruption in routine can subsequently lead to a permanent care home admission, ironically defeating the very purpose of the respite care to be able to continue care at home.

This study found that while respite remains the most significant and critical coping mechanism for carers, it appears to have unintended negative consequences for the person with dementia. Unfamiliarity and confusion in the person with dementia could lead to other difficulties, such as aggression or incontinence arising from simply not being able to find the toilet, causing additional further stress. In the absence of any form of dementia care education for family carers, respite may well only exacerbate already fragile care arrangements at home.

9.5.4 Support for Informal Carers

To determine the sustainability of care at home, this study proposes three key aspects to support informal carers – holistic assessment of needs (of the person with dementia and carers), enhancement of carer awareness, knowledge and skills in dementia care, and support to maintain and expand carer coping strategies.

The limitations of current carer assessments were explored and presented in detail in this study. A comprehensive assessment that combines the needs of and the availability of household capitals (including social capital) could improve realistic and effective care plans. Carer training that focuses on enhancing their knowledge and skills to care is essential and should be a regular intervention. Finally, understanding the array of existing coping mechanisms accessible to the individual carer and support to maintain and even develop such strategies is essential to improved care in the community context.

9.6 Strengths of the Research

The key strength of this study is the use of mixed methods in clear and purposefully planned stages. This allowed for interpretation and integration of the research findings at different points. The first stage of qualitative interviews required considerable time to be spent with the carers, mostly at their homes, which was useful to gain insights into individual situations and relationship dynamics between the carer and the person they cared for. In addition, having personal experience as a carer helped in understanding many aspects of the situations people were in and provided a sense of affinity and empathy, as well as enabling me to come to terms quickly with the terminology used. However, caution had to be taken not to impose any unconscious bias; this was achieved by employing strict reflexivity within the research and my approach to it. With conscious mindfulness of the positive and negative aspects of ‘insider and outside status’ (Dwyer and Buckle, 2009, p. 59), by regular discussion with my supervisory team and by adopting mitigating strategies such as keeping a reflexive journal, I was able to use my status to strengthen my research. Interviewing service providers offered further insight to crystalize issues with a more holistic perspective. Subsequently validating qualitative interviews by an online carers’ survey and a focus group discussion with a mixed group of participants (carers and service providers) to present emergent findings proved successful in allowing me to scrutinise and finalise the study findings.

An additional strength of this study is its unique multidimensional conceptual approach. The integration of the pragmatist philosophical worldview with Sen’s capabilities theory and the sustainable livelihoods framework offers an action-oriented analysis on dementia care as a protection of varying aspects of functioning through the utilisation of various forms of capitals. My past exposure to the sustainable livelihoods approach and Sen’s development philosophy provided me with a familiar conceptual background to weave these diverse strands together.

9.7 Limitations of the Research

Upon reflection, and with the benefit of hindsight, I can identify a number of areas that indicate some limitations to this study and which could have been addressed differently. The first limitation is the involvement of people with dementia in the study. At the outset of the study planning, the decision was to include informal carers of people with advanced stages of dementia and service providers of dementia. Persons living with dementia and being cared for by these carers were excluded on the basis that unintended negative impacts could result from attempted inclusion. Ethical challenges arising from interviewing both carers and the person with dementia would also have had to be considered carefully and addressed. However, in the course of the interviews, I had the opportunity to meet and spend time with all except three people with dementia being cared for by the carers. The three people I did not meet arose for a number of reasons: at the time of the interview of their carers, one was in hospital, one was in a day care facility and another was asleep in a different room. I had social discussion with nine others and these conversations provided extremely useful insights. However, although they were included as part of my research journal, they did not form part of my research data and therefore were not analysed. This was a huge loss, as this study could have been enriched if the perspectives of the people with dementia were included in the design and I would certainly do so in the future.

A second limitation was my inability to reach and include domiciliary carers. From informal carers' interviews it was very clear that many respondent carers used domiciliary carers on a regular basis, from various private sector providers. However, despite my repeated efforts to recruit, and several positive responses, arranged interviews did not materialise for several reasons. One such reason was my inability to financially compensate individuals for their time to participate in an interview with me. Not only did I have very limited resources to undertake the study, but it also would not have been an ethical decision to pay some individuals and not others for their time due to a clear desire for equity in practice. Although I managed to include a manager from a private sector domiciliary care provider in the Focus Group Discussion, I feel this provided only a limited opportunity to capture actual care workers' perspectives on dementia care in the community, and that remains a limitation of this study.

The third limitation was not having alternative options to the survey formats. Conducting a survey online with carers was a practical, cost-effective and dynamic/pragmatic decision to enhance the qualitative phase of the study and subsequent ethical amendment approval to undertake the survey was obtained. However, sole use of an online survey and not having an option for a paper version (due to resource issues) resulted in some limits to potential participation. No promotional initiative was undertaken in order to minimise the potential for any bias or coercion, as any promotion would have required the researcher to make contact with potential respondents. As a result, it took much longer to reach potential respondents and gatekeepers who could have further circulated the survey. The survey did however generate interest among different health and care professionals from various locations both within and outside East Anglia, who made contact to enquire if they could circulate the survey link. However generally this was not encouraged further in order to maintain the carer's 'self-selection' status. This resulted in a relatively small sample size being able to complete the survey, which thus limits overall generalisation of the findings.

The fourth limitation was my inability to maintain PPIE involvement at later stages of the research. Whilst having a five member PPIE group and their active involvement at the beginning of the project, which was extremely useful, it was not possible to maintain the same level of engagement at later stages, due to changes in individuals' circumstances and their availability. Limitation of resources also played a part as this involved travel and time on their part. Although I managed to meet with two PPIE members to discuss the study findings individually, it would have been far more effective if a group discussion with PPIE members could have been arranged. In addition to the need to make resource provision for such involvement, in future in such a situation I would consider taking advantage of virtual meeting platforms such as Zoom or MS teams.

Finally, while the study included dementia service providers, the focus was on professionals who were largely responsible for the people with dementia. It would also have been useful to have included general community nursing and others who provide services in the community including to some people who might have dementia but for whole the main reason for contact/service was not dementia related. Inclusion of wider experience and viewpoints would have enriched the study findings and is something I would consider in the future.

9.8 Theoretical Contribution

This study proposes a novel model of dementia care domains, which is relevant to a better understanding and delivery of dementia care at home. It deepens the perception of the informal carer by treating the role of informal care as an asset or 'capital' that contributes to the overall objectives of integrated care. The utilisation of wider capital-based models in the context of dementia care highlights the limitations in the current needs assessments that narrowly and principally focus on financial resources. Dementia care is a household decision made in the context of the availability and interplay of household resources or capitals. The person with dementia experiences a gradual reduction in human capital which is supplemented by their social capital in the form of informal care. Informal caregivers require that their own human capital be enriched in order to fulfil this role, which can be achieved by appropriate training interventions that both support and enhance their knowledge and skills. This study argues that the investment in the informal carer's human capital expands care capacity not only within the family but also in the community and society as a whole. The domain approach used in this study has not been empirically applied in the context of dementia care at home prior to this research. It is my belief that a better understanding of holistic care domains can lead to enhanced comprehensive needs assessments and care education to support carers and people with dementia in such a way that sustains care at home more effectively.

