An Exploration of the Role of Neighbours in Providing Support and Care to Older People Living with Dementia in their Own Homes

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Declaration

I declare that this thesis has been composed solely by myself and that it has not been submitted, in whole or in part, in any previous application for a degree. Except where states otherwise by reference or acknowledgment, the work presented is entirely my own.

Acknowledgements

Several people were instrumental in getting this research to completion, but some deserve special mention.

I would like to thank my supervisors, Professor Andrew Clark, and Professor Anthea Innes, for their great feedback, guidance and patience. I could not have had better supervisors and I am very grateful.

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Abstract

People now live longer because of improved health and medical sciences. However, ageing if often accompanied by various health and social challenges. Research suggests that as families become more geographically dispersed, there has been a reduction in the availability of kin as primary caregivers for many older people, including those living with dementia. Therefore, there is a need for a better understanding of the complexities of the delivery of support to older adults in the community. While much research has focused on informal care provided by kin, little attention has been paid to the nature of support delivered by non-kin such as neighbours, resulting in their support being relatively overlooked.

This study contends that non-kin care is not adequately understood, resulting in a gap in understanding the intricacies of informal care giving. The objective therefore is to enhance understanding of the experiences of support provision by neighbours to older adults aged 65 plus, living with dementia in their own homes and particularly in situations where family members are not available. Focusing explicitly on people living with dementia, this research adds to our understanding of the relationships between neighbours providing and receiving informal support.

Drawing on the principles of person-centred care, applied to qualitative framework, I investigated the experiences of neighbour caregivers in providing care and support to older people living with dementia in their own homes. I gathered data using semi-structured interviews. Six older people living with dementia and seven neighbours with experience of supporting older people living with dementia were interviewed. The data was analysed using thematic analysis and themes identified show the existence of pre-care giving relationships; care giving motivated by compassion, community service, and friendship; varied, stressful and complex support system that sometimes leads to tensions; selfless and non-transactional relationships that emanate because of living alone and loneliness. I argue for a better understanding of the non-kin neighbour dementia support system and to incorporate our understanding into care planning in the community. These findings have implications for policy making, social work practice, and the sustainability of non-kin support relationships.

Dedication

I dedicate this research to all volunteers registered with the Join Dementia Research (JDR) website.

Volunteers like you have made this study possible.

Thank you.

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1 Introduction

This chapter introduces the research by detailing the study problem and rationale, and the aim and objectives. It also introduces the researcher and presents the research in the context of the United Kingdom’s policy context and dementia pathway. Finally, it presents the research questions and outlines the remainder of the thesis.

1.1 Statement of the Problem

This thesis presents an investigation of the experiences of neighbours providing support to older adults (65+) living with dementia in the community. There is a popular expectation that support for older people (65+) living independently will be provided via formal, familial organisations and individuals. However, social changes have produced different family structures which alongside increases in the number of older people living with complex support needs, make it necessary to revisit how care and support might be offered. It is also anticipated that due to demographic changes and a widely supported policy of ageing, the number of older people living in the community will continue to increase, meaning that supportive neighbourhoods will be widely needed (VanDijk, 2015:1771). This study explores the role of neighbours in providing support and care to older people living with dementia in their own homes.

“*Dementia is an acquired loss of cognition in multiple cognitive domains sufficiently severe to affect social or occupational function*” (Arvanistakis et al., 2019:1589). In a recent study, Bennett et al. (2018:34) suggested that dementia is potentially the most complex and challenging condition that social care services are required to support, and people are facing huge costs to pay for care and support, and they would not be expected to make this sacrifice if they had another medical condition.

According to the Social Care Institute for Excellence, (SCIE, 2021), about 920,000 people are living with dementia in the United Kingdom, and 880,000 of this number are over 65. Moreover, the number of people living with dementia will rise to about one million by 2024 (Alzheimer’s, 2019) which is expected to increase to two million by 2051. About 225,000 people are diagnosed with dementia annually, while one in six people over age 80 have dementia, 60-61% of people who have dementia live at home in the community in their own homes, and 39% live in a care home (Clarkson, et al., 2018; SCIE, 2021).

There are about 700,000 unpaid carers of people living with dementia in the UK, and the condition cost the UK economy about £35 billion in 2019; significantly, 40% of this was from unpaid care (SCIE, 2021). According to Powell and Baker (2019:6), these costs are expected to continue to rise. The annual costs of mild, moderate, and severe dementia were estimated at £3.2 billion, £6.9 billion, and £14.1 billion, respectively. Furthermore, the average costs of mild, moderate, and severe dementia were estimated to be £24 400, £27 450, and £46 050, respectively, per person, per year; these are expected to treble by 2040 as the number of those diagnosed with the disease is assumed to double by the same year (Department of Health, DOH, 2020, 2015)

Wittenberg et al. (2019:1095) argued that "*social care costs are three times larger than health care costs - (£10.2 billion and £3.8 billion respectively), and £6.2 billion of the total social care costs are met by users themselves and their families, with £4.0 billion (39.4%) funded by government*". About one in three people will care for a person with dementia in their lifetime, and about 50,000 of these carers have left work altogether to care for people living with dementia (Powell & Baker, 2019:6).

These figures suggest a complex, expensive care system that needs greater understanding and insight. The figures also suggest higher dementia costs to which the family and other unpaid carers make substantial contributions. Furthermore, the accelerated ageing of the population also means that demand for unpaid carers will continue to increase (Wittenberg et al., 2019). Thus, considering these factors, alongside changing family structures, it is important to understand the role of neighbour support givers in a complex care system for older people living with dementia in the community.

Van Dijk et al. (2013:150) have argued that public policy increasingly emphasises the importance of informal support and increase in one person households is invariably increasing the need for informal carers. The situation is critical because of declining fertility rates, smaller family sizes and greater social mobility. This implies that help from kin may be limited while support from non-kin, such as neighbours, is more accessible (Seifert & Konig, 2019). Moreover, if family activity declines, outside activity increases and so does morale. The number of older people who are facing limitations to their everyday lives has increased, as well as their reliance on their immediate neighbourhoods (Wenger, 1990; Seibert & Konig, 2019). These trends have significant implications for the care needed in the future (Maher & Green, 2002). There is also an appetite for new approaches to support the quality of life and wellbeing of older people living with dementia in the community (Phinney et al., 2016).

According to the Department of Health and Social Care (2018) *an informal carer is someone who provides unpaid help to a friend or family member needing support due to illness, older age, disability, a mental health condition or an addiction, as long as they are not employed to do so*. This is like the definition of informal care as adopted by Triantafillou et al (2010) who argued that *informal care is generally defined as the unpaid care provided to older and dependent persons of a person with whom they have social relationships, such as spouse, parent, child, other relative, neighbour, friends or other non-kin.* These definitions point to the fact that informal carers give voluntary and unpaid care or support to kins or non kins, whom they have social relationships. In 2021/22, 4.9 million or 7% of the population in UK provided informal care (The Family Resources Survey, 2023).

Despite the preponderance of family carers, "*a significant proportion of dependent older people receive informal help from others, and a caregiving linkage is that between an older person and his or her friends, neighbours, or other unrelated people*" (Barker, 2002:158). It is estimated that between 5% to 10% of older adults living in the community receive informal care and support from friends and neighbours, Nocon & Pearson, (2000). Support by non-kin carers is therefore believed to play a critical role in keeping adults in their homes as they age (Nocon & Pearson, 2000:3410; Wittenberg et al., 2019; Lapierre & Keating, 2013).

People are increasingly relying on informal rather than professional care, Bredewold et al, (2019); long-term care systems are dependent heavily on provision of care by informal carers, Courtrin, Jemiai, Mossialos, (2014), and the contributions of informal carers have been considered critical to the sustainability of the National health Service in England (Foley et al, 2023). At a time when health and social care services are under pressure to cut costs, informal carers are relied upon as the main providers of long-term care. However, little is known about the availability of direct and indirect support for informal carers (courtrin, Jemiai, Mossialos, 2014).

According to Wenger (1990), non-kin carers like friends and neighbours have received little attention in UK studies and policy, and less has been written about the broader nature of relationships with friends and neighbours, which suggests this is an area requiring research. Wenger further argued that despite the low profile accorded to friends and neighbours in much of the social gerontological literature, they play important contrasting but complementary roles in the lives of older people, Wenger (1990:166). In the same vein Ruanavaara (2022) argues that one overarching theme of the limited literature available on neighbour relations is the growth of the neighbour role, despite modernisation and the individualisation of societies. This study explores the role of neighbours in a dementia care context. Similarly, Lapierre and Keating (2013) argue that non-kin care/support is inadequately understood, which leaves a gap in understanding the intricacies of informal caregiving. The complexity of the UK care system can be evidenced by the finding that many people living with dementia do not have contact with an informal carer (Eicher et al., 2016), and 7% of those living with dementia aim to recruit a carer where one is available (Clare & Nelis et al., 2014).

While population ageing presents unprecedented challenges to social care systems, informal care provision and its challenges have not been a major component of response to the phenomenon (Courtrin, Jemiai, Mossialos, (2014), and the savings and cuts regarding professional care are increasing demand for both kin and non-kin informal care, even as demographic and societal changes, including changes in family structures limit the availability informal care givers (Groenou and Boer, 2016). This means that there would be reduced availability of professional care underwritten or backed by government, and older people in need of care would depend more on informal carers like neighbours and friends. This has led to greater need for research of the informal care system (Bredewold et al, 2019). Given unprecedented challenges posed by population ageing, further research and better data are needed to capture and monitor information on informal carers to help design adequate support policies (Courtrin, Jemiai, Mossialos, 2014).

The focus of informal care giving research has centred on the exploration of the nature of tasks performed by the informal care givers to care recipients; examination of the values and motivations of the informal care giver in the support system; investigation of the burden and costs associated with care and support giving; exploration of the nature of the reciprocity associated with informal care giving relationships (Bredewold et al, 2019); identifying the nature of tensions that may arise in the care giving relationships, and the contextual factors associated with the need to provide care (Groenou and Boer, 2016).

Drawing from the above this study investigates the roles of neighbours in providing support and care to older people living with dementia in their own homes. The study rationale is detailed below.

1.2 Study Rationale

(a) Considering that non kin care is not adequately understood, this leaves a huge gap in understanding the intricacies of informal care at a time when the number of people living with dementia is rising, and kin and formal carers are less available. Therefore, my research is significant and germane at a time when there is a gap in literature about informal care, especially in the context of neighbour dementia care. It is therefore necessary to explore the experiences of neighbour care giving to older persons living with dementia, especially in instances where there are no alternative carers (Silverman, 2020). Accordingly, my study is significant because it adds a new perspective to existing literature and helps to inform decisions and policy about the intricacies of informal non-kin neighbour dementia care in the community. My study is also significant because it helps to highlight the nature of the relationship between ageing, dementia and neighbour informal care giving.

(b) My study is consequential at this time because it provides fresh perspectives and understanding of the nature of the development of neighbour dementia care, the motivations and reciprocity in the neighbour dementia care relationships, the nature of support that neighbour dementia care givers, give; the tensions that may arise in the neighbour relationships and how they might be addressed, and how the relationships could change as cognition of the persons living with dementia declines. Understanding these complexities are significant because it will help in facilitating and enabling ageing in the community by older persons living with dementia, rather than in care homes (Magid et al, 2021).

(c) Furthermore, my study is justified because it provides more insight as to how informal non kin care especially neighbour dementia care in the community could be sustained especially as number of older people living with dementia in the community continues to rise, and as the formal care sector continues to come under pressure in funding for support of older people in the community. The decline in appetite by the welfare state for social support such as provisions for formal help and care, can create a situation in which families and neighbours are obliged to rely heavily on one another (Seifert and Konig, 1019:3).

(d) This study is also justified because it has implications for dementia care, social work practice, policy development, and neighbour care (see more details on Implications of Study).

1.3 Aim of the Study

To this end, the aim of this doctoral research is:

To better understand the experiences of support provision by neighbours to older adults living with dementia in the community, particularly in instances where family members are not immediately available.

This aim was met by addressing the following objectives:

1.4 Objectives of Study

a) To explore how dementia care giving relationships develop in the context of a need to provide informal care for older people living with dementia in the community.

b) To identify the nature of care or support that neighbour dementia care givers give and their motivations.

c) To explore how tensions can arise in informal neighbour dementia care giving relationships and how the tensions might be addressed.

d) To discover how the informal neighbour dementia care giving relationships fit within a wider network of household and family members and formal care providers.

e) To determine the nature of reciprocity in the neighbour dementia care giving relationship.

This research has practice and policy implications for dementia support in the community, particularly regarding how informal carers like neighbours provide support to older adults in the community. It also has policy implications for social work practice about the role of neighbours in the provision of dementia support. I adopted an exploratory and qualitatively driven approach in my methodology, and data were collected using semi-structured interviews from two samples. The first sample comprised neighbours providing care and support, and the second, older people living with dementia in the community who reported receiving support or help from a neighbour.

1.5 Introducing the Researcher

Having introduced the research, this next section introduces me, the researcher of this study. This is especially important considering that this is a qualitative study that applies an interpretive approach to the analysis of data; thus, the view of the researcher matters.

I am a qualified social worker. After completing my studies for a master’s degree in social work in 2012, I started work with a local authority in London. One of the major roles of my team was to conduct assessments and review the needs of service users; such assessments involved referrals from different sources in the community. A significant number of referrals reaching my team from the community came from neighbours of older adults living in the community, and the referral summary sheets consistently indicated that most neighbours making the referrals had supported the individual living with dementia in various ways before calling for help. Some of the referrals included stories such as “*I have been caring for Mr or Mrs A, B or C; I am not doing it anymore, after all, it is not my job; I am only helping. Please come and see him/her and try to support him/her*”.

Another significant aspect of the referrals was that when my team responded to the referrals by visiting the individual living with dementia for a face-to-face assessment, they either insisted on the neighbour being present, or the neighbour wanted to be physically present. Another important observation was that most of the potential service users referred did not have family members living with them, or who appeared to be interested in their welfare. The above trend continued as I worked in and across six local authorities over seven years, and eventually prompted me to develop a research proposal about my observations to explore and better understand the role of neighbours in dementia care in the community. So, the above narrative is not only a short history of the researcher but also a short history of this study.

Furthermore, I have a history of helping people and working with vulnerable individuals to help them to live independent lives and maximise their potential. I bring my extensive professional social work experience to the study and had no doubt from the outset that the research would culminate in recommendations for policy changes about informal dementia care in the community in general, and for care and support by neighbours of older adults living with dementia. Therefore, I had an agenda to explore on what was going on with neighbours providing help, and to consider the implications for policy and practice.

1.6 Introducing the Policy Context: Dementia Care Pathway

Although this research focuses on the complexities of informal care and support, decisions in the formal sector - including budget reductions – inform the overall picture concerning the complexities of the care sector affecting the provision and development of care and support. According to Samsi and Manthorpe (2014:2055), "*care or critical pathways are used to systematically plan patient care and refer to patient's route into services*". They incorporate care and support from both formal and informal carers. It is vital to show how this complex interacting care system has worked and persevered, including whether it has worked fully or failed. It is also important to consider the extent to which they have accommodated care and support from community networks and groups like neighbours. My research does not answer these questions directly but contributes to a collective awareness of the issues. Some key points or stages have been identified along the dementia care pathway and include: the stages of early response or symptom identification and first service encounters; the assessment stage/process, and the diagnosis and diagnostic disclosure stage. It matters when and how the information about dementia is delivered to service users, and the post-diagnostic support and appropriate intervention stage is key, which includes access to appropriate interventions as the needs of service users change (Samsi & Manthorpe, 2014).

The relevance of the care pathway to this study lies in identifying the relevance of informal care and support as the dementia stages progress. It is important to understand the experiences of older adults living with dementia and their neighbours with regards to non-kin informal care and support, from early signs and diagnosis to later stages of the pathway. Furthermore, determining whether informal carers like neighbours are relevant to the pathway, and if so, it is important to understand the nature and intensity of the care and support they give. In a review by the National Housing Federation in 2015, 436,000 older and disabled people who would have been eligible for care and support under the previous eligibility framework (Fair Access to Care Framework), are no longer eligible for such help under the Care Act 2014 (HACT, 2015). The study also argued that at a time of budgetary restrictions and a rapidly ageing population, the need to find radically new ways of support people to live well in later life is becoming increasingly urgent. The policy shift to care for people from hospital to the community has been a key focus; however, "*this has yet to translate into a major shift in service provision*" (HACT, 2015:1).

Most important intended outcome of this study is to understand relevant relationships and networks identifiable in the care pathway, and the nature of the relationships and support at each stage. This includes identifying who is involved in initial help, coping with changes, and planning for the end of life. It is essential to determine whether informal carers like neighbours can be located along this care pathway. According to the National Housing Federation (2015:8), "*taking a person and family centred approach helps to counter systemised ways of organising services that are often designed with the needs of organisations and professionals in mind*". They argue that a person and family centred approach will ensure a more holistic response to the changing needs that a diagnosis of dementia brings. In other words, the assets and resources within the local community must be factored into any planned system of care and support interventions.

This study investigated relationships to inform our understanding of the role of neighbours in care provision and how their roles may be better embedded in planned systems of care as part of the holistic and person-centred interventions available. The general idea is that people with dementia and their families must be supported to achieve their best wellbeing as their condition progresses; however, the greatest challenge is to translate these policy ambitions into everyday practice.

1.7 Research Questions

The questions addressed in this study include:

- How do neighbour caregiving relationships develop within the context of a need to provide informal support or care for older people living with dementia in the community?
- What is the nature of support that neighbours provide, and what are their motivations?
- What tensions can arise in such relationships and how might these be addressed?
- How does this support or care fit within a wider network of household and family members, as well as formal and third sector support and care providers?
- What is the nature of reciprocity of support in the caregiving relationships?

1.8 Summary

Having presented the statement of the problem, the rationale of study, aims and objectives of study, the research questions, and the research gap, above, I describe below the framework of the rest of the research.

In chapter two, I present a critically analysed literature review which embodies my literature search strategy, including the definition of neighbour and friends. I also present literature on neighbouring and neighbourliness, the neighbourhood as a social and physical space, motivations for care and support giving, and the reciprocity of support. I also present literature on social capital, living alone, and loneliness in relation to people living with dementia. My literature review chapter also explored previous dementia care strategies, policies and plans, different approaches to care, and the research gap that my study addresses.

In chapter three, I present the research design of the study, which includes why I adopt person centred and critical social gerontology approaches as frameworks for this study. I also present my research methods and methodology, the inclusion and exclusion criteria for the research samples, and details of my sampling and participant recruitment. I also analyse the rationale for using a semi-structured interview method for the data gathering and present a detailed description of the area of my study, the issue of theoretical saturation in relation to my research sample and recruitment, my data management strategy, and the thematic analysis. I also present my reflections in relation to the research and explain issues concerning consent, capacity, and confidentiality in relation to the research participants. Moreover, I discuss the nature of power imbalances between me and the research participants, the ethical considerations taken, and the issue of Covid19 pandemic.

In chapter four, I discuss the findings of the research which includes the relationships between the care givers and the older persons living with dementia, the processes of neighbourly support, motivations for care giving, the nature of the care giving relationships, and the nature of support given in relation to financial management. I also analysed my findings in relations to older people living alone living with dementia, the complexity and/or burden of care, the nature of reciprocity in the care giving relationships, tensions in care relationships, and the issue of gender in care giving relationships.

In chapter five, I discuss the findings of the study in relation to existing literature regarding the processes of neighbourly support, motivations of support, the nature of support given, issue of older people living alone, complexity of the care giving relationships, the reciprocity of support, tensions that arise during care relationships, and the issue of gender in care relationships.

Finally, in chapter six, I summarise my study to show the correlation between different chapters of the study. I also identify the key contributions of the study, and outline recommendations in relation to policy development, neighbour care givers, social work practice and community dementia care. I also identify the limitations of the study and outline recommendations for future research.

2 Literature Review

In chapter 1, I introduced and described the background to this study, identified the problems to be investigated, and detailed the aims and objectives of the research. To determine the scope and understand the context of this study, it is necessary to define and review existing literature related to the research terms and phrases identified in chapter one. The literature, terms and phrases are identified as: Neighbourhoods and dementia, neighbour carers and older adults living with dementia, dementia care strategies, and policies and plans. It was necessary to also review the meaning of the terms neighbouring and neighbourliness, neighbourhood as social and physical space, social capital.

From the above, the literature review has been structured to critically detail the search strategy, explain the meaning of 'neighbour' in the context of the study, define and differentiate between the concepts of friends and neighbours, discuss the concepts of neighbouring and neighbourliness, and define the meaning of neighbourhood as a social and physical space. It also critically reviews the nature of support potentially given by neighbour carers and their motivations, including the nature of reciprocity in care giving relationships. Furthermore, the concepts of social capital, issues of living alone experienced by persons living with dementia, and dementia care strategies, policies and plans are also reviewed. Finally, different approaches to care are analysed, alongside the research gap that his study addresses.

2.1 Literature Search Strategy

I searched the electronic databases for materials using key terms relevant to the research topic and phenomena. Some of the databases searched included theWeb of Science, Research Gate, Academia Edu, Google Scholar, Dementia, The International Journal of Science, and Cambridge Core. I used different search terms for different databases. Table 1 illustrates an example of my search strategy, including the search terms, databases searched, number of hits, and number of articles chosen for review.

Table 1: Example of the search strategy used

Database	Search Terms	No. of 'hits'	No. articles chosen

Web of Science	Friends, neighbours, dementia, informal care, neighbouring, informal care giving, older adults with dementia, older adults with dementia and their carers, older people, carers	97	18
Academia.Edu	Friends, neighbours, dementia, informal care, neighbouring, informal care giving, older adults with dementia, older adults with dementia and their carers, older people, carers	564	22
Social Care Online	Friends, neighbours, dementia, informal care, neighbouring, informal care giving, older adults with dementia, older adults with dementia and their carers, older people, carers	984	11
Web of Science	Friends, neighbours, dementia, informal care, neighbouring, informal care giving, older adults with dementia, older adults with dementia and their carers, older people, carers	53	20
Dementia	Friends, neighbours, dementia, informal care, neighbouring, informal care giving, older adults with dementia, older adults with dementia and their carers, older people, carers	20	3

These databases were available through the university database. Although each search produced many ‘hits’, namely potentially relevant articles, I needed to select the most relevant to the study. Thus, I read the abstracts of the articles and made decisions about those to include and exclude based on their relevance to the study, topic and research questions. In addition, I read the conclusions to determine their relevance to my study, which meant:

a) Considering the relevance of the article to the topic (in terms of its focus on neighbour carers, informal carers, people living with dementia in the community);

b) Considering/reviewing all relevant articles regardless of the date of publication. This helped to ensure that foundational literature was also reviewed, and their accounts considered;

c) Checking the language in which the article is written (only English Language);

d) Ensuring the subject is related to a);

e) Checking the appropriateness of the methodological approach (qualitative methodology preferred);

f) Checking the data collection methods applied – in-depth interviews were preferred because such studies were better tailored for a qualitative study such as this;

g) Considering whether the arguments and conclusions are convincing, and if the work contributes in any significant way to a greater understanding of the subject (Margaret, 2020).

I completed the search and literature review between October 2018, and March 2021. However, I updated my literature review following more searches between September 2022 and March 2023. The second search and review were prompted from the initial findings of my data collection when it also became necessary to update my work with the most recent studies and with more foundational articles. I conducted further searches on specialist documents and reports related to government-commissioned projects on dementia care. I also searched important charities' websites, such as those of the Alzheimer's Society and Age UK. I also searched other specialist social work websites like the Social Care Institute for Excellence (SCIE) and Community Care. Finally, I used other contacts, such as other PhD students, and searched through references in the key articles I reviewed.

For purposes of clarity, I hereby start by clarifying what I mean by Neighbour, in the context of this study.

2.2 Neighbour

The concept of neighbour is central to this study, and therefore has been critically defined and reviewed in relation to my research focus. According to Bulmer (1986), those defined as neighbours live mostly within walking or close distance and are individuals with whom frequent face to face contact is possible. In essence, Blumer considers neighbours as people who live near each other (Blumer, 1986; Wenger, 1990). Silverman (1986) and Rosenblum (2016) also define a neighbour in terms physical proximity, as people who live near each other and/or live close to the private space of one's home. Although neighbours live geographically near each other in a neighbourhood, they could be acquaintances or strangers, especially in situations where neighbours know little about each other, have no contact, and do not recognise each other as neighbours (Morgan, 2009). However, Rosenblum (2016) argues that neighbours cannot be total strangers (Ruonavaara, 2022).

It has been argued that the spatial factor alone does not adequately define a neighbour. While the necessary condition is that neighbours are found in close spaces, the sufficient condition stipulates that there must be contact and interaction. According to Ham (1973), neighbours are social groups that interact because of the commonality of the place of residence. Seifert and Konig (2019:1) also define a neighbour in terms of interaction and argue that the term neighbour "*defines a person's role and attitudes, expectations and negotiations deriving from the resulting interactions.*"

In addition to being a physically close group, Rosenblum argues that for neighbours to be such, they must influence each other's lives. This means that people next door are not neighbours until they establish contact. However, it has been suggested that merely identifying people who live close as neighbours can be satisfying as it gives a sense of security and belonging (Henning & Lieberg, 1996).

However, it is also important to understand what is meant by proximity or living near each other in the context of definition of neighbour. Indeed, those living in towns and villages tend to only define themselves as neighbours to those living within a short radius, while those living in more dispersed areas may count people living as far away as a mile as neighbours, especially if they have known them, and grown up together. (Wenger, 1990). So, a neighbour has also been defined in relation to urban and rural areas. While the definitions by Bulmer (1986) and Silverman (1986) would be applicable to urban environments, people in rural areas who do not live near each other may still consider themselves neighbours. According to Ruonavaara (2022:381) "*neighbours are persons living at a closer distance to us than other people, whatever that distance may be*". This means that in rural areas, persons/households are neighbours even if they live far from each other, so long as they are the nearest inhabitants to each other. Thus, the concept of neighbour has attributes of boundary, proximity, distance, supportiveness, privacy.

Some authors adopt a subjective definition, and view neighbours as whoever people in the neighbourhood call neighbour (Ruonavaara, 2022) i.e., if people who live in the neighbourhood call a set of people neighbours, then they are neighbours, and vice Moreover, according to Van Eijk (2011) those who live in adjacent houses or in houses immediately next to above, below, or opposite each other are typically considered neighbours (Ruonavaara, 2022). These definitions prompt a need for greater clarity of the following terms: near, close, nearby, very close, adjacent, above, and it is important to understand how close or nearby. However, researchers argue that even those who do not live close to each other are often considered neighbours, as they focus not on the spatial aspect but on the relational element.

These definitions indicate that the concept of neighbour has both spatial, and relational characteristics. Neighbours are classed as such not just because of living in proximity, but because they make contact and interact with each other. The interaction could take the form of support and/or care from one neighbour to the another.

The definition of neighbour in the context of this study is persons who live near each other and who make contact and affect each other’s lives in different ways, especially by providing dementia care and support. So, I adopt the definition of neighbour that touches on both spatial and interactive activities. I therefore adopt the definition of neighbour by Seifert and Konig (2019:1) who define neighbour in terms of interaction, attitudes, expectations, and negotiations deriving from the interactions of people who live in proximity. I adopt this definition because it reflects the nature of care giving relationships between neighbours in this study. In other words, the definition reflects not just the proximity and privacy of neighbours but the supportiveness of neighbours in care giving relationships.

Having defined and reviewed the concept of neighbour in the context of this study, the next section critically reviews the perception of neighbours as friends and vice versa, to further clarify the concept of neighbour.

2.3 **Friends or Neighbours**

The concept of friends and neighbours are sometimes confused and discussed uniformly in relation to neighbour care relationships. This therefore needs to be clarified early in this research. Occasionally, neighbours are considered friends, and friends viewed as neighbours. According to Wenger (1990), both neighbours and friends in the context of care relationships may not fit into either category or may fit into both. The confusion in the categorisation is derived from the care and support both give to neighbours. They are considered two important components of most support networks and contrast with one another (Wenger, 1990).

Relevant literature tends to discuss friends and neighbours alongside each other. Both are highlighted as contrasting but complementing roles in the lives of older people. According to Baker (2002) one informal care giving linkage is that between an older person and his or her friends and neighbours and assistance from friends and neighbours has been shown to have a critical role in keeping older adults in their own homes (Lapierre & Keating, 2013). Though they play similar roles in a neighbour care relationship, they are not considered in the same category of care givers and should not be confused as such. While friendship is based on choice, rapport, and shared interests, “neighbour relationships are founded on proximity and shared locality, and while some neighbours may become friends, friends are based on reciprocity and freely chosen relationships, while neighbours are accessible, and are less freely chosen with no clear obligations” (Wenger, 1990:150-166).

According to Block (1980), a friend is a person, not kin, with whom you feel close, talk personally, and on whom you rely. Block’s definition could easily confuse a friend with a neighbour, because a neighbour could also easily pass as non-kin, to whom one feels close, talks personally, and could be counted upon.   Blumer attempts to clarify the difference between friends and neighbours and argues that neighbour relationships are relatively limited, and being a neighbour is considered more specific and more narrowly framed than being a friend, and being a neighbour is a role relationship to which certain norms apply (Blumer, 1986). However, the conception of neighbour being narrowly framed and to which certain norms apply may not be tenable in an unbalanced care relationship, where the neighbour role could be wide and far reaching, and tend not to conform to any norms, as the neighbour responds and gives support as needs arise.

Furthermore, when a neighbour becomes a friend the relationship usurps the neighbour relation, but a neighbour friend does not cease to be a neighbour (Ruonavaara, 2022; Keller 1968). Thus, notwithstanding how a care giver defines their neighbour (neighbour or friend), a neighbour does not cease to be such and is generally defined in terms of proximity and relationship.

I adopt the view of Ruonavaara (2022) that a neighbour does not cease to be a neighbour even when their relationships seem to depict them as friends. I therefore adopt the concept of neighbour in terms of physical proximity and relationship. This clarification is important to properly define the concept of neighbour as applied in the study.

Having fully defined and reviewed the concept of neighbour in the context of my study, I have explored and critically reviewed below the concepts of neighbouring and neighbourliness to understand the nature, trends and pattern of care giving relationships between neighbours in the community.

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2.4 Neighbouring and Neighbourliness

I have critically reviewed existing literature in relation to neighbouring and neighbourliness in the context of my study and identified gaps and lessons in existing research. I reviewed existing literature on these concepts because issues about neighbouring and neighbourliness are central to informal care in the community. For example, neighbour dementia care relationships are forms of social relationships that impact in one way or the other on the care relationships.

Philip Abrams defines neighbouring as the actual patterns of interaction between neighbours. Moreover, Bulmer (1986) and Keller (1968) refer to neighbouring as activities engaged in by neighbours and the relationships these engender among them. According to Bulmer (1986:3), "*social relations between neighbours are a significant form of social exchange, and in addition to social contact, neighbours provide support for each other in form of tasks performed or services given*". Bulmer's work also linked informal caregiving as a survival model for social minorities, as they give care and support to each other.

Although a neighbour relationship is based on proximity "*the core component of the concept of neighbouring is the considerations of contact and help exchange within a given neighbourhood*" Seifert and Konig, (2019:2). Neighbouring is characterised by mutual help, sociability, and the respect for boundary; those who adhere to these characteristics are considered ‘good neighbours’ (Ruanavaara, 2022). This means that neighbours are considered as neighbours because of their proximity and the contact they make.

“Neighbour relationships are characterised by availability, friendliness, coupled with respect for privacy, and these characteristics also form the bases for good neighbourliness” (Wenger, 1990:166). According to McGahan (1972), a good neighbour is someone friendly but not a friend and someone willing to chat, but at the same time does not intrude on your privacy. This means that neighbourly relationships involve negotiated support, friendship, and conversation but at same time maintain an acceptable level of privacy. Moreover, relationships with neighbours are more instrumental than the expressive nature of friendships and involve a feeling of security because of their proximate presence (Wenger, 1990:166). The availability and instrumental aspects of the neighbour relationship suggests a level of interaction beyond transactional relationships and point to a support relationship.

There is a need to differentiate between positive and negative relationships between neighbours. According to Morgan (2009:19) neighbouring is a positive term used to refer to neighbours’ willingness to carry out some chores for each other. However, some authors have argued that neighbouring refers to the general aspect of neighbour relations, while neighbourliness refers to the positive aspect of neighbouring. This means that there are negative aspects of neighbouring. According to Ruanavaara (2022), all positive neighbourly interactions are referred to as neighbourliness, and neighbourliness is not an emotion but a practice that supports or increases a neighbour’s quality of life (Rosenblum, 2016). Such practice that increases a neighbour’s quality of life may include the instrumental support a neighbour may receive from another neighbour. This is significant for my study which concerns positive neighbour care relations in dementia context.

Neighbouring has also been linked to maintaining the tension between cooperation and privacy, helpfulness and interference and between friendliness and distance (Allan, 1983). Neighbourliness is therefore potentially more of a ‘middle-range intervention’, as it means not being intrusive, but at the same time not keeping a distance (Crow et al., 2002).

Neighbouring, therefore constitutes "*social relations between people living nearby, and neighbourliness is used to discuss positive neighbouring relations*" (Buonfino & Hilder, 2006:8). Neighbouring assumes a positive, negative, or indifferent status (Berry et al, 1990; Keller, 1968; Skjaeveland et al., 1996). This means that the social relations that may arise between people living close to each other may emanate from good intentions, aim at mutual support, and lead to good outcomes for both parties. However, such relations may arise because of negative intentions and lead to social services' safeguarding investigations because one party attempts to or abuses the other. There is no doubt that neighbourly ties can result in negative outcomes. These could range from anti-social behaviours, intrusive behaviour by "nosey" neighbours, and non-committal neighbouring (Buonfino & Hilder, 2006). This means that the concepts of neighbours and neighbourliness can connote some negativity that points to or is linked with anti-social behaviour. This contrasts with the previous definitions indicating "*close ties, mutual support and solidarity*". However, some of the positive aspects of neighbouring include the enhancement of health and wellbeing, social efficacy, crime reduction, the feeling of safety, and belonging and protection (Buonfino & Hilder, 2006:8). Other factor that is perceived to affect neighbouring include the invention and availability of care and home entertainment systems (The Young Foundation, 2010).

Bulmer (1986) also viewed neighbouring in the context of power relations, whose presence has declined with the rise of urban industrialisation and the welfare state. Changes in neighbouring have been linked to globalisation and modernity as increased mobility to cities has led to the fragmentation of familial and kinship ties. In addition, the combination of increased labour, longer life expectancies and the breakdown of the extended family have changed the extent of neighbourliness (The Young Foundation, 2010). So, it is appropriate to ask whether neighbourly support has been lost or whether globalisation has reinforced local ties and bonds and fortified the care and support available to the vulnerable in local areas. Nonetheless, there remains a good reason to pay attention to neighbouring as a social process because neighbouring is of great importance to those who lack social power, namely children, women, the disabled, and older people (Popenoe, 1988).

According to Buonfino and Hilder (2006), neighbourliness is important and indicates an innate human need to bond as people are drawn to each other despite changing dynamics. Part of the changing dynamics include the greater mobility of people, which in turn poses many challenges to neighbourliness. Also contributing to the increasing dynamics of neighbourliness in the neighbourhood is the changing housing market, better transport networks, violence in neighbourhoods and insecurity. However, there is evidence that residents continue to interact with their neighbours, and they still influence their lives (The Young Foundation, 2010; Coulson et al., 2011).

A disposition to be friendly and helpful to neighbours positively impacts older people, but too much bonding can lead to self-segregation and a breach of privacy (Buonfino & Hilder, 2006). According to Hoefman et al. (2017), 67% of the public would be willing to provide informal care in future and willing to provide more support tasks than personal help or nursing. Their study concluded that formal support is likely to be substituted by informal support. This alludes to the perspective that - notwithstanding the nature of changes in local communities people still bond and help each other. The nature of any such support received by older people living with dementia in the community, is the focus of this study.

Mann (1954) identified two types of neighbourliness (latent and manifest). Manifest indicates observable social interaction and the exchange of help and goods, face to face interactions, chatting over physical home boundaries, and using neighbours as a constant source of informal help. In comparison, the latent aspect of neighbourliness manifest when there are urgent support needs (Mann, 1954). Mann also posits that too much manifest neighbourliness may lead to resentment.

Measuring neighbourliness ranges from seeing it in terms of low-level individual interactions to collective actions to promote common interests. The individual and collective actions may include casual greetings, chatting, the exchange of greeting accessories like cards, providing information, lending minor household items, occasionally knocking on and looking out for neighbours, giving emotional support in times of distress e.g., bereavement, socialising and engaging in collective activity, such as environmental activities (Crow et al., 2002).

The Young Foundation (2010) states that 42% of people in a neighbourhood socialise with their neighbours or friends at least once a week, and the level of interaction tends to depend on the level of satisfaction of the people living in the neighbourhood. The level of satisfaction of people in the locality therefore encourages them to get involved in local activities. Well maintained public attractions could easily encourage people to meet and interact with each other, as people spend time outside their homes. Elements that could facilitate a tendency for neighbourliness include "*well-managed spaces for social interaction including parks and health centres, homes with front gardens, extended school systems, local street events and parties and internet-based local information services*" (Buonfino & Hilder, 2006:6). This means the nature of the spatial environment or neighbourhood affects the level of interactions that take place in them.

While life patterns have changed, evidence suggests that good relations at the local level still have benefits for the quality of life, and that neighbours who behave in a neighbouring way are valued in the local community (Buonfino & Hilder, 2006) The basis for neighbourliness may not be family, close friendships and strong ties as these were more accessible in the past; but now includes care and support in times of difficulty, respect and friendliness. Although neighbourliness may not be for everyone; moves to engage and stay in contact at the local level amongst people in a locality can engender a "*rediscovery of the local and help people, in particular, the most vulnerable, including older adults to live more happily*" (Buonfino & Hilder, 2006:8). People's attitude of keeping or not keeping in touch in the local community maybe influenced by their values. Other factors that may determine the extent of neighbourliness include the design of the environment, levels of criminality, trust, neighbourhood governance, the nature of the local area's demography, and the availability of local facilities and amenities like shops, cafes, and pubs. It is also argued that in neighbourhoods where there are children, nurseries, or primary schools, older people or a higher percentage of homeowners tend to be more neighbourly (The Young Foundation, 2010).

The identifiable gap in this review is that neighbouring and neighbourliness were discussed in general terms, and not linked to a particular condition like dementia. It was not clear in the studies reviewed how a condition like dementia could affect the nature of interaction or pattern of neighbour relationships. My study helps to address this gap by exploring the nature of neighbour care giving relationships in dementia care giving context. The lessons from this review are that proximity do not automatically mean neighbourly relations; it is a necessary condition for interaction between neighbours. Interaction between neighbours, in the context of this study refers to interaction in dementia care context. So, though a neighbour relationship is based on proximity, considerations of the nature of the help exchanges within the neighbourhood matters. Another lesson from the review is that though there could be negative aspects of neighbourliness, positive relations in the neighbourhood thrive and are beneficial to the vulnerable and the less powerful in society.

Having reviewed the concepts of neighbouring and neighbourliness, it is important to explore the nature of the space where the relationships take place.

2.5 Neighbourhood: Social and Physical Space

I critically reviewed the concept of neighbourhood as both a social and physical space in the context of my study and identified gaps and lessons in existing research. I reviewed existing literature on neighbourhood as a social and physical space because I believe that the neighbourhood as both a physical and social space is relevant to my study, and the review helps to better understand on a wider scale the nature of social interactions in the neighbourhood where dementia care giving relationships take place.