9.9 Recommendations for Practice

The findings from this study support a number of concrete recommendations that could improve and help to sustain dementia care at home. The recommendations define a pathway to better understand and assess the care needs of people living with dementia at home within the context of relevant resources available to a family. In this regard, they seek to navigate the complex process by which families make, continue, or end care arrangement decisions at home. Wherever applicable, these recommendations link to current and existing practice guidelines.

- ***Understanding of informal care in dementia***

Current NICE dementia guidance for the diagnosis, management, and support for carers (National Institute for Health and Care Excellence, 2018a) assumes the presence of a single carer in the home, and this assumption is also reflected in a number of government policy documents, such as in the provision of the carers allowance. This study, however, finds that informal dementia care is inevitably a team effort, where primary carers, often older spouses with health issues of their own, can access a wider network of other informal carers by mobilizing accumulated social capital. It is recommended that service providers take into consideration this broader informal care network when designing support programmes. In the context of dementia care, informal care must be understood in terms of these complex arrangements of informal care comprised of multiple actors, so that appropriate support provisions can be employed and used to greatest effect.

- ***Dementia Care Domains in Assessing Needs***

The dementia care domains identified in this study offers practitioners a practical framework for assessing care needs, not just currently but throughout periodic review points. The incorporation of a care domains assessment in integrated care would improve the design of sustainable care plans for people being cared for at home. A comprehensive needs assessment underpins supportive, effective care packages, and it is essential that these assessments acknowledge the unique demands of dementia care. In a dementia-specific needs assessment including care domains, asking whether or not someone with dementia can perform specific activities of daily living, such as food preparation, is replaced with asking how nutritional and hydrational needs are to be met. This should be individualised/personalised and flexible enough to address changing needs as the condition advances. This domains approach to dementia home care provides a foundation to further develop comprehensive assessment tools and associated training packages for dementia carers.

- ***Informal Dementia Carers Practical Training***

The study also identified a significant gap in the existing training regimen available to informal carers. Despite notable efforts in dementia workforce development, particularly in institutional care settings and addressed by national policy frameworks (Health Education England and Skills for Care, 2018), informal carers are mostly excluded from such training initiatives. Although informal carers provide a vast quantity and range of regular care tasks, training frameworks currently only focus on the training needs of professionals and fail to address those of informal carers. The findings of this study have shown that in the context of an increasing demand for dementia care, informal carers are likely to constitute the primary workforce for people with dementia and, perhaps even more broadly, for the health and care delivery system. It is recommended, therefore, that the development and provision of adequate training and skill development for informal dementia caregivers be commensurate with their contribution to overall care. Such training would enable them to provide care more effectively whilst potentially greatly reducing adverse consequences for their levels of wellbeing. The delivery of training packages for such informal carers to improve their knowledge, skills and attitudes in dementia care is an essential element of care in the community. Current guidance, e.g., dementia training standard frameworks (Health Education England and Skills for Care, 2018) need to include training needs and provision for informal carers as well as for health and social care service providers.

- ***Respite Care in Care home Placement as Tertiary Prevention***

The Care and Support statutory guidance (Department of Health, 2014) and subsequent updates promotes respite care for carers as an important tertiary prevention measure to delay permanent institutionalisation of individuals. By enabling carers to continue to live a life of their own alongside their caring duties, respite measures can help minimise negative effects for carers of people, including those living with disability and progressive neuro-degenerative conditions like dementia. Local authorities are obliged to make such provisions available to carers. The most utilised form of carer respite support is to place the person with dementia in a care home, thus giving the carer some time off. Whilst this mechanism might be an effective tertiary prevention approach for people without cognitive difficulties but still in need of care, this study suggests it may have the opposite effect in cases of people with dementia. Cognitive abilities require adjustment and readjustment between their home and temporary care home placement, which is often confusing and on balance increases the stress for both the person with dementia and their carers. Use of this from of respite care should be limited and perhaps an alternative form of care should be considered that does not require the person with dementia to move away from the familiar surroundings of their own home, such as provision of a short-term live-in carer. This could mean that the carer would need to be away from the home however, so careful consideration of the suitability of such arrangements for both the carer and the cared for person would be required in order to achieve a balance between care needs and equitable or balanced arrangements.

- ***Role of Dementia Cafes and Community Organisations***

This study has documented the invaluable support dementia cafés and community organisations provide in the lives of people living at home with dementia and their carers. Current practice guidance such as the Care and Support statutory guidance (Department of Health, 2014) and subsequent updates acknowledges the important role of dementia cafés in providing short respite, peer support, and emotional support for carers. It was clear in this study that where available, such places have filled the gap created by the decreased availability of day care centres that were once financially supported by Local authority Adult Social Care Services. Despite their importance, the availability and quality of dementia cafés is inconsistent. The recommendation from this study is that such organisations should be better supported by the integrated health and social care initiatives. As these are run by community-based organisations, a greater level of coordination or federation might also provide them with greater capability.

- ***Inclusion of Informal Care in Integrated Care***

NHS England’s guidance (NHS England, 2020) on integrated care promotes person-centred, personal level coordinated care, tailored to the needs and preferences of the individual, their carers and family. However, this research found integrated care remains somewhat rhetorical and something that informal carers are yet to really experience in the home care context. Piloted models (such as the Vanguard model) of integrated care appear to operate from a top-down and institution-focused level, and the bottom-up integration models that actively include carers and a care-at-home context are yet to be introduced. Widely accepted as the future of health and social care, integrated care initiatives should invest in piloting person-centred, integrated dementia models that would be inclusive of the informal carer. Such a model would include informal carers as an integral (or central) part of the provision, their expertise is recognised, valued and sought in order to co-produce effective care plans and provisions. Also, the wider objective of integrated care should be disseminated among service providers to reduce misinformation and narrow perceptions, and which would also benefit the people with dementia and their carers. This understanding must go beyond an approach of integrated care equals multi-disciplinary team work within or between services, or a simple cost-saving focus to an actual person-centred model.

9.10 Recommendations for Further Research

This research started with the pragmatic intention of eliciting some practical, actionable findings applicable in a real world. The sets of findings are linked to the four key research questions. Key insights from this study not only influence future practice but also inform and call for future research that could lead to positive changes in the areas of dementia care at home listed below.

- ***Comprehensive Assessment of Needs in Dementia***

There is a profound lack of knowledge and practical tools to holistically assess and address the needs of people living at home with dementia and their carers. Further research is necessary to develop practical assessment tools based on the dementia care domains. A potential name for such a process could be Comprehensive Assessment of Needs in Dementia (CAN-D). Such a person-centred holistic assessment should be conducted at an early stage of the dementia, where the person with dementia can be involved and should take into account all types of assets available during the different stages of dementia. This could also then be adapted for use at various subsequent review or assessment points, as the condition progresses.

- ***Understanding Aggression and Incontinence***

One of the unanticipated findings in this study was the correlation between early episodes of incontinence, especially among men, and aggressive behaviours displayed in dementia. Often aggressive behaviours are attributed to the condition of dementia and care decisions are made on this basis. Medical interventions to manage aggressive behaviour and ending care at home appears to be fairly common. The connection between these two aspects deserves further research, as it has significant consequences for people living with dementia as well as their carers as they learn to manage urinary and faecal incontinence.

- ***Effectiveness of Respite Care in Care homes***

To provide respite for the informal carer, people with dementia are frequently placed in care homes for short stays of one to two weeks. This study found a clear indication that such short respite is not only ineffective but may also be counterproductive. It seems to further confuse people with dementia upon their return home thereby only serving to heighten the stress levels of carers. The impacts and after-effects of respite care on individuals when they return home should be further investigated as it has serious consequences for the well-being of the people with dementia and their family carers.

- ***Vanguard Model Pilot with Informal Carers***

Among the various integrated care models in the UK being piloted, one that includes informal carers as key partners in the co-production of care has yet to be considered. As this study documented, integrated care is currently focused on organisational levels and appears to have stalled at the level of rhetoric when it comes to involving the provision of informal care at home. Thought and attention should be given to developing a bottom-up approach to dementia care that begins with the affected person and their immediate care and support structure. This requires flexibility, open-mindedness and continuous awareness of various relevant interventions. People with dementia must remain the top priority at all times in dementia care whilst simultaneously achieving a balance with the needs of their carers. This equilibrium between the care of the family member with dementia and the co-resident informal carer must be further explored, with a view to finding more effective ways to support and strengthen this fragile system. The involvement of informal care as part of the integrated care system would contribute to this, and a pilot study, with rigorous evaluation to test how this could best be achieved, would be very useful in this regard. The following Table (9.1) presents a combined list of recommendations for practice and future research.

Table 9.1: Table of Recommendations for Practice and Research

For Practice ….	**For Further Research…..**
Inclusion of Dementia Care Domains in within the Assessment Framework	Comprehensive Assessment of Needs in Dementia (including and testing 6 care Domains)
Development and Provision of Practical Training for Informal Dementia Carers	Understanding Aggression and Incontinence and possible inter-relationships
	Effectiveness of Respite Care in Care home and effect on return home
	Vanguard Model Pilot including Informal Carers

9.11 Researcher's Reflexivity

I started my doctoral research journey with some anxiety about my ability to keep my objectivity crystal clear. This was due to the fact that I was caring for my relative with severe dementia and every day was different, with various levels of distress as well as occasional frustrations while dealing and negotiating with professionals. It is extremely difficult to be a totally objective researcher whilst also having a service user's experience and forming rather subjective views of the research topic. I discussed this matter with my supervisory team and decided to maintain a written account of my reflections along the journey of the research process. I maintained this personal reflective account throughout the study. But the process for recording such reflection gave me a great deal of mental 'switch on and off' time between my roles as a carer and as a researcher. To begin with I planned 'strategies to manage my potential subjectivity' that I had already gained, formed from my daily experience as a caregiver. I had an added benefit to understand and to connect with informal carers and to discuss the care system with service providers as a then-current user of the services myself. Having such 'strategies' helped to minimise any possibility of being biased in terms of data collection as well as data interpretation.

Initially I decided not to mention anything about my caring role to any group that I met with for the purposes of recruiting potential participants. I managed to maintain this 'self-anonymity' of my role as a caregiver. Self-identity is a complex concept and arguably all of us have multiple identities. My strategy was to stick with my identity as a 'postgraduate research student at UEA' wanting to learn from carers and service providers. There was one exception that arose during a carer group meeting at a dementia café. I was with 10 carers and the group facilitator. As I introduced myself as per my strategy (UEA student), and did my recruitment pitch about the research, one of the carers asked me directly: – 'do you have any experience in caring for someone with dementia?' After recovering from a little surprise, I said 'yes, I do'. Although I gave the briefest possible reply to further questions, my answer seemed only to elevate the group curiosities even more.

Although I was initially a bit startled with the series of direct questions and realisation that one of my key strategies had failed, I thought through my options. I had three choices, to lie (e.g. say no), or not to lie but also not to tell the truth (e.g. to say I can't discuss that at this moment/ I prefer not to say) or just to tell the truth. I decided to tell the truth as I thought it would be the best from a moral and ethical point of view, so I told the group: –'I have been caring for my relative for the last 5 years, who has severe dementia and lives at home with me and my partner'.

Though I was brief but truthful, the group seemed to be surprised. However, afterwards I realised that this exchange had not only generated genuine interest for participating in my research but I also gained a group of allies and some credibility from the group members. I was ‘one of them’ and they wanted to help me and my research. I reflected upon this encounter many times, although it was not repeated in other groups, and I kept to my previous approach of introducing my identity as a PhD student at UEA. It is important to note here, only two participants in the original group met the inclusion criteria but two other members helped me with contacts for two further respondents who did not attend the dementia café, and without these facilitated introductions I may not have reached these individuals. While I interviewed the two carers who knew I was a carer myself, I explained at the beginning that the interview was about their experience. I also said that if they had any questions about my experience then we would have to discuss that later or another time and not during the interview. This approach worked for these situations.

9.12 Conclusion

This research contributes to our understanding of dementia care at home and the role of the informal carer in the community. It identifies through empirical research the essential care domains and proposes how the understanding of these domains can improve the quality of care for persons with dementia. It concludes that the role and contribution of the informal carer is inadequately accounted for in the current Integrated care models. A well-coordinated person-centred dementia care requires the integration of informal carers into the overall care approach. This study concludes that quality care for individuals living with dementia at home depends on appropriate care education and skills training for informal carers to ensure carer readiness. Based on the results, a necessary first step in incorporating the informal carer into the integrated care approach is to improve the person-centred holistic assessment. Such an assessment takes into account the multiple needs of the person in all care domains in the context of the assets available to/within the household and the community, including the informal care network, and with the full involvement of the person with dementia. Informal care is highly complex and is likely to represent a lifetime investment in building social capital which can then be drawn upon at this time of need. This research lays the foundation for a comprehensive dementia care approach that integrates informal and formal care delivery based on the cornerstone of a holistic dementia needs assessment, and which incorporates the six key domains as key elements.

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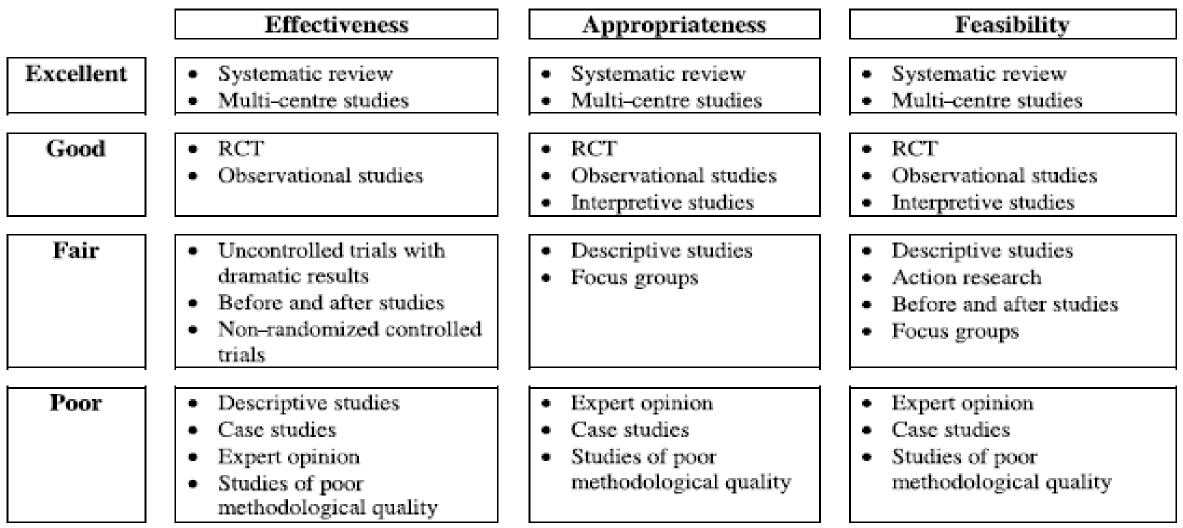
Annexes