The concept of the neighbourhood has been defined and conceptualised in both physical and social/relational contexts. According to Keady et al (2012:150), to develop a neighbourhood model for dementia, research must examine "*the relationship and interaction between the neighbourhood as a social space and as a physical space along with the active role of people living with dementia*". This thinking is in line with the view of Wenger (1990:166), who argues that neighbour relationships are founded on proximity and a shared locality, and neighbourhoods in their modern form are social constructions rather than passive geographical entities. My study focuses on the relationships and interactions between neighbours in a dementia care context, so neighbourhoods in this study are therefore viewed in terms of both social networks and sites of face-to-face interaction.

Neighbouring takes place within the confines of a geographic space, and while neighbouring refers to the social and support activities pursued by neighbours, a neighbourhood describes the spatial area that is physically and symbolically different from the greater environment (Seifert and Konig, 2019). These views point to the fact that a neighbourhood comprises elements of social interaction rather than a mere physical environment. This also means that neighbour dementia care relationships take place within the confines of neighbourhoods and are outcomes of social relationships within a neighbourhood. This means that a neighbourhood must be meaningful to the people living in it and are defined in terms of geographical and behavioural parameters (Ruonavaara, 2022).

This study investigated the nature of social constructions by studying the experiences of neighbours supporting older adults living with dementia in their own homes. In essence, this study focused on neighbouring in a dementia care context in the neighbourhood. There is therefore a need to understand the role of the neighbourhood location in the lives of people living with dementia as neighbourhoods offer an attractive system of support to enable or restrict a sense of wellbeing which is associated with social connection (Keady eta al 2012). It also facilitates social health by enhancing a sense of active engagement and connectedness (Clark, et al, 2020).

A further understanding of the social and physical contexts of neighbourhoods can be viewed from the concept of “ageing in place”. “Ageing in place” helps older people to “*maintain social connectivity with friends, family, and social support,”* and has been defined as *“remaining living in the community with some level of independence, rather than in residential care*” (Arcus et al, 2004:133). This means that people must find reason to be attached to their neighbourhood environment and interact in a meaningful way. Similarly, Mitchell (2010:12) argued that “*since most people with dementia live at home; unless their external environment begins to be dementia-friendly they are likely to be Care Home bound*”. They must be able to use their neighbourhoods safely in order not to be relocated to a residential home. Thus, the outdoor environment plays an important role in the health, health independence, and wellbeing and cognitive function of people living with dementia (Forsund et al., 2018). It is therefore vital that communities and neighbourhoods are welcoming, safe, easy and enjoyable to access. As a result, six design principles were identified and suggested, which included familiarity, legibility, distinctiveness, accessibility, comfort, and safety (Mitchell, 2010:12). These suggestions point to functional, symbolic, and emotional attachments, and meanings people attach to their homes and neighbourhoods (Wiles & Leibing et al., 2012), that make them want to live in the community, rather than move to a residential home. This means that people want to be familiar with the environment, and the neighbourhood must be attractive. It also implies that the environment must be convenient, reachable and special to the people living in it. It also means that the neighbourhood must be congenial and secure to retain its residents.

Therefore, as demography changes and older people reside more in the community, supportive neighbourhoods enabling older people to age successfully are highly valued and regarded (Dijik et al., 2015), since most people living with dementia live at home. However, unless their external environment begins to be dementia friendly, they are likely not to age in place (Mitchell, 2010:12). They must be able to use their neighbourhoods safely, in order not to be relocated to a care home. The outdoor environment therefore plays an important role in the health, health independence, wellbeing and cognitive function of people living with dementia. It is therefore vital that communities and neighbourhoods that are welcoming, safe, easy and enjoyable to access, visit and use, are encouraged and developed. This means that as communities and neighbourhoods begin to expand because of population growth, neighbourhoods must be built with older people in mind, and should be dementia friendly, welcoming, and promote social citizenship to ensure that older people living with dementia continue to live their lives in the community with dignity.

Walker and Hiller (2007) explored neighbourhoods in a different way and explored the social and physical dimensions of neighbourhoods and variations between lower or higher social status areas; they found that a reciprocal and trusting relationship with neighbours underpinned older women’s sense of satisfaction and a feeling of security within the neighbourhood. Other factors that were found to be important included living near services and existing social networks. This means that neighbourhoods must be places of safety that engender trust, confidence and positive interaction. People living with dementia drew on both existing networks and neighbourhoods to sustain their independence and social connections. Residents living in less advantaged areas were more conscious of social disconnection in their neighbourhoods. For the residents in these less advantaged areas, bonding with their neighbours became a priority and this has implications for their health and wellbeing (Walker & Hiller, 2007).

So, it is useful to establish the ideal place to grow older and what makes an environment acceptable for use by older people. As older people reside for longer in the community, supportive neighbourhoods enabling older people to age successfully, are highly valued and well-regarded (Dijik et al., 2015; Mitchell, 2010). The neighbourhood is therefore a significant place where social contexts are forged and is important not only because of its nearness to residents but also due to the high turnover of special relationships (Odzakovic, 2019). The neighbourhood helps to condition connectivity, inclusion and exclusion, depending on how it is perceived and managed.

It is important to explore the concept of the neighbourhood in relation to how people living with dementia interact with their neighbourhood. Odzakovic et al. (2019), explored how to empower people living with dementia to live in their neighbourhoods and reduce institutionalisation. For people to sustain an acceptable level of wellbeing in old age, they must remain connected to their social environment. To this end, the way relationships develop, grow, and change matters. This means that the processes that lead to relationships between people who live with dementia and their neighbours, matter; and so also the nature of the reciprocity of the relationships, tensions in the relationships, and how such tensions are resolved.

However, the “stigma of dementia contributes to isolation as even friends begin to disconnect from those living with dementia”. However, stigma “could be reduced by maintaining social connections with the community and promoting a more public personal awareness of dementia policy” (Odzakovic, 2019:18). This means that targeted policies of educating the people about dementia and living with dementia is germane and vital. Moreover, understanding the challenges in living with dementia in the community is vital to improving an individual’s quality of life and to addressing problems of social isolation and dementia-related stigma. This implies a need for social education and understanding about dementia that includes what living alone with dementia involves, and how to reduce the risk of solitude and isolation (Odzakovic, 2019).

It is also important to examine the contributions and nature of engagements of people living with dementia, with the neighbourhood spaces. This implies viewing the neighbourhood from the perspective of connections, interactions, and social engagement for people living with dementia (Clark et al, 2020), and establishing the connection between ageing, the local environment, and neighbourhood places. The study concluded that locally situated connections provide a form of support in different ways and for different purposes (Clark et al., 2020) and neighbours as a group provide emotional and practical support to older adults living with dementia in the community.

Four key dimensions of a dementia-friendly community play an active role in the lives of people living with dementia (Swarbrick 2020), They are, people, places, networks, and resources. This implies that dementia friendly communities are characterised by individuals, the neighbourhood, the social networks, assets and funds for maintenance. According to Ward et al, (2018), these dimensions not only set limits and constraints but also offer opportunities, help and support. The focus is on the socio-spatial aspects of socially led lives and "*as lived place offers a way to get to know people both in place and through place*" (Ward et al., 2018:877). This means that people in the neighbourhood, not only live in the neighbourhood, but they also allow the neighbourhood to pass through them by engaging in positive interactions with others.

The condition and wellbeing of older people living with dementia have been associated with density of the population. According to Murayama (2018:1537), denser neighbourhood network in a district is associated with a lower likelihood of subjective dementia symptoms among women. It is not clear in the study why there were such association among women, but not among men. However, there is no distinction in terms of gender in relation to correlation between physical aspect of the neighbourhood or open spaces and quality of life in later life. According to Sigiyama et al, (2009) the pleasantness and safety of open spaces are relevant to the life satisfaction of older people. This outcome is limited because it is not linked to individuals' health status.

On the other hand, it has been argued that social citizenship is constructed and revealed through community activities that help vulnerable people claim a place in the community. According to Phinney et al., (2016) activity of walking in the neighbourhood results in keeping the focus off dementia, to create a place of belonging to which helps people living with the condition to claim a place the community. This means that outdoor creative adventures for people living with dementia improve their quality of life.

The focus, therefore, is on community based activities and groups that can enhance social citizenship. Social citizenship is "*the relationship, practice, or status in which the person with dementia is entitled to experience freedom from discrimination and to have opportunities to grow and participate in life to the fullest extent possible*" (Bartlett & O'Connor, 2010:37).

Community activities help members to assimilate with others in the physical neighbourhood, to play roles in society, feel valued and respected, build connections with others, promote a sense of emotional connection and social belonging among the people. However, it is not clear how walking in the community helps older people to construct social citizenship.

Dementia-friendly neighbourhoods could be measured and characterised by different factors. According to The World Health Organisation's global health citizen's guide, dependence on the neighbourhood is dynamic and affected by an individual's changing social and physical conditions. Moreover, neighbourhood's characteristics influences the health of older people who spend their lives in such communities (Philips et al, 2005). The need for supportive neighbourhoods further increases with the growing number of communities accommodating older people. WHO (2007) acknowledges a need for friendly systems of transportation, housing, social participation, respect and social approval, civic participation, communication and information, community support and health services.

A major gap in the studies reviewed above is that they have not focused on the experiences of neighbours providing support to older adults living with dementia in the community. Furthermore, they have not asked questions as to the history and context of neighbouring as a set of relationships. The learning from the review is that there is need for a person-centred approach to understanding issues concerning dementia care relationships, that enables the care givers and recipients to tell their own stories and their lived experiences. These are the issues and questions that my study explored and helps to answer respectively.

2.6 Possible Support

Here, I critically reviewed the nature of possible support given and the circumstances and processes that lead to the care giving relationships. I did this review because I believe that it is relevant to understand the social context under which dementia caregiving relationships develop, and the forms of support giving that arise because of the care giving relationships. Finally, I identified gaps in literature and the lessons learned.

Dementia is a debilitating condition that causes a lot of mental, physical, and mobility problems alongside other limitations that impede the accomplishment of daily activities (Seifert & Konig, 2019); and older people who live alone in their own homes in the community could receive support from their neighbours because of the physical proximity and the instrumental nature of their needs (Wenger, 1960). The above assumptions point to the fact that in the event of illness or accident older people tend to turn to whoever is nearest. This means that older neighbours' needs are likely to be recognised initially by other neighbours, which is particularly important where the speed of reaction is important. This also signifies that neighbours play an important role as initial line of support (Wenger, 1990) and suggests that older people in the community who have a form of illness or impairment are reassured that help is possible from neighbours when needed.

Nevertheless, it is important to indicate that care recipients have preferences in relation to whom they wish to accept support from no matter the level of their care needs. Moreover, some care recipients wish to maintain their privacy no matter the severity of their conditions. Consequently, the proximity of a potential neighbour care giver is not a guarantee for the development of a care giving relationship.

However, It has been argued that those who receive regular help are usually those who cannot manage without it because of health based restrictions, while those in good health with fewer limitations on the instrumental activities of daily living are more likely to provide care (Seifert & Konig, 2022). The former, may include older people who live with dementia in the community, who are highly dependent, and need emotional and instrumental support. Other older neighbours who may need support may include those who have lost their partners. However, it has been argued that older people who are childless or have children living in a different city or country generally receive little social support and rely more on formal support (Seifert & Konig, 2019:3). Thus, it is arguable whether older neighbours living alone rely more on formal support or on available neighbours.

It is vital to note that while older neighbours receive care, they also could be care givers and that the time neighbours spend in a neighbourhood may affect the help they give or receive. According to Seifert and Konig, (2019), the amount of time that neighbours have lived in their current homes can affect the likelihood of giving or receiving help. This implies that living in a neighbourhood for a lengthy time may increase the probability of support among neighbours. The older people who are likely to give rather than receive support are retired individuals, women, and widows (Seifert & Konig, 2019). Nevertheless, an older person, whether a giver or a receiver, could be characterised by other factors, rather than whether they are retired, a widow or a woman. The state of health, (including their physical and mental strength) and their relationship with neighbours may help to determine who could be a care giver or not.

It has also been argued that neighbours who give support also offer reassurance and monitoring by (for example) telephoning or receiving telephone calls from vulnerable neighbours, shopping, gardening, and providing support with transport and occasional chores (Wenger, 1990). Therefore, what starts as a normal neighbourly relationship can develop into increasing dependency and bigger commitments as an individual’s condition deteriorates. This may also lead to stress and a burden on the part of the care giver as the care giving relationship becomes more imbalanced (Wenger, 1990). In addition, the norms of interaction and care giving among neighbours are also moderated by respected for privacy, cultural backgrounds of neighbours, and their motivations.

The identifiable gap in literature regarding the possible nature of dementia care giving relationships is in relation to the source of their needs and understanding their preferences in relation to source of support. However, the lesson learnt, is that instrumental support needed by neighbours living with dementia is largely a function of the dementia induced deterioration in their physical conditions. Moreover, the role of neighbours available to give support becomes more important because some of the dementia care recipients live alone. My study helps to fill this gap by investigating the processes of dementia care giving relationships.

2.7 Motivations and Reciprocity

I critically reviewed the nature of motivations and reciprocity of support and the determinants of reciprocal or one-sided care giving relationships. In other words, I reviewed literature on the possible factors that influence neighbour dementia care relationships, and the nature of the reciprocity identifiable or inherent in such relationships. I did this review because it is important to identify how the care giving relationships could be sustained and tensions, resolved. Finally, I identified gaps in literature and described the lessons learned.

Generally, the need and motivation to support a neighbour while at the same time maintaining privacy is conditioned by factors like locality, generation, social class, religion, cultural differences, and ethnic identity (Ruanavaara, 2022). This means that the level of support in relationships between neighbours is governed by cultural norms, personal and contextual variations, and personal characteristics. Health related circumstances, social factors, family related conditions, and available resources are factors that determine the nature of support relationships between neighbours (Seifert & Konig, 2019). Moreover, it means that the role and relationships between neighbours are defined by a system of mutually agreed norms (Schiefloe, 1990:90).

However, it has been argued that neighbour relations are not entirely devoid of formal regulations because there are laws about respecting privacy, property law, and tenancy contracts (Ruonavaara, 2022). This may be true of transactional neighbour relationships which experience a greater balance of reciprocal support, but not in imbalanced neighbour care relationships in which reciprocity is leans more towards the person living with dementia. However, the formal, legal, and informal factors that govern neighbourly relationships were captured by Herbele (1960) who argued that a neighbour not only refers to persons who reside close to each other, but to persons who are socially related by specific rights and duties established by custom and in part by law (Nuavaara, 2022).

This means that the nature of neighbour relations may vary according to different factors, so the extent and nature of neighbouring is subject to socio-cultural variations across cultures and subcultures (Morgan, 2009; Kusenbach, 2006).

The learning from this is that neighbouring is influenced by the context in which people live, which includes the community or locality as well as the culture and sub-culture of the people in the locality (Seifert & Konig, 2019). This also means that the factors affecting the reciprocity of care are unclear and that support relationships in the community are driven by varying factors and characteristics.

The influence of culture and sub-cultures on neighbouring has led to the debate that minority ethnic people - especially of Asian origin - mistrust, fear and feel stigmatised when using formal services, and depend on a culture of inclusive family relationships to support each other in times of need (Herat-Gunaratne et al., 2020). South Asian carers may therefore conceptualise dementia as a natural aging process and are likely to find support within their network, rather than from formal means (Herat-Gunaratne et al., 2020). This means that carers from minority ethnic groups "*find meaning and identity from their cultural and ethnic heritage, and cultural identities and values influence their experiences, negotiation of their caring role and relationship with services*" (Herat-Gunaratne et al., 2020:332). This also suggests that there may be culturally sensitive care and support via informal networks. Moreover, a significant number of carers from minority ethnic groups for older people living with dementia may view caring as a natural course of family life and relationships. However, this should not be seen as a general norm, as some ethnic carers may not feel culturally obliged, prepared and/or willing to provide support (Parveen & Oyebode, 2018).

This finding aligns with Kitwood's model of personhood which sees dementia as a socially embedded phenomenon (Kitwood, 1997). Nevertheless, although carers from minority ethnic communities may feel culturally obliged to provide care, it does not automatically indicate that all minority ethnic carers are willing to provide care for people living with dementia. Thus, general assumptions should not be made that minority ethnic persons living with dementia do not require support from the formal sector because of their cultural values (Parveen & Oyebode, 2018). However, their cultural values and religion may have a significant impact on their motivation to give or receive support. This suggests that ethnic based communities can survive modern times as important sources of social ties and support (Schiefloe, 1990).

Neighbour care is a contested concept, as it connotes a mix of both informal and formal support, of egoism and altruism, reciprocity and patronage, autonomy and social control, tradition and innovation, and self-help and dependency (Titmuss, 1970). However, anonymity and distance must be maintained in social care as a means of eliminating the self-oriented sides of altruism. In other words, recipients of care should be strangers (Bulmer, 1986). There is also a challenge in terms of how neighbour care is assessed, such as through the accommodation of values and co-existence of moralities. Marcus (1978) states that it is essential not to degrade people by caring for them, and vice versa, which suggests that integrity and privacy of persons living with dementia must continue to be maintained throughout any support. The complexity of the care system can be seen in the fact that many people living with dementia do not have contact with an informal carer (Eicher et al., 2016), and 7% of people living with dementia aim to recruit a carer where one is available (Clare et al., 2014).

Some consensus exists that caring is primarily an altruistic activity and as such morally and socially desirable, although some writers consider it as self-centred and patronising, because the altruistic acts of donors violate the autonomy of recipients (Illich et al., 1977; Simpkin, 1979). Therefore, the caregiving relationship could also be evaluated based on egoism, altruism, reciprocity and custom, which suggests that the process is based on the power imbalance inherent in caring relationships.

Reciprocity is an important element for a neighbourhood based caring community and its norm assumes that people tend to maintain a balance among support exchanges and prefer the relationship of give and take (Seifert & Konig, 2019). Although this suggests that neighbour care giving relationships thrive better with the exchange of reciprocity, this may not be the case in situations where the person living with dementia has become vulnerable and reciprocity tilts in their favour.

According to Kendig (1986), neighbours are accessible sources of help but have no obligations to one another other than the norms of reciprocity (Wenger, 1990). Thus, a neighbour relationship is mutually negotiated and consented, lasting the extent of the consent. Furthermore, the degree of intensity of reciprocity varies during the relationship because the level of reciprocity is not constant but varies according to the neighbours’ capacity to reciprocate.

The identifiable gap in literature about motivations and reciprocity is in dearth of knowledge about how a mutually agreed balance is reached between care givers and care recipients to maintain some level of privacy and boundary. There is also a gap in literature about understanding motivation and reciprocity in neighbour relations that involve care giving, and in relations where there is no care giving between the neighbours. In other words, it is not clear whether there is an ethos of reciprocity in situations where a neighbour in need of support is vulnerable and cognitively impaired. To help to fill the gap, my study has therefore investigated the nature of motivations and reciprocity in neighbour dementia care giving context.

The lesson learned from this review is that reciprocal nature of neighbourly interactions is rarely made explicit and often not evident especially where a person living with dementia has become dependent; this is particularly the case when an ethos of reciprocity underlies much of the relationship. Nevertheless, although offers of help imply reciprocity, it may not come directly from a person living with dementia, but from his or her relations. This is group reciprocity (Wenger, 1990) and confirms that reciprocity in relationship is more difficult to maintain in situations where asymmetrical needs exist and where long-term support is required. Therefore, this prompts the need for multi neighbour care to help to cushion the risk of stress and burden and ensure the sustenance of such relationships.

Strains develop when the reciprocal nature of the relationship is impaired (Wenger, 1990). However, it could be argued that strain in care relationship does not arise because of a loss of reciprocity, but because of the burden and stress of care giving. Invariably, it could also be argued that the burden of stress of care giving is a function of the lack of reciprocity.

2.8 Social Capital

The focus of my literature review here is on the nature of social networks in relation to neighbour care giving relationships. Social capital is significant for this study because it lies at the core of its knowledge base, incorporating the contacts, relationships and resources available to older people living with dementia in the community. To this end, I reviewed the issue of social capital and discussed the relevance to my study, the gaps identified, and lessons learnt.

Social capital has been applied in this study in terms of its derivable value in neighbourly support relationships. Social capital refers to connections among individuals, social networks, and the actual or potential resources, collective value and tendency of the networks to help each other in bonded relationships (Putnam, 2001; Bourdieu, 1986; Dill, 2015). Social capital also involves the norms of reciprocity and trustworthiness that arise from relationships and networks, and its inherent value for individuals (Putnam, 2001; Hauber, 2011). In relation to this study, it is a form of neighbourly relations with the features and norms of care and support. According to Waters (2022), has a neighbour ever checked your mail for you while you were out of town? That's utilizing social capital. This means that we gain social capital from belonging to a social network and by leveraging social connections to solve problems and improve wellbeing (Waters, 2022). So, social capital represents "*the links, shared values, and understandings in society that enable individuals and groups to trust each other and work together*" (OECD Insights, 2007:102). It is the "*the range of social contacts that give access to social, emotional, and practical support*" (Evridiki et al., 2015:2898). Social capital is therefore characterised by shared values, interpersonal relationships, trust, cooperation, reciprocity, a sense of belonging and social support. How these characteristics interact and impact on people's lives in a neighbourhood,

is at the core of social capital.

Research has found that "*social capital scores were higher for non-care givers in the neighbourhoods with significant differences, and that understanding the relationship between care giver burden and social capital will enhance the ability to explore the concept and meaning of social capital to the benefit of dementia care givers in the community*" (Evridiki et al, 2015:2900). Thus, the stress associated with caring in the community could reduce the level of social networks or capital available. This also implies that the stress and burden associated with caring may affect the social lives of carers and limit their relationships in the community. It is therefore vital to understand the factors that affect the level of social capital for carers as their roles are very important for the wellbeing of people who live with dementia in their own homes in the community. A broader view of social capital theory predicts that higher associational activities inside a community can foster a sense of civic engagement where cooperation, reciprocity and mutual trust are developed and used to solve collective action (Bhandari and Yasunobu, 2009). It could also be used to solve individual problems especially in situations where an individual develops dementia and needs help while living in the community.

According to Putnam (2001), as people now spend more time alone, they have become wealthier, but their sense of community has withered as people have less time for volunteering, joining community groups, and socialising with neighbours, friends, and family (OECD Insights, 2007:102). However, other scholars have argued that social relations and networks have not withered but evolved, in other words, Putnam was wrong when he stated that social engagement is eroding (OECD Insights, 2007). A more appropriate description of events is that people now join other groups that are not necessarily based on their primary circles, and while new groups share common values and interests, there are doubts as to whether the new forms of community are the same as traditional ones.

Social capital is grouped into three categories - bonds, bridges, and linkages - and the general concept of social capital is that relationships matter (Andriani, 2013; Waters, 2022). Bonds refer to the links people forge based on common identity and include ties with friends, family members and neighbours. Bridges refer to linkages with further relationships like office colleagues, and linkages focus on people or groups further up or lower down the social network (OECD Insight, 2007). Bonding, as a category of social capital, is relevant to my study as it refers to the nature of networks that can bond and support each other within the local community. The assumption is that neighbours bond to help and support each other in times of need and the support is reciprocated. A major assumption of this study is that some neighbours are motivated to support older people neighbours living with dementia in the community in different ways.

However, bonds are not always experienced as positive; according to OECD (2007:104) "*bonds can hinder people because their lack of social bridges can turn them into social outsiders from wider society, and it engenders restrictions on individual freedom*". However, social capital is beneficial because the bonded can support each other socially, economically, and emotionally; and in countries where the rule of law is weak or where the state offers few social services, bonded and close-knit groups can look after orphans and older people (OECD 2007). Furthermore, social capital could also be used to harm others, if the links, trusts, and bonds identifiable with stakeholders of an entity or sub-culture are always used inwardly and fail to consider external influences. However, social capital still provides the glue that facilitates cooperation, exchange, and innovation (OECD: 2001).

An investigation of how people living with dementia in the community engage with people around them and the nature of the social health benefits of such engagement help to clarify the advantages of social capital. According to Ward et al. (2018:701), social health involves striking a dynamic balance between opportunities and limitations, which are affected by external conditions such as social-environmental challenges. Social health involves the condition of forming "*interpersonal relationships, adapting comfortably to different social situations*" (Koshuta, 2018:1); reaching and maintaining these possible outcomes requires traits like effective communication skills and empathy for others, and having a sense of accountability (Koshuta, 2018). This study explored the issue from the experiences of neighbours who support older adults living with dementia in the community. The assumption is that neighbours make contacts, communicate, and support each other in times of need in their proximate living places.

Neighbourhoods constitute incubating hubs for social capital where social networks form over time and they are comprised of social networks that are embedded and built over time (Odzakovic, 2019). Neighbourhoods provide a directly accessible arena for establishing new connections and maintaining existing relationships. This means that a safe physical, and dementia-friendly environment or neighbourhood is not only relevant for older people living with dementia, but also for neighbour carers who use the same environment. According to Silverman (2020:9) such environments should be welcoming, helpful and accessible, and such places should help carers to exercise and enjoy their social citizenship free from discrimination.

Some neighbourhood based economic factors also affect older adults' social health, and the choices available to them. According to Dijk et al. (2012), older adults who may never have owned their homes and are now reliant on means-tested benefits, and younger persons who may be in debt because of student loans and unable to get on the property ladder, may depend on other sources of help in older age. This may limit their choice regarding neighbourhoods which they would normally want to live in at an older age. Other helpful projects and innovative ideas have also evolved to ensure beneficial outcomes for both the older adults involved and caregivers. For example, a time banking system, where time is used as a currency that can quantify and record the contributions people make in helping neighbours, has been introduced in some parts of the United States. The system is comprised of time deposits against which a withdrawal of deposits is made when the depositor needs help. Thus, a volunteer who helped an older neighbour could elect to be paid using his bank credits (Cahn & Gray, 2015).

According to Layard (2003), for most people it is not money but valued personal relationships with family, colleagues, friends, and neighbours, that provide the best guarantee of happiness; and the more people speak to neighbours, the happier they tend to be. Moreover, the greater the tendency for globalization the more people will value their localities (Amin, 2001; 2002). In addition, the level of time people spends in their locality matter as well as the type of housing, accessibility and quality of public space. Social interaction in a neighbourhood is also dependent on the kind of people living there (Campbell & Lee, 1982). For example, people with higher education, married, and with high incomes, have larger networks than people who do not have children or partners. Moreover, people with a low level of education and income are more likely to have intense relations with their neighbours. Other factors are those of age and common interests as older children can be keener to participate in village life than their parents (Bulmer, 2006).

The major gap in literature on social capital in relation to dementia care giving as discussed above is that it is not clear whether people who do not bond in the community, can benefit from support accruable from networks. It is not also clear how individuals upgrade their adaptation to changing community and social networks. My study helps to fill this gap by investigating the nature of neighbour dementia care giving relationships. The lesson from this review is that social networks change and bonding to networks can lead to alienation in the larger community.

While the discussions above focus on social capital and how this affects the life and rights of persons living with dementia in the community, the next section reviews literature on living alone, loneliness and dementia.

2.9 Living Alone and Dementia

I reviewed existing literature on the nature of the living conditions of older adults living with dementia, and the review helped me to understand the circumstances of the lives of people living with dementia in the community that may trigger the intervention of a neighbour caregiver (Victor et al., 2020). Reviewing previous literature about living alone also provides vital knowledge on how care giving relationships develop in the context of the need to provide informal care for older people living with dementia in the community. I am concerned about the risks of living alone for persons living with dementia. However, it is important to indicate that living alone does not equate to being isolated or being lonely (Ward & Rummery et al., 2021). To this end, I reviewed the issue of living alone and identified the gaps and lessons in the knowledge base.

A review of the living conditions and circumstances of persons living with dementia in the community shows that some live alone and maybe lonely. According to the Alzheimer’s Society (2023) some people living with dementia choose to live alone because they may feel happier and more in control in their own homes, as their homes provide a base where they can maintain their routines and remain in the community. They may also live alone because their partner has passed on, or someone they lived with has moved out, in some circumstances they may not have partner, family, or friends they can move in with (Alzheimer’s Society, 2023). Moreover, having people willing to support a person living with dementia can be very helpful, as they can offer support with practical things which may prove difficult because of their condition. The nature of the support could include looking out for the person’s wellbeing or just being there to speak to and spend time with the person living with dementia. The support network of a person who lives alone with dementia may include family, friends, neighbours, and professionals (Alzheimer’s Society, 2023).

Neighbours are considered important in alleviating the risks and negative consequences of living alone (Wenger, 1990). In addition, the lack of neighbours is not compensated for by the involvement by children of the persons living with dementia who do not live close (Wenger, 1990). Neighbours are therefore considered very important, particularly for those with no children, as they provide companionship and constitute a vital source of social contact and interaction especially for those who live alone (Kivett, 1985; Wenger, 1990). This is the case even where relationships are casual as neighbours constitute a source of company and moral support.

While social isolation in old age has been associated with the risk of developing dementia, people living with dementia are also at risk of loneliness (Moyle et al, 2011; Wilson et al., 2007). Isolation refers to the objective circumstances of being cut off from other people, and loneliness points to how individuals evaluate their level and quality of social contact and engagement, which may lead them to feel some loss of sense of meaning, freedom, and identity (Jewell et al, 2017). Loneliness has also been defined as the discrepancy between the expectations of quantity and/or quality of relationships and what is achieved (Victor et al, 2020). Thus, it is important to recognise that living alone does not automatically equate to being lonely or isolated.

Studies have found that 17% of the over 65s are considered socially isolated, and 7% are considered lonely (McCarthy & Thomas, 2004; Jewell et al, 2017; Alzheimer Society, 2013). It is therefore perceived that there is an increasing tendency to live alone; however, questions arise as to whether local social networks are important (Palmer, 2006; Bennett & Dixon, 2006), and to what extent are neighbours linked in a care dyad with vulnerable older adults within their neighbourhood? According to Moyle et al. (2011), there is an association between the absence of meaningful relationships and the experience of loneliness during the early stage of dementia, and a factor that may contribute to loneliness is the deteriorating ability to communicate that is associated with dementia.

Some older adults consider living alone as an achievement as they view it in terms of privacy and independence; in addition, living with others does not necessarily guarantee satisfactory social relations. People living with dementia are also said to experience a level of loneliness that is comparable with that of their peers who do not have dementia (Victor et al., 2020). This means that while dementia may be considered a predictor of loneliness, living alone could be a way to maintain their independence and privacy. Furthermore, its prevalence does not significantly exceed that found amongst people not living with dementia. People living with dementia in the community may also be lonely because of the dwindling of their cohort, and their reduced activity and mobility (Jewell et al., 2017; Moyle et al., 2011). Loneliness has been identified as one of the factors that hinder the ability to live well, which is defined as the best achievable state of health that includes all dimensions of physical, mental, and social being (Institute of Medicine, 2012).

Some other studies have also highlighted the prevalence of living alone, loneliness, and relationships in the neighbourhood. Studies show that working-aged men between 25 and 44, and women between 40 and 50 now have an increased propensity to live alone (Palmer, 2006; Bennett & Dixon, 2006). In some cases, it is now easier to speak with friends and relations living abroad than to chat with neighbours living next door. Modern communication technology has made this possible. Malcolm (2005) argues that while the population has grown by 5% over the past 30 years, the number of households with just one occupant has increased by 31%. According to Halpern et al. (2002), 47% of people trust many in their neighbourhood, 37% trust some, while only 2% trust none (Home Office, 2003). Moreover, up to 71% feel a sense of belonging to their neighbourhood, 42% regularly socialise with neighbours and 65% believe people in the neighbourhood work together to improve it (Home Office, 2003). These research outcomes indicate the prevalence and nature of living alone, loneliness and the nature of relationships. The figures also paint a picture of the living condition of the care recipient before the intervention of neighbours.

The literatures have not revealed the overall circumstances that lead to lone living or loneliness i.e., whether it precedes impairment of the care recipients or occur because of their impairment. This is the gap that my study will help to fill in the context of neighbour dementia care giving relationships. Nevertheless, the lesson learnt from existing literature is that living alone does not necessarily mean being lonely or socially isolated. Sometimes, living alone could be positive, as it helps people to maintain privacy and independence.

I hereby review below, the different care policies, strategies and plans that have been applied to manage the formal and informal dementia care arrangements.

2.10 Dementia Care Strategies, Policies and Plans

I reviewed existing literature on different dementia strategies, policies and plans in England. This review is important to ascertain how formal strategies and policies have affected dementia management and care especially regarding issues of awareness, stigma associated with dementia, dementia risk reduction, early diagnosis of dementia, and accessibly of support. This review has also helped me to identify gap in literature. My study helps to fill the identified gaps by focusing on the problem in neighbour dementia care context.

Many plans, policies and strategies have been adopted by different care stakeholders at different times to streamline and navigate complex formal and informal care settings. The strategies, policies and plans discussed here are in relation to England. The devolved nations have different policies, but their policies were not discussed here.

Dementia plans, policies and strategies have always been reviewed to meet new challenges and meet the changing needs of persons living with dementia including those living in communities. Some of the policies, strategies and plans adopted to navigate dementia care, costs, research, and services include The National Dementia Strategy (2009), The 2012 Dementia Challenge, The Challenge on Dementia (2020), The NHS Long Term Plan, the Fix Dementia Care (2019), and The Hidden No More: Dementia and Disability APPG (2019). These strategies and policies have reviewed and/or assessed the relationships between persons living with dementia and their carers.

The National Dementia Strategy (2009) was the government's first national dementia strategy, entitled "Living Well with Dementia", and aimed to "*improve the quality of life for people living with dementia and their carers*" (Powell & Baker, 2019:10). Some of the aims of this strategy included: raising awareness of dementia and removing the stigma that accompanied the condition; improving diagnosis rates for people living with dementia; and making more services available to them and their carers (Powell & Baker, 2019). This points to the fact that issues of awareness, stigma, and early diagnosis are germane to dementia management and care. The 2012 Dementia Strategy reviewed the improvements made by the 2009 dementia strategy, including the reduction of the use of psychotic medicine for people living with dementia.

Furthermore, a challenge was launched in 2012 to deliver major improvements in both dementia care and research, and its change focused on creating dementia-friendly communities that understand how to help, including the establishment of dementia-friendly communities with the Alzheimer's Society (Powell & Baker, 2019). The 2012 strategy, also advocated for, and sought to drive, improvements in health and care including better diagnosis, improved care in hospitals and care homes, more information for patients and families, and greater support for carers (Powell & Baker, 2019).The 2012 Dementia Challenge was reviewed in February 2015, and government outlined the progress made, including a record increase in diagnosis, a boost in research funding, the greater training of health and social care workers, and an increase in the number of dementia friends in the community (Powell & Baker, 2019). The review of progress made by the 2012 Dementia Challenge led to the launch of the Challenge on Dementia 2020.

The policy framework, called the Prime Minister's Challenge, published in February 2015, focused on supporting dementia research, ameliorating and enhancing care, and raising awareness about dementia. It "*provides the Strategy for transforming dementia care by 2020 and aims to ensure that everyone diagnosed with dementia receives meaningful care*". The strategy proposes that services must provide inevitable care efficiently and cost-effectively, and the main focus of the strategy is to make England, the best country in the world for dementia care and support, and the best country for people with dementia, their carers, and families to live in; and the best place in the world to research dementia and other neurodegenerative diseases (Prime Minister's Challenge on Dementia 2020:1; Powell and Baker, 2019:11). In essence, by 2020, the Challenge seeks widespread awareness and understanding of the indicators and risks associated with developing dementia. Specifically, this focused on: access to diagnosis of dementia; meaningful care and interventions for everyone diagnosed with dementia; adequate training for all relevant health and social care staff regarding cures and support for people diagnosed with dementia; the designation of all hospitals and care homes as dementia-friendly health and care places; a partnership with the Alzheimer's Society to recruit about three million dementia friends in England; the encouragement of businesses to become dementia friendly, and greater participation in research by people diagnosed with dementia (Powell & Baker, 2019).

An implementation plan for “Challenge 2020” was published in 2016, which espoused how the policy would be implemented. The plan emphasised risk reduction, health and care, dementia awareness, social action, and research (Powell & Baker, 2019). Challenge 2020 was reviewed in the 2019 progress review, which detailed its achievements, further implementation plans to improve the lives of people living with dementia, including those of their families and carers: and the prescribed way forward. Some of the achievements enumerated included: the recruitment of a high number of dementia friends (about 2.8 million); a strong commitment by government to dementia research; the introduction of a dementia recovery fund, and the establishment of a dementia research institute (UKDRI), (Powell & Baker, 2019).

Further developments included the government’s 2018/2019 mandate to the NHS, which aims to ensure at least a two-thirds diagnosis rate for people who live with dementia. There is also the NHS Long Term Plan 2019, which “*commits the National Health Service (NHS), to continue to improve the care provided to people living with dementia through a more active focus on supporting people in the community through community multi-disciplinary teams and the application of NHS comprehensive model of personal care*” (Powell & Baker, 2019:10). Additionally, the Dementia Connect Programme gives advice and support to people after diagnosis. “*Dementia Connect, from the Alzheimer's Society, is a new personalised support service for people living with dementia their carers, families, and friends. The service connects people affected by dementia with free support and advice available by phone, online and face to face*” (Alzheimer’s Society, 2020:1).

FIX Dementia Care (2019) was also launched following the review of the Dementia Challenge, 2020; it aims to set out a new dementia fund to help people diagnosed with dementia access affordable and high-quality care. It stated that it would “*invest in £2.4 billion long term dementia funding that shares the cost of dementia funding across society and ensures the cost of disease like dementia is covered by the NHS*” (Powell & Baker, 2019:16). An extra review of the Dementia Challenge 2020 policy has also led to efforts by the All-Party Parliamentary Group on Dementia 2019 to launch the programme entitled Hidden No More: Dementia and Disability, which provides a dementia care framework based on disability rights. The framework makes recommendations in six areas to improve the lives of people living with dementia. One such area is social care in which it recommends that "*the medical and social care support available to people living with dementia is inadequate and inaccessible*", and that the expected social care reform must acknowledge and meet the needs of people living with dementia now and in the future (Powell & Baker, 2019:17).

A brief overview of the policies, plans and programmes points to a system that pays little or no attention to the informal non-kin support sector. My study is aimed at helping to fill this gap in the context of neighbour dementia care. A major lesson in this review is that issues of awareness, risk reduction, social action, research, and accessibility of support are central to dementia management and care. Moreover, review of strategies, policies and plans is important to accommodate new research findings. This is why most policies and programmes are constantly reviewed to accommodate new findings and address fresh challenges.

Next, I have reviewed the complexities of different sources of care.

2.11 Different Approaches to Care

Finally, I reviewed existing literature in relation to different sources and characteristics of care givers and the roles they play in the complex care system. This review is important to understand the dynamics of different sources of care and explore their complementary and supplementary roles. This review has also helped me to identify the gap in literature, and how my study helps to fill the identified gap.

Previous studies have attributed diverse caring roles to different carer characteristics and categories like neighbours, friends, and family kin carers. For example, Lapierre and Keating (2012:4) made a distinction between the care provided by neighbours and friends to older adults living with dementia and argued that "*friends and neighbour carers differ in age, marital status, geographical proximity, and relationship closeness*". They also argued that friends were more likely than neighbours to assist with personal care, bills, banking, and transportation, while neighbours were more likely to assist with home maintenance. The study concluded that the closeness of the relationship largely explains differences between friends and neighbours. The caregiving roles and responsibilities of families and friends can also often be intense and time-consuming, and therefore have major impacts on caregiver's health and overall lifestyles

(Lieberman & Fisher, 1995; Schulze et al., 1995). This means that care giving can lead to serious burden, which if not checked would have adverse effects on the wellbeing of the care recipients.

Researchers have viewed the issue from the perspective of culture. Hamilton (2016) explored the need to inform culturally competent support for caregivers, thereby improving the quality of life for both persons living with dementia and their caregivers. Hamilton (2016) discovered that "*assistance from informal caregivers such as family members, friends, or neighbours is crucial to adequately monitor and manage the complex care of heart failure patients*". While Hamilton (2016) focused on informal caregiving and the management of older adults with heart disease, the research by Szczgiel et al. (2018), explored the scope, structure, and experiences of the informal social support network available after stroke treatment in hospital. Szczgiel et al. (2018) concluded that family remained an important source of social support, and bonding experiences with non-kin social groups such as neighbours also remain relevant and important. They recommend a coordinated formal and informal support, which they consider beneficial for patients, their caregivers and the care system.

Studies have also explored informal care relationships with older adults in the community in the context of gender and sexual orientation. Knauer (2016) explored the high level of caregiving by non-relatives in the LGBT community. The study investigated "*motivations for friends, neighbours, and community members to provide care for someone whom the law considers a legal stranger*" (Knauer, 2016:1). The study found that, instead of depending on relatives, the older adults in need of care and support depended on "chosen relatives", and that LGBT older adults largely care for each other. According to Knauer (2016), relatives provide only 11% of all elder care. Therefore, as the ageing population becomes more diverse, ageing policies will have to become more inclusive to address the different needs of various communities. In this instance, the needs of the LGBT community are addressed.

According to Mann (2018) care for people with dementia is too patchy and inconsistent and some do not receive enough support; their conditions can transform very quickly and require alternative support. The nature of relationships between informal carers and older adults has also been viewed from the perspective of changing family structures and dynamics. According to Lapierre and Keating (2012), there is a greater dispersal of families and significant progress in female labour employment has resulted in the non-availability of those who have historically been considered the primary family carers.

The availability or unavailability of carers has consequences on the amount and duration of care and support available to persons living with dementia, and "*proximity and relationship closeness significantly predicated the amount of care provided*" (Lapierre & Keating, 2012:1449). In essence, proximity between the persons living with dementia and the caregiver matters because a person living with dementia could have a friend, but they may not be easily reached when needed. In comparison, a neighbour can be contacted quickly because of their proximity to the person living with dementia.

This has also been explored from the perspective of informal carers who know about dementia and regarding the geographical location of the care dyad. According to Heron and Rosenberg (2019:340) informal carers, whom they referred to as 'partners in care' "*provide bulk care to people living with dementia across a range of community services*". The study argued that the experiences and contexts of informal caregiving for people living with dementia in rural areas are understudied (Heron & Rosenberg 2019). They found a dearth of carers who understand dementia in the immediate community, and identified issues such as inadequate support hours, resistance to support and respite by people living with dementia, and pressure on carers to provide long term care. Significantly, Heron and Rosenberg (2019) focused on dyadic relationships in rural areas, and the inadequate number of carers in the 'surrounding community'. The findings of Heron and Rosenberg (2019: 340) present a "*unique understanding of the challenges faced by informal carers using a relational approach to the study of older people and the services they need in rural communities*." Therefore, different geographies will have different impacts on people's experiences and influence their access to different kinds of support (Innes, 2020).

Considering the provision of immediate care by informal carers and neighbours, Jamieson et al. (2006) argued that some non-familial relationships eclipse familial relationships and posited the existence of a fluid network of intimates including friends, lovers, and neighbours. They argued that this form of relationship may take over practically and emotionally, offer a relationship in people's lives, and undermine the cultural dominance of conventional family relationships as the idealised relationship to which may be aspired.

It is known that some people living with dementia have irregular contact with an informal carer and they are at greatest risk of poor outcomes (Alzheimer's Society, 2018). The irregular contact may be caused by stigma associated with dementia According to Low et al. (2017), there is a diminishing number of family carers to provide domestic care in future and there is a global shortage of informal carers. Low et al. (2017) also explored the general decision-making experiences and types of decisions that family members usually need to make with older persons living with dementia. They examined how services have helped family members to meet their own needs and challenges when caring for older relatives living with dementia. The study concluded that interventions can be planned to support informal caregivers, and support may ensure their reach of support will continue even when they transit to residential or other services.

I have reviewed existing theories, frameworks, strategies, plans, and approaches concerning informal caregiving to older adults living with dementia in the community. However, it is important to determine the values, philosophy, and principles that explain the relationships between informal caregivers and recipients. Furthermore, what are the policy frameworks and knowledge base that emerge because of these principles, and how do they inform practice?

According to Innes et al. (2012), there should be an appreciation for the social structures that condition the experience of dementia, and the way care practices are expounded and carried out. It is, therefore, germane to consider the assumptions of different perspectives such as biomedical and psycho-social, on dementia and the associated care. It is vital and relevant to apply the "*strengths of these perspectives to provide the best possible care and support for carers and influence policy; hence support high-quality care practices*" (Innes et al., 2012:26). While dementia attracts the attention of diverse professional backgrounds and disciplines, the best practice interventions to improve the quality of care have also assumed multicomponent dimensions (Innes, 2012; Zabalegui et al., 2014).

According to Pierce et al. (1991) social interactions between individuals lead to heterogeneous relationships that have different levels of supportiveness, and social network groups are categorised into primary and informal groups (Eunhee, 2007). The social support approach to care for older persons "*conceptualises social support as the function that is provided by social relationships*" (Uchino, 2004:16). This approach is concerned with the benefits of care and support that are based on social identity, control or loneliness, and emphasises the impact or outcome of belonging or not being part of a network, rather than on processes. The positive impacts of social interaction and participation include self-esteem, increased meaning attached to life, and positive effects on health while not belonging leads to negative health outcomes (Stoebe & Stroebe,1996). Accordingly, social support is healthy because it shields people from exposure to negative life events (Uchino, 2004).

Task-based perspectives to informal care and support argue that different relationships produce different forms of aid to caregivers; for example, "*spouses live together and provide social support to each other over a long time*" while "*neighbours live close by, and unlike spouses, they do not typically provide long term commitments*" (Eunhee, 2007:25). This assertion is debatable because there are instances where neighbours provide long term support. The hierarchical approach proposes that older adults first prefer the support of spouses; but if not available, they prefer children, other relatives, friends, and neighbours in that order (Cantor, 1991). It is, however, not clear whether this hierarchy reflects reality as it does not seem to recognise the fact that children leave home. The hierarchy also does not seem to recognise divorce trends and family and sibling feuds. Family structures and roles have changed; consequently, the relationship in which the hierarchy is supposed to be based is either partially in existence, or seriously weakened.

This does not diminish the relevance and importance of the family as a source of informal care and support for older adult members, but it offers an insight into the present reality of the institution. Thus, older family members can only begin to prefer a hierarchy of support that is achievable.

A major gap in the existing literature is that only little has been investigated about non-kin care especially in situations where old age is not just the reason for needing support, but a condition like dementia. My study helps to fill this gap, by exploring the nature of neighbour care giving in dementia context. A lesson learnt from this review is that family remains an important source of informal care, notwithstanding demographic changes in family dynamics. Moreover, policies that govern the complex care system are not constant; they change whenever necessary, to address increasing diverse needs and disruptions caused by socio-economic changes. The review also shows that proximity of care givers to care recipients is important in dementia care.

2.11 Research Gap Addressed by the Study

A strongly held culturally held presumption is that family is the appropriate resource on which people should rely for assistance in old age. This expectation underlies much social policy and provision of services for older people (Barker, 2002). Although family still comprises most people providing informal care and assistance to frail older people (Abel, 1991), many older people have never had or have exhausted family resources and are receiving care from a variety of other informal sources as well as paid professionals (Barker, 2002).

Changes in family structure and expected caring roles mean that it is no longer assumed that family members are expected to provide the bulk of direct care and support for older people without at least some input from external agencies and bodies, the voluntary sector, and friends and neighbours. While the review of existing works and literature have pointed to studies that outline informal care provided by kin, little attention has been paid to the nature of support delivered by non-kin carers such as neighbours and friends. Many writers make frequent, but often only casual or passing, references to the impact of friends and neighbours on the wellbeing and continued community living of many older people living with dementia (Barker, 2002; Nocon & Pearson, 2000). Despite the ongoing importance of non-kin caregivers to the daily wellbeing of older people in the community, few investigators have undertaken a sustained examination of this phenomenon (Barker, 2002). Most importantly when informal carers like neighbours are mentioned there is little or no study of the experiences of neighbours caring and supporting older adults living with dementia. This is the research gap addressed by this study. I have therefore investigated the role of neighbour informal carers in providing support and care to older people living with dementia in their own homes.

2.12 Conclusion of Literature Review

Summary and Key Problem under examination

To summarise this chapter, there is a societal expectation that close-knit family or kin provide health and social care for older members, support them psychologically and emotionally, help manage finances, and enable dignified and active ageing. However, changes in family structure and expected caring roles mean that it is no longer assumed that family members are expected to provide the bulk of direct care and support for older people. This doctorate therefore explores the role of neighbourly support for people living with dementia in their own homes, to help to identify sustainable solutions to the problem of informal care giving in the community.

The need for this research focus emerged from a review of the existing evidence on non-kin care for older people and my experiences as a qualified social worker. While this review has pointed to existing work that outlines informal care provided by kin, I am worried that little attention has been paid to the nature of support delivered by non-kin such as neighbours. When informal non-kin carers like neighbours and friends are identified, they are often considered peripheral and inconsequential (Lapierre & Pearson, 2012). As a result, I contend that non-kin care and support is not well understood, especially concerning the relational contexts within which it develops. This review indicates that the dyadic relationships between informal carers and older people living with dementia are complex and diverse, and touch on several aspects of human activities of daily living.

Conceptual framework

In the next chapter, I apply person-centred and critical social gerontology theoretical approaches to investigate the problem. The approaches provide explanations about the social context under which care giving relationships thrive between neighbour dementia care givers and their care recipients. The approaches also provide an insight into how older people living with dementia are predisposed to receiving support from non-kin informal carers like neighbours.

Tools used in the work.

In the next chapter, I also apply a qualitative design method to generate, collate and analyse data on neighbour dementia care giving in the community, to better understand the complexities of the development of relationships between neighbour dementia care giving dyads, and to ensure that the study is corroborative and flexible. I also apply a purposeful sampling method because the sample frame is hidden; and a semi-structured interview method to ensure that participants' experiences are fully captured in the interview. Finally, I apply thematic analysis to analyse the data.

Details of the application of these tools can be found below in chapter three.

3 Methodology

3.1 Research Design

This chapter presents the research design of the study which includes how I carried out the study. It includes why I adopted person centred and critical social gerontology approaches for this study, the research methods and methodology, and the inclusion and exclusion criteria for the recruitment and sampling for the study. I also present the rationale for using a semi-structured interview method to gather data, and details of the area of my study, the issue of theoretical saturation in relation to my research sample, my data management and thematic analysis strategies. Finally, I also outline my reflections in relation to the research and the issues associated with consent, capacity, confidentiality, the power imbalance between me and the research participants, ethical approval, and the Covid19 pandemic.

In designing this research, I have taken note of the general circumstances of people who live with dementia, to tailor the design to their specific needs and circumstances. For example, I note that people who live with dementia are known to have difficulties with memory, thinking, planning, and verbal communication (Quinn, 2017). According to the American Psychiatric Association (2013), people living with dementia can experience significant neurocognitive impairments which affects their cognitive domains such as memory, language, the execution of purposeful movement, recognition, and visuospatial function.

Lloyd et al. (2006) and Cridland (2016) also argued that dementia impairments result in vague speech, decreased vocabulary, poor reasoning of verbal information, and confused word associations. These conditions could also be compounded by behavioural conditions like agitation, aggression, and restlessness, which may make it more difficult to be involved within in-depth interviews. However, older adults living with dementia constitute only 50% of the research sample while the other half comprise neighbour carers.

3.2 The Adoption of Person Centred & Critical Social Gerontology Approaches

My study adopts Kitwood's person-centred and critical social gerontology a approaches as the framework for a holistic assessment and investigation of the nature and experiences of caregiving relationships of neighbours and older adults living with dementia in the community. I adopted these approaches as the framework of study after considering other approaches like social capital and co-production.

As detailed in the literature review, social capital refers to connections among individuals, social networks, actual or potential resources, collective values and the tendency of networks to help each other in a bonded relationship (Putnam, 2001; Bourdieu, 1986; Dill, 2015). However, I have not adopted a social capital approach in this study because it is not well defined, and it overlaps with other issues like social cohesion, common goods, charity and voluntarism (Dill, 2015). Moreover, most research on social capital focuses on the United States which means it is difficult to transfer the approach to other cultures, particularly as it does not have uniform contents and meanings (Dill, 2015). However, I note that social capital approach overlaps in analysis, discussions, and arguments with the main approaches used- "person centred and critical social gerontology approaches". For example, I have shown how social capital can be used to explain neighbour dementia care relationships in this study.

I also considered co-production as a framework for this study as it is committed to inclusivity (SCIE, 2022). Co-production can be defined as an approach that involves the consultation and partnership of people who use services including professionals and carers who come together to find solutions to shared problems (SCIE, 2022). It requires collaboration between decision makers and citizens who use services to work together to create services.

According to Heaton et al. (2015), Ostrom propounded the idea of coproduction in the late 1970s and defined it as a process through which the inputs used to develop a product or service are shaped by contributions from individuals who are not in the same organisation. This means that co-production is more about people who contribute or collaborate in the production of the public services that they use. Co-production is founded on: the principles of the active rather than passive agency of service users; equality in relations between users and professionals; relationships between professionals and service users on a reciprocal and beneficial basis; service users' participation which leads to the redesign of services, and the participation of users facilitated by networks and organisations. So, the theory is developed to conceptualise a particular type of relation between the providers of goods or services (professionals and public officials) and the users of services (the public). Co-production is therefore an approach that is meant for organisations and professionals, in equal partnership, to apply in projects about people who draw on care and support towards shared goals. The approach emphasises equality, namely that no one group or person is more important than the other; diversity; the accessibility of needs to ensure equal opportunity for participation, and reciprocity to ensure that participants receive something back for putting something in (SCIE, 2022). The idea of coproduction emphasises equality, i.e., that no one group or person is more important than the other; that equality and diversity are important; the need for accessibility of needs to ensure equal opportunity for participation, and reciprocity to ensure that participants receive something back for putting something in (SCIE, 2022).

I rejected coproduction as a framework for this study because the approach was designed for formal, professional, projects and persons living with dementia, while my study is an investigation of the role of an informal care giving (neighbours) group in providing support for older adults who live with dementia in the community. Co-production is better suited for investigating issues in a formal rather than an informal setting like this study. Although co-production involves consulting people who use services, it is more concerned with the relationship between organisations, professionals and care users in order to achieve shared goals. It involves a conscious attempt by professionals and citizens to plan and deliver support together. While co-production is concerned with a formal assessment of needs among formal groups and persons living with dementia, my study investigates the role of an informal group in the delivery of services to persons living with dementia.

Having considered and rejected the above approaches as frameworks for this study, I adopted Person-Centred and Critical Social Gerontology to inform the framework for this study. Kitwood's person-centred approach was adopted because it helped in understanding the role of neighbours in care giving in the community and encourages the participation of people living with dementia to view themselves as people whose perspectives can help us understand more about informal care giving in a dementia context (Cotrell & Schulze,1993). Moreover, Kitwood's person-centred approach particularly attempts to explain the nature of informal care giving in a dementia context. The approach is therefore relevant and germane to this study. On the other hand, Social Gerontology helps to provide a broad socio-political context within which to understand the phenomenon associated with ageing individuals, communities, societies, and policy. It also helps to understand the social construction of ageing and dementia care giving, rather than a biomedical view of dementia (Kricheldorff et al., 2015).

3.3 Person-Centred Approach

Part of the negative consequences of the biomedical model of dementia "*was that the person experiencing the disease became largely neglected, as dementia was defined by a distinct set of clinical and pathological features with the goal of diagnosis being to identify methods of treatment and prevention"* (Bruens, 2018:82). This led to the emergence of the person-centred approach advocated by Kitwood and led to the focus of attention from the disease on the person with dementia (Bruens, 2018). Kitwood's approach brought about a change in focus from dementia as a medical condition to a focus on the person with dementia, and beyond the biomedical model. It is clear that "*there are more aspects of life that influence dementia and the person living with dementia, including the social environment and the life that the individual lived*" (Bruens, 2018:83). The change in perspective has led to changes in care plans for people living with dementia in different care settings in order to understand the condition better. I have therefore analysed the person-centred approach and showed how it explains the care for persons living with dementia in the community.

Kitwood's person-centred care approach has been considered one of the most enduring contributions to the dementia field as it develops thinking about how to act rather than simply to reflect (Innes et al., 2012). The approach provides a framework of values that is ethical, humanitarian, and respectful of the person with dementia (SCIE, 2019), as the idea of focusing on the "*selves of people with dementia offers a way to provide person-centred care*" (Innes et al, 2012:30).

Person-centred care contributes to a model of care underpinned "*in the concept of positive care relationship, through positive care practice, hence the personhood of the people with dementia can be promoted*" (Bosco, 2018:18). This implies that people living with dementia must be placed at the core of the care conversation. Person-centred care, therefore, becomes the gold standard of care (Bosco et al, 2018).

The approach is therefore relevant because it moves away from professionals deciding what is best for service users and places the person at the centre and as the expert of their experience (SCIE, 2019). Thus, the person and their carers become equal partners in the planning of their care and support ensuring that their needs are met. The approach runs through both individual and group settings allowing service users to be involved in their care and in the design and delivery of services (SCIE, 2019).

A person-centred approach, therefore, ensures that service users - in this instance older adults living with dementia - are valued and remain at the centre of their care arrangements and plans. The perspective also: accounts for people's preferences and chosen needs; accommodates emotional support involving family and friends; ensures that service users have access to the care they need, when and where they need it, and ensures that people get all the information they need to make decisions for their care and support (SCIE, 2019).

The perspective is therefore relevant as a framework for investigating experiences of neighbours supporting older adults living with dementia in the community because it ensures that both the older adults and their neighbour caregivers are given the chance to tell their own stories and narrate their experiences via in-depth interviews. The perspective brings into practice the approach of in-depth interviews of research participants and explains the nature of the relationship between older people living with dementia in the community and their non-kin carers like neighbours.

The person-centred approach informed the deployment of in-depth interviews to decipher participants’ experiences; along with critical social gerontology theory, the person-centred approach informed and explained how and why people like neighbours engage and are engaged in supporting older adults living with dementia. These two approaches therefore inform not only the investigative approach of this study but also the complexities of informal caregiving.

Some professionals who work with people living with dementia may continue to exclude them in the decision-making process because they continue to portray dementia as a living death (Birt et al, 2017), and because of the assumption and stigma that they cannot be involved in their care (Sherry et al, 2011). However, the person-centred perspective presents an alternative approach that views persons with dementia as equal partners in the context of dementia care, support, and formal services. The approach helps to counter the narratives of the negative outlook of people with dementia by focussing on their strengths and positive accounts of living well with dementia and the preservation of identity and self. Furthermore, dementia support groups provide social platforms and structures that enable people to perform social citizenship roles through actions that appreciate their rights to live without discrimination (Birt et al., 2017; Bartlett et al., 2014). By focusing on the individual living with dementia the person-centred approach adopts a procedure that values the person living with dementia and the caregiver. It highlights the nature of dementia care triads which comprises the person living with dementia, their informal carer, and the health and social care professional, and focuses on the social practices that contribute to inclusion and exclusion of triad members (Sherry et al., 2011).

Kitwood’s approach, therefore, embodies both the process and experience of dementia by bringing together ideas and ways of working with the subjective experience of people diagnosed with dementia (Bruens, 2018). This brought into focus the subjective experiences of people living with dementia by broadening the understanding of the condition beyond that of neurological impairment to include psychological and social dimensions. This emphasises that the interaction of these aspects play a vital role in forming a person’s condition, and means that the personhood of people living with dementia must be understood and their perspectives taken into consideration. At the centre of this approach is the position of the person living with dementia who is vital in the care process and must be central. Kitwood’s approach also involves an attempt to not only be empathetic but also address issues of care that may arise because of the condition. The caring aspect of this approach is relevant to my study due to his recognition of the full humanity of those living with dementia, through adequate care and empathy (Kitwood, 1997a). Indeed, the concept of personhood “*is a standing or status that is bestowed upon one, in the context of relationship and social being. It implies recognition, respect, and trust*” (Kitwood, 1997a:8).

Although the self could change over time it persists during the period of dementia. People living with dementia must continue to be valued and respected throughout the dementia process. This suggests that in caring for a person living with dementia in the community, the focus should not only be on the medical support he/she receives from the doctors, nurses, and other medical professionals, but also on the support that is available from friends, family, neighbours, and community organisations. According to Boise & White (2004) and Telerico et al. (2003), a major feature of person-centred care is the recognition that human life is grounded in relationships, including the fact that people living with dementia need a social environment that enables opportunities for personal growth while compensating for their cognitive impairments (Grand et al., 2011). In other words, it concerns a person’s physical being and how it is managed medically, alongside a more holistic insight into what is happening in the older adult’s social world.

Discovering the individual experience of dementia helps to provide an alternative picture of the process of dementia. Unless people start treating those living with dementia with some sense of respect and recognition, their personhood will be undermined, which will harm their wellbeing. The challenge not to view and treat people with dementia in this manner is for all to consider. People living with dementia, therefore, do not need to have a greater burden from their condition because of how others treat them or what Kitwood refers to as “malignant social psychology” (Bruens, 2018:84). The traits of malignant social psychology could be found in attitudes that ignore, outpace and disempower persons living with dementia.

Also significant is the Care Act 2014 that consolidates and strengthens the recognition of both the kin and non-kin carers of people living with dementia in the community, by recognising and making carers assessment by professionals, mandatory. The Mental Capacity Act [MCA] (2005) also facilitates and ensures that assessments and support plans are carried out in a person-centred manner. The Act has five principles which include the assumption of capacity, which ensures that even if a person has dementia and an assessment of his/her capacity has not been completed, it must be assumed that the person has capacity. This goes some way to eliminate any abuse and assume that incapacity is a direct and automatic consequence of memory loss in every situation. The Act also ensures that the service user is supported in making decisions about his/her care to ensure they have all the information necessary for the decision. The Act also stipulates that the service user must be allowed to make unwise decisions and take responsibility for them, and in case of incapacity, decisions should be made in the person’s best interest and such a decision must be the least restrictive option. In essence, the law is designed to protect the person living with dementia while navigating the complex care system and ensure that abuse is eliminated.

The person-centred approach also ensures improved wellbeing through positive interaction, which termed “positive person work” (Bruens, 2018:84). Positive interaction includes consultation on their needs, and ensuring that their safety and care are paramount (Bruens, 2018:84). The focus should therefore be to maintain personhood when caring for people living with dementia. This is achievable through meeting their personal needs, which include comfort, attachment, inclusion, occupation, and identity; meeting them will enhance and improve their wellbeing (Kitwood, 1997a).

However, a person-centred care framework does not focus on the social context of caregiving nor proffer a change strategy (Innes et al., 2012). Although the focus on the individual is important, the approach does not address issues that place them at a disadvantage in the wider community or how they could be better cared for by groups, such as neighbours. Thus, the social contexts of people living with dementia inform the nature and source of care they receive.

Person-centred care has also been criticised as lacking empirical support, while personhood has been termed an undeveloped concept. According to Flicker (1999), Kitwood's person-centred approach is not supported by empirical data and tested methodologies. His ideas are therefore considered imaginary and lacking empirical data or methodology to support his research. Moreover, his methodological considerations do not have clear guidelines of how to apply the theory in practice (Bruens 2018), although his approach creates a pathway of care for older people living with dementia.

Moreover, there is no clear connection between Kitwood's assumptions about personhood and citizenship, as his concept of personhood has limitations in the broader social context as some socio-political factors can discriminate against the person living with dementia and even engender inequalities (Bruens, 2018:86). This, therefore, means that Kitwood's propositions are limited to the older person's micro-environment rather than the larger macro-environment. However, the idea of neighbours supporting older adults living with dementia in the community is within the limits of the micro-environment; hence, this can be said to be captured within Kitwood's approach. However, his approach perceives personhood as conferred on an individual; it does not promote the vision of an active social agent but focuses on maintaining status rather than stimulating opportunities for growth and development (Bruens, 2018). The approach has also been criticised as having an idealised concept of care and does not see the person living with dementia as an active autonomous participant in a caring relationship (Bruens, 2018). However, this is not necessarily the case as a person-centred approach has been successfully adopted and applied to individuals in long-term care settings; it recognises and identifies care preferences and the needs of older people living with dementia to guide caregiving and individualised care plans (Grand et al., 2011).

Nevertheless, person-centred care is comprised of an individualised care that is meaningful and respects individual values, preferences, and needs; it requires a caregiving relationship built on trust, freedom of choice of the person living with dementia, and the enhancement and promotion of emotional and physical comfort. Finally, it necessitates the involvement of the adult, his friends, kin and non-kin carers and/or their care networks in decision making (Grand et al., 2011; Telerico et al., 2003).

3.4 Critical Social Gerontology

According to Ranzijn (2015), critical gerontology is an analytical approach to gerontology that examines its normally ‘taken-for-granted’ assumptions to provide a broader socio-political context within which to understand the phenomenon associated with ageing individuals, communities, societies, and policy. The approach posits that ageing is a social construction, and it is society’s attitudes and the stereotypes designed to serve healthy younger people that create the needs and disabilities associated with ageing (Kricheldorff et al., 2015). It therefore needs a systemic altering of social systems to create an age-inclusive society. This approach attempts to counter the propositions of the biomedical model from the perspectives of gender, race, sexual orientation, socio-economic class, and disability (Ranzijn, 2015).

Critical social gerontology presents an alternative to the biomedical model of ageing (Phillipson and Walker,1987), and therefore draws attention from the individual to the social-environmental aspects of the society in which the individual lives. In other words, the approach has a wider view on social and structural issues as they affect the lives of older people in the community. They do not see the ageing individual, but rather the ageing process (Ranzijn, 2015). The approach, therefore, posits an alternative to assumptions that underpin individualism, determinism, positivism, and reductionism, and hence sees beyond the individual, has a view beyond the controlled contextual factors and measurable data, and views the phenomenon holistically rather than through its separate parts.

To fully understand the arguments of critical social gerontology, it is vital to have a brief purview of the biomedical model of ageing. The biomedical model focuses on health regarding biological factors and sees ageing and disability in terms of the impairment it gives the individual. This limited view of the aged leads to the treatment of older people as infantile and incompetent, which is particularly the case for the aged living with dementia whose personhood is often disregarded (Ranzijn, 2015). Strickland and Patrick (2015) argued that the biomedical model dominated thinking about mental and physical disorders for much of the nineteenth and twentieth century. The model suggests that psychological conditions - recognised as disorders - are not illnesses and that all mental illness is a brain illness. It is therefore important to understand whether the disease embodies only the biomedical facets of a person or includes their psychological, sociological and behavioural factors. It also considers whether biological factors arise in the context of socio-environmental factors. Critical social gerontology therefore views the experiences of ageing from the perspective of spatial contexts as it understands that the neighbourhood influences a person's environment, relationships and the care setting through the inclusion of resources and spatial space (Kricheldorff et al., 2015).

To this end, Critical Social Gerontology was applied in this study to enable an understanding of the status of older people living with dementia in the community (Innes et al., 2012). This perspective argues that the assumption underpinning biomedical models of ageing - including that older people are a burden to society - is flawed and argues that many of the problems associated with ageing are due to social structures which limit the abilities of older people (Ranzijn, 2015). For some older people, the deliberate development of non-traditional households centred on non-kin has become an important strategy to offset the effects of poverty and a lack of familial resources (Chalfie, 1995).

Critical social gerontology brings to attention the interplay of class, age, and gender, and advocates the lived realities and power dynamics at play in the complex care networks of older people (Innes et al., 2012). The approach helps us to understand the experiences of different groups, including older adults living with dementia, by bringing into focus the reality of their social environment, the lives they live, and the networks they can access. In other words, the social factors that shape their lives are highlighted (Ranzijn, 2015; Innes et al., 2012). The perspective goes beyond the individualism advocated by social psychology and determines how we evaluate and explore the condition through a complex care system linked with people living with the condition.

Critical social gerontology has been criticised as too obsessed with negativity in social structures and institutions. According to Ranzijn (2015), the approach can go too far in its critique blaming all problems and disorders of old age on social structures while ignoring the disorders and disabilities that affect older people's quality of life regardless of how supportive and effective the social structures and institutions may be.

Dependency is not a function of ageing itself but a consequence of the social structures and processes that impact older people; it is vital to approach the needs of older people from the person-centred view by trying to understand their needs from their lens and the circumstances of their physical environment. It is therefore vital to view the care of the older adults living with dementia from a person-centred perspective.

3.5 Research Methods

In this section, I considered the ontological and epistemological bases of my work. The ontological aspects of my study are the social world relevant to my study (neighbours and older people living with dementia), and the epistemological world is the knowledge/evidence relevant to my study. The relevant questions were: ‘what principles and methods will help to express my epistemological position’; ‘how best can I generate data from my data sources’, and ‘what will be my data generation and engagement techniques and where will I find the data?’ (Mason, 2018).

I reviewed a range of methods, namely interviews, surveys, participatory methods, focus groups, written stories and accounts, visuals, photos, tasks, and arts-based exercises (Mason, 2018). My focus was on how to make decisions based on the most appropriate methods for my study. I talked my research through with other PhD students and my supervisors to

help reach informed decisions as the most appropriate method for my study. My thought process also involved tracing links between specific methods and my research questions (Mason, 2018).

The factors that influenced my selection of a particular method were the costs of its adoption, the possible links between my research questions and my research method, and what I intended to find out with the methods. I also needed to decipher what the method I chose would generate, vis a vis my research aims and objectives and the nature of the link between the method and my research questions. I also considered the line of enquiry that methods might enable me to pursue, and which methodological approach would help me to achieve my stated aim and objectives more effectively and efficiently in a cost-effective manner (Mason, 2018). The possible evidence/knowledge that each method would generate was also central to determining the method I chose to adopt. I also made sure that the method I chose was practicable for the circumstances of my study, and the cost implications of choosing the method.

I needed to make initial but vital evaluations of the sample population and possible sample size, as I adopted a purposeful sampling technique. I needed to be realistic about what was feasible financially and would satisfactorily address the research questions. I also considered the fact that neighbours who care for neighbours do not always identify themselves as carers, so I acknowledged that it could be difficult to find neighbours to interview. Eventually, my research design emerged via an engaged and reflexive process rather than being decided before the research commenced (Mason, 2018).

3.6 **Methodology**

My research design was built around generating, collating, and analysing data/evidence around dementia care in the community. I operationalized assumptions of what dementia care looks like and looked at better ways to gather data about neighbours’ experiences supporting older people living with dementia in the community. The strategy informed decisions throughout the study to ensure that the data and analysis were meaningful, my arguments convincing, and the research of good quality (Mason, 2018).

This is an exploratory study. Data was collected via semi-structured interviews with neighbours and older adults living with dementia. The research adopted a qualitatively driven methodology to understand the experiences of care provision among people living with dementia and their neighbours. This study was exploratory because it explores the research questions and does not intend to offer final solutions to existing problems related to the topic (Dudovskiy, 2008). The research adopted a qualitative methodology to better understand the complexity of the development of relationships between people living with dementia and their neighbours, as well as the nature of the care and support that is provided.

A qualitative approach helps to ensure that research is corroborative, flexible, and can explore issues including mixed and ambiguous attitudes (Cridland et al., 2016). A qualitative approach is appropriate because it employs a person-centred style where participants are supported to make informed decisions regarding participation in research and allows them to tell their own stories and consent to their data being used in the research. According to Mason (2018:110), the approach allows for "*interactional exchange of dialogue*", adopts a relatively informal style, and "*operates from the perspective that knowledge is situated and contextual*".

3.7 Inclusion and Exclusion Criteria

Two groups of participants were recruited: neighbour dementia care givers and older people aged 65+ living with dementia in their own homes

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Criteria for inclusion in this study for neighbour care givers, were that they must be a neighbour providing informal dementia care and/or support for an older person aged 65 plus and living with dementia in the community. "*Dementia mainly affects people over the age of 65, and 1 in 14 people in this age group have dementia*" (Powell & Baker, 2019:6). Indicators of care and support range from; help with personal care, support paying bills, home maintenance, housekeeping, meal preparation, dressing and undressing, support with transportation, shopping, help to manage bills and write letters.

Secondly, the second group of my participants were older people aged 65 years or more in age, who were living with dementia in their own homes in the community and had care and support needs resulting from dementia. Although inclusion in the sample was purposeful, other eligibility criteria required the care relationship to be negotiated between the neighbours and voluntarily accepted by both parties, and that the care is freely offered by the neighbour giver.

Moreover, the neighbours would be performing care and support that included personal care tasks, shopping, support with documents, housekeeping and maintenance, and prompting the older adults to perform some personal care tasks (also considered as tasks). In addition, the neighbour (caregiver) was not related to the older adult living with dementia who they supported; were not paid for the care and support they delivered; were not providing care and support in a professional capacity; were delivering some form of care and support at least once a fortnight; were physically close to the older adult such as in the same street or opposite or on an adjoining street (Barker: 2016:158). The neighbour also gave support even if the older adult was unwell with illnesses other than dementia.

If the neighbour giving care and support was a professional like a nurse or doctor or social worker or any other professional, he/she had to be performing the role unpaid. In other words, the care support given had to be due to neighbourly relationships and the tasks performed had to be undertaken regularly, and for at least three months. The caregiver neighbour could be of any ethnicity and gender. Interviews were conducted in English. I note that the strategy of only conducting the interview in English would reduce the ethnic diversity of the study, but it also helped to reduce the complexities of arranging translation, and interpretation.

3.8 Sampling and Recruitment

I adopted a purposeful sampling method for this study because the sample population or frame was hidden, as there were no lists or existing data anywhere for either older people living with dementia in the community with experience of neighbour support, or neighbours with experience of supporting older adults living with dementia in the community. I also chose a purposeful sampling technique because the research population was not located in a particular area of the country and the research population was hard to identify. According to the JDR (Join Dementia Research), out of about 3000 carers who registered as such on their website, none expressly identified as a neighbour carer. This does not mean that neighbour carers do not exist, but that they tend not to see themselves as carers. This makes it difficult to identify them for research. The purposeful sampling technique therefore helped me to search for participants who met my inclusion criteria.

Therefore, a major challenge in conducting this research was in reaching and accessing the hidden sample population. Only a select group responded to the leaflet publicity materials (Table 2 lists the number of participants recruited from different sources) and, as already indicated, neighbour carers often do not identify themselves as carers which makes it difficult to identify them for research.

The recruitment of participants via just one clear source is difficult when searching for individuals such as non-kin, non-paid carers supporting older adults living with dementia. As a result, participants were sought via multiple sources including Join Dementia Research, community voluntary organisations, and via the distribution of research information leaflets. I purposefully searched for participants via charities and voluntary community organisations that particularly work with older people living with dementia. The following describes my search.

First, I contacted in-home service organisations that reach people living with dementia in the community. I therefore contacted Alzheimer's UK, Age UK, United Kingdom Home Care association, Dementia Cares Organisation, Carers in Essex, Carers UK, Dementia UK, HH (Home Care). I also created a website for this study to advertise my study, known as PhD Dementia Care Research (https://phddementiacareresearch.blogspot.com). Table 2 lists the details of contacts made including the date of contact, response from the agency or organisation, and remarks. Some of my contact with these organisations led to further referrals for contacts with other relevant organisations. For example, my contact with the Alzheimer's Society led to their referral to contact Join Dementia Research (JDR).

So, I contacted the Join Dementia Research (JDR) initiative in the UK via a referral from the Alzheimer's Society. JDR links dementia researchers with members of the public who are willing to take part in dementia studies. I also engaged with JDR because, according to British Broadcasting Corporation [BBC] (2015), in 2014 JDR were successful in promoting a 60% increase in people participating in dementia research. The motive for this study is to encourage dementia advocates to participate in research. It was also hoped that persons living with dementia in the community would act as leads to identify neighbours who care and support them and vice versa.

Therefore, I applied to JDR to include my study on their website and my application was accepted. My study was therefore divided into two 'arms' (a persons living with dementia arm, and a carer arm) and added on the website. As already indicated, there are about 3000 carer volunteers registered on the website. Of the 3000 carer volunteers, 540 volunteers from Join Dementia Research (JDR) website matched my study within a 30-mile radius of Dartford and Gravesham NHS Trust. I contacted them via their registered email on the website, attaching further information about my study.

After extensive vetting of the 50 volunteers who responded to my email by using my study inclusion and exclusion criteria, only seven were eligible, comprising five neighbour carers and two older adults living with dementia. Seven potential participants responded to my publicity materials and after careful vetting using my inclusion and exclusion criteria three eligible participants (two neighbour carers and one older person living with dementia) were recruited and interviewed. Seven possible candidates for the study were referred to me by community organisations rom which I recruited three eligible participants (all persons living with dementia) after applying the inclusion and exclusion criteria. Table 2 shows the number of participants recruited from different sources.

After recruiting seven participants from JDR, JDR adjusted their catchment areas for each study registered with them and based them on the chosen NHS Trust used as a base. For example, they first put my base catchment area as those volunteers living within a five-mile radius of Gravesham NHS Trust but subsequently adjusted it up to a 10-mile, 15-mile, and 20-mile radius as the recruitment progressed.

I provided detailed information on recruitment material (including information about the expected positive outcomes of the study) to ensure that potential participants were aware of the potential benefits of the study. This included the use of the research to inform a new model of informal care and support, its benefits to people living with dementia in the community, and its implications on social work practice regarding practice within the informal care sector.

The nature of the information that I provided on the information sheet for participants included information regarding the purpose of the study, why the participant was being invited to participate in the study, discretion about participation, what it entailed to participate including how long the interview would last, the venue for the interview, the nature of the questions to be asked or that would guide the interview. Other information included the recording of the interview, data protection issues associated with the interview, expenses and payments, disadvantages, risks, and the advantages of taking part in the research. Issues bordering on confidentiality and withdrawal were also addressed. The information sheet also contained details about the sponsor of the study and data storage issues. Thus, at the end of these processes seven neighbours supporting older adults living with dementia in the community, and six older adults living with dementia in their own homes in the community, making a total of 13 participants, were recruited for this study.

Table 2: Number of Participants Recruited from Different Sources.

Source of Participants	**Leaflets and Publicity**	**Join Dementia Research (JDR)**	**Community Organisations**	**TOTAL**
Neighbour Care Givers	2	5	0 (Zero)	7
Persons living with dementia	1	2	3	6
Totals	3	7	3	**13**

A summary of the contacts I made in recruiting participants for this study can be found below.

Table 3: Recruitment Contacts

No.	**Name of Agency Contacted**	**Date of Contact**	**Response from Agency**	**Remarks**
1	Alzheimer’s Society	March 2020	23/3/2020 Recommended using Join Dementia Research to support my recruitment for participants.	Follow-up on this led to JDR Application No participant directly recruited from this website.
2	Use of publicity materials. The material/flyer described my research and eligibility for the study. 100 distributed.	March 2020	7 responses	3 participants were recruited.
3	Join Dementia Research (JDR)	April 2020	15/4/202 Response from JDR, and requested	Application ongoing for research to be published on their website 7 participants recruited.
4	United Kingdom Home Care	April 2020	23/4/2020 Referred researcher to contact members via their website.	Direct contacts were made, but

	Association (UKHCA)			no volunteer was recruited.
5	Age UK	March 2020	No Response	
6	Dementia Cares	April 2020	23/4/2020 Response from Manager for more details of the research, so that it would be included in Dementia Carer's website.	26/4/2020 Details of research sent to Manager No participant was recruited from this.
7	Carers in Essex	April 2020	NO RESPONSE	
8	Carers UK	April 2020	20/4/2020 Sent a response to students to search their website for relevant information.	No participant was recruited.
9	Dementia UK	March 2020	Referred researcher to ALZHEIMER'S Society.	No more contact with them is needed.
10	https://phddementiacareresearch.blogspot.com/	May 2020	Website purposely created for study	Website running, no participant recruited.
11	HH	March 2020	Based on the information I provided promised that they have about seven possible participants that may fit in.	Three participants were recruited.
12	TA	March 2020	Possible carers that may fit into requirements.	No participant recruited

3.9 **Rationale for Semi-Structured Interviews**

I adopted in-depth interviews as a qualitative method after considering the nature of the data needed and how best to generate the data. The questions I needed to answer centred on why I needed to use interviews, why I needed to speak to people and informally interact with them to generate the data. I also considered the nature of my research questions, the best way to generate data that would answer the research questions, and why other structured forms of data gathering like the use of questionnaires should not be deployed. I also considered the disadvantages of applying an in-depth interview method in this research.