Annex 1: Two-Step Critical Appraisal of Literature

Step 1: Six-point checklist	
Source/ Where (and year)?	Literature source - peer reviewed journal article/ book chapter/ policy document/ evaluation paper etc
Purpose/ What?	Purpose and Focus of the study/ paper
Data source management/What?	Type(s) of data presented in the literature, qualitative/ quantitative/ mixed/ secondary reviews
Data source and management/ How?	Source of data, how collected and managed, and any bias/ limitation reported.
Analytical approach & Validity / How?	What approaches being used, reported/ not reported How validity was addressed, reported/ not reported.
Key message/ result/ what?	What are the key messages/ results/ key findings?

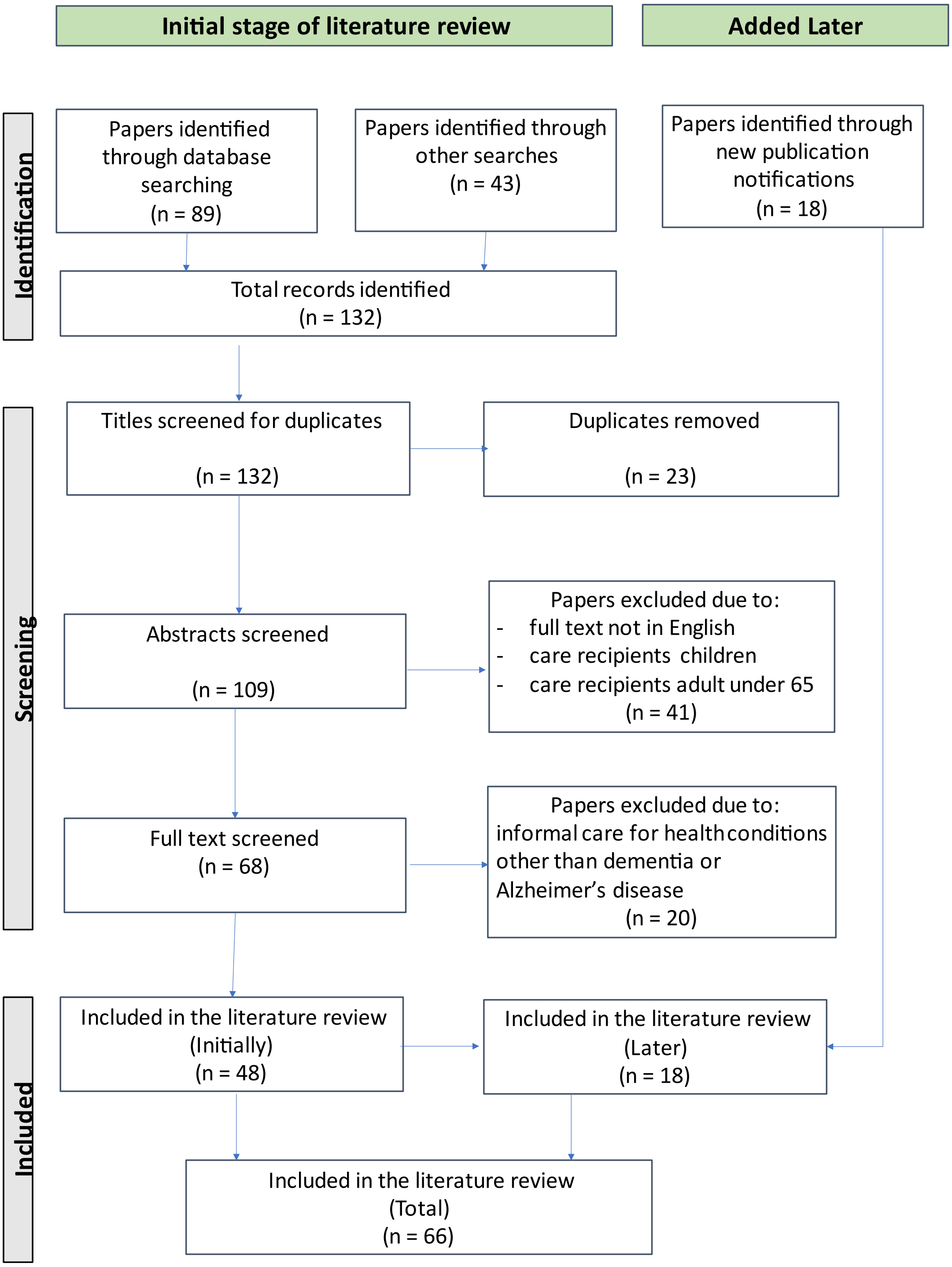
Step 2: Hierarchy of Evidence



	Effectiveness	**Appropriateness**	**Feasibility**
Excellent	• Systematic review • Multi-centre studies	• Systematic review • Multi-centre studies	• Systematic review • Multi-centre studies
Good	• RCT • Observational studies	• RCT • Observational studies • Interpretive studies	• RCT • Observational studies • Interpretive studies
Fair	• Uncontrolled trials with dramatic results • Before and after studies • Non-randomized controlled trials	• Descriptive studies • Focus groups	• Descriptive studies • Action research • Before and after studies • Focus groups
Poor	• Descriptive studies • Case studies • Expert opinion • Studies of poor methodological quality	• Expert opinion • Case studies • Studies of poor methodological quality	• Expert opinion • Case studies • Studies of poor methodological quality

Hierarchy of evidence: ranking of research evidence evaluating health care interventions (Evans 2003)

Annex 2: PRISMA Diagram



Annex 3: Research Ethical Approval letter

Faculty of Medicine and Health Sciences Research Ethics Committee

University of East Anglia

Research & Enterprise Services
Floor 1, The Registry
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

Telephone: +44 (0) 1603 591490
Email: fmh.ethics@uea.ac.uk

Web: www.uea.ac.uk/researchandenterprise

Priti Biswas
MED

12th July 2017

Dear Priti,

Project title: Informal carers in an integrated care model for improving dementia care in the community.
Project Reference: 2016/2017 - 88

The amendments to your above proposal have been considered and I can confirm that your proposal has been approved.

Please could you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance and also that any adverse events which occur during your project are reported to the Committee. Please could you also arrange to send us a report once your project is completed.