I applied a qualitative in-depth interview method because I believe that the proposed participants' experiences, perceptions, narratives, and interactions are significant "*properties of the social reality that my research questions sought to explore*", and an in-depth interview was the most appropriate mode of gathering such information (Mason, 2018:111). As my study centred on exploring the role of neighbours in supporting older adults living with dementia in the community, I interviewed both relevant older adults and neighbours. To this end, I also discovered that a qualitative in-depth interview was most appropriate because I was also adopting a person-centred approach which presupposes that participant would have a choice to tell their stories freely in an informal setting. As a result, the most meaningful way to achieve this was to have a conversation with participants with the focus and aim of answering my research questions.

According to Mason (2018:111-112), using the interview method stems from the need to "*talk and interact with people; ask them questions; listen to them; see them as witnesses of research phenomenon; and analyse their use of language and discourse*". I adopted in-depth interviews to "*generate a fairer and fuller representation of the participants' experiences and perspectives and also allow for interviewer/interviewee interaction rather than simply asking questions*" (Mason, 2018:115). Moreover, in-depth interviews allow participants to share their opinions without bias from other participants and avoids having a few participants dominating or answering most of the questions. The in-depth interview method also explores how close the answers get to the real view of respondents rather than how accurately the different answers of respondents can be compared (Mason, 2018). However, I was aware that qualitative in-depth interviews on the issue of participant's experience of dementia care are dependent on their "*mental capacities to express themselves, to observe, to narrate, to interact, to conceptualise, to analyse, to listen, to understand, and to remember*" (Mason, 2018:112).

3.10 In-depth Interviews

Interviews were conducted with both persons living with dementia and neighbour carers who have supported a neighbour living with dementia. Older adults living with dementia and neighbours supporting or with experience of supporting older adults living with dementia were also interviewed. Interviews were conducted via telephone with persons living with dementia, with their family members or carers present during the interview to prompt them as the interview progressed. So, no vulnerable older adult living with dementia was interviewed alone, but rather interviewed with either their daughters present (in three cases), or their neighbour carers present (in the other three cases).

Each interview lasted for one hour each with the six persons living with dementia. Their interviews were limited to one hour because of their dementia condition and I made sure that they did not exceed this because of a very high-risk of distress and/or tiredness during the interview. However, prior to the interviews I conducted with contacts with the persons living with dementia and/or their family members to arrange the interviews. I contacted four cases twice (J, WB, JW, AH) for 30 minutes on each occasion making a total of four hours; and two cases I contacted once (HB and J) for one hour each, making a total of two hours. The total of all pre-interview contact with the adults living with dementia and their families was six hours. The interviews for each persons living with dementia was for around one hour each, making a total of six hours. I therefore spent a total of 12 hours on making contact and conducting the interviews on older persons living with dementia.

I interviewed seven neighbours with experience of supporting older adult/s living with dementia in the community. Prior to the interviews, I contacted all seven participants via telephone and email. These email and phone conversations enabled me to explain the reason for the study, the nature of the interviews, and the delivery of the interview guidelines, agreement and personal information sheets. My pre-interview contacts with the neighbour participants were for an average of one hour per participant, making a total of seven hours. The interviews took place for an average of one and a half hours per neighbour interviewee, totalling 10 and a half hours for the seven interviews. The total contact time for both the pre-interview contact and interview was therefore for 17.5 hours. I also had further phone contact with neighbour carer participants (L, B, J, SB, and T); except for B, this contact was not for further interview purposes. Instead, the other contact was to clarify aspects of the interviews, and in one of the cases the participant contacted me. For example, participant (Neighbour L) called me back to enquire where and how she could become a social worker. I referred her to websites of universities of her choice for guidelines. Neighbour B's first interview was stopped after one hour because she needed to attend to some personal issues, and we re-arranged to continue the next day. The interview with her (B) the next day also lasted for one hour, and that gave me the opportunity to go through details of the interview the previous day, and to have a further conversation about her support for her neighbour living with dementia, especially regarding the disagreement she usually has with him. Further contact with SB and T, aimed to clarify whether she was the appointee or had lasting power of attorney (LPA). Furthermore, clarification was given on earlier comments about not performing personal care tasks. I had further contact and phone conversation with neighbour J (a retired school principal) because she asked for more information about my work and the "super neighbour scheme" running in Kent to support older people during the COVID19 pandemic, at the same period of the interview.

The overall time it took me for more contacts and interview for neighbour carer participants, after the initial interview, was an average of five hours. My pre-interview contact with participants aimed to ensure and check that they were willing to be involved in the interview, and were not having a difficult day that would make it difficult, impossible, or unadvisable for them to participate in the very day. There is evidence that interviews with people living with dementia must be conducted at an appropriate pace and that rapport should be built (Cotrell Schulze, 1993; Harman & Clare, 2006). Therefore, I ensured that I made adequate contact with the interviewees and their carers, and that interviews were conducted at the agreed pace.

There were no mental capacity issues in interviewing the seven neighbour carers because their capacities were not in question, but I ensured that the six participants living with dementia were in their early stage, and as already indicated were all supported during the interview by either a family member or his/her neighbour carer. I was flexible and sensitive to the specific circumstances and dynamics of each interaction.

I engaged the participants in in-depth interviews, which involved comprehensive conversations guided by the participant's perceptions, opinions, and experiences. The interviews also aimed to understand the participants' lived experiences and in this sense, the interviews were considered more complex than simply asking questions or talking to people (Cridland et al., 2016). Their experiences included the history of the relationship, their origin, trajectory, and change over time, the nature of activities and tasks undertaken, and their overall experiences in the relationship from their perspectives.

The interviews would have been conducted face to face, but the mode of the interview was changed because of the COVID-19 pandemic and subsequent lockdown. I had an amendment to my ethics approval to change the mode of the interview for both neighbour care giver participants and older people living with dementia, to include telephone/video modes of conducting the interviews, and the ethics committee approved the change. The interviews were focused on the relationships that had developed between the persons living with dementia and the caregivers (carers). Both categories constitute the interview participants of this study.

Semi-structured interview topic guides were used by the researcher to ensure a consistent approach across all interviews - of the neighbour care givers and the care recipients (older people living with dementia). The topics covered include when, where and how the care relationship started; the nature of the care/support given and received (if any); the nature of the neighbour's role in relation to kin family support (if any); how long the relationship had endured; the nature of any conflict in the relationship; general impacts of the care relationship on the caregiver; the nature of the costs and burden of caregiving on the care giver and his/her family; implications if the older adult does not receive care from the neighbour, and whether the person living with dementia also receives formal care/support. The interview also sought information regarding the socio-demographics of the participants. I also asked questions relating to the relationship breakdown, tensions in the relationship, and how it is managed, and how it affects the care dyad.

The interview guide was flexible and designed to enable participants to discuss aspects that matter to them. The answers were not restricted to any variables, but interviewees could answer questions to the best of their knowledge. Due to the nature of the data sought, I interviewed both adults living with dementia with experience of neighbour support, and neighbours supporting older adults who live with dementia. For example, older adults living with dementia were asked questions regarding the nature of support they receive from their neighbour carers if any; how they met their neighbours and/or how and why their neighbours started to support them; why they trust them to provide support, and any matters arising (if any) because of such care and support.

I reflected throughout the process of data collection and interview; I used my social work skills to ensure that all plans were working as envisaged and made changes if necessary. As already indicated, one of the changes made was to re-apply to the School of Health and Society's Ethics Committee to amend my ethics approval to include interviewing via telephone or the use of video platforms (Appendix 7 shows the ethical approval forms).

3.11 Area of Study

Although the data collection approach was purposeful, and centred on nature of the care giving relationships, it is important to provide the neighbourhood and participant contexts of the study in order to give an insight into the social and spatial environment and circumstances in which the participants live. The study participants were resident in Kent, London, and Essex. I have therefore presented a description of the areas in which the participants live in, and the demographic characteristics of the participants (shown in Table 4).

Table 4: Residential Area of study participants

Area	**Neighbour Carers**	**Persons living with dementia**	**Total**
Essex	2	5	7
Kent	2	0	2
London	3	1	4
Total	**7**	**6**	**13**

Table 4 shows out of the seven neighbour carers interviewed two were resident in Essex, two in Kent, and three were resident in the London area. Moreover, out of the six older adults living with dementia interviewed five were resident in Essex, and one in London. It also meant that of the 13 participants interviewed in total, seven were resident in Essex, two in Kent, and four resided in London. Moreover, as already indicated, my study was focused on the care giving relationships between neighbour givers and their persons living with dementia, notwithstanding their residential areas. However, the neighbour dementia care givers L and T resided in Essex, ED, J, and CM resided in Kent, while B and SB resided in the London area. On the other hand, amongst the interviewees living with dementia, L, J, WB, JW, and HB lived in Essex, while AH lived in London.

London is the capital of United Kingdom; as of 2021, it had a population of approximately 8,799,800 people (51% females and 49% males), and a land area of 1,572 square kilometres (km^2). At that time, London's population comprised 53.8% White British, 20.8% Asian and 13.5% Black people, while a mixed population also constituted up 5.7%, and others 6.3%. Moreover, in 2021, London had population density of 5,596 per km^2 (Office of National Statistics, 2021). In addition, Essex is a county in the east of England, and in 2021 had a population of 1,832,752 (51% female and 48.9% male), and a land area of 3,670 km^2. It had a population density of 499 per square km^2, and comprised 90.8% White British, 1.3% Asian, and 1.5% Black people (Office of National Statistics, 2021). Finally, Kent is a county in Southeast England, and in 2021 recorded a population of 1,846,478 people (50.9% male and 49.1% female). Kent had a land area of 3,736 km^2, with 494 people per square kilometre. In 2021, Kent was comprised of 93.7% White British (Office of National Statistics, 2021).

Having presented the demographic characteristics of the area of study, I have also presented the demography of the research participants in Table 5. This includes their age, ethnicity, marital status, nature of the house lived in, affluent or less affluent and/or sub-urban or urban environment.

Table 5: Demography of Research Participants

No.	**Participant**	**Demographic Characteristics** (age, ethnicity, marital status, nature of the house lived in, affluent or less affluent and/or sub-urban or urban environment)
1	Neighbour L	45, Black African immigrant, female, married & lives in a flat with her family in a suburban less affluent area of Essex, known person living with dementia for 12 years.

2	Neighbour ED	82, White British, female, lives alone in a house in affluent and suburban area of Kent, known person living with dementia for 30 years.
3	Neighbour B	58, Black Caribbean Immigrant, female, lives alone, in a flat in a less affluent area of London, known person living with dementia for 28 years.
4	Neighbour J	70, White British, female, lives with her husband in a house in an affluent area of Kent, volunteers in memory café, retired secondary school principal, known person living with dementia for 5 years.
5	Neighbour SB	78, White British, female, lives in a house in affluent area of London, is a known person living with dementia for 50 years. Has lasting power of attorney for person living with dementia.
6	Neighbour **CM**	66, White East European, female, lives in a flat, in a less affluent area of Kent, known person living with dementia for 5 years.
7	Neighbour **T**	78, White British, male, lives in a flat, in a less affluent area of Essex, known person living with dementia for 7 years.
8	Person living with dementia **J.**	90, White British, female, lives in a house in a less affluent area of Essex, known the care giver for 12 years.
9	Persons living with dementia **AH.**	92, White British, female, lives in a flat in less affluent area of London, known the care givers for 10 years.
10	Person living with dementia, **J**	73, White British, male, lives in a flat in less affluent area of Essex, known the care giver for 7 years.
11	Person living with dementia, **WB.**	85, White British, male, lives alone in a flat in suburban Essex, known the couple care givers for 12 years.
12	Person living with dementia, **JW**	65, White British, male, lives in a downstairs flat in less affluent urban Essex, known the couple care givers for 5 years.
13	Person living with dementia, **HB**.	87, White British, female, lives in a house in suburban affluent area of Chelmsford in Essex, known the couple care givers for 15 years.

3.12 Theoretical/Data Saturation

One of the guiding principles of my approach to data collection, sampling, and recruitment was to recruit until I reached saturation point i.e., the point at which no new insight emerged aside from known context/individual specific experience. Data saturation was employed as a conceptual yardstick to estimate and validate the sample size in this study. Applying the concept of theoretical saturation helped me to answer the question as to how many qualitative interviews were enough. I reached a point where adding further participants did not give me any further appreciable insights in relation to my research questions. According to Boddy (2016), a sample size of 12 in qualitative research may be sufficient to achieve data saturation.

The idea of data saturation was first introduced to qualitative research by Glaser and Strauss (1967) work *The Discovery of Grounded Theory* and was defined as the point at which no additional data are found whereby the researcher can develop properties of the category (Guest et al., 2020). The idea of data saturation has since been redefined in a wider perspective, as "*the point in data collection and analysis when new incoming data produces little or no new information to address the research question*" (Guest et al., 2020; Boddy, 2016; Malterand, 2015). This is essentially the point at which data stabilises in the process of testing and building theoretical models.

In this study, seven to ten interviews produced the majority of the new data for the entire data set, and little or no new information was received as the sample size reached 13 interviews. Across this study's entire data set 95% to 99% of all the data identified were within the first ten interviews, and 80 to 90% of all the identified themes were generated within the first ten interviews.

Some studies calculated saturation based on the proportion of new themes in relation to the overall number of themes in the data set. However, for this study I applied the approach developed by Guest et al. (2020) to calculate and report saturation. This involved using simple percentages and operationalising saturation (the point during data analysis at which incoming data points or interviews produce little or no new insight to the study objectives). Three distinct elements were used to achieve this - the base size, run length, and the relative amount of incoming new information. The base size is how the body of information identified is subsequently used as a denominator; the run length is a set of consecutive events, i.e. the number of interviews within which new information (theme) is searched and calculated, and new information refers to the level of new information that would indicate saturation (Guest et al., 2020). For this study, the indicator of no new insightful information was minus 0% and 0% for new information thresholds. This meant that the lower the new information threshold, the less likely an important number of themes remained undiscovered in later interviews if the data collection stopped when the threshold was reached (Guest et al., 2020). Consequently, the concepts (base size, run length and new information) allowed me to determine when the saturation point was reached in this study.

Moreover, according to Malterud (2015) the more information the sample size holds relevant for the study, the lower number of participants is needed. Information power relates to the aim of the study, the sample specificity, the use of established theory, quality dialogues, and the analysis strategy. In a similar study, Valileiou et al. (2018) concluded that samples in qualitative research tended to be small to support the depth of case-oriented analysis that is fundamental to this mode of inquiry. Additionally, qualitative samples are purposive, namely selected by virtue of their capacity to provide richly textured information relevant to the phenomenon under investigation.

Table 6: Theoretical Data/Saturation Table for this Study

Interview Number	**1**	**2**	**3**	**4**	5	6	7	8	9	10	11	12	13
New Themes	2	2	1	1	1	1	1	0	1	0	0	0	0
New Themes in Run				5		2	2	1	1	1	0	0	0
% Change Over Base						40%	40%	20%	20%	20%	0% Saturation point	0%	0%

Source of Theoretical Saturation Model Used: Guest et al. (2020).

As shown in Table 6, to test the data saturation of the interviews, I applied a base size of four interviews, a run length of two interviews, and an information threshold of 0%. Again, the baseline is the body of information identified over a certain base number of interviews (**denominator**). In this case I used my first four interviews as the base size. The run length is the subsequent number of interviews from which I looked for more themes after the base size, and the run is the **numerator.** The threshold of 0% is the level at which no new information or theme was found (saturation).

Using data in my study to test this approach, I calculated the number of themes found in the first four interviews, and the resulting number of themes was five. Therefore, five represents the denominator in the equation. Since I used a base length of two, I included data for the next two interviews after the base set i.e., interviews 5 and 6. Data in Table 6 shows that interview 5 generated one theme, and 6 also generated one theme, making it a total of two more themes. Then, I divided the number of new themes (two) by the number of themes in the base set, i.e., five themes multiplied by 100%, equal to 40%. Since 40% is more than my 0% threshold, I continued with the second test.

For the second run, I added the new themes for the next next interviews, i.e., interviews 6 and 7. Both interviews generated two themes in total. So, two themes divided by the base set themes of five, multiplied by 100%, equal to 40%. This (40%) is also more than my 0% threshold, so the test continued. For the third run, I added the new themes generated at the next two interviews i.e., 7 and 8. Interview 7 generated one theme, while interview 8 generated no themes, making it a total of one theme. I then divided one by the base set of five themes, multiplied by 100%, equal to 20%. Since 20% is more than the information saturation thresholds of 0%, the test continued.

For the fourth run, I added the new themes generated at interviews 8 and 9. Interview 8 generated no themes, and interview 9 generated one theme, making it a total of one theme, divided by the base set of five themes, multiplied by 100%, equal to 20%. Since 20% is more than the information threshold of 0%, the test run continued. For the 5th run, I added the new themes generated for interviews 9 and 10, i.e., one and zero respectively, giving a total of one theme, divided by the base set of five themes, multiplied by 100%, equal to 20%.

At the point of the 6th and final run, interviews 10 and 11 recorded zero new themes. This gave a total of zero themes, divided by the data set of five themes, multiplied by 100%, equal to 0%. This is the point of saturation when no new themes or insights in relation to my study questions and objectives were generated. This means there were no new insights generated from interviews 10 and 11, and hence 0% new information.

This also means that saturation was reached at the 10th interview when no new insight or theme was generated (0%). Each of the next three interviews, 11, 12, 13, were conducted to verify that no new themes and insights occurred.

I therefore conclude that by using a base size set of four, I reached 0% new information threshold at 10^{+3} interviews. The +3 interviews are the interviews 11, 12 and 13. I continued to interview three more participants after saturation had been reached to ensure that I was not missing any important information. This data saturation method is justified because according to Guest et al. (2020:6) "*the most prevalent high-level themes are identified very early on data collection within about six interviews*".

3.13 Potential Drawbacks of Theoretical Saturation

One could also argue that some important information may have been missed by limiting or stopping the sample at the point that saturation was indicated. This argument also points to the fact that if they continue after the saturation point, there is a likelihood that some information or themes may be generated. This argument counters the idea that most themes are generated at the first six interviews in qualitative research. As already indicated, Boddy (2016) states that a sample size of 12 in qualitative research may be cases where data saturation occurs and Guest et al. (2020:6) argued that "*the most prevalent high-level themes are identified very early on data collection within about six interviews*". This means that there is a need to rely on empirical research that "*shows that the rate at which new information emerges decreases over time and that the most common and salient themes are generated early*" (Guest et al., 2020:6).

However, it is difficult to determine whether new information and or themes would have been generated if more interviews had been conducted. Nonetheless, historical trends regarding the generation of themes and the prevalence of new information emerging earlier in qualitative interviews suffices as a guide to determine saturation. This also considers the probability or possibility that further information would be generated if interviews proceeded beyond the saturation point.

Further questions have also been asked regarding the possible effects of the order of interviews. For example, would the identification pattern of themes in a data set of 13 interviews (as in this study) appear the same if for example, interviews numbers 5 to 10 were conducted first rather than later. To check this, previous researchers have used a bootstrapping technique data set to corroborate findings and assess the distributional properties of metrics. The findings give information on how saturation may be reached at different stopping points (Guest et al, 2020).

Finally, it has been argued that the sample as in this study, may consist of people providing extensive care only and people who recognise themselves as doing so, thereby excluding potential participants with different experiences from those expressed in the study. However, a counter argument is that the inclusion and exclusion criteria for participation in most qualitative studies (including this one) are very clear and detail the criteria for inclusion or exclusion. Such inclusion criteria may have indicated that a potential participant must give a defined level of support before inclusion in the study. This means that the criteria for participation in this research is pre-determined by the research's inclusion and exclusion criteria. For example, if it stipulates that a carer must give small level of support, then those who give extensive support would be excluded, and vice versa. This means that if any category of carers are excluded from the study, they were not needed for the research in the first place because of the study's objectives or research questions.

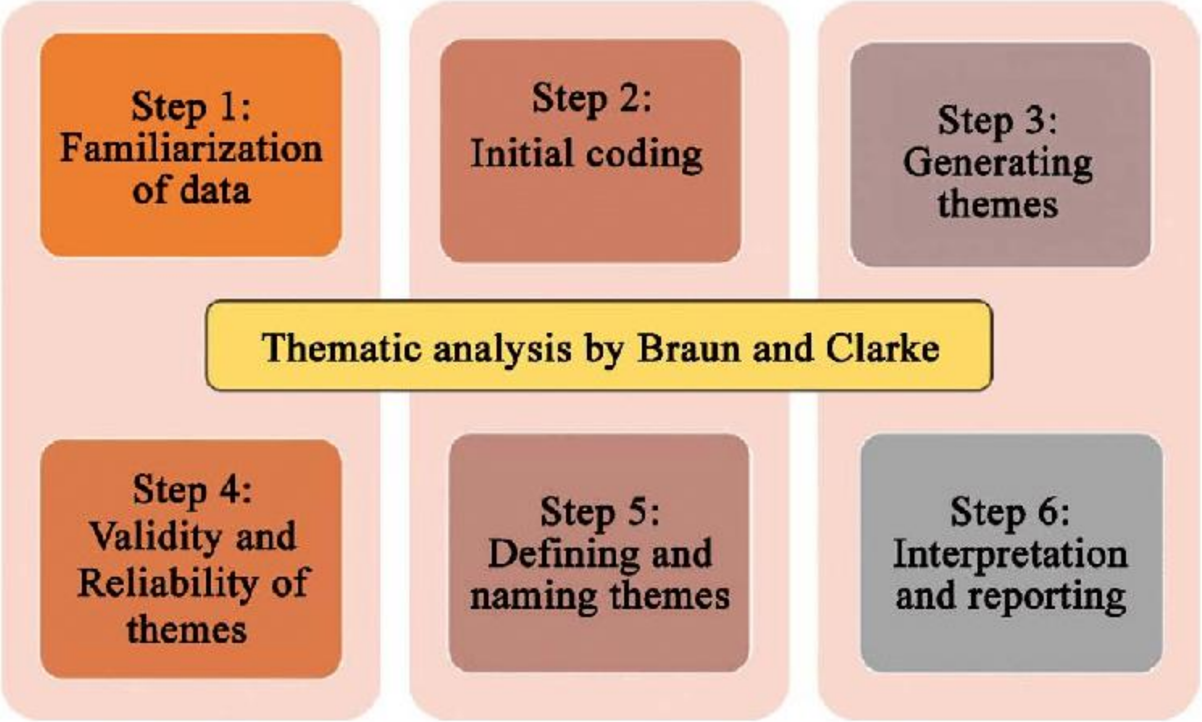
Moreover, inclusion and exclusion criteria in qualitative studies are determined by several factors and/or restrictions, including the ability to analyse extensive data over a limited period of a research, the cost of conducting and analysing extensive research data, and the practicability of conducting extensive research with less restrictive inclusion criteria. Finally, it has been argued that the determination of a saturation point is a difficult endeavour because researchers depend on what they have found, and a saturation point is determined by judgement and experience (Tran et al., 2017). However, I have been as objective as possible in assessing and determining the saturation point of this study.

3.14 Data Management Strategy and Thematic Analysis

According to Mason (2018), the important point in any data analysis is knowing the nature of the evidence to be produced. Analysis at this stage of the research process turns data into evidence or knowledge. I needed to determine my options for managing and organising my data. My task was to align my analysis to both the ontological (social world) and epistemological (knowledge) positions as embedded in my methodological approaches (Mason, 2018). I grouped my data into categories according to their similarities and differences, and practically and realistically, I needed to group the evidence into themes using codes to address my research questions.

I adopted the approach of Mason (2018) and Braun & Clarke’s (2006) thematic analysis guide and used their illustration below to illustrate my analytical approach of the data collected. To ensure the methodological processes were transparent, and my findings reliable, I adopted the steps shown in Figure 1 to code the thematic analysis. This approach also ensured that the methodological processes were rigorous.

Figure 1: Thematic Analysis Steps



Source- Braun and Clark, 2006

Step 1: Familiarisation of Data

The first step in my analysis was to transcribe the audio recorded notes and familiarise myself with my data by reading and rereading the transcripts many times. According to Mason (2018), the researcher must be familiar with the intellectual puzzle and research questions. This involves going back and forth across the theoretical framework in an interactive manner. In other words, I immersed myself in the data and became familiar with my data corpus through reading the transcripts several times. A corpus is all the data collected for a research project (Braun & Clarke, 2006). My data included audio-recorded data, jotted and/or written scripts, and emails. Audi-recorded interviews were transcribed verbatim. I had to decide as to whether to manually transcribe the audio recorded interviews or use voice recognition software to produce the transcripts. I adopted the option to manually transcribe the audio recorded interviews because manual transcription "*helps to reduce and eliminate mistakes; consider contextual variations; and achieve a high rate of accuracy*" (Wizscribe, 2020:1). Thus, the best accuracy comes with manual transcription. Although automated transcriptions would have helped me save time, "*its quality and accuracy could never exceed that of manual transcriptions*" (Wizscribe, 2020:1). I reflected as I went through the mass of data collected to ensure that nothing was left out. I went through the recordings, scripts, and emails three times to ensure that no conversation during the interviews were left out.

I completed this first procedure/step by organising, assembling, and retrieving all the data. I determined what amongst the data might provide insights and the materials I needed to put together a meaningful analysis. I, therefore, took stock of the data I generated and assessed their evidential/epistemological value (Mason, 2018). I tracked what could be considered data for my research, which involved a lot of reflection on the epistemological foundations of my study, and the implications for my research aims, objectives, research questions, and methods (Mason, 2018). Determining what counts as data enabled me to better understand the connections between my data, the world of my study, my intellectual puzzle, the methods, and the research questions. The critical question for me was to determine what could be considered data for my study, taking adequate consideration of the intellectual puzzle. Identifying and applying a thematic analysis of my data also helped to review my research focus. In other words, the identified data helped me to review my research questions and objectives. My focus was on determining what the data meant, represented, signified, and what I could infer from them, and the phenomena they pointed or lead to (Mason, 2018). I also reflected on things that were not said during the interviews, because depending on the environment of each interview, they could mean a lot for the phenomena studied. My reflective evaluation of the data involved recollections on my interactions about what was said and not said.

Step 2: Initial Coding

Secondly, I started and completed an initial manual data coding of relevant evidence that would guarantee interpretations (Mason, 2018). At this stage, I managed data interpretively and reflectively. Coding involved a consistent system of indexing which was applied across all my data sets using some key principles and indicators. I manually generated the codes instead of using software like Nvivo. According to Mason (2018:195), the software can be seductive, alluring and timesaving. However, I did not use software in order to retain my position as a researcher in charge of the data management thought process. Although software can help to catalogue, search, and retrieve data; it does not analyse or interpret the data or build argument and does not help the researcher to be creative or apply creativity in his or her study (Mason, 2018). Coding my data manually rather than through using software helped me to become familiar with the data generated.

I used highlighters to make notes on my transcript and applied as many codes as possible at this stage. A code "*is a shorthand label usually a word, short phrase, or metaphor, often derived from the participants' accounts/stories which are assigned to data fragments defined as having some common meaning or relationship*" (Carpenter & Suto, 2008:116). After coding, all the data identified by the same code were collated (How to Use Thematic Analysis: 2020).

I therefore used codes as epistemological indicators and evidence to demarcate my data into themes. According to Mason (2018:194) codes are thematic, descriptive, conceptual, axial, interpretive, analytic, hierarchical, loose, rough or open. The purpose of applying indicators or codes is to find a common method of cross indicator compartmentalisation (Mason, 2018:194/5). This means placing similar ideas into categories. The codes were applied to ensure the easy and systematic index of data and to guarantee easy access to the data for analysis. To achieve adequate coding, I considered my theoretical framework including my study aims and objectives and my overall data. I used different codes to tag different sections of my transcribed data. I did not use software for my coding but coded by hand.

Step 3: Generating Themes

Third, I searched for themes from my already identified and specified codes, and sorted the codes into themes. A theme is an idea that captures something important about the data concerning the research question that represents a pattern in response (Braun & Clarke, 2006). Themes are made up of a subset of codes (How to Use Thematic Analysis, 2020). I used tables to create the themes (see Appendix 11).

Step 4: Validity and reliability of themes

To validate and ensure the reliability of my themes, I reviewed and refined the themes from my data set. Data sets "*are subsets of the data corpus that are used for particular analysis*" (Braun & Clarke, 2006). I reread my data sets that pointed to themes to ensure that they maintained a clear pattern. To validate my data, I also reflected on my sampling and interviews to uncover any biases. Although my study focused on exploring the role of neighbours in providing support, I was re-assured that it was positive interviewing both neighbours with experience of providing support to older adults living with dementia in the community, and people living with dementia. This made my study as person centred as possible.

I also reviewed the record keeping of my data to demonstrate an accurate data trail and to check that the participants' accounts were described verbatim, whenever necessary, to support my findings. My post interview contacts, and the subsequent interview also helped to revalidate the interview conversations and gave me the confidence to conclude that the final themes and concepts reflected the phenomenon studied. This was also the stage when I employed the concept of theoretical data saturation as a conceptual yardstick to estimate and validate the sample size in this study. Applying the concept helped me to answer the question as to how many qualitative interviews were enough. Overall, these helped to validate my data. It was reassuring to note that at this stage that most of my data fitted into themes. I also used a thematic matrix to show the links and relationships between the themes (see Appendix 11).

Defining and Naming Themes

Finally, I defined and named my themes. This involved identifying the purpose of each theme and how they fitted into my study narrative and questions. The themes characterise the perceptions and experiences of research participants in relation to my research questions; they represent the outcomes in terms of how I understood the data. At this stage, I also defined what the themes were about. The themes that emerged were: Process of neighbourly support relationships, motivations, nature of support given, finance management, lack of kin care, complexity of burden, reciprocity, tensions in relationships, gender.

Stage 6: Interpretation, Reporting and Making My Arguments

The process of my study seems to follow this pattern: intellectual puzzle, data generation, coding of data, indexing, emerging themes, analysis, argument, explanations and conclusions. I adopted a person-centred approach to develop my analysis and arguments. This meant that I placed the experiences of the care giver and persons living with dementia at the centre of my analysis and considered them the experts of their experiences.

Having completed the coding and indexing of my data, the next task was to interpret my data. This involved active epistemological and interpretative thinking (Mason, 2018), and formed the analytical part of my study. I was imaginative and creative in the interpretation of my coded materials, in order to find insights. However, Mason (2018) states that any qualitative researcher who is an active epistemological thinker and conducting an investigative piece of research will be making interpretations throughout the whole data generation process. Interpretation is therefore a process that spans from the intellectual puzzle, theoretical framework, data collection, and data analysis stages. I asked vital questions about my data and then explored how they answered the research questions. I tried to understand what the different data sets meant with regards to my study, where they pointed and lead my study. I, therefore, looked for patterns and distinct stories that pointed to my research questions and tried to interpret them. I also looked for facts that pointed to alternative interpretations, and different directions from my research questions. I undertook this to discover data that could contradict my thoughts (Mason, 2018) and the line and pattern that my research was developing. However, I did not find any significant counter positions to my research puzzle. Instead, I found thoughts and evidence that reflected my thought process; I did not originally think about them but rather sought insights rather than just filling descriptions (Mason, 2018). In other words, I sought findings that were “fascinating, intriguing, and puzzling” and looked out for data sets that were striking and convincing. Evidence of these is in the next section of this chapter, interpretation, arguments and findings.

Making my Arguments

This is a qualitative study that applies employs person-centred and critical social gerontology approaches. The person-centred approach is relevant because it moves away from professionals deciding what is best for service users and places the user at the centre as an expert of their experience (SCIE, 2019). Thus, the person and their carers become equal partners in the planning of their care and support, ensuring that their needs are met. I also applied the qualitative approach because it helped me to incorporate the human experience, made it possible for me to understand attitudes, provided insights that were specific to my research topic and allowed flexibility and prediction in my analysis (Brandongaille, 2020).

Due to the above framework, I was able to make comparisons, identify certain phenomenon and develop a thread (Mason, 2018). Moreover, I constructed and presented different interpretations and perspectives of my arguments and reasoning in a related and logical manner.

I applied arguments about how the relationships between neighbours and older adults emerged from the data generated. I applied this form of argument at the start to provide a context for my argument. I also interpreted the data and showed how the different phenomenon is related. The data generated in this study are mainly about the experiences of neighbour caregivers supporting older adults living with dementia in their own homes in the community, so I adopted experiential arguments to emphasize the role of human experience and encounters in my explanatory logic (Mason, 2018).

My analysis was reflective and interpretivist. I am aware that interpretative analysis may lack objectivity and have many inputs from personal experiences and feelings. Nevertheless, it is person-centred and person-oriented and captures the opinions of individuals. I was aware that my data does not constitute an argument on its own, but merely presents a way for my argument to develop.

Reflective Practice & Other Issues

In the following section, I discuss the issues of consent and capacity, confidentiality, risk mitigation strategies, reflections on research, power imbalances between the researcher and participants, expectations and anxieties, the resolution of issues and how the Covid19 pandemic affected my study.

3.15 Consent and Capacity

Risks, benefits, and consent are important to consider in dementia research (National Health & Medical Research Council, 2015). I obtained informed consent from all participants of this study to ensure they clearly understood its aims, the risks and benefits associated with their participation and the expected results; I also ensured that they were willing to participate. The contents of the consent form and personal information sheet were approved by the ethics committee of the School of Health and Society of the university (see Appendices 2 and 3 which show the Ethics Consent).

The capacity to make decisions regarding involvement in the research is central to the involvement of participants who have dementia (Crickland et al., 2016). The ability of people with dementia to provide informed consent is also a central issue for their involvement in research, as dementia can impair an individual’s capacity to make decisions (Crickland et al., 2016). This is not to say that a diagnosis of dementia automatically means that the person cannot give consent or decide, i.e., the ability to understand, retain, weigh, and communicate information (Mental Capacity Act, 2005). I, therefore, applied a person-centred approach to drive my study, to determine whether participants could give consent to participate in the study. Although 13 participants were involved, this issue only impacted six (those living with dementia) where their capacity was potentially considered in doubt. They were therefore supported during the capacity and consent assessments by their family members and/or carers. This helped them to relax and feel comfortable with the entire process; it also ensured that all consent received, were not only informed but willingly given.

I also adhered to Dewing’s (2007) Process Consent and participatory research model. This is an ongoing consensual process that involves the researcher and participants in mutual decision making and ensures that the participant is kept informed at all stages of the research process. In essence, it is an assent procedure where the participant is allowed to consent or approve participation in the research (Dewing, 2007; Slaughter et al., 2007). Assent was received verbally or non-verbally as the research progressed.

I determined the capacity of individuals to participate in the study by establishing that the participant lives with an impairment, i.e., dementia, and then asked questions to establish whether the intended participant could understand, retain, weigh, and communicate information about participating in the research process. A “no” answer to any of the questions constituted incapacity, while a “yes” answer to the questions constituted capacity to participate in the research process.

Questions I asked in the process of reaching any conclusions included:

- Will you be able to answer questions regarding your relationships with your carer?
- Are you able to remember what your neighbour does for you?
- Do you want your carer to be available during the interview or not?

These questions were repeated to establish understanding, retention, the weighing of information, and the communication of answers. As indicated above, vulnerable participants were supported to go through this process by their carers and/or family members, especially their daughters.

I created a consent form and had discussions about the aims of the research and participant commitment throughout the research to ensure that consent/assent was ongoing (Agnoin, 2014). The consent form enabled each participant to confirm that they had read and understood the information sheet, confirm that they knew their participation was voluntary, that they could withdraw from the research at any point in time, agree that the interview could be audiotaped, agree to respect their right to confidentiality and that data would be anonymised and used in reports, publications, and presentations.

3.16 Confidentiality

I outlined confidentiality procedures which indicated that all information given during the interview would only be used for the study. A problem was envisaged concerning people who wished to keep their problems to themselves and found it difficult to share their experiences; this could be particularly pertinent for those at the early stage of dementia who had not come to terms with their diagnosis and/or condition. The carers who supported them also may not have the permission of the person living with dementia to tell their stories as it related to the care and support relationship. Nonetheless, the interviews were completed in a manner that guaranteed participant confidentiality. For example, although the interviews were conducted via telephone, I made sure that I was alone so that nobody overheard my side of the interview conversation.

I extensively discussed issues of participant confidentiality with the participants. It was helpful to conduct joint interviews with the older adults living with dementia and their carers because the carers were able to provide prompts for the persons living with dementia with dementia, and clarified things as the interviews progressed (Pratt, 2002).

Participants were also advised that data would be kept for five years after the end of the award and that all paperwork would be carried inside a locked bag, and all digital materials would be saved in an encrypted USB flash drive during transport from one place to the other, which entailed the use of car or train. They were also advised that data on the encrypted USBs would also be used to transfer data over secure computer units whenever necessary.

3.17 Challenges and Risk Mitigation Strategy

I envisaged difficulties identifying neighbours who give care and support to older adults living with dementia because my experience as a front-line social worker indicates that they do not identify as carers. However, I identified this set of informal carers through carer groups and through the use of Join Dementia Research (National Institute of Health Research). My research topic was uploaded onto their website under two arms - the dementia arm and the care arm - which attracted the attention of potential volunteer participants and recruited seven participants via their website. However, I also envisaged that some carers c be protective and decided that the research could be confrontational and/or uncomfortable for the adult living with dementia. However, I assured all potential participants that the interview would be conducted sensitively and would bear in mind their dementia conditions. However, the eligible volunteers did not express these concerns during the interview process.

As I interviewed most participants over the phone due to COVID19 restrictions, this necessitated a change in the original plan to interview all participants face to face. There were no risks in interviewing over the phone because seven of the participants were neighbour support givers whose capacity to give consent to participate in the research were not in doubt. Moreover, all older participants interviewed were supported during the interview by either their daughters/carers or their neighbour carers. This helped to mitigate any risk of confusion and or agitation during the interview.

3.18 Reflections

My role in this project is as a researcher, but professionally I am also a qualified social worker. Although the participants in this research were not my practising social work clients, my role as a social researcher triggered ethical issues and dilemmas, especially concerning the acceptable boundaries and role crossing inherent in the different statuses involved. Reflective practice is associated with the act of purposefully revisiting issues, events, and activities with the need to learn from a situation (Lynette & Allie, 2016). It was, therefore, necessary to reflect on the processes to ensure that the methodological and ethical standards approved by the ethics committee were being followed. The reflections also helped to ensure that the study focused on meeting its aim and answering questions, and that there was no deviation from the expected standards.

As a professional social worker, I am expected to be caring, fair, empathetic, supportive, anti-discriminatory and anti-oppressive. My work in this role involves acting as an advocate, change agent, referrer, assessor, helper, and empowerment agent. As a social researcher, I am expected to be critical, factual, and objective. The dilemma here, therefore, is to discern the boundary where both roles meet, conflict, and/or reconcile. The goal of social work is mainly to change people’s wellbeing for the better, while scientific research attempts to describe, explain, and understand the phenomenon as it focuses on the development of knowledge in social work practice

(Landau, 2018). Thus, there are clear tensions between the two roles due to the lack of clear boundaries.

However, this dilemma can differ depending on the research framework. The framework of this research was me as a social worker researching experiences of non-clients in a non-therapeutic setting. This meant that my research subjects were not my social work clients, and I was not providing them with services. This was the context within which my study was conducted.

The dilemmas that arose during the research related to issues of consent, expectations, participant anxieties, privacy, disclosure, data protection, and ethical constraints. A reflection on my relationship with the care participants during the research was therefore necessary to consider the ethical issues that arose. I have reflected on my role as a researcher, and my profession as a social worker, and the issues of boundary-crossing during the research. Social work has been described as a value-based profession that promotes social change, human rights, and wellbeing (Landau, 2018). According to the British Association of Social Workers [BASW] (2021), social work is a practice-based profession that promotes social change and development, social cohesion, and the empowerment and liberation of people. It also upholds the principles of social justice and human rights, while respect for diversities is central to social work. The values of social work include service to the people and community, social justice, the dignity of the people, integrity and competence. These are the values on which the ethical principles and ideals are based and to which a social worker should aspire (National Association of Social Workers, 2021).

I adopted the principles of justice and respect for autonomy, as described by the Belmont Report (1976). This helped to ensure that the welfare of the research participants was a priority and that the participants were not harmed in any way throughout the research process. Moreover, it also ensured that the research was conducted in a manner that benefitted all. I also checked that all participation in the research was based on informed consent about the nature, aims, and expected outcomes of the study (Belmont Report, 1976).

These principles also relate to the professional standards of the social work profession in England and Wales. This means that social work values do not diverge from the ethics of research with vulnerable human participants. However, there remain several tensions, including the fact that a social worker is constantly required to make judgements in the context of varying values, interests, and loyalties (Landau, 2018), and in ambiguous and uncertain circumstances.

Issues associated with dual relationships did not arise in the course of my work with research participants, as none of the 13 participants interviewed was (or is) a friend, employer, teacher or has any other relationship with me other than as a researcher/research participant. Dual roles raise boundary issues stemming from the conflicts of interest that inevitably arise. The only relationship between me and the participants was the research role relationship. To avoid the development of dual relationships, I ensured that throughout the research relationship the relationship was not exploitative, manipulative, deceptive or coercive. This reflected my requirements of my professional practice whereby, according to Landau, (2018), the duality of the role of social worker researcher is a major source of ethical dilemmas in social research work.

To avoid dilemmas that emanate from clarity on my role, a personal information sheet was given detailing the purpose of the research, and the limits of my role as the researcher. If the relationship had been with my clients as a social worker, it would have created confusion amonst the clients about the nature of the interaction, such as whether it was a therapeutic, service-based or research-oriented activity. It could also have raised questions about who benefitted more from the study - the client or me as the researcher.

Six of my research participants were clients of other professionals including social workers. This relationship raised boundary issues; for example, how would I respond if I discovered issues bordering on carelessness, incompetence, a lack of compliance with the law, or if any of the participants complained about their social workers (or any other professionals) to me. I would be in a difficult position in balancing loyalty to my professional colleagues and ensuring the welfare of the participants. However, there no such concerns were raised during the research relationships with participants.

Some of my participants were also receiving support from social services. This raised issues about the extent to which their consent was voluntary. A question emerged as to whether they were thinking that they would undermine the services they received if they refused to participate. However, these participants were not my direct clients and the conditions for participation were adequately explained in the personal information sheets given to them before they participated in the study.

Six of my research participants have dementia, and their limited memory raised concerns about their ability to give consent. In all cases in this study, the daughters of the clients represented and supported the participants to negotiate consent for the study. It was not planned that the daughters of clients would step in to negotiate consent; however, it happened to be that all intermediaries for consent were daughters of the clients. Representatives of community organisations also helped to negotiate and explain the research to the clients. Representatives of the organisations and the daughters of the clients were all physically present during the interview. The arrangements described above ensured that vulnerable clients were protected throughout the recruitment process and during the interviews.

3.19 Power Imbalance

There were also issues of the power imbalance between me (a social work professional and researcher) and some of the participants (vulnerable older people living with dementia in the community). The imbalance stemmed from my knowledge, skills, and the position I held as both a researcher and practising social worker. Although D'Cruz, (2000) however argued that such a power relationship is always fluid, dynamic and changing, this does not diminish the fact that as the researcher and professional social worker, I have the authority, status, knowledge, and specialist skills that some of my study participants do not (Landau, 2018). I was therefore aware of the power differential between me and the participants and reminded them about their rights including the right to withdraw from the research at any point. Details of their rights and the research process were contained in the personal information sheet, given to all research participants. However, participants were not just passive during my interactions with them or just accepted my professional knowledge. Some of the participants asked questions about the purpose of the study and why I was undertaking the research. One of the neighbour participants (a former headteacher), showed a lot of confidence while answering the questions, and even signposted me to an ongoing

COVID19 related project called Super Neighbours, where neighbours were recruited to support older adults in the community (with their consent) by shopping and delivering medications to them, and by chatting with them.

Three of my study participants were recruited via a local group that works with them. This posed a power issue as to whether the participants agreed to participate because the local group asked them on my behalf and/or because of their dependency on the services of the group. According to Landau (2018:574) the feeling that they must comply "*whether they want, may arise*". However, 60% of my participants were already volunteers for dementia research on the JDR (Join Dementia Research) website, and some signposting to me was undertaken by local groups and friends. None of the neighbour participants had memory issues or were vulnerable. Moreover, all of them had the capacity and willingly decided to participate in the study so there were no issues of compulsion to participate. I reminded the participants about their right to leave the study at any point. Information and details about this were contained in the personal information street.

Reminding the participants about their rights to withdraw from the study ensured that they were still giving their consent to participate as the research progressed. Consent is not given once only, and this assumption can be misleading and insufficient (Hem et al., 2007). It has also been argued that the idea of consent to participate in research may prompt panic amongst vulnerable potential research participants, but may also cause them stress (Yassour-Borochowitz, 2014). However, there was no such issue with panic or stress amongst my participants regarding consent. This may be because they were adequately supported by their family members to complete the tasks and because the conditions for participation were properly explained to them before being asked to consent.

3.20 Expectations and Anxieties

I also considered whether my research participants saw me as a researcher or as a social worker with the dual functions of care and control. It would have been a difficult and awkward position to be in if any of the research participants had asked for assistance or treated me with suspicion because they felt that I was indirectly looking into their care packages. There seems to be a sense of wariness by persons living with dementia because they believe that practitioners are out to cut their packages because of government austerity. Moreover, according to Landau (2018), the typical view of social workers as members of a profession whose main function is to assist distressed people may lead to unrealistic expectations of the researcher.

Nonetheless, this was not a social worker/client study, so there was a limited possibility that participants would expect me to proactively review their care package or help to solve problems unrelated to the study. These did not occur in my research because of my proactive explanation of the purpose and aim of the study. Moreover, some participants were selected from JDR (Join Dementia Research), so they were already aware that it was a study and had nothing to do with service provision.

Some participants wanted to be informed of the findings of the study. This is a relatively common expectation and there was already a plan to send a copy of the research outcomes to all participants at the end of the study. One neighbour participant I interviewed asked me how she could become a social worker, and I referred her to university websites where she could find admission notices on social work. I have not had any contact from any of the participants since my interview with them.

As a practising social worker, I was also conscious of the fact that by the very nature of my training, I am attuned to being empathetic to vulnerable people regardless of the setting. However, most of my interviews with vulnerable participants were conducted by telephone because of the COVID19 pandemic. In other words, the boundary of my roles as a social worker and researcher was likely to have been tested if the interviews were conducted face to face. I may have been faced with the dilemma of offering participants information to improve their welfare. I am aware that when the situation involves a threat to life, I have the responsibility or duty to intervene. However, all interviews for my study were one-off meetings and this limited the probability of encountering such dilemmas. It has also been suggested that a pro-active offering of help could be unwelcome because it could cause stress to the participant. (Landau, 2018); thus, social workers’ unanticipated and unwanted interventions could be distressful to the participant. However, it has also been suggested that not disclosing information may account for a failure in professional responsibility.

3.21 Terms Used to Describe Participants

This study explores the role of neighbours in providing support to older people live with dementia in their own homes. I am therefore conscious of the use of words or phrases that could stigmatise, label, or patronise participants especially in relation to the word ‘dementia’. According to Alzheimer’s Society (2018:1)

> “*using the wrong words, painting an inaccurate picture or leaning into stereotypes, when reporting can impact how people with dementia feel about themselves. It can also influence how other people think about dementia. Using the right words in the media, however, can have a positive impact on how people living with the condition feel and how society thinks about dementia*”.

I have carefully evaluated some of the words and phrases used to identify participants who live with dementia. I have considered words and phrases like dementia, care recipient, dementia sufferers, persons living with dementia, people living with dementia, and adults living with dementia, to describe older people living with dementia in this study. As the Alzheimer’s Society (2018:1) recommends the use of the phrase “*persons living with dementia*” or “*people living with dementia*” to describe people living with dementia, I have adopted these phrases in this study. I believe the phrases are non-stigmatising, non-labelling and non-stereotyping. I also believe that phrases like “person living with dementia” aligns with the person-centred approach of this study.

3.22 Resolution of Issues

Finally, I was conscious of the fact that I was responsible for resolving any ethical dilemmas arising from dual roles; hence, I was also conscious of the standards imposed on me as a social worker registered with Social Work England, the regulating body for social workers in England and Wales. I ensure that informed consent was sought and that there were provisions to deal with privacy and confidentiality issues. These were embedded in the personal information sheet given to participants.

I also applied my ethical thinking and judgement, making decisions as the study progressed. According to Haverkamp (2005), what makes research ethical is not its design or procedures but the researcher’s individual decisions, actions, and commitments and delivery. These attributes are additional to any research or ethical guidelines and are important in the face of ambiguities and difficulty in the application of the principles (Landau, 2018). Therefore, I combined the values of social work and research ethics in the way I approached my participants and in the conduct of the fieldwork.

I took personal responsibility for the ethical conduct of my research and made sure that those sharing their experiences were protected. I was also conscious that old wounds could be reopened by the interview conversation, hence I was restrained and maintained a lot of caution throughout the relationship. I also had a referral clause in the personal information document to appropriately refer to relevant agencies for attention if necessary. However, I did not have the need to make such a referral throughout the interview relationship, and all my vulnerable participants were adequately supported by their carers during the interview sessions.

I intended my approach to be proactive and open throughout the process of contract, consent, interview, and post-interview contacts. I verbally clarified and explained in the "personal information sheet" the nature and anticipated length of the research relationship, and the expectations of the researcher and participants. Moreover, I was aware that the relationship was based on trust, and therefore provided information warning prospective participants that I was under obligation to report any disclosed information that pointed to criminality. There was no confusion as to the boundary of the research as I made my role as a researcher clear and explained the limitations to this role at the beginning of the study and/or during contact with the participants. I drew on my emotional coping skills as a social worker to address the emotional issues that arose during the study and in particular throughout the data collection stage. Finally, I considered how to approach participants some of whom lived with dementia. I also reflected on my race as the researcher, and found ways to resolve any challenges that arose.

3.23 Ethics Approval and COVID-19

My data collection was taking place at the same time as the emergence of the COVID-19 pandemic and subsequent lockdown. This limited the possibilities and options available to me on how to meet my potential participants and or hold in-depth interviews with them. Most significantly, Join Dementia Research (JDR-NIHR) made it a condition that my ethics approval had to be amended before my study was uploaded to their website. However, I received ethical approval for my study before COVID19 which subsequently changed the plans. The lockdown conditions meant there was only a slim possibility that I could meet participants face to face for interviews and distribute research flyers. Consequently, I reapplied to the ethics committee to amend my approval to allow me to conduct interviews with my study participants over the phone. The committee approved my application and amended my ethics approval. This enabled me to conduct interviews with my study participants over the phone. The COVID19 pandemic and subsequent lockdown did not have an impact on the data I collected and the choice of participants. However, it affected the mode in which I conducted the interviews, which meant I held phone conversations, rather than face to face interviews.

3.24 Chapter Summary

In summary, in this chapter I have presented the approach to my study and the research method and methodology. I have also shown how I carried out the research, including my sampling, sampling procedures and recruitment of the study participants. I have also presented a description of the study area and the demographic characteristics of the research participants, which has described their backgrounds. Furthermore, I have shown how I managed and analysed my data and the themes that emerged thereof. I have also presented other important issues about the research including those concerning reflection in research, challenges, the resolution of issues, and ethical issues. This discussion has outlined the pathway of my study and answered the why and how questions in relation to my research method and methodology. I therefore present the findings of my study in the next chapter under ten different subheadings.

4 Research Findings

In this chapter, I present the findings of this study. The subheadings are organised according to both the research questions and the themes that emerged after the data analysis, and the research questions are included in brackets. I present the demography of the research participants and provide a detailed context and background of the types of socio-structural backgrounds and environments of my research participants. This has helped to understand the social status and relationship contexts of the research participants.

Furthermore, I describe the nature of the relationships between the neighbour care givers and persons living with dementia who participated in the study, and then analyse my findings with specific reference to the processes of neighbourly support relationships. This considers how participants use the social capital available to them to forge and maintain care giving relationships. Next, I present and analyse my findings with regard to the motivations of neighbour care givers, and then present my findings and analysis regarding the nature of care given to persons living with dementia. Later, I analyse my findings regarding the nature of the relationships between the care givers and persons living with dementia, with specific reference to the management of finance for the persons living with dementia.

Next, I analysed my findings regarding the lone living of persons living with dementia. This became necessary because all six persons living with dementia who participated in this study lived alone. I also presented my findings regarding the complexity of care giving to persons living with dementia and considered the nature of reciprocity in care giving relationships. Moreover, I considered findings on the nature of tensions that arise in care giving relationships, and finally analysed my findings with regards to the gender of neighbour care givers and its relevance to my study.

In line with the person-centred approach of this study and the need for inclusiveness, the neighbour participants living with dementia are referred to as persons living with dementia while neighbour participants are referred as a “neighbour”. Persons or older people living with dementia are the terms also generally used to describe neighbours diagnosed with dementia in this study. In addition, details on the socio structural backgrounds of participants are given in Tables 7 and 8 (demography of the research participants).

4.1 Relationship between Neighbour Carers and Persons Living with Dementia: How do neighbour relationships develop in the context of the need to provide informal support and care?

I interviewed six older adults living with dementia in the community who have experience of neighbour support and seven neighbours with experience of supporting older adults who live with dementia in the community. I interviewed neighbours with experience of supporting an older adult who lives with dementia in the community or an older adult who has experience of being supported by a neighbour carer. Table 7 details the neighbours who provided care and Table 8 details the older people living with dementia who received care.

Table 7: Characteristics of the Neighbours Interviewed

S/N	**Date of Interview**	**Age/ Initials of Participant who provided care**	**Age/Initials of Person Supported** (some ages estimated)	**Race/ Gender of Participant**	**Race/ Gender of Person Giving Support**	**Area of Residence**	**Length of time known each other**	**Remarks**
1	24/06/2020	45 L	90 J	Black/ Female	White/ Female	Essex	12 yrs	
2	26/06/2020	82 ED **(JDR)**	89 C	White/ Female	White/ Female	Kent	30 yrs	
3	07/07/2020	58 B	89 J	Black/ Female	Black/ Man	London	28 yrs	
4	15/7/2020	70 J (Memory Cafe) **(JDR**)	68 & 85 S & V	White/ Female	White/ Male	Kent	5 yrs	
5	10/3/2021	78 SB	97 MN	White Female	White Female	London	50 yrs	Neighbour has LPA (Finance, property and welfare)
6	15/7/2020	(66) CM	(85) J	White/ Female	White/Male	Kent	5 yrs	

		(**JDR)**						
7	19/8/2020	78 T	75 J	White/ Male	White/Male	Essex	7 yrs	This is the neighbour that supports JJ, below.
Ave Age		68.1	75					

Table 8: Characteristics of the Persons Living with Dementia Interviewed

S/N	**Date of Interview**	**Age Group/ Initial of Participant Who Received Care**	**Age Group/ Initial of person Supporting.** (Some ages estimated)	**Race/Gender of Participant**	**Race/Gender of Person Supporting**	**Area of Residence**
1	24/06/2020	90 J (Person living with dementia)	40-45 L	White/Female	Black/Female	Essex
2	30/7/2020	92 AH (Person living with dementia).	45 Three Neighbours supporting her.	White Female	All 3 are White	London
3	1/8/2020	73 J (Person living with dementia)	78 T	White/Male	White/Male	Essex
4	1/8/2020	85 WB (Person living with dementia)	65 &75 Couple Neighbours	White/Male	White/Male and Female	Essex
5	1/8/2020	65-70 JW (Person living with dementia)	55 & 65 LD (Couple Neighbours	White Male	White Couple/Male and Female	Essex
6	19/10/2020	87 HB (Person living with dementia)	70-72 Two Neighbours	White female	Two white women	Essex
Average Age		82	58.8			

Of the seven neighbour carers interviewed, six were female and one was male. Of the six older persons living with dementia interviewed, three were female and three were male. Moreover, five of the older persons living with dementia were supported by female neighbour carers. One was supported by a male neighbour carer. Overall, this meant that nine females (neighbours and persons living with dementia) and four males (neighbours and persons living with dementia) were interviewed for the study.

As indicated, I interviewed care dyads (the care giver and person living with dementia) in only two instances (Neighbour L and Person living with dementia J, and Neighbour T and Person living with dementia J). Tables 7 and 8 give further details. Of the remaining 11 interviews, I interviewed persons living with dementia who have experience of neighbour support and neighbours who have experience of supporting persons living with dementia in the community.

The average number of years that seven of the neighbour participants in this study have known their neighbour - persons living with dementia - is 19.5 years, (Neighbour L 12 years; Neighbour ED 30 years; Neighbour B 28 years; Neighbour J 5 years; Neighbour CM 5 years; Neighbour T 7 years; and Neighbour SB 50 years). This points to the fact that non-kin neighbour support may be rooted in a long-term association or relationship. This is new and original knowledge in a dementia neighbour care giving context.

It is, however, important to acknowledge that care relationships could develop even in short term pre-care relationships. The relationships start before the caregiving relationships commence. This means that the relationships predate any reason for caregiving relationship, and this helps to build confidence and trust in the relationship. Lang and Fowers (2018:4) argued "*it seems more plausible that long term caregiving is often motivated more by commitment, shared history and attachment than by benefits to the caregiver*".

Two care dyads were interviewed in this study; Neighbour L and Person living with dementia J, and Neighbour T and Person living with dementia J. Neighbour L is from a black minority ethnic group and describes a highly bonded relationship with the older adult living with dementia whom she supports and treats like a mother. Neighbour L is 45, and her neighbour living with dementia whom she supports is 90. Neighbour L also described a relationship that includes not just her, the care giver, but also her entire family as her children also visit and relate well with their neighbour living with dementia.

A person living with dementia J spoke of a good neighbour who supports and cares for her. Neighbour L has so bonded with her neighbour living with dementia, she (care giver) said the person living with dementia trusts her above formal carers and professionals. Neighbour L had known J for 12 years.

Neighbour T had known the adult he supports, J, for 7 years, and they were friends before J had needed support. Both indicated they were family friends and remain so, though their wives have passed on. Neighbour T is aged 78 and J is 73. Neighbour ED (aged 82) was recruited through Join Dementia Research and has known the neighbour living with dementia (aged 89) whom she has supported for 30 years. They were family friends before the need for support. Just like Neighbour T's relationship with J, their families knew each other and went on holidays together. Both have now lost their husbands and live alone. However Neighbour ED continues to relate and monitor her neighbour, who now has dementia, and visits daily to offer support and talk to her.

Neighbour B (aged 58) is supporting her neighbour (aged 89), who now lives with dementia. They have known each other for 28 years. This means that they knew each other as neighbours even before there was a need to provide care. According to Neighbour B, their relationship is cordial, and he depends on her for, among other things, to cook Afro Caribbean foods for him. Neighbour J (aged 70) volunteers at the local memory clinic, and this was where she met the neighbours she supports. After the first meeting at the memory clinic, they discovered they were neighbours and live very close to each other. Neighbour J said that she now extends her support to them beyond the activities at the memory clinic.

Neighbour SB (aged 78) has known the neighbour she supports for 50 years. Neighbour SB said that she and her children have bonded with their neighbour (aged 97) and have continued to support her to meet her needs. Neighbour SB and her children have lasting power of attorney for their neighbour and manage her finance. Their neighbour had no children and was never married. Neighbour CM (aged 66) works and supports her older adult neighbour living with dementia. She has known her neighbour for five years, and they have a very close neighbourly relationship. She also acts as a link between her neighbour and his daughter.

Person living with dementia, AH (aged 92) has a care relationship with three of her neighbours. She said that some of the neighbours are much younger than her (40-45); moreover, one is a 70-year-old man who lives above her flat, and the other two are women – a single mother and a professional carer. However, the professional carer does not support her in her capacity as a professional. According to AH, their overall relationship is good, save for minor disagreements about the extent of support given by the male neighbour.

WB, aged 85 is a person living with dementia, and is supported by a married couple who are neighbours. He did not know them until he became diagnosed with dementia. They relate and bond very well to the extent that they manage his finance. JW, aged 70 is also a person living with dementia and is supported by a couple, whom he said have key to his flat, and help him with all aspects of life. They have known each other for more than ten years, before JW had need for support. HB, aged 87 is a person living with dementia and is supported by her neighbour, who they have known for several years, before she needed support. Both the care giver and person living with dementia classify themselves as white. HB is strictly independent, and she determines when and how her neighbours relate with her.

Overall, I found that the neighbour relationships were largely positive because they are characterised by friendship, flexibility, availability, spontaneity, and humanity. For example, Neighbour L mentioned that although her neighbour living with dementia has nephews she only wants her support and has always contacted her:. Neighbour L explains, *“she lives alone, and we have developed very close relationship with her; she calls me whenever she is in need. I take her to hospital with my husband driving, and my children visit her sometimes to chat with her”.*

These qualities of friendship, flexibility, spontaneity, and humanity make caring possible, and sometimes guarantee availability with no-strings-attached support from neighbour carers. According to AH (person living with dementia) and referring to the three carers that support her “*they are always there for me including the one with a child. She is always around and comes around to check if I need anything”.* Neighbour J said that “*she needs to do more”* in her neighbour caregiving role, and Neighbour L said “*I took her to health clinic when she fell and was bleeding. My husband drove”.*

All these point to sense of humanity, availability and spontaneity in the care giving relationships.

These qualities and attributes develop over time and with emotional attachments and bonds. The route to non-kin informal caregiving is traceable to attachment and bond-building as caregiving is triggered by care and support needs that arise from the impairment caused by dementia. The relationships are unregulated but based on terms of friendship and neighbourliness. In this study, neighbour carers and persons living with dementia have known each other for an average of 19.5 years, including the time they knew each other before the need to give support. So, there has been a period of bonding and attachment before a need arose to provide care. I have analysed this more in the next section.

4.2 The Process of Neighbourly Support and Social Capital: How do neighbour care giving relationships develop in the context of the need to provide informal support?

I found that neighbour non-kin care relationships developed in four different ways in the context of the need to provide care. The ways in which they developed are:

a) I found that neighbour care giving relationship developed while some neighbour carers and their neighbours living with dementia had fictive kin type relationship before the person living with dementia had been diagnosed. A fictive kinship relationship is a form of social tie that is not based on blood relations, although the relationship appears like one based on blood relations. According to Barker (2002:165) “*the relationship had a family-like quality*”.

b) Secondly, I found that some support relationships developed with the occurrence of a significant or unusual behaviour or activity by either the carer or the person living with dementia.

c) Thirdly, I found that a care giving relationship developed when a neighbour and sometimes his/her entire family sought to proactively support their neighbour living with dementia.

d) Finally, I found that some neighbour care relationships developed when a neighbour carer met a neighbour living with dementia in a formal group setting, like the memory clinic, and their neighbourly relationship commenced after and beyond the formal event or activity.

These four classifications of the development of neighbour dementia care giving are new knowledge and original to this study. The contacts and sources of support also indicate that persons living with dementia source support from their social capital and/or networks in their neighbourhood.

As an example of classification (a), ED had known the neighbour that she supports for a total of 30 years, which include the years before she needed care. The same applies to B, who had known her neighbour for 28 years; and SB said that she had known her neighbour for 50 years. Examples of classification (b) include relationships that started with significant and/or unusual behaviour or activity by the person living with dementia. This applies to HB, a person living with dementia, who was found by her neighbours in front of her door, confused, and looking at her broken milk bottles. The classification (c) is when a neighbour - and sometimes the entire family - proactively wanted to support their neighbour living with dementia whom they believe needs support. This applies to Neighbours L and CM. This category of neighbour is motivated by a genuine concern and compassion for those living with dementia and in need of support, and proactively ask and or make efforts to negotiate support. Finally, for classification (d), the neighbour living with dementia and the neighbour carer met in a formal setting or group and their neighbourly relationship commenced after and beyond the formal event. This applies to neighbour J, who met the two neighbours she supports in the Memory Clinic. These are the four processes or paths identified in this research that led to neighbour caregiving relationships.

One of the processes described above - (a) - shows that neighbourly caregiving relationships developed after periods of attachment and bond-building. According to Crisp and Robinson (2010:42), "*attachments are relationships underpinned by an explicit belief in the importance of neighbouring that manifests in a commitment to support others in times of need or through sociability beyond the exchange of pleasantries*". Sometimes the attachments manifest as bonds between the neighbours as they become friends before the need for care arises. The processes described also show that some neighbour carers met their neighbour living with dementia because they were involved in social networks/groups within the neighbourhood.

Neighbour ED had been family friends for about 30 years with the neighbour who lives with dementia whom she now supports. Neighbour L approached her neighbour living with dementia because "*we found that she is an older person when we moved in here",* and Neighbour J said that she met the two neighbours that she supports who live with dementia in a memory cafe: "*I met them at the Memory Café, and we knew that we were neighbours. I could not leave them even after the Memory café activities."* Furthermore, neighbour L also said: "*When we moved in here, we noticed that she is an older person", while* neighbour ED stated, "*my family and her family have been friends for a long time, as we have lived as close to each other for 30 years, and we went on holidays together".* Finally, neighbour SB, said that she had known the person living with dementia who she cares for, for 50 years adding that *"she never married and does not have any children".*

The different forms of initial contact described by participants point to contacts within the group in the neighbourhood, and the subtle building of attachments due to neighbours' expectations of offering support to an older person. This enabled the building of bonds between families before the need to care for the neighbour arose. While neighbour J accounted for how she met the neighbours she is supporting in a group setting, neighbour L considered it an obligation to support a neighbour who was living alone, and an older person.

The daughter of AH (person living with dementia) also described how her mother started being supported by her neighbours before her diagnosis: "*before that time, my mother's* relationship *with her neighbours was limited to brief chats over the fence or when they occasionally passed in the street. It was not a close relationship but was a trusted relationship".*

This means that although they had short discussions over the fence and every party maintained its boundary and independence, there was nevertheless contact. "*Though not a close relationship, it was a trusted relationship*". According to AH, it also means that convivial but trusted relationships eventually developed into caring relationships beyond the mere exchange of pleasantries because her mother's neighbours now support her to meet her daily needs. The issue of neighbourly trust was also demonstrated when J (person living with dementia) had a home visit by her GP following a fall and was not happy that the GP came with the wrong equipment. She told her neighbour carer who was present during the home visit "*Well you have done everything for me before he (GP) arrived".* This points to the level of trust she had in her neighbour carer to successfully deal with even her medical needs.

In essence, there is no specific pattern in which support commenced in such relationships. While there were instances of a process of transition from a general neighbour relationship to caregiving relationship, the direct motivation to support an older neighbour typically constituted the reason why the first contact was made in some instances. For example, neighbour T said "*J has been my friend since he became my neighbour here; we chat and joke and even my wife was friendly to his wife, but now I do bits and pieces for him".* Neighbour ED said, "*my family and her family have known each other for 30 years and her husband and mine used to go to the pub together, and we used to play in their big garden".*

The initial contact could be considered transactional before the non-transactional relationships developed from the need to provide dementia care. Transactional relationships are built on the expectation of reciprocation and parties are concerned about how they will benefit from the relationship (Cook, 2021). The focus of this study is not transactional relationships, but rather care giving relationships due to neighbourliness which was linked to need for care by one of the neighbours. However, some of the care giving relationships are off shoots from transactional relationships, i.e. relationships that existed between neighbours before the care giving relationships started because one of the neighbours developed dementia and needs care and support. While the initial contact in the care relationships commenced in varied ways, such relationships among the care dyads grew from "small beginnings". This included asking for help, maintaining the garden, and asking for support bringing medication from the pharmacy (Pleschberger & Wosko, 2017). For example, neighbour J said that small beginnings were evident in the development of her care relationship: "*I discovered that we have the same pharmacy, so we agreed that I should bring his medications whenever I go with my husband for our medications. My husband drives me to the pharmacy"*

According to AH (person living with dementia), "*my neighbour living at No 1, alerted my daughter when she saw that I could not handle my milk bottle and it fell and broke on my door area".* It appears that these small beginnings helped to test relationships, and build confidence and trust in the caregiving relationship. The daughter of HB (person living with dementia) described the small beginnings of caregiving from her mother's neighbours as follows:

> "*The next-door neighbours supported my mother when she was caring for my father, but only when she asked for help from them. This support relationship continued when she lived alone but was primarily a matter of keeping an eye on her and for example letting me know if they had not seen her for several days … the neighbours were about 20 years younger than my parents. They were both retired. They had offered unspecified support to my mother when they realised that my father was unwell".*

The nature of the help described above shows that the small beginnings of support from HB's (person living with dementia) neighbours started in two ways; monitoring and contacting the kin carer. There is no indication of any physical support. The neighbours only observed and ensured that nothing unusual was happening, and (if at all) reported to her physically absent daughter. They also offered "*unspecified support*" meaning they generally asked, "*how they could help*?"

The small beginnings also indicate how the attachment and bond-building developed and/or manifested and are expressed in form of shared values and eagerness for positive relationships or neighbourliness. HB (Person living with dementia) responded to the small offers made to her by her neighbours and started to proactively ask for support from her neighbours. According to her daughter who supported her for the interview:

> *"My mother became accustomed to asking them for help on relatively rare occasions when she could not manage something on her own and could not wait for me or my sons to get home from work. However, she was fiercely independent and did not like seeking help".*

This means that although HB was fiercely independent and valued her privacy she balanced it by proactively approaching her neighbours for support (Crisp and Robinson, 2010:45). Thus, although Mrs HB relied on neighbours to meet some of her needs as someone living with dementia in the community, she did so with a strong sense of independence as she tried to distance herself as much as possible from the same neighbours that supported her. Although she reluctantly started to contact her neighbours for help, overall she remained independent. This also means that the sense of independence of the persons living with dementia can constitute a form of barrier to the development of neighbour caregiving relationships.

Neighbour caregivers who have been friends with the family of the persons living with dementia tend to be closer in age with the persons living with dementia, than the carers whose relationships to the individual do not have any prior history of friendship and only emerge because of their informal caring role. I also found instances where entire family members - including their children - wer friends with athe person living with dementia, the neighbour, or neighbours, that they eventually started caring for.

For example, neighbour ED and J (aged 90) had been family friends before ED took on a care support role as J developed dementia, Moreover, neighbour J is 70 and supports a neighbour aged 68, while neighbour T is 78 and supports a neighbour living with dementia, aged 75. In all situations, the participants knew each other in different capacities before their relationships developed to include care. While neighbour ED and members of her family were "*across the street friends*" for 30 years with the family of the neighbour she currently supports, neighbour T's family was also friends with the family of his neighbour (person living with dementia) whom he currently supports.

This means that both the bonds that have developed over time and their close age create a friendly, nostalgic, and emotive caregiving relationship. For example, according to neighbour ED, *"I have lived here for 30 years, and she has become a good neighbour. She is like an auntie for my children. She has a big lawn, big garden, and we knew her husband. When her husband passed away, she normally came with us on a summer holiday".* Neighbour T also said *"I have been supporting him as a friend, and I also get him some milk from the shop. His family knows me. My wife and his wife were also friends".*

These were emotive statements that pointed to the passion and enthusiasm associated with the support that the neighbour carers give. The friendly atmosphere also helped to soften the burden of the care relationship, as the rigour and stress of the caregiving are softened on the recognition that the person living with dementia is a “friend” and that the support is freely given.

Carers, whose relationship with the neighbours they supported started directly because of their caregiving, were much younger than their persons living with dementia. The closeness of the age of the care dyads is explained by the fact that the neighbour carers who support persons living with dementia whom they have known before the need for care, were people of same age cohort who lived as neighbours beforehand. But the neighbour carers who started supporting persons living with dementia due to the provision of support happened to be younger in age. The younger carers in the latter circumstance were just motivated to support an older neighbour whom they stated that they needed support. The two carers that support AH (person living with dementia) are under 30 years of age, while AH (person living with dementia) is 92. According to AH’s daughter, most of her Mum’s neighbours are young people and not the people she grew up with: “*they have all moved, and the two under 30 neighbours who support her are professional carers, though they are not paid to support her”.*

This is in contrast with the circumstances of neighbour carer J, who supports a neighbour whom she has known for about 30 years in their neighbourhood; they lived close to each other and have seen one another as “family”. Neighbour J now fills the need for support for her good “friend” now that she needs support, and acts as a contact for her person living with dementia’s daughter whenever the need for extra support arises. This is also the case with J, who told her neighbour carer L (aged 40), that “*she is tired of staying because all her age mates are all gone”*. Neighbour L, is much younger and L (person living with dementia) has made it clear that she is tired of living because all friends of her age, which reasonably translates to the people she grew up with, are all gone.

An aspect of the two neighbour carers supporting AH (person living with dementia) is that one is a professional carer and the other is a young single parent with two children. It has been argued that young, single persons are unlikely to engage in informal caring, and that people who are involved in professional caring roles are likely to be involved in informal caring (Klerk et al., 2020). So, in this case, having children has not constituted a barrier for support for AH (person living with dementia), and in line with some thoughts about the probability of a professional carer engaging in informal care. According to Klerk et al. (2020:4) "*whether someone has ever worked in the care and welfare sector and provided help to clients or patients is considered an affinity with providing care*". The authors also argued that having children is also considered a barrier to informal caregiving (Klerk et al., 2020). However, it has not been a barrier for the single parent with children supporting AH.

Neighbour L said she has lived as a neighbour to J (person living with dementia) for about 12 years, and started supporting her because she and her family *"saw that she was an older person when they arrived in the neighbourhood"*. This suggests supporting a lonely older person and points to an older person living alone, without contact with the people she grew-up with including her husband who passed away about 15 years ago. According to neighbour L, "*J, had no children and lives alone with little or no contacts with anyone".* All these circumstances created a feeling of compassion, obligation, responsibility, and solidarity to support her.

I conclude on this theme that neighbour care giving relationships may start as small beginnings, little attachments, bonding, or incidents. This means there is no specific pattern in which neighbour care giving relationships develop. One common thing about the various ways through which the care giving relationships develop is the presence of some sort of altruism and motivation to negotiate and give care by the neighbour carers.

4.3 Motivations: What are the motivations of neighbours in the support they give?

I found that neighbour carers are motivated to give support to their neighbour (persons living with dementia) for selfless reasons. They are not motivated to care for their neighbours because of what they would gain from the caring relationship, and their motivations are driven by reasons connected with culture, religion, selflessness, a sense of community and friendship. I found that the motivation to give support by a neighbour carer ranged from compassion for older people, a compulsion to support informed by upbringing, cultural background, social responsibility, and a sense of community service and urgency.

I found that the motivation to provide care also depended on individuals’ dispositional factors and external conditions that facilitated or restricted the provision of care. This was also in line with the assumptions of Boer and Groenou (2016:272), who argued that the factors and conditions include cultural, religious, general and normative beliefs.

According to neighbour L, “*I told her that it is part of my culture to help older people”* while neighbour J, added, “*I have got to be doing something useful. My parents have dementia and I worked in a hospice*”, and neighbour ED, said, “*There are other people down the road that I still go and check on, but they do not have dementia. That is what community is all about”.* Neighbour B pointed out that she is Black Caribbean like her neighbour living with dementia, as such she helps to cook him culturally relevant food. According to neighbour B, “*he likes to eat Caribbean foods that I cook for him. He does not like to eat meals that are not Caribbean, which other carers used to cook for him; carers sent by the local authority”.*

This means that some neighbour carers are motivated and driven by values that are rooted in cultural beliefs, socialisation, affinity in the community, norms, concern for helping others, and social responsibility. These indicators interact to motivate neighbours to assume neighbour caring roles and are captured in the participants' statements of “*doing something useful, caring for the older people*”, and being “*part of my culture*”. Moreover, the processes that lead to informal neighbour caring shows that “*becoming a caregiver is not a random process*” (Klerk et al., 2020:2).

Neighbours L and B attributed their reasons for care to cultural and religious influences. Their statements (above) raise issues about minority ethnic carers, cultural values, coping styles and their perception of dementia and health systems. Their statements also raise questions as to whether people’s health issues draw them to religion, or whether religious people are drawn to people who have issues such as dementia for support.

Religious capital is embodied in rituals, knowledge and beliefs, and religious involvement increases the size of social network and provides support from people on whom one can count (Shapiro, 2021). However, in this study religious persons and people who believe it is part of their culture to help (carers), are drawn to older persons living with dementia. The older people living with dementia (in this study) do not necessarily belong to the same religious organisations as their care givers, and in some cases do not belong to any religious organisations at all. So, neighbours L and B are driven by their religious beliefs and values to support their neighbours living with dementia, not because the persons living with dementia belong to their religious groups. This means that persons living with dementia can be benefactors of social capital linked to the religious involvement of others (neighbour carers). This also means that religious norms may help to form bonds amongst congregants; it can help to engender a sense of responsibility towards others. This is the situation in this study as persons living with dementia did not show evidence of participation in any religious activities, but some neighbour carer participants (B and L) attribute their motives for care giving to their religious values and beliefs. This means that aspects of religion such as beliefs, behaviours, rituals, and perspectives serve as a resource or capital. Religious capital denotes these aspects of religion: how they impact on the lives of members and others outside their religious circle. It is about the application of religious culture for the good of people as beliefs can lead to prosocial behaviours like volunteering (Iannacone, 1994; Shapiro, 2021).

I found that minority ethnic carers feel culturally obliged to provide care and use religion and spirituality as coping strategies in care giving. The argument is that carers from minority ethnic groups feel a sense of satisfaction and pride from fulfilling their care duties and meeting their religious obligations. Neighbour B felt fulfilled and satisfied that she provides culturally sensitive meals for her neighbour living with dementia, while neighbour L is also satisfied with providing support to her neighbour living with dementia, as it satisfies her cultural and religious beliefs and values.

Although this study is about neighbour dementia care giving in the community, it is vital to point out that ethnic minority carers perceive the support they provide as a natural dimension of family relations (Parveen & Oyebode, 2018). This suggests a belief that minority ethnic families are culturally obliged to provide care for elders and can do so because of extended family networks. However, if ethnic minorities are inclined to care for their family members who live with dementia, a question arises as to why this has not occurred forthe persons living with dementia supported by neighbour B who is Caribbean. According to neighbour B, *“it seems his family does not want to have* *anything to do with him, and they informed him of a family burial only about 24 hours to burial time".* Nevertheless, it could also be argued that this is an exception as family carers still dominate care for the elderly amongst minority ethnic groups, and they view caring as natural and expected. However, it could be argued that although minority ethnic groups are positioned and guided by their values, they are still affected and impacted by the larger environment in which they live. Such factors that affect them in UK include the ever-changing immigration laws that make it difficult for families to unite, pressure on working age adults to relocate away from parents in search of jobs, and the absorption of aspects of the dominant culture. These have led to the dispersal and fragmentation of ethnic family members. Moreover, mere "*feelings of cultural obligation to provide care does not translate to willingness to provide care*" (Parveen & Oyebode, 2018:4).