Yours sincerely,

Professor M J Wilkinson
Chair
FMH Research Ethics Committee

CC Bridget Penhale & Michael Hornberger

Annex 4: PPIE Member Information list

Initials	Background	Location
JD	PPIRes member, advised other UEA research resident in West Norfolk area	West Norfolk
SR	Was an informal dementia carer for their father, CEO of a Voluntary organisation that runs day centres in Norwich area	Norwich
JM-D	Was an informal dementia carer for their mother, runs dementia café in Thetford area	Breckland
RL	Member of U3A (University of Third Age), was an informal dementia carer for their spouse and worked for many years in adult social care. Resident in South Norfolk area.	South Norfolk
KV	Manager of a carers support voluntary organisation, in the Norwich area	Norwich

Annex 5: Interview Guidelines

Semi-structured Interview Checklist/Questions for Participants (carers)

Introduction to include preamble about study, reconfirming consent (+recording), taking breaks, stopping interview.

1. Tell me something about you. (After initial introductions, this will be conversational start in order to put the interviewees at their ease.)

2. Please can you tell me how you first became a carer … and your journey since? (this will be conversational to describe times and trajectories in the carers journey)

3. What do you think about the ‘most rewarding’ in your role as a carer (if any)?

4. What do you think is the ‘most challenging’ in your role as a carer (if any)?

5. Please can you tell me what services do you use? (I will use a Venn diagram for this discussion – to list different services involved, their roles and amounts of involvements.)

6. Please can you tell me about your experiences of ‘assessments’? (Something was done to access the services may be.. For yourself and for the person you care for?)

7. Please can you tell me your thoughts about the services you receive?

8. In your experience do the services work together? Do they work in partnership? Can you give me an example please?

9. What do you think about ‘integrated care’ (what you know, your experience of any changes). What does ‘integrated care’ mean to you?

10. Please can you tell us about a time (if there was any) when you consider institutional care (care home) . What was the trigger? What was the situation? Where did you go to find help? What happened…

11. If you had a magic solution to make dementia care better which will help people to live at home to the end what would that be?

12. If you had a magic solution to improve the ways informal carers work with formal services what would that be??

13. Are there any comments or questions you would like to raise here? Is there anything you would like me to explain? Would you like to tell me anything else?

Thank you so much for your time and the interview.

Semi-structured Interview Checklist/Questions for Participants (Service providers)

Introduction to include preamble about study, reconfirming consent (+recording), taking breaks, stopping interview.

1. Tell me something about you. (After initial introductions, this will be conversational start in order to put the interviewees at their ease.)

2. Please can you tell me about your job-role (when you first started to work with people with dementia and their carer…. this will be conversational to describe times and trajectories in the journey a dementia service provider)

3. Please can you tell me your thoughts about the services you provide? (Process of access, referrals, pathways..)

4. Please can you tell me about your experiences of 'assessments'? (Something you yourself or someone in the team have to carry out to determine who should get access to what services.. For the person with dementia and their carers?)

5. In your experience do they services work together? Do they work in partnership? Can you give me an example please?

6. What do you think about 'integrated care' (what you know, your experience, training, any changes). What does 'integrated care' mean to you?

7. Please can you tell me who you work with in partnership to provide dementia services? (I will use a Venn diagram for this discussion – to list different services involved, their roles and amounts of involvements.)

8. In your opinion - what roles informal carers can play in integrated care? Any examples?
9. What do you think about working in partnership informal carers? (pls note the difference - not carers as service users but service delivery partners)?

10. Can you think of any opportunities and/or challenges in working in partnership with informal carers?

11. In your experience what trigger the transition from home to care homes? Please can you give me any examples…).

12. If you had a magic solution to make dementia care better which will help people to live at home to the end what would that be?

13. If you had a magic solution to improve the ways informal carers work with formal services what would that be?

14. Are there any comments or questions you would like to raise here? Is there anything you would like me to explain? Would you like to tell me anything else?

Thank you so much for your time and the interview.

Annex 6: NSFT Dementia Care Pathways

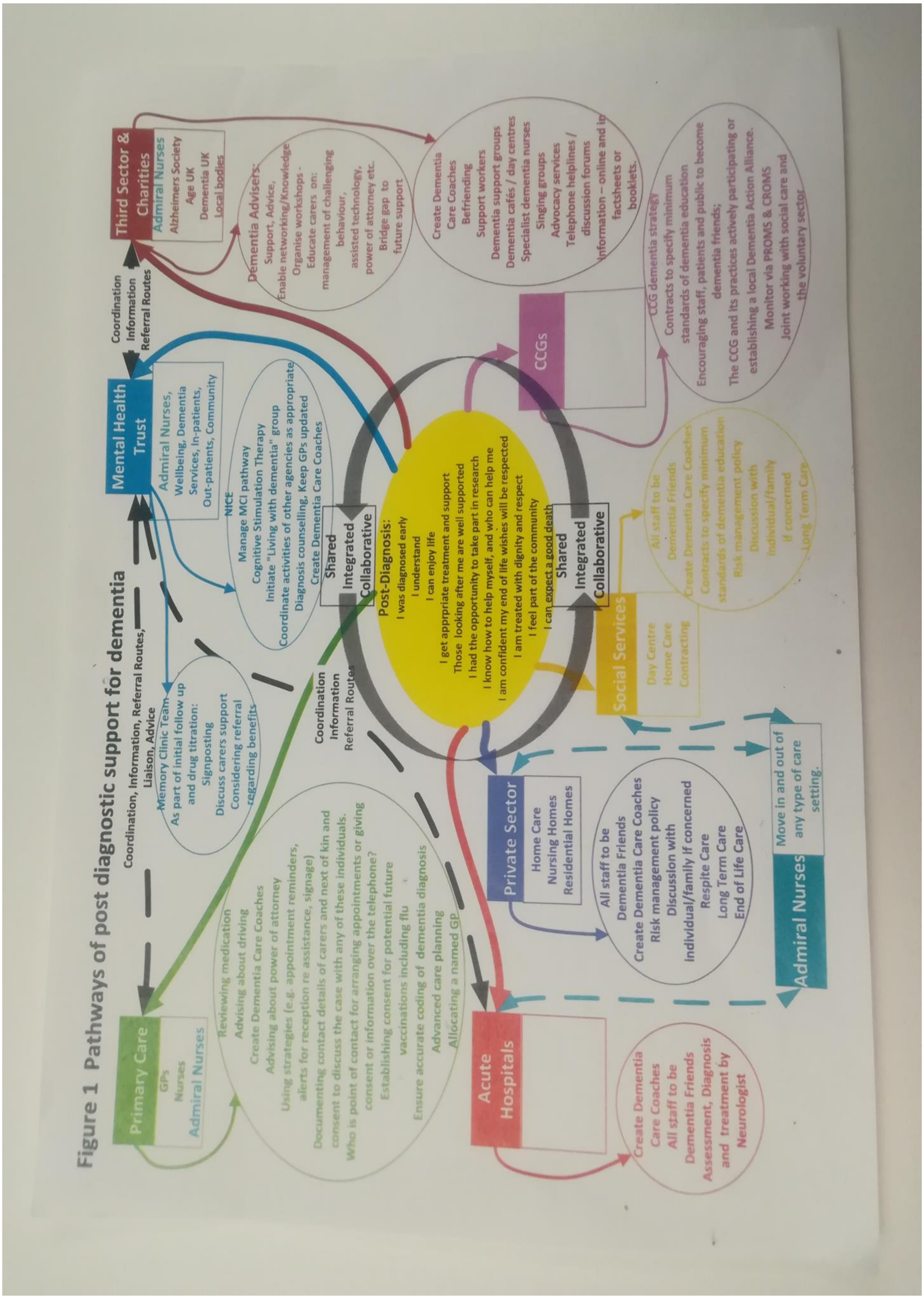
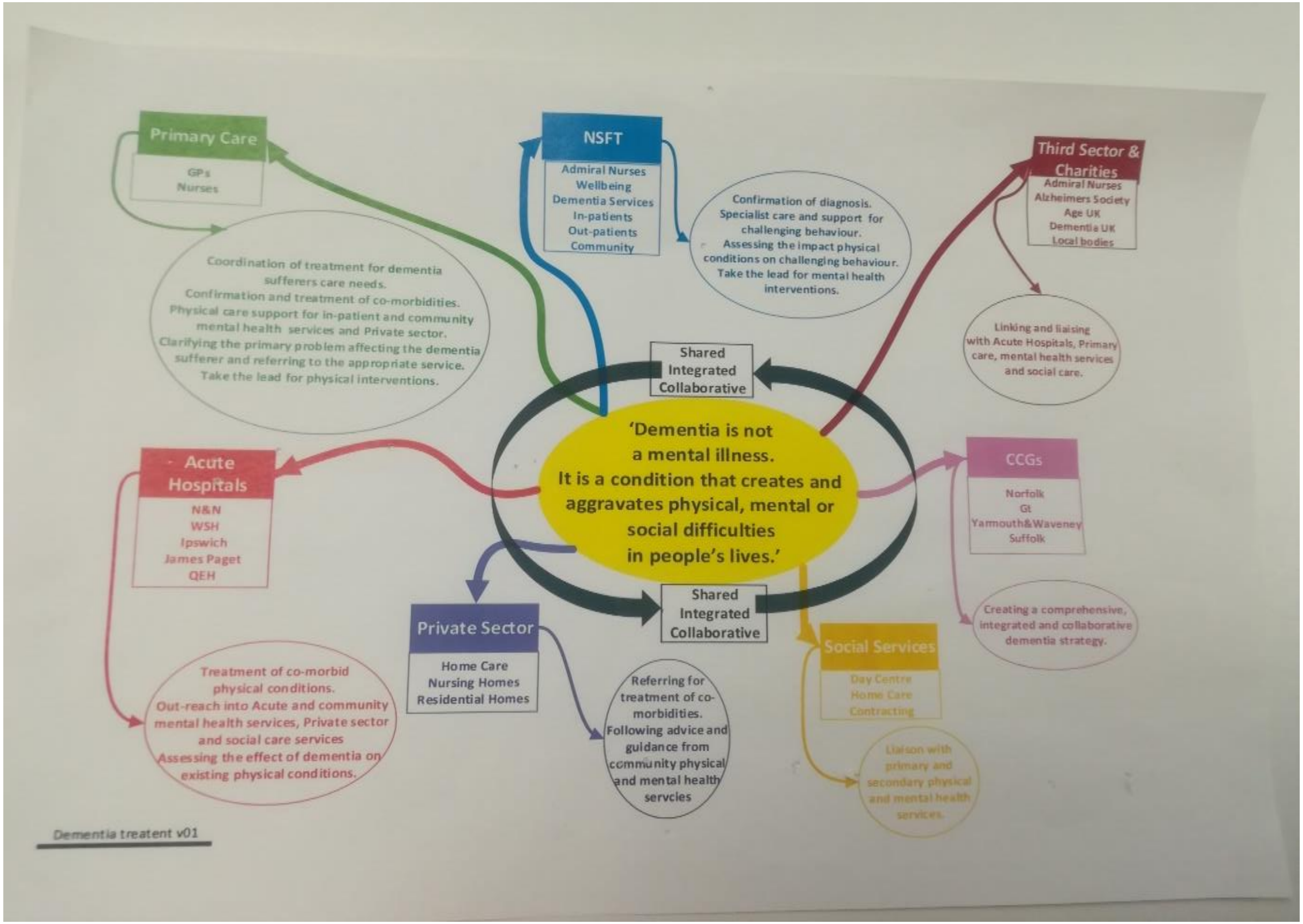


Figure 1 Pathways of post diagnostic support for dementia



'Dementia is not a mental illness. It is a condition that creates and aggravates physical, mental or social difficulties in people's lives.'

Shared
Integrated
Collaborative

Shared
Integrated
Collaborative

Primary Care
GPs
Nurses

Coordination of treatment for dementia sufferers care needs.
Confirmation and treatment of co-morbidities.
Physical care support for in-patient and community mental health services and Private sector.
Clarifying the primary problem affecting the dementia sufferer and referring to the appropriate service.
Take the lead for physical interventions.

NSFT
Admiral Nurses
Wellbeing
Dementia Services
In-patients
Out-patients
Community

Confirmation of diagnosis.
Specialist care and support for challenging behaviour.
Assessing the impact physical conditions on challenging behaviour.
Take the lead for mental health interventions.

Third Sector & Charities
Admiral Nurses
Alzheimers Society
Age UK
Dementia UK
Local bodies

Linking and liaising with Acute Hospitals, Primary care, mental health services and social care.

Acute Hospitals
N&N
WSH
Ipswich
James Paget
QEH

Treatment of co-morbid physical conditions.
Out-reach into Acute and community mental health services, Private sector and social care services
Assessing the effect of dementia on existing physical conditions.

CCGs
Norfolk
Gt
Yarmouth&Waveney
Suffolk

Creating a comprehensive, integrated and collaborative dementia strategy.

Private Sector
Home Care
Nursing Homes
Residential Homes

Referring for treatment of co-morbidities.
Following advice and guidance from community physical and mental health servcies

Social Services
Day Centre
Home Care
Contracting

Liaison with primary and secondary physical and mental health services.

Dementia treatent v01

Annex 7: Survey Questions

Study on informal carers in integrated care

Project Introduction and Consent

Thank you for your interest in this survey. Before you decide whether to take part or not, it is important for you to understand why this study is being done and what it involves.

We are reaching out to people who are known as ‘informal carers’ (e.g. providing unpaid care to someone with dementia living at home) and who live with the person they care for at home, to take part in this study. In the survey we will be asking you about your views on your training and experiences of caring for someone with dementia, assessments that you have been subject to, and your ideas on how informal carers like yourself can be part of the integrated care system (e.g. health and social care working more closely together).

The purpose of this study is to find out about ways to include informal carers in the integrated care model in order to improve dementia care service delivery in the community. If you wish to learn more about the project or need further information please contact Priti Biswas on p.biswas@uea.ac.uk or call Mobile: 07376711839.

There are no direct benefits from, or financial incentives for, taking part in this study. However, if you take part, you will be helping the researcher to better understand the role of informal carers within integrated care and hopefully to improve practice. Taking part in this study is totally voluntary and is entirely up to you. This research has been reviewed and approved by UEA/Faculty of Medicine and Health Sciences Ethics Committee (**Project Reference: 2016-2017 – 88**).

The survey will take approximately 25 mins to complete. We are extremely grateful to everyone who takes time to complete the survey.