Neighbour B and L suggest that carers' cultural identities and values influence their caring experiences. People from minority ethnic groups find meaning and identify with their cultural and ethnic heritage, customs, tradition, religion, and language. Neighbour L said that she is performing her neighbour caring duties because they align with her cultural background. Neighbour L's belief is so strong that she would continue to perform the duties even if it poses a risk or creates tension in her family. For example, on one occasion, she satisfactorily cared for her neighbour before going to pick up her son from school. These levels of motivation are in line with Kitwood's model of personhood, which described dementia as a socially embedded phenomenon whereby functioning and wellbeing are determined by interactions of a person's neurological impairment and their social environment (Kitwood, 1997).

Overall, I conclude in this theme, that the motivation to provide care to neighbours living with dementia is determined by various factors including cultural and religious beliefs, a sense of community, and the values of the care givers. While their care motivations are altruistic and selfless, carers from minority ethnic groups are driven more by their cultural beliefs and religious practices.

4.4 The Nature of Care Given: What nature of support do neighbours give?

I found that neighbour carers in this study gave diverse care to the persons living with dementia whom they support; furthermore, the care and support they gave was not restricted to any particular form. This is new and original knowledge in the context of neighbour dementia care giving because it contrasts with existing literature which restricts the nature of care/support that neighbours give to their neighbour persons living with dementia (Lapierre & Keating, 2013; Baker, 2002). I found that neighbours gave instrumental support which needs physical presence, and emotional care.

In this study, the nature of care given to older persons living with dementia is diverse, but the most common were monitoring, shopping, home maintenance, support with financial management and personal care. This means that the nature of the support given by non-kin neighbour carers in this study cut across both instrumental help, the routine activities of daily living, and companionship. A summary of the nature of support that neighbour carers said they gave can be seen in Table 9.

Table 9: Table Showing the Type of Support given to Older People Living with Dementia by their Neighbour Carers

	Neighbour L (40)	**Neighbour B (50)**	**Neighbour J (70)**	**Neighbour SB (78)**	**Neighbour CM (66)**	**Neighbour T.**	**Neighbour ED(82)**
Nature of Support Given	-Monitoring -Companionship -Personal care -Minor medical support -Support with Transport to the medical centre -Shopping -advocacy during professional assessments -Preparing and serving meals	-Managing of finance -Preparing meals -Shopping -Companionship -Personal care especially when there is (accident) -Housework -Prompt to administer medication	-Shopping -Medication	-Manging of finance (LPA) -Shopping -Cleaning	-Companionship -Take him shopping -Chatting -Contacting his family	-Minor shopping -Chatting together -Companionship	-Companionship -Shopping -Preparing meals -Tidying up -Housework -Ironing Clothes

The wide-ranging support that neighbour carers gave (as indicated in Table 9) included the management of finance, personal care, support with shopping, preparing and serving meals, administering medication, monitoring the service user, making calls for them in an emergency, escorting them to hospital, maintaining their garden, companionship, and chatting with them. The data and analysis indicate that it is understandable and reasonable that as neighbours they gave a lot of instrumental support, which demands a physical presence.

I found that on some occasions whenever a neighbour carer provided support, the extent to which he/she can go is not generally hindered by any norms. Neighbour carers are highly motivated to help. For example, neighbour L provides a wide range of support which she believes she must engage in to meet her neighbour living with dementia’s diverse needs. The extent of the support she gives ranges from monitoring, companionship, personal care, prompting to take medication, transport to the medical centre, and advocacy during professional assessments:

> *“I do everything for her really, I was sleeping and had my phone ring. She called me, and I got the key, and I came, and she said that she fell. She had a bleeding nose, and I called the ambulance. She said that she was trying to use the toilet. I took her to the toilet and supported her while she used the toilet. I helped her to change her underwear, and administer some first aid, and made her relax, and did an oral rehydration solution (ORS) for her.”*

Moreover, neighbour L said:

> *“I helped her to pinch her nose to stop the bleeding. You must help them. I made toast for her. The bleeding stopped, and I took her to the sitting room. It seemed she had constipation. I advised her to take warm water first thing in the morning. My Mum is a Nurse. When I was growing up, we had Pharmacy. I took her downstairs. she was a bit lonely. Ambulance people came in and said that there was nothing they could do for her, that I had done everything”.*

In this support task, neighbour L, completed personal care tasks, completed some medical emergency tasks, called the ambulance, and prepared tea for her neighbour in need of care. By the time she performed these tasks, she was motivated to go to any extent that would make her neighbour comfortable and safe until the ambulance arrived. She also said that she does everything for her, and it is also vital to note that her neighbour had no formal carers at the time of this support episode.

Neighbour L showed a lot of normative, rather than reciprocal, solidarity. According to Boer and Groenou, (2016:273), "*normative solidarity indicates the degree to which someone feels obliged or expected to provide care*". Neighbour L also states that "*even with my grandma, older people are attracted to me",* indicating she was obliged to support her older person neighbour whom she compares to her grandmother. According to Klerk et al. (2020:4), "*neighbours should help their neighbours if they need help*".

Neighbour B also supports her neighbour in need of support, in a similarly diverse and open-ended form. According to neighbour B, she manages his finances, prepares and serves meals, does shopping, offers companionship, and personal care especially when he has "accidents", does housework, and prompts him to take medication:

> "*I cook for him, clean the toilet, clean his house, and make sure everything is fine. I also do shop for him. It is very tiring for me. I give him his medications*. *He has a lot of "accidents". I wash them all, I do help him. He said he does not want the carers to cook for him, because he has a bad experience of them, cooking for him. He does not want them to cook for him. But it is becoming difficult for me. I cook traditional food for him, but it is too much for me. I cook things like fish, salmon, yam, green banana, and spinach for him".*

Neighbour B narrated the support she gives to her neighbour in need of support:

> *"He just called me; he wants me to go to Brixton and buy him socks. His feet are swollen, so he wants special socks. I do his money, paper works, transfer money to his cards. I withdraw money from his card. I know his PIN, and I have got the key to his house. Sometimes, I sleepover on a settee. Last Saturday, I slept there and left on a Sunday".*

Like neighbour L, neighbour B performs several tasks for the person living with dementia that she supports, even as she complains that it is tiring for her. Of all the seven neighbour interviewees in this study, only two (neighbours L and B) provide personal care support to their neighbours living with dementia. This agrees with and contrasts existing literature on the provision of personal care to persons living with dementia by neighbour carers. For example, according to Lapierre and Keating, (2013:1447) "*there is evidence that non-kin may provide assistance with more intimate care tasks such as personal care and money management, and even unpleasant tasks like cleaning up after toileting accidents*". On the other hand, according to Barker (2002), most tasks provided by non-kin like neighbour care givers involved instrumental and socialising rather than personal care.

Other neighbour carers provided significant support to their neighbours in need of support. Neighbour J provides two types of task to her two persons living with dementia - shopping and delivering medication - while neighbour CM said that she takes her neighbour living with dementia to the shop, chats with him, and coordinates support with his family. The same types and level of support apply to neighbour T. Neighbour ED supports her neighbour by offering companionship, getting shopping, preparing meals, doing housework, and ironing clothes. According to neighbour J*:*

> *"I met them through memory clinic. They attend a memory clinic where I also volunteer. I have got to be doing something useful. I do shop for them when I shop with my husband, so we go shopping and I get them some shopping too and drop for them. My husband drives me".*

Neighbour J. further explained that:

> "*They need help. They live down in the road. I shop for them at least twice a week. I get shopping and drop for them, and I also support them with getting their medications. Our doctors are down the road, you can get my medications from the Doctors."*

Neighbour J. not only supports her two neighbours with shopping but also with getting and delivering their medications because they share the same doctor. This involves trust and confidence in her, by her neighbours with dementia. It also involves an agreement with the Doctor's surgery to pick up medications for them, and shows how neighbour support connects with other institutions within the neighbourhood. In this case, it is a doctor's surgery shared by the same neighbours that facilitates the caring relationship by permitting an agreement whereby one of the neighbours supports the other. It also suggests that some neighbourly support is not possible without the cooperation of a third party and means that the unwritten agreements between two dyadic care relationships may not be enough, in some circumstances, for a successful neighbourly caregiving relationship. However, it is important to note that the delivery of medications in England is changing as medications could now be delivered to the home by some pharmacies. Nonetheless, it may still need a third party to make the arrangement.

In response to a question about what she does for her neighbour living with dementia, neighbour CM stated that “*I keep him company when I am at home, helping him with his shopping. As time went by, I am the one who contacts his daughter, whenever things start to go wrong”.* This means that while neighbour CM helped with companionship and shopping, she also acted as a contact link between her neighbour and his kin family member. Neighbour CM did not elaborate on what she meant by “*when things start to go wrong”,* but it is noteworthy that she did not give personal care. It is not clear whether giving personal care constitutes crossing the boundary of support she can give, and would trigger the contact of a family member.

HB (person living with dementia) also described the nature of support she receives from her neighbour carers by indicating that despite her condition she still wants to remain independent and do things for herself. According to her daughter who represented her during the interview: “*The neighbours contacted me (the daughter) by phone or Facebook message if they noticed that my mother’s curtain had not been opened or any issues with the physical structure of her house”.*

This shows that sometimes the neighbours do not directly contact the person living with dementia if they notice any issues but use information technology to directly contact kin (in this case a daughter) if they have concerns. However, data shows that sometimes they also make direct contact just to re-assure HB (person living with dementia).

> *“They (the neighbours) provided emotional support and reassurance to my mother, for example, when dementia caused her to imagine that I was trying to sell her house, they agreed with her, to let my older brother know if any strangers were looking around her house”.*

This is evidence that neighbour carers also give emotional support to their neighbours living with dementia. HB (person living with dementia) has to liaise with her physically close neighbours to monitor whether anyone was viewing her house, which she believed had been put on sale by her daughter. The impact of her condition prompted a loss of confidence in her daughter whereby HB stated had, “*put her house on sale*”. In contrast, she found confidence and security in her neighbours who agreed to help by monitoring and ensuring that her house was not sold. Neighbour carers, therefore, gave reassurance. However, HB's daughter indicated that the "*confidentiality*" agreement that her mother had with her neighbours was broken by the neighbours:

> "*The neighbours did decide not to maintain my mother's confidentiality in the situation described ... instead, they contacted me so that I could tell my brothers and we could all do what we could to reassure my mother".*

Although the neighbours took responsibility for reassuring HB (person living with dementia) about her house, they broke the confidentiality agreement they had with her, albeit, about an imaginary sale of her house, by discussing it with her daughter. This could be a source of tension between HB (Person living with dementia) and her neighbour carers if she knew they broke the confidentiality. This is because she genuinely believes that her house has been put on sale, so she would find it difficult to understand why her neighbours broke the confidentiality. However, the support that HB received did not go beyond emotional support: "*I did not receive support from the neighbours in terms of personal care, housekeeping, shopping, cooking, gardening etc. I did all that for herself. I did not want any personal care"*. This means that HB did not only set boundaries as to the type and level of intervention in her life by others, but she did all she could to maintain her independence.

Neighbour T said that he supports his neighbour by doing minor shopping in the local shops for him, chatting with him, and keeping him company. Neighbour T also reported that he would never offer personal care, which expressly and overtly set the boundaries of support. Finally, neighbour ED said that she supported her neighbour with companionship, monitoring, shopping, meal preparation, housekeeping and ironing clothes:

> "*I took her out for shopping at several times to test whether she could be steady on her feet shopping alone. I also support her with ironing clothes and advise her. I help her with tidying up her house and other housework".*
> *I keep eyes on her curtains upstairs because that tells me when she has woken up or gone to sleep. I check whether the cotton is still drawn or not".*
> *I go to her house every evening to make sure she has a meal. She turns the light out before she goes to sleep. I chat with her always about everything. I encourage her to talk about her family, to keep her brain active. She has three children and lost one".*

ED's support for her neighbour changed from purely being family friends in a relationship that spanned about 30 years, and she lives in the same street, opposite her person living with dementia. The physical location of her house has made it possible to remotely monitor her neighbour living with dementia to ensure that she is not at risk. According to ED, she reports back to her neighbour's daughter whenever she notices anything unusual regarding her movement, and physically visits daily to ensure she has taken her meals. These tasks are only achievable because of the familiarity and proximity of her residence to her person living with dementia. It could therefore be argued that proximity and the building of trust and confidence are vital to determine the nature and extent of support given and received by persons living with dementia. Thus, building trust also entails the building of attachments and bonds with the person living with dementia.

Neighbour ED added that "*I offer to help her, sometimes she agrees, I prompt her to do somethings. I invite her to my house for coffee".* ED seems to be supporting her neighbour in a manner that confirms familiarity and a long-term relationship started before her neighbour needed support. She also finds a way to apply the confidence and trust (bond) she has earned in the long-term relationship whenever she calls on her neighbour. For example, she starts a discussion on their past endeavours and their families and children, and tries to make her (the person living with dementia) remember the 'good old days'. According to ED, she encourages her to talk about her family to keep her brain active. According to Lapierre and Keating (2013), various aspects of the relationship including relationship closeness and geographical proximity may operate as subtle forms of obligation influencing willingness to provide care. These subtle forms of obligation are also considered a form of attachment building (Crisp & Robinson, 2010).

This is not to say that there were no clear boundaries regarding the nature of support given by non-kin caregivers. For example, none of the male neighbour carers in this study offered personal care suggesting that "*neighbourliness has clear boundaries when it comes to providing care*" (Lapierre & Keating, 2013:1460). Sometimes, the neighbour caregiver set the boundary, as in the case of neighbour T who said: *"I can do most things for him. He is sat there on his chair consistently as long as he does not ask me to change his nappy".* Moreover, the daughter of AH said, with regard to the neighbours who support her mother, that “*One of the older neighbours throws tantrums and would not help with physical things”.* Moreover, AH’s daughter said:

> “*I do have neighbours where I live. I help them with gardening, moving furniture. She has had cerebral palsy, since her 60s. A problem I notice in supporting neighbours is that you do not know the extent to help. I helped a neighbour, and the brother came and knocked on my door and said that the paper works I helped his family to complete were a private matter which I was not supposed to have helped”.*

On the other hand, the person living with dementia also set the boundary as to the support they received. According to J (person living with dementia) “*I don’t want some of these people hanging around to help me. Sometimes they ask to help to carry my shopping in my trolly, but I politely decline. I don’t trust some of these young people, do you?”.*

The views from neighbour T, AH (person living with dementia) and J (person living with dementia) show that although some neighbour carers set boundaries on the extent to which they can offer support, the person living with dementia also set boundaries as to whom they would receive support from. For example, neighbour T indicated he was unable to support with personal care, and the male neighbour supporting AH was also unable to offer support with physical aspects, despite having a key to her flat. Furthermore, J decides on whom she receives support from which is based on age and trust: “*I don’t trust some of these young people, do you?” This* points to a lack of trust due to generational differences. AH’s daughter also reported that she was verbally reprimanded by a relation of her neighbour for helping her neighbour’s family with some paperwork. These are indications of clear boundaries and suggest the limits of non-kin caregiving. The older person who supports AH and could not help with physical support is 70 years old.

The issue of boundary and independence is also reinforced by HB (person living with dementia). According to her daughter: *“I am fiercely independent and resent any support which I see as interference unless I asked for it”.* This means that while neighbours have compassion and want to support their neighbours living with dementia, not all offers are accepted. Sometimes the boundaries are explicitly set, as in the case of HB (person living with dementia). Four of the 13 care giving situations agreed they had experience of personal care support. This included two neighbour carers who said that they give personal care support to their persons living with dementia, while the other two said that they receive personal care support from their neighbour carers. Most of the personal care support was delivered by formal carers.

Informal kin carers, especially daughters of the older adults, featured extensively and their roles mainly focused on managing and coordinating the support network. However, evidence in this study shows that relationships mostly precede any form of caregiving relationship amongst the care dyads; thus neighbourly relations seem more akin to support from friends that have transformed to caregiving at the onset of the dementia diagnosis. This reflects other research findings, for example non-kin carers may represent close relationships that have become so close and have such strong commitment that they are thought of in terms of kin relationships (Spencer & Pahl, 2006). Overall, I conclude that the care given by neighbour carers is diverse, and the extent of the care given depends on the needs and privacy settings of the persons living with dementia and the extent of the negotiated level of support.

4.5 Finance Management: What nature of support do neighbours give?

I found that, unlike in existing literature, neighbours gave financial support to their neighbours living with dementia and acted as appointees and attorneys under a lasting power of attorney. This is new and original knowledge in the context of neighbour dementia care giving. According to Pleschberger and Wosko, (2017:562) "*assigning financial issues to non-kin carers were rather the exception rather than the rule.*"

Three of the 13 participants in this study supported a neighbour in need of help with financial management. While two neighbours reported that they manage the finance of their neighbours in need of support, one person living with dementia reported that he is supported in managing his finance by one of the neighbour couples. According to Neighbour B:

"I do his money, paper works, transfer money to his cards. I withdraw money from his card. I know his PIN, and I have got the key to his house. He cannot read or write. He does not understand financial transactions. He has memory problems…. I do paperwork…He does not remember more complicated things".

Neighbour SB, who supports a 97-year-old person living with dementia, said "*she is in later stages of Alzheimer's and has delirium, and not aware of where she is most of the time. My daughter and I are her Attorney for finance/property and welfare".* According to JW (person living with dementia), "*I have couples L and D, supporting me. D (husband) helps me with my garden. I have known them for about 1 year now, and L (wife) handles my money. I met them on the road there".*

The description regarding neighbour B presents a situation whereby the person living with dementia is challenged with memory issues. It also portrays a circumstance where trust and confidence have been developed to the extent that the neighbour carer has the PIN of the adult's debit/credit card and could transfer money from his account. Neighbour JW describes a situation where the money of a person living with dementia is managed by a neighbour whom he described as having met "*on the road there*". Neighbour SB has known the neighbour they support for about 50 years, and according to her the adult has no kin at this time. She never married and has no children.

As neighbour B indicated, she knows the debit card PINs of her neighbour in need of care, and withdrew money from cash machines for him. She also manages his benefits from the Department of Works and Pensions and helped him to process the payment of his contributions for the cost of any formal care he receives from the local authority. She also handles all paperwork regarding financial transactions and deals with the banks on his behalf. These three examples seem to be the exception rather than the rule regarding neighbours managing the finance of their neighbour living with dementia. According to the daughter of HB (person living with dementia): *"My mother did not receive any support from neighbours in terms of personal care. She accepted my support with managing the complex finances that she had inherited from my father, but she managed her banking".*

This suggests that HB neither allowed her neighbour support givers to manage her finances nor allowed her kin carer daughter to manage it. Instead, she did it by herself. She asserted her independence over her financial matters, despite her condition. It is also important to note that JW (person living with dementia) is supported by his neighbours, whom he has known for only one year, to manage his finance. It is not clear why JW was able to build and have confidence in neighbours in a comparatively small amount of time to manage his finances and deal with all his financial paperwork.

However, what is arguably common to the three instances is that the neighbour living with dementia have built a relationship of trust and confidence with their neighbour carer supporters, to the extent that they have allowed them to manage all their financial matters. It is also vital to note that "*financial abuse is one of the most prevalent forms of abuse in the UK amongst older people*" (Knipe, 2015:1). Financial abuse involves the theft of money from a vulnerable person for one's benefit. However, there is no indication of financial abuse in the care relationships featured in this study.

Overall, I conclude that neighbours managed the finance of their neighbour living with dementia. Some of the neighbours had known the person living with dementia for a long time, while others knew them for a very short period. According to JW (person living with dementia) *"My carers (formal) are always here, but I have my neighbours (couple) who support me with my money and my garden. I am not in close contact with any other people now".* This gives an insight as to why he is supported to manage his finance by neighbours he has known for about two years. This is new knowledge, and not in line with existing literature regarding the nature of support that neighbours give to neighbours.

4.6 Living Alone with Dementia: How does support or care fit within a wider network of household and family members as well as formal and third sector support?

I found things about the relationships that people living with dementia who live alone have with their neighbours. This is new and original knowledge in the context of neighbour dementia care giving. Moreover, the neighbour care givers have a network of carers or support that includes kin and formal carers, and they maintain some sort of relationship with them although they physically live alone in their houses or flats.

According to Barker (2002), many older persons living with dementia lack kin to whom they might otherwise turn for assistance. For example, neighbour B describes the lack of kin support in the life of the person living with dementia that she supports: *"I have known him now for 30 years. Basically, he left wherever he came from; so, he does* *not have a family. He came from Wolverhampton and started staying in London".* Neighbour B used these words above to describe the family life of the person living with dementia, who had migrated from middle England to London, without any family, but had found companionship in her for about 30 years. Her description suggests that she is the only one in close contact with her neighbour whom she supports. However, AH describes a situation which captures support from her family (kin) and non-kin. According to AH (person living with dementia),

> *"My daughter does not live here, she often visits, but I have wonderful people who come in to help me. Three of them pop in often to chat and support me. I can't do much on my own now. They come in daily to help me. I am often under the weather"*.

Moreover, JJ (person living with dementia) said *"I live alone since the death of my wife, and my "friend", T, helps me. He comes in to see me. My daughter also visits occasionally, but she lives a little far off"*. Neighbour JW said:

> "*I live alone, ands sit here more often but I get help from the couple who live across the road. He takes care of my garden while his wife manages my money". According to J (Person living with dementia), I have my nephew's children come to visit me sometimes. They do bits and pieces when they come, but I don't border them."*

I found that all six adults living with dementia involved in this study live alone. This is new and original knowledge in the context of neighbour dementia care giving. This means that none of the adult participants live with either children, grandchildren or any other relatives or extended family members. Of the six persons living with dementia involved in this study three have daughters who visit occasionally, one has a nephew who visits occasionally, and the other two have no family members involved in their care. This is not to say that living alone means the same thing as loneliness, but living alone coupled with the condition can create physical and emotional gaps that are often filled by their neighbours. The extent of the isolation could also be seen by HB (person living with dementia). According to her daughter:

> *"I visit my mother once a week by agreement with her, and my sons (together) also visit her once a week. My older brother telephoned her once a week. Since January 2019, my older brother came down from Aberdeen every three months to spend a long weekend with my mother and do any handyman jobs that were needed".*

Moreover, HB confirmed "*Yes, they visit me, but I have lost count of who visits when. But I see them often. They have their own families".*

None of the daughters involved in the care of their parents lives with them. The neighbour carers in these situations are the main carers and work alongside formal carers in some cases. Therefore, kin carers' interventions are substantially supplemented by neighbour carers. This also suggests that availability and physical proximity to the person living with dementia are significant to informal caregiving, and the wellbeing of a person living with dementia.

The relevance of absent family members also featured in my study as neighbour CM said when asked what she does for the person living with dementia whom she supports: *"Mostly, just a friend- I keep him company when I am at home, helping him with his shopping etc, as time went by, I am the one who contacts his daughter when things started to go wrong".*

Neighbour CM points out that she has a neighbour living with dementia who lives alone whom she keeps company and acts as care manager when things begin to go wrong, by contacting his daughter. In other words, she fills a physical space created by the partial or complete absence of kin family members.

As indicated, family members are sometimes physically not available, and both formal paid carers and non-kin carers fill the gap. However, evidence in the literature especially regarding minority ethnic groups point to the fact that the majority of carers of older people in the community are still family carers. However, in this study, statements from the neighbour carers and persons living with dementia interviewed, illustrate the physical absence of kin family members. According to J (person living with dementia): "*I was working with Ford Motors and lived here with my husband. My husband died about 15 years ago, and we did not have children".*

Neighbour ED states that: "*Her daughter visits regularly but does not have time to chat often with her"*. Neighbour B said this, of the circumstances of her neighbour living with dementia: "*he does not have a family. His sister died in Wolverhampton. They called him Tuesday night, while the burial was Wednesday; I believe they did not want him to attend".*

Neighbour J described the situation of one of the neighbours she supports:

> “*The 85-year-old one has a wife who is also in her 80s. Her husband has dementia, and she cannot leave him, because of his vulnerability. He could leave the house and not find his way back, so she is always with him inside the house. Their son lives 60 plus odd miles away from them, and the daughter lives in Spain.”*

According to AH (person living with dementia): *“I will be 92 next month. I am supported by my neighbours living in number 9 and number 1. They come in to make tea for me”.* Moreover, neighbour JJ, described the nature of the absence of family members of the person living with dementia, he supports:

> *“I used to live with my wife here. But lost my wife and he lost his wife too (referring to his neighbour). But he had a key to my Flat, even when his wife was still around. We can take the mickey out of each other. Far away, my granddaughter lives in Bxxxxxxxe”.*

WB (person living with dementia) also lives alone but is supported by both formal carers and his neighbours:

> *“I have formal carers who help me, and they help me to prepare meals, administer medications, assist with personal care, and tidy up. My neighbours at number 3 take away my rubbish. I can ring them up. They have my number, and I have their own too. They have the key to my house. I have called them more than two times and they came and helped me. They are husband and wife. Both help me. They have my key and know my key safe number and can call an ambulance for me in case of emergency”.*

Participants’ experiences tell a story of neighbour carers and older persons living with dementia in the community. Such older persons do not have children, or their children live far away, or they may have a disability or have passed away; alternatively, they may have no family member involved in their care because of a family feud. The story also implicitly describes how neighbours and formal carers fill the physical absence and support the person living with dementia. However, the lack of ongoing physical presence of kin carers does not mean that they do not visit or are unable to call their parents or grandparents to chat to them in order to give emotional support. However, there are limitations as to the extent that a person in need of support is able to engage over the phone over a reasonable period. This is discussed in greater detail in the next theme.

Alzheimer’s Society argues that if appropriate services are put in place older persons living with dementia and living alone can maintain social contact and overcome loneliness (Alzheimer’s Society, 2020); this is significant as loneliness can lead to early death (Holt-Lunstad et al., 2010), and only 45% of people with dementia feel part of their community (Alzheimer’s Society, 2014). According to neighbour ED, *“I believe that if more neighbours helped each other people may be able to stay long in their own homes. Stay at home, people should be in their own homes”.*

It is therefore important to build a support network with people who are not related by blood. The emerging position is that gap in care created because of the absence of kin carers is inevitable and will get worse. A way forward is how to adjust to fill that gap to mitigate the loneliness of older persons living with dementia living in the community. It is also necessary to state that the gap created by the absence of kin carers impacts older people in need of support in different ways depending on their specific needs, and neighbours help to reduce the void by providing different forms of support.

Moreover, while the needs arising from dementia constitute the primary objective stressor, living alone could be considered a secondary stressor. Both the primary and secondary stressors point to the fact that an individual in a social network needs care (Boer & Groenou, 2016). This means that while the older person living with dementia and in need of care develops instrumental needs arising from the condition, the lack of physical presence of kin compounds the situation. However, this can be ameliorated by the intervention of neighbourly support.

Overall, I conclude in this theme, that though I found that all the neighbours living with dementia in this study live alone, they are still supported by kin carers. Thus, most of their instrumental needs are met by their neighbour carers. However, care should be taken in generalising this find, because existing literature provides evidence that family kin carers still dominate informal care giving in the community. This is elaborated more in the next chapter.

4.7 Complexity of Care: What tensions can arise in neighbour caring relationships and how might this be addressed?

I found that neighbour carers are not the only ones caring for older adults living with dementia in the community. They are also cared for by formal and family/kin carers. I also found that because of the stress of care, tensions arise in the relationships between carers, and between carers and persons living with dementia.

This theme emerged from data about the complex system of care associated with caring for older people living with dementia in the community. My research found that different support networks exist, that persons living with dementia have care preferences, and that there are different levels of reliance on specialist support. I also found that informal networks, financial barriers to support, the condition of kin carers, and the wishes and values of persons living with dementia, determine the care received. All create a complex care system around older adults living with dementia in the community.

There is an assumption that the health status and functional limitations of the cared-for adult determine who cares for them. Those who have limitations in daily functional activities and cognitive functioning are more likely to depend on formal care (Coley et al., 2015; Li & Song: 2019). However, findings from this research tend to deviate from this conclusion. I find that in some cases formal care is only retained by adults in need of care who have the necessary financial power to continue to pay the assessed financial contributions to their care. So, financial considerations are very important for a person living with dementia when deciding whether to engage with or keep formal support. Formal support arranged for and provided by local authorities in the United Kingdom are means-tested, and this means that depending on the financial assets of persons living with dementia the outcome of their financial assessment could be that they contribute partially to the overall cost of their care, become self-funders or do not contribute at all.

Although formal support can be free, depending on the outcome of the financial assessment, those assessed to pay significant contributions from about £50 upwards a week decline the full formal support package to avoid such contributions. Instead, they may depend on informal carers like neighbours and family members. For example, neighbour B states that according to her person living with dementia: *“he does not want formal carers from the local authority. He thinks paying £66 a week contribution to his support from the local authority is too much, but I told him that it is not”.* This implies that the affordability of assessed cost contributions is a significant determinant of who engages with and sustains informal care support. Some of the formal care support, like six-week “re-enablement”, given to an adult discharged from a hospital in England are also free for a six-week duration.

Formal carers are allocated by local authorities to support the older adult for six weeks to enable them to regain strength and independence. However, if the support exceeds six weeks, then the cared-for person, is assessed to make contributions to the cost of care from the seventh week. However, some persons living with dementia who are unable or unwilling to pay their assessed financial contributions, do not necessarily abandon the formal support given to them.

It is important to note that neighbour B’s neighbour living with dementia, kept his clinical formal carers but rejected the local authority provided domiciliary formal support. The reason for this decision is because such clinical support is always free with no assessed contributions to make towards the cost of care. According to neighbour B, *“Nurses come in now to inject him. He is strong though have memory issues… He is a tough man”.*

The persons living with dementia and their adult children also find a reason not to use formal support and continue to depend on informal carers like neighbours. According to AH (person living with dementia), *“I stopped the formal carers coming because they were inconsistent with the timing of their visits, and they do not stay with me up to my allocated minutes. They stay for only 10 minutes”.* This is a clear indication that AH, has no confidence or trust in formal caregiving. She has no confidence in formal caregiving arrangements because they undercut their allocated minutes for care calls, and the care for her mother is only 10 minutes. She seems to have more confidence in her mother’s neighbours who voluntarily visit her and care for her. She also believes that they are more motivated to care for her mother than paid formal carers who seem to be interested in the money they earn. According to Kerpershoek et al. (2019:45) the “*number of hours spent on caregiving is an important predictor of caregiving*”.

Care burden is a term used for caregivers and is a kind of distress that caregivers can experience when caring for a person living with dementia (Jafari et al., 2018). Neighbour carers report stress and fatigue after caring for their neighbours living with dementia, and their stress is also worsened as the condition of their person living with dementia deteriorates and their needs become more complex and difficult to manage.

The nature of the care arrangements become more intense and complex as the service user declines both cognitively and physically. This is the stage at which the person living with dementia is no longer able to support themselves in any way and they need more hands-on care.

This study found that the deterioration in the condition of the person living with dementia has huge consequences for both the neighbour carer and the neighbour carer's family. The impact on the carer is both emotional and physical as they make themselves more available to support the person living with dementia, even as they complain of being under serious strain. For example, according to neighbour B:

> *"I cook for him, clean the toilet, clean his house, and make sure everything is fine. I also do shopping for him. It is very tiring for me. He is relying on me, and I said I need to back out now, but he still wants to rely on me. He does not want formal carers from local authorities. I give him his medications. He has a lot of accidents (pooing on himself). I wash them all, I do help him. He said he does not want the carers to cook for him because he has had a bad experience. He does not want them to cook for him. But it is becoming difficult for me. I cook traditional food for him, but it is too much for me".*

Neighbour B reports the enormous support she gives to her neighbour living with dementia but expressed the huge burden on her, stating that it is tiring and becoming difficult. She seems to be looking for an escape route after 28 years of bonding and support, and hopes they would take her friend and neighbour to a residential home. She believes that the professionals working with her person living with dementia will assess that there is now too much risk for him to continue to live alone without both kin (family) and her support, and therefore hopes he will be moved to a residential home. Considering her feelings of being overburdened at this stage, she will not resist any attempt to move her person living with dementia to a residential home.

Neighbour ED also describes how her neighbour living with dementia, deteriorated, and her daughter started to visit more often; however her neighbour living with dementia became more confused about her daughter's more frequent visits. According to the neighbour carer, she felt relaxed about her continued neighbourly visits and support. The neighbour carer explains that this may be because she had a good chat with her about the past and the things they did together, and she always looked forward to her visits, particularly as her daughter did not have the time to chat. According to her *"she only helped with the garden".*

On a different note, neighbour B also described that she was beginning to realise that she is at the closing chapter of her caring role for the man she knew and supported for the past 28 years: "*I think they will put him in a residential home".* Overburdening could take different meanings. While it could amount to a heavy load of tasks that a neighbour carer is expected to provide in supporting a neighbour in need, it could also be a bigger burden if a neighbour carer is expected to perform a particular task that they would not normally want to do. For example, neighbour T, indicated that he would offer support to any extent "*as long as he does not ask me to change his nappy"*. In other words, this would signify a serious burden for him if the care relationship reaches a point that he is expected to provide such intimate personal care or complete a task he would prefer not to perform. This means that he as a neighbour carer has boundaries regarding the type of task he is willing to undertake in the care relationship. This also means that the neighbour caregiver has limitations regarding the level of the burden he will take in the care relationship.

However, there are instances when the person living with dementia may wish to have their private time and maintain some distance from their neighbour carers or other helpers. For example, neighbour L states *"I also notice that she needs her space sometimes. It is like when she needs help, she calls. But I have told her to call me anytime she wants or needs my help, even if it is at midnight".* Neighbour L. also said, "*she told* us a *story about someone who asked her in the past why she did not allow someone to carry her bag and she said that she was afraid these younger ones would run with her bag".* These comments suggest that the person living with dementia needs some privacy and to maintain their independence. Moreover, in some cases, they may refuse support because of a lack of trust in the source of help. This represents another barrier to informal caregiving, namely a lack of trust of some people in the neighbourhood either because of generational differences, negative past experiences or a perception about some section of the neighbourhood. This also means that support is negotiated and that there must be mutual trust and confidence in a care relationship before any acceptance or reciprocity of support can take place.

Neighbour L also reported that her neighbour would not agree to be moved to a residential home: *“no she will not agree to reside in a care home, based on what I know about her. Her home space is part of her life”.* This means that she has stipulated her care preferences and would not like to be moved to a residential home regardless of what happens. Moreover, while the person living with dementia may be assessed as needing formal support, the person living with dementia may reject the offer. For example, neighbour L, reported that, “*She had an assessment with social services, and they gave her a carer to be visiting her two times a day. These carers move about during the COVID-19 period. She was not comfortable about having the carer, so she told the carer to stop coming”.* She took this measure to protect herself from the COVID-19 pandemic. However, she decided in consultation with her neighbour carer. This means that her rejection of formal paid support from the local authority, is not just because of safety reasons, but because she does not have any bonding with the formal carers. At the same time, she receives support from her neighbour whom she is well attached to.

Another noticeable complex aspect of the caregiving role of neighbours to their neighbours living with dementia relates to the neighbours’ assumption of unqualified medical professional roles. A significant proportion of neighbours in this study report giving medical advice/care to their persons living with dementia, and in some cases talk about their person living with dementia having more trust in them regarding medical advice than the professionals such as nurses and doctors. Some claim to have a family medical background including parents who were professionals, such as pharmacists, nurses or doctors and consider it an acceptable basis for giving medical advice.

For example, according to neighbour L, “*My mum is a nurse. When I was growing up, we had pharmacy. Ambulance people came in and said that there was nothing they could do for her, that I had done everything.”* The carer also reported, “*there was another time during this COVID-19 time, she fell again…I went to her, and reminded her about our agreement, to remember to take water.”* Neighbour carer L also narrated that “*she was not happy with the GP again because he came with the wrong equipment and said that I could have been a better GP for her than the GP”.* There was also a report of statements like “*my parents have dementia and I worked in a hospice.”*

(Neighbour, J). Carers could earn some useful experience in previous or other ongoing formal and informal roles that could be useful when caring for adults diagnosed with dementia and in need of support. However, care should be undertaken on the basis that the unqualified person does not give serious medical advice to their person living with dementia.

Nonetheless, it is important to note that neighbour L encouraged her person living with dementia to go to the hospital and took her to a walk-in-centre when she became unwell. Thus, it may be inappropriate for an informal neighbour carer to be giving medical advice to a person living with dementia despite having medical professionals as family members and having learnt some information them.

Overall, I conclude in this theme, that neighbour carers constitute a significant source of support for older people who live with dementia in the community. Family carers also make up a major source of support, but persons living with dementia negotiate their care according to their preferences and circumstances. Care givers experience varying levels of distress as result of the care they give, and the situation worsens as the dementia condition deteriorates.

4.8 Reciprocity of Support: What is the nature of reciprocity of support in the care giving relationship?

I found that neighbour carers are not engaged in support for their person living with dementia due to what they would benefit from. In other words, I found that reciprocity is tilted in favour of the person living with dementia because the neighbour care givers offer support because of their belief in community service, a duty to care, and the expression of friendship, rather than any reciprocal benefits.

According to Reid et al (2005:186), "*a relationship is defined as reciprocal if the benefits of each party are approximately proportional or equal to their contributions*." The importance of reciprocity may depend on motivational factors; therefore, the need for reciprocity is a type of motivational drive, and the strength of the drive depends on the motivation and goal orientation of the individual (Reid et al., 2005).

Throughout this study, and regardless of whether prompted, neighbour carer participants consistently explained that they supported their neighbour living with dementia without any expectation of reward. According to neighbour L, *“I told her no, I do not support you because of what I can get from you.”.* Neighbour SB said, *“she is Godmother to 2 of my children, and it is payback time”.* Neighbour L said that she made the above statement when the older adult she supports wanted to give her money to help to pay for her taxi to pick her child from school. Furthermore, neighbour SB, made a “*payback time*” comment to indicate that she believes in the importance of giving every possible support to MN at a time when she is living with Alzheimer’s disease. However, there is no evidence in data collected to indicate that the two neighbours were motivated to engage in dementia caregiving or any relationship before the need for care commenced, or because of what they would benefit from in the relationship.

Nevertheless, Lang and Fowers (2018:1) argue that relationships are only valuable to the degree that they provide benefits and that relationship partners are predominantly motivated by self-interest. This position contrasts with those of all neighbour participants in this study; for example, according to neighbour L, “*Since we came, we noticed that she is an older person”.* Neighbour L is a black woman of African origin who explained during the interview that she supports persons living with dementia because she is attracted to older people and because it is a cultural expectation for her to do so. Moreover, neighbour L is not alone in supporting her neighbour in need of care as is joined by her children who also give emotional support: “*my son and daughter go to sit down with her”.*

I found that caregiving is generally unbalanced, as the neighbour caregiver seems to continuously resist any form of reward while the person living with dementia consistently looks for avenues or ways to reciprocate support. The caregivers generally engage in caregiving without expecting any reward and resist any overt attempt by the persons living with dementia to reciprocate support. At the same time, the persons living with dementia enthusiastically and proactively look for a way to reciprocate support, but in most situations the moves are rejected by the caregivers. This means that the level of reciprocity that exists in the caregiving relationship is conditioned and determined by the motivation of the neighbour caregivers i.e., to give support without payback, and/or to honour their cultural, religious or community commitments.

However, there are instances where caregivers genuinely and inadvertently agreed on or indicated the existence of some sort of reciprocity, but without knowing the act was a form of reciprocity. For example, in referring to her neighbour living with dementia, neighbour L said "*we support each other in every way possible. She drops gifts for my children during Christmas. We are very friendly. She signed my children's passport when we applied for British passport".* However, it may be argued that this was not a form of reciprocity but a transactional act. According to Crisp and Robinson (2010:47), "*transactions comprised a willingness to provide small acts of practical support or engage in convivial relations*". So the occasional exchange of gifts, and gifts across the fence may be considered transactional but these do not meet the requirements of a reciprocal relationship.

Neighbour L recounted a situation when her neighbour in need of care found a clear opportunity to reciprocate support but she refused her offer:

> "*We (carer and her husband) took her in our car to a walk-in-centre. It was good she agreed to go. When we came back my son's school called me on my mobile phone and told me that my son was unwell and that I should come and take him home. She (person living with dementia) overheard my discussion with the school, and she brought out £120 from her handbag and tried to give it to me and asked me to hire a taxi and go and pick my son from the school. I told her 'no'".*

While the person living with dementia wanted to reciprocate the relationship, her caregiver refused her offer because their caregiving relationship was not motivated by the rewards that the caregiver would receive in the relationship. Their relationship would not end if she did not pay for the cost of transport, reciprocate in monetary terms, or if the caregiver neighbour did not accept the money. The neighbour in need of care seemed to have been feeling a sense of guilt and frustration that she was a burden to her neighbours and her frustrations prompted her to say that: *"she is tired of staying because all her friends and age mates are all gone".*

Neighbour ED said: "*I never consider myself as a carer. I feel I am just assisting",* meaning that she is not expected to be rewarded in any way for her caring role. She sees rewards, especially financial, as unacceptable and damaging to the relationship, and instead insist "*They are just assisting*". Indeed, neighbour J when asked whether she would like to be paid for her role answered "*No, I will not like to be paid".*

Neighbour participants in this study report experiences of happiness and fulfilment, and value the outcome of their efforts; furthermore, they consider the costs or burden as inconsequential.

> “*I visit her, and we have good chat, she knows my children and our husbands used to go to the pub together for a drink, and there are other people down the road that I still go and check on, but they do not have dementia. That is what community is all about I believe that if more neighbours helped each other people may be able to stay long in their own homes. Stay at home; people should be in their homes”* (Neighbour ED:

Neighbour T, described it thus:

> *“I have been supporting him for six years now, though we have known each other for more years. I still work. I work for 2 days a week part-time, only 2 days a week, only half a day 7-12. But I always see him daily, and we chat. I buy him a kebab from the shop. I consider him as a friend, and I also get him some milk from the shop. His family knows me. His daughter visits my friend’s grandchildren. My wife and his wife were also friends, but both have now passed away. We used to play cards and dominos. I keep him amused”.*

These two accounts by neighbours ED and T describe a relationship of friendship, companionship, family, socialising, community, and help that enables persons with dementia to age in place. Moreover, such relationships also include romanticism, neighbourliness, memorable relationships, and entertainment. They describe a wholesome relationship unhindered by its one-sided nature in favour of the person living with dementia. However, a vital question is whether the physical, mental, emotional, psychological and time costs incurred in providing support are sufficiently negligible for the caregiving to continue over a long period? Indeed, the aforementioned descriptions indicate their caregiving is a product of friendship.

Neighbour carer participants view the outcome of the support they give not in terms of financial or any other form of reward, but as selflessness, compassion, and a sense of duty. Describing her guilt during the COVID-19 pandemic after delivering medications to her adult neighbour in need of support, neighbour J. said *“I felt so guilty that I did not ask his wife if he wanted me to stay with her husband for a while so that she could go out from the house for a while”.*

This suggests that she viewed her support to her neighbour in need of care and her family, as a means-end activity, with some of the ends being the minimisation or reduction of guilt and of feeling fulfilled and/or securing her self-esteem. However, this was not the case with the experiences of other caregiver neighbours. They pointed out they were not on some sort of ego trip or seeking emotional and psychological satisfaction, but simply there to help.

My interpretation is that these carers generally do not want to be seen to be benefitting in any manner, whether material or otherwise, and would consider any alternative suggestion as offensive and unacceptable. Indeed, neighbour J said *“There are things in life you have to do without being paid. No question.”* Their position is that caring for a neighbour they have known for years, even before their diagnosis, cannot in any way be viewed in a business or cost-benefit tangent. The direction of the care they are giving today could have been directed at them. So, caregiving has been an integral part of their long term “family to family” relationship before and during the adult in need of care’s condition was diagnosed. Furthermore, it will persist even after the passing of the adult. According to neighbour ED:

> *“She is my neighbour and I live across the street. I have lived here for more than 30 years, and she has become a good neighbour. She is like an auntie for my children. She had a big lawn, big garden, and we knew her husband. When her husband passed away, she normally came with us on the summer holiday. But she started developing concerns. Her daughter works but does not live with her. She lives local and visits”.*

This clearly shows that ED sees her relationship with the adult in need of care as family, and something that pre-dates her current condition. She does not consider herself a carer but rather as a neighbour caring for her fellow neighbours who happen to currently need support. In other words, the care they give is not an instrument to any pre-determined ego-driven or material end; rather it is to improve the wellbeing and independence of the adult in need of care. To them, it does not matter if they are successful in reducing pain or stopping a progressive deterioration in their neighbour’s condition; what matters to them is that they have not failed to act, support, or help when expected or needed. Their reward seems to be that they know that their neighbour knows they have helped and continue to support. They view the support they give as being in tangent with their values of empathy and friendship; they view their help as inevitable; their relationship with the adult in need of care is compulsive; their care an expression of loyalty, and their consistency of support in the face of progressive deterioration of the condition as faithfulness.

I conclude here that neighbour dementia care giving is generally selfless and altruistic, and driven by a motivation to help, and a sense of duty to care. Sometimes, the lack of reciprocity is not because the persons living with dementia do not try to reciprocate but because the givers resist it. While reciprocity is a common feature in general neighbour relationships, the level of reciprocity is reduced as the recipients decline cognitively, become vulnerable and dependent.

4.9 Tensions in Care Relationships: What tensions can arise in such relationships and how might this be addressed?

I found that tensions arise in the care relationships because of burden of care, and this increases as the condition of the persons living with dementia deteriorates. In this study, while a relatively high proportion of neighbour caregivers are believed to offer and give no strings attached caregiving to the adults in need of care, some tensions in the relationships still arose. My research finds that there can be tensions for people living with dementia and among informal caregivers (including kin and non-kin) under their particular care arrangements. There can also be tensions between people in need of support and their families; tensions also arise between informal non-kin carers and their own families, and between non-kin carers and the person living with dementia.

According to Zhang et al. (2019) tensions may arise in dementia caregiving relationships because of the stress and burden incurred. Other sources of tension include a lack of understanding of the condition, the financial burden, limited or expensive support services, and the disability of caregiver. A neighbour carer reported that the burden is not only on her but also on her husband as she supports two of her neighbours and her mother. According to neighbour J: "*I do shop with them when I shop with my husband, so we go shopping and I get them some shopping too and drop for them. My husband drives me. I have sight problems; I can't see properly.*" Neighbour L also reported, "*that her husband drove her and her neighbour, to a walk-in centre".*

These were two instances where family members (spouses) of a neighbour caregiver are involved in the caregiving efforts of the neighbour caregivers. This means that a neighbour caregiver can be reasonably supported by his or her own family to give non-kin support to a neighbour. This is important because if there is strain connected with the caregiving role within the neighbour caregiver's family, the entire support arrangement may collapse. In the two instances above, the husbands of the female neighbour caregivers were supporting their spouses to support the neighbours in need of support. They were the "car drivers" that made the specific support possible, i.e., driving to a walk-in–centre and shopping.

Although it is not known whether the spouses of the neighbour caregivers complain or are unhappy driving their wives (neighbour care givers) as they shop and drop things to their neighbours, there are clear extra stress on them. Their wives' support for their neighbours would not be possible without their partners' support, particularly because, in one situation one of the neighbour carers has a sight impairment. This is an important factor as Pleschberger and Wosko (2017:563) reported a situation where a participant in a study was confronted by her husband with the argument that "*her role seems too high for a non-relative*".

However, tensions and conflicts can arise from complex interwoven care arrangements. There is evidence of tensions between neighbours and neighbours in need of support, kin (family) carers and neighbours, and the adult in need of care and formal carers. The sources of these tensions are linked to disagreements over the nature of the care that the persons living with dementia need, and how to achieve the expected care outcomes.

While family kin carers live away from the persons living with dementia in most study scenarios, in this research there are instances when they visit, and in most cases they are the care managers trying to arrange and re-arrange existing care plans for their parents' support. This can be particularly stressful in instances when there are tensions. According to the daughter of AH (person living with dementia) *"I do not live with my Mum. I live in London really, the other side. I support my husband too. One of the older neighbours throws tantrums and would not help with physical things. But my Mum is also supported by two other neighbours who live next door".* Thus, while the daughter of AH does not live with her mum, who has dementia and needs close monitoring and support, there are tensions between her and her mother's neighbour who lives just above her Mum in the same building. According to the daughter of AH, he (the neighbour) would not support her mother with "physical things". The neighbour's lack of interest in physical aspects of care was highlighted in the study by Pleschberger and Wosko (2017), friends are more agreeable to take on physical aspects of care than neighbours. However, it is vital to point out that the neighbour who is less agreeable to giving physical support is 70 years old. AH and her daughter also reported:

> *"I want to ask the other neighbour in No 1, if she would be interested to pop in to make sure I do not have to be in much need, especially regarding food … the one who had the key to my house is on the top floor and is in his 70s. He remains the key holder, but I intend to transfer the key to the lady living in No 1. If she agrees to have it".*

AH's daughter became a kind of 'care manager' for her mother, not only to ensure that there were no gaps in her support needs but also to manage the tensions arising from supposed non-performance by one of her neighbour carers. She decided to take the key to her Mum's house from one of her mother's neighbour carers and gave it to another neighbour whom she thinks would better support AH. This implies tension for the person living with dementia, her kin (daughter), and the non-kin neighbour carer. The tension could be exacerbated on the part of the neighbour when the key is taken away from him, which implies a lack of confidence and trust in him.

Furthermore, according to neighbour J:

> *"I am more worried now that COVID-19 lockdown is lifted. The one, 68, the wife is physically disabled, and her mobility is very poor. She also needs support herself. I believe the entire care and needs situation of her family affects her mentally. I can tell from my experience in memory café, that, it is the situation with a lot of couples there, as they get older".*

She further narrated the need for respite for kin carers: *"Yes, a kind of respite. There is the cxxxxxxxs organisation in Gxxxxxxxd, a voluntary group, where someone will come and sit with someone, and the main carer will go and do something else for a while. I must go; I must wear a mask. I feel I could do more".*

This was the experience of a neighbour caregiver who met her neighbours in need of care via the memory clinic. Her narrative recognises that tensions arise because of the vulnerability and disability of the main carer spouse of an older person living with dementia in the community. The kin carer is disabled, with poor mobility, and caring for her spouse in need of care, and the participant (neighbour J) posits that tensions that arise because of these conditions makes her eligible for respite which would give her a break in her caring role. This is understandable; she also recognises that the situation is made worse because of the COVID-19 pandemic, which has led to lockdowns and physical contact restrictions in the community.

Further tensions and conflicts identified in the complex care arrangements are between a neighbour carer and the neighbour in need of care regarding issues linked to formal care support and disagreements over taking of medications. For example, neighbour B narrated how she had a serious disagreement that involved the police because she advised her neighbour person living with dementia to stop throwing his medications away, and instead take them as prescribed. She said that the neighbour was so angry that he pulled a sword and wanted to harm her, hence she called the police. According to neighbour B:

> "…he *said that he was going to kill me. He just got up and said that I was going to kill you. He said that I was trying to poison him. He was not taking his medications, and I told him that he needed to be taking them because it would be a waste if the nurses continue to visit him and prescribe these medications and he refuses to take them".*

According to neighbour B, that single incident adversely affected the trust and confidence built over the 28 years that she has known him. Although she continues to support the adult in need of care, she said that she has become more careful and takes precautions about her safety. Neighbour B also believes that her neighbour living with dementia is deteriorating fast. The medications in question here were prescribed by doctors and nurses supporting B's neighbour living with dementia. Neighbour B said that she has reduced her level of support and informed her neighbour's formal carers about her limited level of support going forward, and she now believes that they will take him to a care home.

It is also worth noting that tensions arise in caregiving relationships because of financial pressure on the carers and service users. According to AH (adult in need of care):*"They withdrew pendant alarm service and the only service available is charged (not free), and that will leave me with less amount of money for other important things.*

Her daughter further narrates: *“I do not have a car. Parking outside is £3.00 per hour, and £8.00 a day, and that is half of my attendance allowance”.* This is evidence that financial pressure arising in the course of caregiving can lead to tensions in the caregiving relationships. AH’s daughter visits her mother as she lives at a far end of London where her mother lives. However, she is very worried about the parking charges where her mother lives, which implicitly would add more costs to her visits to her mother if she owned a car. Owning a car would have made things easier. Moreover, her mother is unable to replace her very important pendant alarm system. There is a charge which she could not afford because there were more important things to spend money on. These financial calculations and pressures create tensions in the relationships.

Moreover, neighbour care participants in this study do not only care for older people living with dementia, but some also combine the caring role with work and/or caring for a family member, caring for a child, actively participating in community organisations including a memory café, and/or mutually supporting a spouse, aspiring to be a student or being a student. Most have tried to balance two or more of these statuses for several years while also supporting a neighbour. These are also sources of tension as they try to meet the needs and demands of the different roles. For example, neighbour L said that she is also a formal carer and an aspiring student in addition to caring for her neighbour living with dementia. According to neighbour L, “*I want to study social work and I want to apply to universities close to me, so that I can attend school from home”.* This means that while she continues to care for her neighbour living with dementia, she is aspiring to be a student and actively making applications to study. On the other hand neighbour J volunteers at the memory clinic while at the same time supporting her neighbours: “*I volunteer at the memory clinic. That is where I met my neighbours whom I support now”.* Combining these roles creates tension in her caring role, as she also supports her husband who drives her for all journeys in the locality, because *“she can’t drive because she does not see well”.* It is also important to note that one of the carers supporting AH has a new-born child whom she cares for, and neighbours T and CM work. Thus, combining different roles with that of caring for a neighbour is a source of tension in the caring role.

In conclusion, tensions in the care relationships are caused by different things, including finance, disagreements over the mode of delivering care, deteriorations in the condition of the person living with dementia, and stress associated with delivering care. However, neighbour care givers and the persons living with dementia tend to have an internal mechanism to resolve tensions and give themselves a break in the care giving relationship.

4.10 Gender: How does this support or care fit within a wider network of household and family members as well as formal and third sector support and care providers?

In this study, females are predominantly care givers, both as neighbour carers and family (kin) carers. Although females predominate in the literature on care giving, this is significant because it is related to neighbour dementia care giving. I found that all of the six adults living with dementia involved in this study live alone. Therefore, this is new and original knowledge in the context of neighbour dementia care giving.

It is important to note that this study adopted a purposive approach to selecting participants, so the study did not set out to select only female neighbour carers. Instead, it emerged that all the neighbour participants except one, was female; and for all the older adult participants who have a kin/family in their care network, all the family members are female.

Of the seven non-kin neighbours interviewed, six were female; and of the six older adults in need of care, five were supported by female neighbour carers. This means that 11 females (84.6%) and two males were involved in neighbour caregiving relationships in this study. As already indicated, this is in addition to the fact that all family members still supporting each person living with dementia from a distance were female. So, the issue of gender manifest strongly in my data and analysis. I have given these figures to show a pattern that emerged in my research rather than to generalise the role of females in neighbour and/or informal caregiving.

The figures tend to reflect the national picture of caregiving which is predominantly undertaken by females. According to Barbabella et al. (2018), although recent years have witnessed an increase in male caregivers, most caregivers are still female. In addition, while women tend to take care of emotional needs men are likely to provide financial and legal support. Kerk et al. (2020) also found the predominance of women in informal caregiving but emphasised that care provided by men should not be underestimated. The significance of the predominant role of the female neighbour carer in this study is the first time that it has been found in a dementia care context.

Neighbour L, a black African woman aged 50, supports two of her white older adult neighbours in their 80s and 90s who live next door. In response to a question as to how long she has known her neighbours L said, "*Not recent, it's been long".* Neighbour ED, aged 57, is a white woman and supports a white female (aged 89) living with dementia. In referring to her neighbour in need of care, who she supports ED stated

> "*I have lived as her neighbour for 30 years. I chat with her always about everything, everything. I encourage her to talk about her family to keep her brain active. She had three children and lost one. One of the surviving children is a man, but he is not into caring for her mother. She is cared for by her daughter who visits occasionally and helps to do her mother's garden".*

Neighbour B, a black African woman (aged 58) supports a black African neighbour (aged 89) in the Clapham area of London: "*I used to live upstairs of him. He moved but still lives a walking distance of me in the neighbourhood. He is about 87".* Of all the neighbours of adults in need of care, including males, neighbour B is the person who has bonded and has been supporting him for the past 30 years. Neighbour J is 70, a female, and supports two neighbours, aged 68 and 85 in need of care who she met in the memory clinic. Neighbour J volunteers in the memory clinic, and that was where she met two of her neighbours too who attend the clinic.

Neighbour CM (aged 66) is also a female who supports her neighbour, a male living in need of care. Neighbour CM described her relationship with her neighbour whom she supports as *"mostly just a friend; I keep him company when I am at home, helping him with his shopping".* She also said that she acts as a link between his neighbour (aged 85), and his daughter whenever things start to go wrong. In comparison, neighbour T is the only male neighbour carer in this study. He is white (aged 78) and supports his neighbour (aged 75) who is also white. Neighbour T said that he has been supporting his neighbour for the past six years following his diagnosis of dementia. Their families have developed close ties for more than 20 years, but both of their wives have passed away. This means that in the absence of their wives, neighbour T might have felt little other option than to offer care for his neighbour in need of support.

Although this study focused on the experiences of non-kin neighbour carers, it is relevant to also note that of the six older adults in need of care being supported by neighbours, three are also being supported by the kin members of their families, and all are female. The persons living with dementia supported by neighbours ED, CM, and T are also supported by their daughters. However, the daughters do not live with them. Although the older adults supported by neighbour J have a son who lives 60 miles away, he does not offer any input in support of his parents. Their daughter lives in Spain. In other words, although their son lives within the UK, he has little or no input to supporting his parents. The person living with dementia who is supported by neighbour L, is also supported by her nephew; in comparison, the person living with dementia who is supported by neighbour B has no kin support at all.

Some interpretations and meanings have been linked to the predominance of women in both kin and non-kin caregiving. According to Grover et al. (2016), the predominance could be linked to social and cultural demands; stress coping theories argue that women are likely to be exposed differently to caregiving stressors than men. However, there are inconsistencies regarding gender differences in caring which relate to role expectations, differences in stress, coping and social support and response bias in reporting distress (Grover et al., 2016:).

Neighbour carers have explained their role in supporting older adults in need of care in terms of performing community responsibility, "*that's what community is about*", and that they are attracted to supporting older people. If this is the case, then it is important to understand why men are not similarly attracted to supporting older people or performing "community service". Moreover, if it is a consciously adopted role, both males and females should endeavour to adopt it. Cahil and Begley (2003) have argued that the role of informal caregiving may have been adopted more incrementally by females, in the absence of any family discussion, and that men's roles are peripheral and rarely questioned by parents or daughters.

I found that most caregivers in this study are female. This is in line with existing literature which points to the predominance of females as care givers. However, my finding is significant because it has been discovered in the context of dementia care giving. Females help to coordinate support for the person living with dementia and remain resilient in their support. More research is needed to give greater insight into why females are more dominant than males in dementia caregiving.

4.11 Conclusion

In conclusion, I have presented the findings of my research, and shown the nature of the relationships between the participants, and the processes of neighbourly support relationships. I also analysed the findings relating to the motivations of neighbour care givers and the nature of reciprocity in such relationships. Further analysis of the findings was conducted in relation to the nature of care given, financial management, lone living, the complexity of care, tensions that may arise in care relationships and the issue of gender in care giving. In the chapter 5, I discuss my findings in relation to the existing knowledge base to provide context and perspective.

5 Discussion

Having presented the findings of this study in chapter 4, I present a critical discussion of the findings in relation to existing knowledge or literature in this chapter. This study explores and understands the role of neighbours in providing support and care to older people living with dementia in their own homes. The themes that emerged following an investigation of the research questions focused on the processes leading to caregiving relationships, the lone living of persons living with dementia, the motivations of care givers, the reciprocity of care, the complexity of caregiving, tensions that arise in the caregiving relationships, and the issue of gender in care giving.

I have discussed the themes generally in the context of existing evidence about informal neighbour non-kin caregiving and provide a perspective to enable greater understanding and insight. In my discussion, below, I have contextualised my analysis and presented what it adds to existing literature especially in terms of the similarities and differences. I have also shown how the existing literature helps to explain my findings and how my findings contribute to new ways of thinking about existing literature. I have discussed how my findings add to existing literature on social capital, social connections, and social relationships, in the context of neighbour dementia care support.

5.1 Processes of Neighbour Support

The processes that lead to neighbour dementia care relationships point to care relationships that started in different ways, from long term neighbourly relationships before the need for care, to neighbourliness that started with the occurrence of a single act that prompted support by a neighbour. The processes portend that the social capital or connection inherent in social networks can transition and transform as care networks, and that the available networks of support can develop either over a long period or shorter periods, and in some circumstances reflect the earlier relations and friendships made before the need for support for the neighbour living with dementia. In other words, there was contact and help with exchange before the need to provide care (Seifert & Konig, 2019), so there was neighbourliness even before the need for dementia care (Ruanavaara, 2022).

The processes also mean that the caregiving relationships develop in different forms and involve the exploitation of social connections or capital. It also shows that no single pattern of social connection triggers a caregiving relationship. Neighbours who support their vulnerable neighbours living with dementia, have or had different forms of contact and relationships before the caregiving relationship. This means that in addition to the accessibility and usability of the built environment the social and relational environment is very important to both potential carers and their persons living with dementia. According to Greenwood et al. (2017) and Ward et al. (2018), public gathering spaces like cafes are also important to carers just as they are to older people living with dementia. This also means that carers and older persons living with dementia also seek to maintain their sense of social citizenship, implying that dementia-friendly neighbourhoods can provide avenues for the application of social citizenship and relationships (Silverman, 2020). This also means that to understand the extent of the contributions of neighbour care givers to their neighbours living with dementia it is necessary to place neighbours within the context of the social care networks of the older people they support, including their internal family settings (Lapierre & Keating, 2013). About 10% of community-living older people regularly receive informal assistance from unpaid non-kin caregivers like neighbours (Barker, 2002), and in some situations, family members do not know how to help and have difficulty managing their emotions such as sadness and discomfort because their kin developed dementia; this tends to restrict the kin network of support (Silverman, 2020). However, this has been found not to be generally applicable as kin still constitute a significant part of the care network. Moreover, among people of minority ethnic groups, kin carers are driven by strong cultural and religious beliefs and are available most times, including to give support (Parveen & Oyebode, 2018).

This study therefore highlights the processes and development of neighbour caregiving relationships, i.e., the move from general neighbourly relations to care giving relationship. Neighbourliness is the positive aspect of neighbourly relations, and "*non-kin care giving is heterogenous in the initiation of relationship, form, duration, tasks performed, and association with family care givers*" (Barker, 2002:158). My finding regarding the processes of developing neighbourliness reflect previous findings that proximity, intimacy, the degree of familiarity with an older person's activities and social intimacy are important aspects of the non-kin relationships (Nocon & Pearson, 2000). Relationships arise out of circumstances that are prevalent in the larger neighbourhood or environment and the motivations of potential neighbour caregivers. According to Suanet et al. (2019), ties with the persons living with dementia seem to be measured in terms of proximity, contact, support, and/or co-residence. People in friendship-focused networks also tend to rely on partners, if available, and then friends and neighbours and formal care services (Suanet et al., 2019). These processes resonate with Kitwood's model of personhood, which describes dementia as a socially embedded phenomenon with functioning and wellbeing determined by interactions of a person's neurological impairment and their social environment (Kitwood, 1997).

The processes that lead to different forms of support for older adults living with dementia in the community therefore highlight the relevance of social networks. According to Worcester (1990:140) a social network is "*the number of linkages of contacts with other individuals or groups*". Thus, different levels of social interaction between individuals and groups lead to "*heterogenous relationships that have different levels of supportiveness*" (Cho, 2007:3). The social network groups have also been broken down into primary (kin), informal (non-kin), and formal groups with different tasks to manage (Cho, 2007). So, while different interactions lead to different group alignments, the question is whether specific groups in these interactions are known to perform or manage specific tasks or are agreeable to specific forms of support relationships. The relationships are characterised by some degree of emotional intimacy and instrumental support, and some degree of socialising.

In terms of meeting needs, especially instrumental needs, proximity and contact are important and although there are kin carers who call and/or visit, neighbours or non-kin carers may be needed at some points to give care. The point is that although expectations of contact and assistance are stronger in kin than in non-kin relationships, especially if it involves intensive and prolonged caregiving, kin carers may be involved in conflict, or live away because of work commitments and marriage pressure (Suanet et al., 2019). As a result, neighbours who have previously been in ordinary friendly relations with their neighbour living with dementia, may subsequently transition to become indispensable caregivers as their older adult neighbour develops a disease like dementia. Some of the transition from neighbour to care giver can happen smoothly, but in some instances, it is difficult to identify the point of transition to a caring relationship. According to Pleschberger and Wosko (2017), among friends there was a clear transition from friendship to support arrangements, and it was difficult to identify a specific beginning of the care relationship. In comparison, for neighbours, "*even if they were not total strangers before; it was the act of providing help that constituted a relationship; other forms of small beginnings were initiated through a request for one-time support*" (Pleschberger & Wosko, 2017:562).

It is about the connections between care and quality of life, the development of the social construction of ageing, and challenges in old age. Inequalities in living conditions require knowledge of the social construction of old age. It concerns personal identities, living conditions, social structure, the resources/opportunities available in old age, coping with everyday life, and interactions in old age including the availability of support networks (Kricheldorff et al., 2015).

The processes describe and represent relationships in old age, the level of social participation of older people, and how they secure their needs and rights. It also portrays the nature of self-determination and autonomy in the face of conditions of individual aging such as dementia condition.

In the context of this study, the network of care by neighbours, kin, and formal carers has demonstrated how social relationships in the form of informal care giving are germane in enhancing the wellbeing of people living with dementia in the community.

5.2 Motivations of Care Givers

Interviewees' descriptions of their motivations for supporting their neighbours living with dementia illustrate reasons for support that anchor into community service, culture, religion, beliefs, friendship, empathy and compassion. Interviewees spoke in terms of friendship and community service, and the need to help and be seen to be helping, notwithstanding the individualistic environment where they were brought up. They also indicated that they are happy to contribute and help; this makes them feel fulfilled and part of the community. These factors imply that friendship and feelings of communality in the neighbourhood have survived the concomitants of modernity.

According to Cho (2007:8), “*different types of informal caregivers have different motivations for caregiving*” and there is little variation in what motivates or rewards caregivers as many felt morally obliged to help, while non-kin caring relationships are generally naturally occurring and ubiquitous, built out of acts of sharing kindness between people, especially neighbours. My findings reflect those of previous studies in that caregivers are motivated by a prior history of volunteering, the desire to fulfil otherwise unfulfilled needs, and cultural and religious beliefs (Barker, 2002). Cho (2007) further argues that the caregiving relationship should be considered in historical contexts because it is established from past relationships and a history of interactions. This means that non-kin care arrangements usually do not take place between total strangers but often develop from neighbourhood relations and motivations to help others (Pleschberger & Wosko, 2017). People still find a way to look after each other in the community. In other words, community in the form of neighbourliness has survived the individuality of modern-day societies. This position is in line with the assumption that compassionate communities might have the power to influence the local care culture and encourage citizen involvement in support activities (Pleschberger & Wosko, 2017).

It is vital to elaborate on the idea of carers being motivated by cultural and religious reasons, as noted by some interviewees in this study. According to Shapiro (2021), religious involvement increases a social network size and provides support from people on whom one can count on in times of need. Furthermore, social capital involves the accumulation of social resources that inhere in social relationships through being a part of social networks. This raises questions as to whether people must belong to religious groups to benefit from a network or whether people with certain religious beliefs are attracted to people who need support. My study relates more to the later, as the persons living with dementia are not part of any religious networks but are supported by neighbour carers who are motivated and driven by religious and cultural beliefs. This means that my study shows a new way of thinking about existing literature and processes.

The term religious capital denotes religious beliefs and practices, how they are used as instruments to deliver social support and the ways in which they impact not only the lives of their members, but others outside their religious circles. This implies the application of religious culture and values for the good of people (Shapiro, 2021). Some neighbour participants in this study expressed the view that they are giving support because of their religious and cultural beliefs.

Social capital can help to understand the wellbeing of people living with dementia because it is most well established in health and linked with several positive health outcomes. According to Shapiro (2021), religious capital has been confused with social capital, but religious capital can be viewed on its own merit. Social capital is a feature of religious involvement (Shapiro, 2021). There is substantial evidence in the literature that social capital abounds among people involved in religious practices and beliefs, and religious moral authority regulates individual behaviours by moulding their beliefs and practices (Shapiro, 2021). This means that a network of friends from the church or mosque can be helpful or become a helpful network. These friends embody beliefs, behaviours, rituals, and perspectives that transform into resources and can lead to prosocial behaviours like volunteering (Shapiro, 2021).

Interviewee descriptions of their motivations to engage in neighbour dementia care in terms of their culture and religion have highlighted the relevance of culture and religion in the way ethnic minority ethnic groups perceive, value, and deliver care to older people in the community. According to Parveen and Oyebode (2018), minority ethnic carers feel culturally obliged to provide care. This means that there is an expectation and duty to care, and for culturally sensitive care, as insensitivity sometimes translates to barriers to accessing formal care both in terms of persons living with dementia and care giver (Herat-Gunaratne et al., 2019). Carers from minority ethnic groups also use culture and spirituality as a coping strategy and ways of expressing satisfaction and pride in meeting their religious and cultural obligations. This implies that carers' cultural identities and values influence their experiences and guide their negotiation of the caring role and relationship with services (Herat-Gunatne at al., 2020).

The religiosity of minority ethnic carers and persons living with dementia can be so strong that it becomes a hindrance to accessing mainstream support, as minority ethnic carers limit their care to their community, of those in their religious and cultural circles. Religious obligations explain the connection between cultural obligation and the positive gains found from caring among South Asian communities. Moreover, African American carers have also been found to focus more on spirituality and the positive aspects of care giving, including the satisfaction derived from successfully fulfilling religious obligations (Knight et al., 2010). Although ethnic minority carers employ their cultural and religious values to caring and use them as coping strategies, they also experience racism, a lower socio-economic status, and are often perceived as migrants (Parveen & Oyebode, 2018). The two black carer participants in this study strongly expressed the importance of their culture and religion and how they influenced their relationship and motivation to support older people in the community.

Several barriers prevent minority ethnic communities from accessing dementia services, including dementia not being perceived as illness, the shame and stigma associated with dementia, negative experiences of services in the past, a lack of culturally appropriate services, language barriers, and a lack of awareness of available services - possibility of long-term care in care homes (Giebel et al., 2014; Parveen & Oyebode, 2018: Blakemore et al., 2018). This also reflects findings from a previous study which concludes that black neighbouring behaviour and the norms that govern it are reflections of the group's historical experiences (The Young Foundation, 2010). Moreover, ethnic minorities in general particularly value and rely on social networks at the local level (The Young Foundation, 2010). This explains the experiences of persons living with dementia in this study, particularly the rejection of meals prepared by the local authority paid carers and the preference for neighbour carers from same ethnic origin, who are preferred for support generally, and preparing meals in particular. This also explains why minority ethnic persons living with dementia and care givers are inclined to work with third sector services like the Alzheimer's Society and Age UK which they perceive as more trusted and better equipped to meet cultural needs (Parveen & Oyebode, 2018).

Dementia care in minority ethnic groups might differ from the majority of the population because of social integration, lower income, less formal education, worse employment conditions, which can be found more in minority populations compared with a majority white population (Hrerat-Gunaratne et al., 2019:331). This suggests a reason why ethnic minority groups tend to rely more on caring and carers sourced within their social circles. Nevertheless, social and religious capital can also be negative, especially when group beliefs discourage healthy behaviour or encourage behaviours that can be harmful to health. This can also be the case if people feel abandoned by their religions, which can lead to negative coping with illness. Moreover, some theological beliefs can harm health especially when there is adherence to a dangerous religious explanation of illness, the reliance on divine intervention for a cure or the subscription to the idea of sacred loss (Bock, 2020).

In addition to cultural, religious, and spiritual motivations, interviewees' descriptions of their motivations also illustrate the strength of bonding and attachment that exists in caring relationships before the need for care, notwithstanding the dementia condition. According to Odzakovic et al, (2019:18), "*the exclusion from existing relationships was often something that had arisen after being diagnosed and it is difficult to attribute these changes to the widespread presence of stigma and discrimination surrounding dementia*". Nevertheless, as indicated in this study, the pre-diagnosis neighbourly relationships were maintained after the development of dementia by the neighbour, which contrasts with the views suggested by Odzakovic et al. (2019). The emergence of non-kin neighbour care relationships is a consequence of the need for intervention by non-kin carers to help to meet the changing needs of their neighbour living with dementia; this is due to a decline in health. The person living with dementia at this stage tends to be on a path of increasing physical needs and disorientation (Pleschberger & Wosko, 2017).

The relevance of historical relationships or the contexts of informal non-kin relationships is pertinent to the idea that knowledge about persons living with dementia matters. This means knowledge about what persons living with dementia prefer, want, or need. These are part of the familiarity and person-centred approach of caregiving. Caregivers tend to become familiar with the person living with dementia's needs, characteristics, and preferences over time and the caregiving relationship usually becomes more acceptable and person centred over time. The familiarity is formed during long term relationships, and factors such as commonality, common culture and face to face contact influence the formation and bonding. According to Emmel and Clark (2009) neighbourhoods are comprised of social networks, often built over a lifetime, and embedded within spatial contexts". Familiarity is built within the neighbourhood which in this instance connotes both physical and social space.

In conclusion, carers are motivated to provide support by the values of providing community support, their cultural and religious backgrounds and beliefs, and need for them to express a sense of community, moral obligation and friendship. However, the motivation by a sense of community service, moral and cultural obligations, is inconsistent with the work of Nocon and Pearson (2000) who found that carers denied being motivated by a moral obligation to provide support for non-kin older people. It has also been argued by Parveen and Oyebode (2018), that even cultural and religious expectations to give care, do not always translate to a willingness to give care.

5.3 Living Alone with Dementia.

Persons living with dementia in this study live alone, but there are liaisons between people who live with dementia, their kin, non-kin carers, and formal carers in a network of support relationships. So, there is a link between people living alone with dementia and their kin who live away in the provision of care and support. This finding is in line with the work of Mirando-Costilo (2010), which reports that about one-third of all people with dementia live on their own. According to Pleschberger and Wosko (2017), some older people live alone and have instrumental needs that can only be met via physical contact. The trend is also reinforced by current government policy which aims to enable older people with care and support their need to live independently in their own homes (Alzheimer's Society, 2020).

According to the Alzheimer's Society (2023), the support network of a person who lives alone with dementia may include family, friends, neighbours, and professionals. However, this contrasts with the perspective of Barker (2002) who argues that "*despite the predominance of family, a significant proportion of dependent older people receive informal help from others and many older persons living with dementia lack kin to whom they might otherwise turn for assistance*". My finding also contrasts with the work of Herron and Rosenberg (2019) who argue that although rural communities are often associated with strong family and community support networks, most service users had limited tangible support from family or friends despite whether the family was geographically proximate or distant.

Findings in this study show that kin support remains a critical aspect of support for persons living with dementia. Although kin may live away from the person living with dementia, they are still part of a network of support. This is in line with the perspective of Carers UK (2019) and Parveen & Oyebode (2018) who argue that kin carers are still predominant in caring for older people in the community.

Persons who live with dementia in the community have instrumental needs, and on most occasions their needs can only be met by those physically available, especially in instances where their needs require urgent attention. "*Instrumental support refers to the assistance received from others that is tangible. It is comprised of the things that others physically do or provide to assist*" (Williams, 2021). My findings suggest that the emergence of neighbour non-kin carers in the care system is underpinned by the situations of the interviewees who live alone, but who are willing to accept support from neighbours, especially to meet their instrumental needs. According to Alzheimer's Society (2023) persons living with dementia can make choices about living alone or not, as some may choose to live alone because it makes them to feel happier and in control of their own homes. They may also live alone because their partners have died, they never had a partner or children or they may not have had family (Alzheimer's Society, 2023). These circumstances apply to my findings, as some of the persons who live with dementia live alone because their partners have passed away, and in some circumstances their family members (such as children) have married and moved out, although still contribute significantly to their support. Interviewee reports also indicate that some of the persons who live with dementia were never married. My finding in this regard therefore has some commonality with existing literature.

Living alone and loneliness are factors that cannot be ignored in the complex system of informal care. It is however worthy to note that living alone does not automatically mean loneliness. Internal family disagreements are known to contribute to the lonely living arrangements of persons living with dementia. There are instances in my study where internal family disagreement has led to the marginalisation of the person living with dementia. According to Odzakavic et al. (2019:2) isolation "*is a situation of being alone with absence of social interactions*" and loneliness is based on a "*perceived lack of social relations*". Loneliness has also been considered a basis for receiving social support as it promotes the self-esteem of caregivers, and enhances the health of persons living with dementia (Cho, 2007). This implies that neighbours may support each other because of the benefits in enhancing their self-esteem, as their support enhances the wellbeing of the person living with dementia.

According to an Alzheimer's Society (2019) report, older people living with dementia develop and/or have memory loss, which manifests in forgetting recent conversations and events, losing tasks, difficulties with day-to-day tasks and difficulty recognising faces. They also have delusions; "*believing things that aren't true*"; hallucinations- "*experiencing things that are not there*"; delirium, which causes them to become easily distracted and more confused; and apathy, depression, and anxiety (Alzheimer's Society, 2019:65-75). These conditions create needs that necessitate physical support and guidance. However, family members may live at a (sometimes far) distance; nevertheless, family members or kin carers still constitute a significant source of support of caregiving for the person living with dementia in the community by offering support through emails, phone calls and occasional visits. The situation is not expected to change soon as research suggests that single households will increase in European countries, and considering the link between dementia and ageing, the ageing population will include an increased percentage of those with dementia (Odzakavic et al., 2019).

Herron and Rosenberg (2019) argue that people who live with dementia identified a need to find people who understand dementia within the communities and some people who live with dementia are still uncomfortable about sharing their private health issues and seeking help either from neighbours or from the community. Even when they were offered support by neighbours, some refused the offer and maintained their independence and privacy and/or tried to maintain their independence and privacy. Some participants in my study expressed their independence even as they faced memory challenges because of their dementia condition.

According to Odzakovic et al, (2019:17) "*family connections were important in the sense of supporting people's existing social relations or creating new networks by making plans and organising opportunities to keep neighbourhood connections*". In my study family members helped to coordinate relationships and support despite living away within the neighbourhood. However, there is no evidence that they influenced the start of the neighbourly relationships. Instead, the connections between the person living with dementia and their neighbours commenced before kin became involved either because the neighbours approached them (kin) for clarification on issues relating to the support relationship, or their parent living with dementia told them about their neighbour carers. So, the “proximate alliances”, with neighbours were central to the caregiving relationship network, which includes kin. Parveen & Oyebode (2018) and Hera-Gunaratne et al. (2020) found that family carers still constitute a predominant percentage of carers of older people in the community. This confirms the findings in this study of a network of support including neighbours, formal carers and kin. The nature of the support they gave is discussed below.

5.4 The Nature of Support Given by Neighbours

The complex system of care giving in the community highlights the relevance of the hierarchical compensatory approach of caregiving which argues that older persons in need of support have preferences based on the primacy of the relationship between the caregiver and the older person receiving support (Messeri et al., 1993). The approach proffers that older persons prefer their spouses, children, relatives, friends and neighbours, and then formal groups (in that order) for assistance when in need of support. Although there is no proof of such ordered preferences in my study, persons living with dementia tend to accept support for varying reasons, and in some situations accept mixed support at the same time as the different caregivers bring different types of support, ranging from instrumental, monitoring, and coordination. The flexible schedules of non-kin caregivers particularly suited them when providing care at night or weekends when formal services or family were not available. This echoes previous research findings by Nocon & Pearson (2002) and Barker (2002).