Your data will be kept securely and confidentially only for as long as required for the purposes of this research. Only the researcher and supervisors for the research will have access to the data (for the purposes of analysis).

Your data will remain anonymous in any reports or associated publications or presentations about the study including the survey and it will not be possible to identify individuals from the answers provided. As the survey is anonymous you will not be able to withdraw your consent or your data once your survey has been submitted. Please contact Priti Biswas if you have any queries about this.

UEA will only ever use the information that you give us in accordance with UK data protection law.

Please note that by clicking YES below you are consenting to take part in the survey and to your data being used in the ways outlined above.

Please tick to consent: I would like to complete this survey **YES ☐**

Section 1a: About you

First, I would like to ask a few question about you

2. **How old are you? (in years)**

3. **What is your gender?**
   - Male
   - Female
   - Prefer not to say

4. **What country do you reside in?**
   - England
   - Scotland
   - Wales
   - Northern Ireland
   - Republic of Ireland
   - USA
   - Canada
   - Australia
   - New Zealand
   - Other (please specify)

5. **Who do you care for?**

   - Partner / spouse
   - Siblings
   - Parents /(in-laws)
   - Friend
   - Other (please specify)

6. **How long have you been caring for?**

   - Less than 1 year
   - 1 - 2 years
   - 3 - 4 years
   - 5 - 6 years
   - 7 - 8 years
   - 8 - 9 years
   - 9 - 10 years
   - 10 years or more

7. **Do you live with the person you care for?**

   - Yes
   - No

8. **What is your current employment situation?**

- Work full time
- Work part time
- Retired
- Self-employed
- In education
- Unable to work due to sickness or disability
- Prefer not to say

9. How often do you do something for the person you care for?

- Every day
- Every other day
- Every 2-3 days
- Twice a week
- Once a week
- Once in two weeks
- Once a month

10. How many hours of care do you provide a week (approximately)?
- 6 hours or less
- 7-19
- 20-34
- 35-49
- 50-69
- 70-89
- 90 hours or more

11. Other than yourself, do other friend(s) or relative(s) regularly help in caring for your relative?

- Yes
- No

If Yes, how often?

- Every day
- Every other day
- Every 2-3 day
- Twice a week
- Once a week
- Once in two weeks
- Once a month

Section 1b: About the person you care for

Now I would like to ask you a few questions about the person you care for

12. **How long since the person you care for was diagnosed with dementia/ cognitive impairment?**
    - Under 6 months
    - Between 6 and 12 month
    - 1-2 years
    - 2 - 3 years
    - 3 - 4 years
    - 4 - 5 years
    - 5 - 6 years
    - 6 - 7 years
    - 7 - 8 years
    - 8 - 9 years
    - 9 - 10 years
    - Over 10 years

13. **What type of dementia are they living with?**

    - Mild cognitive impairment (MCI)
    - Alzheimer's disease
    - Vascular Dementia
    - Mixed Dementia
    - Dementia with Lewy Bodies (DLB)
    - Frontotemporal Dementia (FTD)
    - Parkinson's Disease with Dementia
    - Don't know
    - Other type of dementia (please specify)

14. **What stage of dementia are they at (if known)?**

    - Mild
    - Moderate
    - Severe
    - I don't know

15. **Do you have a Power of Attorney (PoA) for the person you care for?**

    - Yes
    - No
    - Not sure
    - I don't know

16. **Do you either receive or purchase any other type of service of support with caring?**
    - Yes
    - No

16a. If yes, which of the following do you use? (tick all that you use)

- Paid care workers – help with personal care
- Paid helper with household chores like cleaning or shopping
- Day care centre - for older/disabled people
- Dementia café / community groups – for person with dementia and carers
- Assistive technology - like care alarms, sensors, remote monitoring devices to help with caring
- Equipment at home - like hoists, grab rails or easy-grip handles on taps, bath lift
- Paid 'live in carer' - someone is paid to live with the person to provide care and support
- Respite care – person with dementia goes to stay in a care home while I stay at home
- Respite care - I go away for short break while person with dementia stays at home with support/care
- None
- Other (please specify)

Section 2: About dementia training

---

17. **Have you received any training about dementia care?**
    - Yes
    - No
    - Not sure

If yes – please select from the following list.

- Dementia awareness/dementia friends training
- Training on Assistive Technology
- Safe moving and handling
- Communication with people living Dementia
- Managing difficult behaviour in dementia
- Food, diet and nutritional needs in Dementia
- Falls prevention in Dementia
- Skin care in advance dementia
- Health and hygiene in dementia care
- Managing continence
- Emotional support to person with dementia
- Reminiscence in dementia
- Art and music in dementia
- Palliative care and end of life support
- Other (please specify)

18. Please tell us which of the following you do to help the person with dementia?

Tasks	**Regularly**	**Sometimes**	**Rarely**	**Never**	**Not applicable**
Companionship (e.g. talking/replying often repeated questions)					
Supervision (e.g. keeping an eye on to keep them safe)					
Preparing meals (e.g. making meals/drinks and eating together)					
Assisting with meals (e.g. cutting up food, reminding to eat/drink)					
Practical help at home (e.g. laundry, housework, household repairs)					
Practical help out of home (e.g. go to shopping, going hairdresser, taking to doctor/hospital)					
Supporting social and leisure activities (e.g. taking out for a walk or drive, or to see friends and relatives)					
Assisting with Personal care (e.g. assist with dressing, bathing, washing, shaving, cutting nails, reminding to use the toilet)					
Reminding about medication (e.g. making sure he/she takes their prescribed pills)					
Helping with paperwork (e.g. writing letters, filling in forms)					
Dealing with financial matters (e.g. dealing with utility bills, banking, household budget management)					
Providing emotional support (e.g. dealing moments of low mood, anger and depression)					
Assisting with mobility (e.g. with walking, getting up and around, getting into and out of bed)					
Carrying out personal care for them (e.g. might be in bed - dressing, bathing, washing, shaving, cutting nails)					
Dealing with emotional outbursts (e.g. managing sudden outbursts, physical or verbal aggression)					
Preparing special meals and drinks (e.g. preparing pureed meals, ‘thick and easy’ drinks)					
Feeding (e.g. if the person can no longer can feed themselves)					
Dealing with episodes of confusions or hyperactivities (e.g. may be caused by deliriums, UTI)					
Continence management and care (e.g. cleaning, clearing, changing incontinence pads)					
Assisting with movements (e.g. turning body positions in bed, operating hoist)					
Carrying out practical healthcare tasks (e.g. giving injections, changing dressings)					
Arranging/coordinating care and support from others (e.g. managing and communicating with paid carers, medical home visits, and any other help)					
Other tasks (please specify)					

19. Please tell us how easy/difficult/ challenging you find the following tasks to be?

Tasks	Very difficult	Difficult	Not difficult	Easy	Not applicable
Companionship (e.g. talking/replying often repeated questions)					
Supervision (e.g. keeping an eye to keep them safe)					
Preparing meals (e.g. making meals/drinks and eating together)					
Assisting with meals (e.g. cutting up food, reminding to eat/drink)					
Practical help at home (e.g. laundry, housework, household repairs)					
Practical help out of home (e.g. go to shopping, going hairdresser, taking to doctor/hospital)					
Supporting social and leisure activities (e.g. taking out for a walk or drive, or to see friends and relatives)					
Assisting with Personal care (e.g. assist with dressing, bathing, washing, shaving, cutting nails, reminding to use the toilet)					
Reminding about medication (e.g. making sure he/she takes their prescribed pills)					
Helping with paperwork (e.g. writing letters, filling in forms)					
Dealing with financial matters (e.g., dealing with utility bills, banking, household budget management)					
Providing emotional support (e.g. dealing with moments of low mood, anger and depression)					
Assisting with mobility (e.g. walking, getting up and around, getting into and out of bed)					
Carrying out personal care for them (e.g. might be in bed - dressing, bathing, washing, shaving, cutting nails)					
Dealing with emotional outbursts (e.g. managing sudden outbursts, physical or verbal aggression)					
Preparing special meals and drinks (e.g. preparing pureed meals, ‘thick and easy’ drinks)					
Feeding (e.g. if the person can no longer can feed themselves)					
Dealing with episodes of confusion or hyperactivity (e.g. may be caused by deliriums, UTI)					
Continence management and care (e.g. cleaning, clearing up, changing incontinence pads)					
Assisting with movement (e.g. turning body positions in bed, operating hoist)					
Carrying out practical healthcare tasks (e.g. giving injections, changing dressings)					
Arranging/coordinating care and support from others (e.g. managing and communicating with paid carers, medical home visits, and any other help)					

Other tasks (please specify)					

20. Please tell us if you have received any training for any of the tasks you do to help the person with dementia? (Please tick all that apply)

Tasks	**Yes**	**No**	**Not applicable**	**Would like to**
Companionship (e.g. talking/replying often repeated questions)				
Supervision (e.g. keeping an eye to keep them safe)				
Preparing meals (e.g. making meals/drinks and eating together)				
Assisting with meals (e.g. cutting up food, reminding to eat/drink)				
Practical help at home (e.g. laundry, housework, household repairs)				
Practical help out of home (e.g. to go shopping, going to hairdresser, taking to doctor/hospital)				
Supporting social and leisure activities (e.g. taking out for a walk or drive, or to see friends and relatives)				
Assisting with Personal care (e.g. assist with dressing, bathing, washing, shaving, cutting nails, reminding to use the toilet)				
Reminding medication (e.g. making sure he/she takes their prescribed pills)				
Helping with paperwork (e.g. writing letters, filling in forms)				
Dealing with financial matters (e.g., dealing with utility bills, banking, household budget management)				
Providing emotional support (e.g. dealing with moments of low mood, anger and depression)				
Assisting with mobility (e.g. walking, getting up and around, getting into and out of bed)				
Carrying out personal care for them (e.g. might be in bed - dressing, bathing, washing, shaving, cutting nails)				
Dealing with emotional outbursts (e.g. managing sudden outbursts, physical or verbal aggression)				
Preparing special meals and drinks (e.g. preparing pureed meals, ‘thick and easy’ drinks)				
Feeding (e.g. if the person can no longer can feed themselves)				
Dealing with episodes of confusion or hyperactivity (e.g. may be caused by deliriums, UTI)				
Continence management and care (e.g. cleaning, clearing up, changing incontinence pads)				
Assisting with movement (e.g. turning body positions in bed, operating hoist)				
Carrying out practical healthcare tasks (e.g. giving injections, changing dressings)				
Arranging/coordinating care and support from others (e.g. managing and communicating with paid carers, medical home visits, and any other help)				
Other tasks (please specify)				

Section 3: About Needs Assessment

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21. Have you had a carer’s assessment?

- Yes
- No
- Not sure

21 a. If yes, which information was asked about? (Tick as appropriate)

- Financial (how much money you have)
- Financial (how much money the person you cared for has)
- Financial (finding out who will pay for care)
- Carers ability to care for the person with dementia
- Carers needs identification
- Respite care
- Carers health status
- Other (please specify)

21 b. How useful was the assessment?

	Very useful	Useful	Little useful	Not useful	Not applicable
Financial (how much money you have)					
Financial (finding out who will pay for care)					
Carers ability to care for the person with dementia					
Carers needs identification					
Respite care					
Carers health status					
Other (please specify)					

Section 4: Carers recognition & involvement

---

22. To what extent do you feel your role as an informal carer is recognised and valued?

	Very well	well enough	Not much	Not at all	Not applicable
By the government					
By health care staff					
By social care staff					
By other paid staff involved					
By public at large					
By friends					
By neighbours					
By wider family					
By close family/ relatives					
By the person you care for					
Others (please specify)					

23. How would you like to be recognised for your role as an informal carers? (free text)

____

____

24. How involved are you in the integrated care system?

- A great deal
- A little
- Not at all
- Prefer not to say

25. How much have you been working together with health and social care professionals?

- A great deal
- A little
- Not at all
- Prefer not to say

26. How much do you know about integrated care?

- A great deal
- A little
- Not at all
- Prefer not to say

27. Any other comment you may have please note here (free text)

____

Finally, we would like to thank you very much for responding to this survey.

28. Please can you tell us how useful you found this survey?

- Very useful
- Useful
- Not useful
- Prefer not to say

Thank you.

Annex 8: Focus Group Discussion Guidelines

Guidelines for Focus Group Discussion with Mixed Group Participants (Informal carers and Service providers)

Introduction

- **Introduce** facilitator and note taker and explain position of the team and what we do. Explain how the session will run, that notes will be taken and analysed, a summary of views will be used within the thesis.

- **Housekeeping** – Mobile phones switched off or at least on silent – leave room to take necessary calls. Take comfort breaks when need to.

- **Aim of the day** – The aim of this focus group is to gain your views and opinions on the initial research findings, and what you think some of the implications might be in practice

- It is also important for you to know that you can drop out of/withdraw from the group at any time and ask for any details held about you specifically to be removed. Please note that as this is a group discussion, an individual contribution, while anonymised, cannot be removed from the record.

- Please respect the confidential nature of this session and keep everything we say within this room (don't discuss what was said with others outside of the session).

- Reminder - if you say something which suggests that you (or someone else) may be at risk of serious harm, some further action may need to be taken in relation to this. I would discuss this with you (outside of the group) before taking any action.

- Talk through GDPR and ethics (check/ sign consent forms).

- **Honest opinions** – I am seeking your honest views on my research findings as this will really help me to finalise them and identify some future directions – it is most important that I learn your honest opinions. All views and opinions count and there are no right or wrong answers.

- **Speak clearly –** Please try to speak one at a time so that we can all hear each other and the note-taker can pick up what you are saying. Please ensure an equal opportunity to talk and avoid interruption as far as possible. Signal to me that you want to make a comment so that you can be brought into the discussion

- **Structure of the FGD –** I will give a brief presentation on my research so far followed by some topical questions I would like us to discuss.

- **Questions -** Any questions before we begin?

- **Discussion topics -**

    - Let's start with your thoughts/ views on the main research findings so far. How do they compare with your own experiences? (Any surprises / Anything to add?)

    - Integrated person-centred dementia care - what are some opportunities and challenges and how may these be overcome/ improved?

    - How could dementia care at home be improved and sustained (specific to where informal care is available)?

    - How could these findings be put into use/ practice in your opinion?

Thank you so much for your time and participation.