Interviewee narratives in my study described readiness to give all kinds of support, including instrumental and emotional. My findings regarding the diverse nature of the support that neighbour care givers give contrasts with previous studies that limited the nature of support that neighbours give to monitoring, shopping, errands, yard work, and home maintenance (Lapierre & Keating, 2013; Wenger, 1990; Nocon & Pearson, 2000). Although I found that neighbours may also provide support for personal care tasks, including money management, it has been argued that given privacy norms between neighbours, such care would not be provided by neighbours as it would violate their privacy norms (Lapierre & Keating, 2013:1447-1448). However, non-kin carers like neighbours have been referred to as generalists that provide support regardless of the task (Cantor & Brennan, 2000; Lapierre & Keating, 2013). This later description of nature of support given by neighbours resonates more with the findings of my study. Nevertheless, the social norms of distance and privacy associated with neighbour relationships may not only limit the tasks they perform for their neighbours in need of support, but also the hours so as not to be seen as intruding on their neighbours' lives (Lapierre & Keating, 2013). The study by Herron and Rosenberg, (2019) also aligns with the conclusions of Cantor and Brennan (2000); according to Herron and Rosenberg (2019) informal carers are also referred to as partners in care, and provide the bulk of care to people living with dementia across a range of community settings. The "bulk of care" signifies that they provide varied types of care and support. This is in contrast with the findings of Laing and Flowers (2018) and Li & Son (2019) which limits the nature and extent of neighbour support. I found no evidence that neighbours are expected to provide any care. The care they give depends on the needs of the person living with dementia, and if they are unable to provide support, they monitor and coordinate the provision of such support by others. However, they are inclined to give instrumental support because of their physical presence and proximity to the person living with dementia.

This means that, depending on the needs of the person living with dementia, neighbours play diverse roles. The types of support they give are shaped by the dementia condition of the person living with dementia (Pleschberger & Wosko, 2017). The diverse types and levels of support they give mean that, generally, the needs of the persons living with dementia determine the nature of the support given in the context of other available caregivers, including kin and formal caregivers.

Having neighbours willing to support a person living with dementia could be very helpful, as they may offer support with practical or instrumental needs which they may find difficult to achieve because of their dementia condition. The nature of support could include looking out for the person's wellbeing, being there to speak to, or spending time with the person living with dementia (Alzheimer's Society, 2023). Some of the neighbour participants in this study give emotional support to their neighbours living with dementia in form of visiting them daily, talking with them, and liaising with their families to provide support.

Dementia is a progressive degenerative disease and as it progresses, the need for constant close support with everyday activities increases as those living with the disease require sustained and sometimes constant care (Heron & Rosenberg, 2019). This means that neighbourly relations are contextual rather than prescriptive, addressing issues in the situations that arise instead of following norms about what neighbours do and do not do. My findings are generally in line with this position because neighbour carers selflessly worked to meet the needs of their neighbour persons living with dementia as their needs arose, rather than prescribing what they wanted to do or not do.

Previous researchers have differentiated the nature of the support given by different types of non-kin carers like friends and neighbours (Nocon & Pearson, 2000; Barker, 2002; Lapierre & Keating, 2013; Pleschberger & Wosko, 2017). As diverse as the support from neighbours may be, my analysis finds that across most caregiving domains, neighbours give wide-ranging support that helps the person living with dementia to remain in their own home, rather than being moved to residential homes. This means that their support has helped the persons living with dementia to continue to live in the community rather than in a residential home. This also means that the empathy, love, and compassion that neighbour carers bring help persons living with dementia to postpone, often permanently, a move to a care home. However, a recent study of dementia-friendly neighbourhoods in Canada argued that neighbours have not played any role in supporting caregiving (Silverman, 2020). According to the report, neighbours are nice and friendly enough, but they are not friends. But some other participants in the same study reported a heavy dependency on neighbour caregivers and concluded that neighbours provided an extra set of eyes and ears (Silverman, 2020).

Other determinants of the nature of tasks performed and the overall relationships are: the availability of the caregiver, the extent of familiarity, the motivation for caregiving, the preferences of the person living with dementia, and the extent of the caregivers' burden. Availability is vital in the caregiving relationship because the caregiver must at least be physically available, especially to give instrumental support. This means that proximity to the person living with dementia is also vital because it facilitates physical availability. Familiarity is also very germane, because if the caregiver and person living with dementia have similar lifestyles, behaviours, characteristics, and knowledge of each other the caregiving relationship will be more stable and acceptable to each other

(Cho, 2007). In this study, familiarity was developed over a long period, and often before one neighbour developed the need for support. Neighbours were family friends with their neighbour living with dementia before they developed dementia.

My findings suggest that neighbour carers are motivated by the need to help, compassion, and a sense of community and altruism. In the process of giving care and support, they develop special caring skills for their neighbour living with dementia and help to manage their condition. According to Cho (2007), the motivation of informal caregivers and the preferences of persons living with dementia, alongside knowledge about dementia caregiving determine to a large extent the tasks they feel available to give. They argue that persons living with dementia have different care preferences, and they want different caregivers to perform tasks for them. Some may want their kin neither to manage their finance, nor attend to their personal care. Their preferences may also depend on family dynamics, feuds, or attachment. The point is that the person living with dementia could have a closer social attachment with a neighbour or friend, and hence more trust and confidence in them for caring needs than with family members.

As indicated, some of the relationships may have already developed before the person living with dementia needed support. The caring process identified in this study is complex and context-specific because of the care preferences of the person living with dementia. The complexity is not merely related to the time devoted to caring, but the constant negotiation of competing and conflicting times for caring and meeting personal needs that resonate across family, the care system, the medical system, bureaucracy, and the workspace. According to Sing et al, (2015:8) "*the caring process is complex and interactive, rather than predictable and linear*". I found that neighbour carers liaise with family kin carers who in all cases in this research live away from the person living with dementia. The family kin carers act as mobilisers and coordinators of the entire care system that support their parents, while neighbour carers constantly negotiate conflicting time demands as they take care of their neighbours who live with dementia (Singh et al., 2015). However, kin family carers are known to live with and provide care to their older relatives living with dementia, without needing non kin carers such as neighbours (Herat-Gunaratne et al., 2020; Parveen & Oyebode, 2018).

The provision of support varies across primary, informal, and formal groups (Cho, 2007); spouses live together with face-to-face contact and provide long term relationships, while although neighbours live close by and have face to face contact, they tend not to provide long term commitments. This seems not to be true with this study as neighbour participants have consistently provided support for their neighbours living with dementia without any break, as their neighbour living with dementia became in need of support. The extent and longevity of neighbour care giving therefore varies according to different cultures and geographical areas. Cho's study was conducted in Philadelphia in the United States.

The availability to give support is a major element of the neighbour caregiving relationship. This means that proximity, commitment, attachment, and bonding are vital factors that make informal caregivers - including neighbour caregiving - possible. Caregivers are therefore often expected to be available for task-specific roles regardless of both duration and intensity (Cho, 2007).

Informal caregiving has been described in terms of the activity or tasks to assist with needs, especially physical and psychological needs, which have been categorised as anticipatory, preventative, supervisory, instrumental, and protective (Bowers, 1987). The nature of support in the caregiving experiences of the participants of this study reflect the different care as described. Neighbour caregiving is in some cases complemented by formal and kin carers. Most of the kin carers involved coordinated the entire support system and helped to coordinate the informal timetable of care inputs of formal, kin, and non-kin carers to ensure that there were no gaps in the caregiving routines. This reflects the nature of the needs of the persons living with dementia.

One important feature of the role played by neighbour carers is that they are physically available most of the time. Some neighbours were even available when the formal carers were giving support. This makes their role essential, especially because the person living with dementia trusts and has confidence in them. In most cases, neighbours are motivated to provide any support, save for limitations like age, but would coordinate and monitor until the task is performed by another carer within the complex care system.

Neighbour caregivers are generally part of a complex care system that also comprises kin and formal carers, and they provide flexible support that suits the persons living with dementia, which supplements the time rigid support provided by formal and kin carers. According to Barker (2002), where family members are available, they undertake other tasks like laundry, shopping, paperwork, and gardening. This is in line with the roles performed by kin carers in this study. Some kin carers manage the finance, paperwork, bills, bank statements, and legal documents of their parents.

It has been argued that stigma, fear, and a mistrust of formal services are possible explanations for the low rate of help-seeking from formal services. Minority ethnic persons living with dementia may not also seek formal support but prefer informal care because of a fear of moving to long term care. (Blakemore et al., 2018; Herat-Gunaratne et al., 2019). People of a minority ethnic origin also find meaning and identity from their cultural and ethnic heritage, and Kitwood's model of personhood described dementia as a socially embedded phenomenon with functioning and wellbeing determined by the interactions of a person's neurological condition and their social environment (Kitwood, 1997; Herat-Gunaratne et al., 2019:). This means that carers', especially non-kin carers', cultural identities and values influence their experiences, the negotiation of their caring role, and the overall relationship with their person living with dementia. Their values determine what they can tolerate, refuse or reject in the care relationships.

5.5 Complexity of Care and Support Relationships

My findings illustrate a complex care system comprised of kin or family carers, formal or domiciliary carers and non-kin carers like neighbours. They also suggest a care system where the preferences, wishes and values of the persons living with dementia tend to constitute the major determinants of not only the support they receive but the source of the support. Moreover, physical availability and the proximity of caregivers to the person living with dementia are also significant factors in the determination of support given or received. This means that informal caregiving like neighbour support should be considered in the context of other care providers like family kin and formal carers. In England, formal paid carers usually come from the social services of local authorities and health institutions following a section nine assessment under the Care Act 2014.

The complexity of dementia caregiving was also captured by the “Anderson Model” which was used in a recent study to determine equitable access to dementia care in Europe. Referring to formal caregiving, the study reports that “*when care is received, it is not of the right type, and possible reasons for inequality of care services arise from differences in availability, quality, costs, and information for different population groups*” (Kerpershoek et al., 2020:45). Kerpershoek et al. (2020) concludes that the “*number of hours spent on care, and factors like lone living and disease severity are important predictors of service use*”. This is in line with the argument that dependence on informal caregivers by persons living with dementia impacts their acceptance of formal support.

It also implies that unavailability, high costs (in terms of contributions to the cost of care), and the poor quality of formal care limits the acceptance of formal care by persons living with dementia, while the generosity of informal care, loneliness, and the extent and severity of need determine the use of services. This means that different factors are at play as to who determines the care and support provided, and who provides them. This is evident in the report by Herron and Rosenberg (2019) which states that the compatibility of home care in terms of eligibility, scheduling, consistency, and quality of workers affects its use over time. Persons living with dementia are said to be frustrated with formal carers showing up late or leaving early to get to other care appointments. Moreover, the portion of 24 hours in which formal carers can give support seems also to be significant, because “*although persons living with dementia felt happy with wandering during the day, they were concerned about falling at night when they felt they would not call neighbours or other family members to help them get off the floor*” (Herron & Rosenberg, 2019:350).

Another element that contributes to the complexity of the caregiving relationship is the nature of the stress associated with caring for a person living with dementia. According to Lilleheie et al. (2021), the burden of care describes the physical, emotional, social, and financial problems that can be experienced by informal caregivers and have been broadly classified into two dimensions: objective and subjective. The objective burden refers to the physical impacts of daily tasks undertaken like the time invested by the caregiver, helping, supervising, and feeding a person living with dementia. The subjective burden refers to the psychological, social, and emotional impact caregivers may experience from the objective burden of caregiving.

My findings suggest that caregiving by neighbours comes with a serious burden in the form of stress, and neighbour carers would benefit from respite in their caring role. However, this does not normally happen as most do not consider themselves carers, and are sometimes not factored in as such by social services. Because dementia is a progressive degenerative disease, the impacts on the caregiver with regard to the care burden are immense as the person living with dementia deteriorates. The care burden relates to the stress and costs that accompany caring for someone in need of support. According to Ory et al. (1999), dementia caregivers report more stress and depression than caregivers for other conditions. A high level of informal caring hours may increase social isolation and confinement for the carer. The level of stress could also be exacerbated by broader socio-political contexts and put pressure on informal carers to provide support (Lilly et al., 2012). This means that the intensity, frequency, and duration of caring for someone living with dementia are often associated with burn-out among informal non-kin carers.

Previous researchers have reported the negative effects of caregiving on caregivers, including the emotional, health, social, and financial problems they experience. These are categorised as caregiver burdens and stress. The physical and mental health strains associated with caregiving and mortality risks of caregivers have been rated much "*higher than non-caregiving controls*" (Cho, 2007:4). Part of the difficulty that informal carers face is learning how to navigate the system i.e., the government and formal care system; finding people who understand dementia; seeking support at home; negotiating respite to get themselves some form of relief from their caring role; negotiating resistance to care, and helping to make decisions about end of life and long-term care (Herron & Rosenberg, 2019).

Considering the extent and level of commitment of non-kin neighbour carers, they also need respite and emotional support in their caring role. This must be recognised by relevant authorities, and informal non-kin carers must therefore be factored into carers' assessments and support provisions. However, some neighbour carers see burden as a necessary cost of caregiving. The complexity of caregiving is also attributable to how non-kin caregivers balance the time to meet their personal needs with time for giving support to neighbours.

The neighbour carer participants in this study are not only caring for persons living with dementia, but also trying to balance the caring role with their work, caring for a family member, caring for a child, actively participating in community organisations including memory cafés, and/or mutually supporting a spouse, aspiring to be a student or being a student. Most have juggled two or more of these statuses between 5 to 30 years. Juggling these complex relationships create tension and can also be burdensome to non-kin carers like neighbour caregivers. Sometimes they get it right, sometimes they do not, and it becomes stressful and overwhelming for them.

Non-kin neighbour carers act as sole carers for their persons living with dementia in some cases, but also as supplementary carers to formal support, and meet needs left unmet by both formal and kin carers. They are more eager to take on any tasks than paid professionals or family carers and perform the roles flexibly and at times convenient to the persons living with dementia. This also means that they are eager to adjust their caregiving times to accommodate the needs of the persons living with dementia, especially those unmet by kin and formal carers.

In addition to the neighbour caregiving role, most of the participants referred to the presence or failure of formal caregivers. The formal caregivers gave domiciliary support, and some were professionals from the NHS (National Health Service) who diagnosed the person living with dementia and performed case management. The different support subsystems were supplementary to each other and most of the formal support was clinical (complementary) while others were given by non-kin carers like neighbours and kin carers. This resonates with the finding of Li and Song (2019) who argue that the nature of support provided is both complementary and supplementary. The complementary model refers to formal care providing service beyond the informal caregiver’s expertise and capability, and supplementary is where formal and informal care provide similar services. While the family kin support system has evolved, non-kin support from neighbours may be increasing to supplement formal and kin support services. Complementary support is said to enable professionals to focus on specialist clinical support like medication prescription and review, while informal support from non-kin, like neighbours, engages in emotional and instrumental support.

Neighbours bear some of the burdens for delivering care, and because the support they give is discretionary, any alleviation of the burden is achieved by their own internal social and family mechanisms. They are supported by their family members to help care for and support their neighbours. Without this support, they would have met their caring roles with much more difficultly. This means that the support they receive from family members is a form of relief from the care burden. Caregiving relationships are complex, but the roles of neighbour carers have helped to balance the caregiving relationship from the perspective of informal caregiving.

5.6 Reciprocity of Care Relationships

Interviewees' descriptions of their motivations for caring for their neighbours living with dementia and the rewards they expect from the relationship, point to a selfless and altruistic care giving relationship, and reciprocity tilted in favour of the persons living with dementia. According to Reid et al (2005:186), "*a relationship is defined as reciprocal if the benefits of each party are approximately proportional or equal to their contributions*". The importance of reciprocity may depend on motivational factors, so reciprocity reflects a motivational drive, and the strength of the drive depends on the goal orientation of the individual (Reid et al, 2005).

My findings suggest that reciprocity is one-sided in favour of the persons living with dementia in the caregiving relationship. Reciprocity, in terms of mutual, complementary, shared help and advantages, in dementia caregiving relationships is one-sided in favour of the persons living with dementia. According to Lang and Fowers, (2018) the one-sided nature of informal dementia caregiving is said to increase as the person living with dementia becomes less able to reciprocate benefits because of the degenerative nature of their condition. The imbalanced nature of the caregiving is also reinforced because caregivers are often determined not to accept any form of favour in return for their caregiving.

Attempts to explain the one-sided nature of dementia caregiving can be found in theories of direct and indirect reciprocity. There is evidence that although direct reciprocity views altruism as problematic and assumes that cost-benefit is inevitable in relationships, it fails to explain long term caregiving, especially for persons with dementia because the cost-benefit ratio is unbalanced in favour of the person living with dementia. The one-sided nature of dementia care relationships has also been described as grounded in the personal characteristics of the person living with dementia (Lang & Fowers, 2018). It is not clear what this means but findings from my study do not suggest any behaviour by persons living with dementia that alludes to entitlement to the care they receive. My study found that persons living with dementia sometimes try to give back the favour in one way or the other, but their efforts are often rejected by the care givers (Pleschberger & Wosko, 2018).

To fully understand reciprocity in caregiving relationships, it is necessary to examine the motivation of carers. Many caregivers view their caregiving role as expressions of love and compassion, and a demonstration of their culture and religious belief in being their “brother’s keeper” (Lang & Flowers, 2018; Parveen & Oyebode, 2018). However, Pleschberger and Wosko (2017:) reported that those who have nothing to offer may be at high risk of getting no support. My findings relate more to the former than the latter, as neighbour carers viewed their support as contributing to the community and society, and hence do not request or expect any form of reciprocity from the persons living with dementia. However, the caregiving efforts of the caregiver have also been viewed in terms of helping to enhance their reputation and dignity in the community, thereby increasing their social status (Lang & Fowers, 2018).

The shared identity theory illustrates and argues that the value of the care relationship is more prominent and overshadows any beneficial individual outcomes (Lang & Flower, 2018). The theory focuses on human motivation to support and benefit others because of their mutual commitment, shared identity, and shared goals. In other words, any attempt to understand the motivations behind caregiving by neighbours to persons living with dementia in the community requires an appreciation of the “*deep and meaningful motivations that often inspire the humanity seen in caregiving*” (Lang & Flower, 2018:1). This statement underscores the motivation of neighbour care givers to care for their neighbour living with dementia.

There is also the view that caregiving operates as a means-end activity, whereby the actions are differentiable from their ends (Lang & Flowers, 2018). However, it is important to determine what the ends are. Some neighbour carer participants in this study view the ends, not in financial terms or any other form of reward, but as selflessness, compassion, a sense of duty, and cultural and religious fulfilment. A sense of community spirit is in line with the principles and argument of Holmes (2013), who argued that communally oriented people are more interested in meeting the needs of others but expect others (not necessarily the individual they supported), to also support them to meet their own needs. This contrasts with the assumptions of an exchange orientation approach, in which a caregiver expects a direct reward or benefit for the time and service given. Furthermore, it is more plausible to conclude that the motivation for long term caregiving emanates more from "*commitment, shared history, and attachment, rather than benefits to the caregiver*" (Lang & Flower, 2018:4). According to Suanet et al. (2019) non-kin caregiving relationships might be more dependent on reciprocity, and family relationships are expected to be more dependent on normative obligations and emotional closeness for support and care, especially if it involves intensive and prolonged caregiving. The above assumptions are problematic considering the level of altruism, sacrifice, and selflessness on the part of non-kin neighbour carers, while the one-sided nature of the caregiving relationship has already been identified as caring for persons living with dementia in the community.

The assumption that kin relationships are less dependent on reciprocity is also problematic as kin carers have been found to be motivated by financial gains and other benefits. In other words, it is not always the case that normative expectations regarding family support make their relationships less dependent on reciprocity. According to Knipe (2015:1) "*financial abuse is one of most prevalent forms of abuse in the UK amongst older people; and abusers can be family members*." An older person may be forced to sign a new will under duress. A continually reinforced threat to no longer visit an older person relative is also considered abusive. It is therefore clear that the care relationship here is not based on normative obligations and emotional closeness for support and care.

In a study by Trip et al. (2020), what constitutes family involved connections and experiences which were informed by memories, or the qualities expected of family members. Those who were biologically family members were not considered as family because they did not visit the person living with dementia. What constitutes family involved connections and experiences which were informed by memories, or the qualities expected of family members. This meant that the roles of those considered as a family are dynamic and cannot be viewed through a linear lens; this shows that reciprocity rather than normative obligations could prevail more in kin/family relations because even biological kin carers could be viewed as non-family members if they do not act or behave in accordance with the persons living with dementia's expectations. Being kin is dynamic and not automatic. This means that reciprocating relationships are based on what constitutes family, and the responsibilities are inherent or expected of its members. Non-kin neighbour carers in this study would be considered as family members by their person living with dementia because they are meeting the expectations of the person living with dementia by visiting, making contact, and giving support and care.

I found that material reciprocity featured as unthinkable as participants proactively tried to demonstrate that their engagement with the person living with dementia is devoid of any motivation for material gains. This contrasts with the work of Pleschberger and Wosko (2017:564), who argued that those who have nothing to offer may be at risk of getting no support. None of the neighbour caregiver participants raised any issues about financial costs or the expenses they incurred as part of caring for their neighbours living with dementia. Carers like neighbour carers do not identify as such; instead, they simply do what they believe is right (Cummings, 2021). So, the case of taking money (i.e., material reciprocity) was avoided and rejected, and references were made instead to emotional reciprocity like gratefulness, giving back to the community, and other cultural reasons (Pleschberger & Wosko, 2017). The neighbour caregivers spoke in terms of natural expectations and a duty to care even though they were caring for neighbours rather than parents, which would have been viewed in terms of reciprocity of parental care given earlier in their lives. So, the relationship could be said to be a form of fictive family relations. According to Barker (2002:165) "*the relationship had a family-like quality*".

5.7 Tensions that Arise in Neighbour Care Relationships

Interviewees' narratives described a high level of stress and burden in the dementia care giving relationships. Tensions are noted in the mental and emotional strains that can arise during the caregiving relationship. These can arise in caregiving relationships because of varying reasons including the stress associated with caregiving, pressures from financial difficulties, and conflicts and frictions within the care networks.

I found that tensions arose between neighbour carers and their neighbours living with dementia over disagreements about care plans, assessments, and the delivery of care plans. Some of the tensions also arise due to financial pressure on the persons living with dementia over the management of finance/benefits, completing paperwork including the Department of Works Pensions benefits paperwork. According to Knipe (2015), financial abuse is one of the most prevalent forms of abuse in the UK against older people, and it often involves stealing money or possessions from a vulnerable individual for one's benefit. When older adults living with dementia are exploited by their carers it creates tensions in the caregiving relationship especially when the person living with dementia becomes aware of the abuse. Some of the cases of financial abuse have been subject to safeguarding and court cases (Knipe, 2015). Money is a focus of stress or source of guilt (Zhang & Clark, 2019), and a lack of money means worry, financial dependence, and insecurity.

Other sources of pressure include issues arising from the dementia condition/symptoms. A person living with dementia may find communication difficult, and the difficulty may cause the person to lose confidence or withdraw from social institutions (Alzheimer's Society, 2015:3). The point here is that families, friends, and neighbour carers may find that these difficulties are frustrating and can increase stress. To help resolve this, friends, family and neighbour carers should support the person to do things for themselves rather than "take over" (Alzheimer's Society, 2015). This is a way to resolve such communication difficulties, induced tension.

Other sources of tension in dementia caregiving relationships include the lack of understanding of dementia, social stigma, and limited support services (Zhang & Clarke, 2019). Stigmatisation may come from the family, community, or health professionals and "*stigma and discrimination leaves people living with dementia feeling lonely and isolated*" (Zhang & Clark, 2019:2). This means that when person living with dementia is not supported in a person-centred manner and their opinion is not considered in the care relationship, they will naturally feel marginalised, and this is likely to cause distress and tension between the person living with dementia and their care networks, as they feel unwanted and humiliated. This also means that the social attitude of stigmatisation creates feelings of disconnection and estrangement for people living with dementia (Clark & Bailey, 2016). Moreover, the knowledge that the dementia condition is degenerative can be distressing over time for people living with the condition. They are at risk of hopelessness and desperation as the general opinion from professionals they encounter is that it is progressive and there is no cure. In other words, the decline is inevitable (Zhang & Clark, 2019). Neighbour carers are engaged in other roles and activities and try to balance these to meet the needs of the neighbour living with dementia.

All neighbour care participants in this study are not only caring for older people living with dementia, they are also involved in multiple other roles and activities in families and the community. Most have tried to balance two or more of these statuses for several years while also supporting a neighbour. As indicated, this could also be a source of tension as they try to meet the needs and demands of the different roles.

Nevertheless, in general, participants did not express the intention to stop support as the condition of their neighbour living with dementia deteriorates. Instead, they felt more compassionate and eager to fill any needs arising from the deterioration. According to Barker (2002:165), "*caregivers fondly sustained relationships with people with increasing mental fragility or those with difficult personalities because of warm memories of the past sentiments and rewarding activities*." This means that the bond built over time before the person living with dementia developed the condition that necessitated the care and support which has sustained the relationship as needs increased. The findings particularly highlighted the extent of the struggle and burden borne by neighbour non-kin carers in the community.

5.8 Gender Factor in Care Giving Relationships

My findings suggest a predominance of female carers in the informal care system. Although the recruitment of participants in this study was conducted purposefully, the gender composition shows that females were predominant, as only one of the seven neighbour carers interviewed was male. This suggests that female carers are not just kin family members but non-kin neighbour carers. According to Odzakovic et al. (2019:21) there is a gendered difference in people's relationships when living in solitude and with dementia.

There are theories that attribute the predominance of female carers to the fact that women are likely to be exposed to caregiving stressors and are likely to cope with the stressors differently from men. However, it is not clear why woman are likely to be exposed to greater care giving stressors. Nevertheless, females are expected to experience a greater caregiving burden, greater physical and material strain, and a very high level of psychological distress associated with the provision of care (Sharma et al., 2016). Over half of persons living with dementia are still cared for by their family members, and in most cases the carers are females (spouses and daughters). This reflects the findings of a related study conducted in Ireland where daughters and daughters-in-law of care recipients dominate as carers (O'Connor, 1998). Moreover, Barker (2002:168) argued that "*family, especially wives, daughters and daughter's in-law comprise most people providing care and assistance for frail older people*." This means that female gender role dominance in care and support, persists. This finding is inconsistent with the finding by Perren et al. (2004) that older men are significantly more likely to support neighbours than female neighbours. Throughout the western world, family caregiving remains a gendered issue with women significantly outnumbering men in care roles (Begley & Cahill, 2003).

Further attempts have been made to explain why women are predominant in non-kin caregiving. It has been argued that females take up the roles incrementally, whilst men do not do the same, and the trend was not challenged. According to the study, caregiving was taken on incrementally in the absence of any family discussion, but prior filial ties, co-residency and geographical proximity were proffered as the main reasons why women became the primary caregivers. The roles of men were found to be peripheral and were not questioned by family members (Begley & Cahill, 2003). However, there are contesting views as men are linked to some level of burden, although smaller in magnitude compared to females. Some other studies claim that although there may be differences, they are small in magnitude, and some of the studies have no difference in terms of ratio, between male and female caregivers. They argue that the predominance of females is only identifiable in those who care for people who have dementia, disregarding those who care for people who have schizophrenia (Sharma et al, 2016). It is believed that the experiences of men in caregiving have not been fully appreciated and explored.

Gender differences may also be linked to methodological variations associated with sampling, design, and the mode of assessments; however, for my research the recruitment of participants was purposeful, yet all but one of the caregivers are females. Li and Song (2019:4-5) tried to explain the prevalence of daughter kin carers in the care of their parents and argued that "*adult caregiver may also be a wife and a mother at the same time and are more likely to divide their efforts between taking care of their ageing parents and providing support to their children*". This position means that while marriage is a contributory factor to loneliness and the physical absence of kin carers, daughters still find time to care for their older adult parents. This resonates with the work by Haberkern et al. (2015) which reports that gender differences in providing intergenerational informal care persist: adult daughters give more in informal care than adult sons.

To conclude, my study has given insight and understanding of the nature of non-kin dementia caregiving by neighbours in the community. The study has shown that neighbour carers are very likely to have been in neighbourly relationships with the person living with dementia before the need to provide support and they are motivated by selflessness and a sense of community. The study also shows that neighbours are more likely to be involved in dementia caregiving because of the instrumental nature of the care needs of the older person living with dementia whom they support, and because of the physical absence of kin carers. I have also demonstrated that neighbour caregivers offer diverse support, they are not restricted to any type of support, and their role sometimes supplements formal and kin support. I have also shown that reciprocity of support is unbalanced in favour of the person living with dementia. The study also highlights that tensions could arise in the relationship because of caregiving stress, privacy, and boundary issues. I have also elucidated some experiential aspects of gender caring.

5.9 Chapter Summary

In summary, I have demonstrated that the processes that lead to neighbour dementia support giving, the motivation to support, the nature of the support given, the reciprocity and complexity of care, and tensions in the dementia support system, reflect the nature of the dementia-related needs associated with older people living with dementia in the community. These have implications for policy, practice, and planning for dementia care, which is significant considering the rising number of older people living with dementia in the community and the subsequent rising cost of dementia care.

In the final chapter, I discuss the conclusions, key contributions of the research findings in relation to policy, dementia care giving, social work practice and neighbour care giving. I also discuss the limitations of my study and make recommendations for future research.

6 Conclusion and Recommendations

This concluding chapter represents the final stage of this research and has been structured to show the implications of the investigation of the research questions, and the significance of my findings in relation to neighbour care giving relationships. I have therefore presented the summary of the study, key contributions of the research, recommendations, implications for and limitations of the research, and recommendations for future research.

6.1 Summary of Study

In this study, I have examined the role of neighbours in providing support and care to older people living with dementia in their own homes. It has presented original data and analysis of the relationship between neighbour caregivers and people living with dementia in their homes. This thesis has also presented new insights into the processes that lead to neighbourliness, the associated motivations, the nature of the support given, the complexity and burden of informal caregiving, and the tensions that may arise during the relationships. It has also highlighted the nature of predominance of a particular gender in support giving.

My argument is that neighbour dementia care giving is not adequately understood which leaves a huge gap in understanding the intricacies of informal care giving. It is also predicated on the notion that previous studies on informal care were centred on kin care relationships, and this has left non-kin care relationships less understood, while the care and support provided by friends and neighbours are often viewed as peripheral and inconsequential (Barker, 2002; Nocon & Pearson, 2000; Lapierre & Keating, 2013).

This is one of a limited number of studies that have explored the role of neighbours as informal non-kin carers, and the research has addressed research questions including:

- How do neighbour caregiving relationships develop in the context of a need to provide informal support or care for older adults living with dementia in the community?
- What are the motivations for such informal relationships?

- What tensions can arise in such relationships and how might these be addressed?
- How does this support or care fit within a wider network of household and family members, as well as formal and third sector support and care providers?

The justification for the study was also based on the need to reduce the gap in literature on informal care relationships in the context of dementia care giving, and the need to help inform decisions and policy on informal care giving and highlight the relationships between ageing, dementia, and informal care. My study is also justified because it helps to bring a fresh perspective on informal care giving, and how it could be sustained.

This study was predicated on person centred framework, so was anchored on Kitwood's model of personhood, which views and describes dementia as a socially embedded phenomenon with functioning and wellbeing determined by the interactions of a person's neurological impairment and their social environment (Kitwood, 1997). The data collection and analysis produced themes that gave an insight into the processes of attachment and bonding between neighbours before the need for care. It also addressed the process of change in role from neighbour to caregiver; the issue of physical absence of kin support of the people living with dementia, and the delivery of diverse levels of support to neighbour persons living with dementia as part of highly complex caregiving networks of kin and formal carers involved in different levels of relationships. My findings also highlight the nature of reciprocity of support and the nature of tensions that may arise in the relationships, and the nature of gender differences in care relationships.

This research gives an insight into the person-centred nature of neighbour caregiving, as it highlights the nature of dialogue, consent and mutual respect inherent in the caregiving relationships; this has implications for the development of strategies and plans for relating with neighbour caregivers to sustain their invaluable caregiving roles. It also means that the least restrictive approach of caregiving is central to neighbour care. The least restrictive model of care enhances an older person's autonomy and respects their rights, individual worth, dignity and privacy. Limitations on support for the older adult should be the minimum necessary and allow them to participate as much as possible in all that affects them (Sykes, 2003; Least Restrictive Practice, 2021). This also means keeping a safe boundary, treating non-kin carers with respect, and working with them and with persons living with dementia in an anti-oppressive and anti-discriminatory manner, as well as respecting their views and not marginalising them in decision making.

Neighbour caregiving develops through bonding and attachment before the development of the need for care. This research also highlights and enhances understanding about the motivations associated with non-kin informal caregiving. While neighbour carer’s motivations may be driven by selflessness, community service and culture, the complexity of the non-kin care system is derived from the multiplicity of different actors in different informal caregiving contexts. (Boer, 2016). While neighbours constitute a significant source of informal care giving, they provide this in the context of other caregivers in complex caregiving relationships.

None of the neighbour participants in this study wanted to be rewarded in any manner for their roles as neighbour carers. My study found that reciprocity is tilted in favour of older adults receiving support. The debate and reforms on care in the community have meant a cut back in professional support for people living with dementia who need help while living in their own homes. I also found risks and burdens (time, financial costs, supporting other people including the neighbour’s family) associated with caring for older people living with dementia. Therefore, it will be crucial to identify non-kin carers like neighbours, and to assess and put measures in place to mitigate their care burden and help to sustain the caregiving relationship.

Caregiving relationships seem to develop selflessly as they are not motivated by monetary or other incentives and support is altruistically given without any expectation of any form of reciprocity (Graham & Brownie, 2018). In other words, neighbour dementia care giving is driven by altruism, compassion, community-spirit, culture, religious beliefs, and practices and undertaken without expectation of reward. Finally, my findings concur with Boer (2016), who argued that individuals are less dependent solely on their family for emotional and socio-economic support; instead, friendships have gained importance, and friends and neighbours are becoming family in a network of fictive kin.

6.2 Key Contributions of the Study

This study adds to literature on the nature of relationships that exist between neighbours and older adults living with dementia in the community in the context of the need for informal caregiving. It has therefore contributed to existing knowledge and helps to highlight the impact and role of neighbours on the wellbeing and continued community living of older people living with dementia. The study helps to focus on the side-lined role of non-kin support in providing care to older adults in the community.

This study helps to highlight that the support neighbours provide is not peripheral and inconsequential and shows that neighbour carers selflessly provide varying types and levels of care and support. According to Barker (2002), despite the importance of non-kin care to the daily wellbeing of older people living with dementia in the community, few investigators have undertaken a sustained examination of non-kin dementia care relationships. When informal carers like neighbours are mentioned there is little or no reference to or study of the experiences of neighbours caring and supporting older adults living with dementia. To this end, this study helps to provide more evidence for a better understanding of the experiences of support provision by neighbours to older adults living with dementia in their own homes.

This study also contributes to knowledge by providing more insight into how neighbour caregiving relationships develop in the context of the need to provide support for older neighbours living with dementia. My findings show that the process of transition from neighbourly relationships to neighbourliness predates the condition that necessitates the need for support of an older neighbour. This study therefore helps to highlight that the relationships between neighbour non-kin carers predate the caregiving relationship in form of bonding and attachment. The neighbour carer is not alone but works closely with kin and formal carers.

My study also contributes to knowledge because it provides insight into the nature of tensions that may arise during neighbourly relationships and how these can be resolved. These findings reflect those of previous studies those of Lapierre and Keating (2012) who argued that non-kin care/support is not adequately understood, and this leaves a gap in understanding the intricacies of informal caregiving.

This study helps to highlight that acts of neighbourliness constitute one source of support in the complex care system. Other sources of care are family (kin), and formal sources of support. The expectation is that family is the resource on which people should rely in old age, and this underlies much of social policy and the provision of services for older people. Although the family is still a major source of support for their vulnerable members, many have exhausted family resources, and in a large part receive support from a variety of other sources as well as paid professionals (Barker, 2002). This study presents evidence that neighbour carers constitute a source of support for older people living with dementia in the community. Seven percent of people living with dementia in the UK aim to recruit a carer where one is available (Eicher et al., 2016). In this context, my study contributes to knowledge by helping to highlight that non-kin carers like neighbours are part of the system that also comprises kin and formal carers. As a result, my study provides further insight into the complex nature of carer networks in which neighbour support thrives.

My study helps to demonstrate that although older adults living with dementia may be living alone, they may not be isolated as they continue to meaningfully connect with their neighbours. In doing so, the work contributes to the process of developing dementia-friendly communities because it highlights the importance of neighbourly relations and neighbourliness in dementia care. This means that the study helps to point to the importance of social networking and the use of local resources. According to Odzakovic et al. (2019), the success of emerging dementia friendly communities will depend on how those who live alone are enabled to thrive alongside their neighbours.

This study has helped to provide insight into how the strengths-based practice perspective to social work practice could be reinforced and applied. According to SCIE (2021), strengths-based approaches focus on individuals’ strengths, including their personal strengths, and social and community networks and not on their deficits. This study therefore rekindles and refocuses practice on the transformative principles associated with the strength perspective (School of Social Welfare, 2021). The source of that capacity and resilience can be found in the social networks from which the individual draws some social strength and capital, which includes support from neighbours. According to Odzakovic et al. (2019:20) and Innes (2008), there is a need to look beyond the biomedical model that currently frames the care and treatment of individuals with dementia. There are therefore important roles to be played by neighbours, community groups, and friends, in supporting older people living with dementia in the community to improve their wellbeing and dignity.

My study has helped to provide more momentum and drive towards a better understanding of neighbour care relationships and has added to knowledge about neighbourly relations in the context of dementia care. Finally, my study explored and provided an insight into the processes that lead to neighbourliness, the gendered nature of the support relationship, the solitude of older adults living with dementia in the community, the nature of the support given, reciprocity in the relationship, and the nature of tensions that may arise in such relationships.

6.3 Recommendations and Implications of Study

A distinctive understanding of the roles of neighbours within complex informal dementia caregiving is vital not only to social care but also to health care practice. Knowledge of the complexities of the nature of non-kin care relations - especially neighbour care and support - are necessary for effective social care policy and practice. I, therefore, outline my recommendations and implications of this study for policy development for neighbour caregivers, social work practice and dementia care practice in the context of existing policies, practices, and knowledge.

Neighbours willingly make or establish contacts with their neighbours without external interference, inducement or encouragement. It is vital that this is not diluted with overbearing formal involvement. It is paramount to sustain neighbours’ free will to develop contacts that lead to care relationships and that the natural trajectory of neighbourliness should be allowed to thrive. This is the bedrock and source of energy in the informal non kin relationship. This will ensure the independent promotion of self-facilitated networks with less interference from the formal sector. This has implications for allowing neighbour care giving relationships to thrive naturally, independently and in a person-centred manner.

6.4 Recommendations and Implications for Policy Development

To sustain the natural orientation of neighbourly relations, I recommend the promotion of local neighbourly contacts and/or neighbour care giving relationships through voluntary organisations like the Alzheimer's Society, Age UK, Carers UK, and dementia befriender groups. Such contacts will help carers to share their experiences, express the burden and stress they experience in their neighbour care giving relationships with the aim of helping to sustain care for their benefit and for the wellbeing of the persons living with dementia. According to Parveen et al. (2017), carers prefer third sector independent community-based service groups because they trust them more, and they are better equipped to meet cultural needs. It is important to emphasise that engaging with independent organisations should be undertaken in a person-centred manner, and carers must make a final decision as to whether to participate in any activities or not. As a follow up to the above point, voluntary organisations should facilitate the creation of public meeting spaces to encourage and promote the awareness of neighbour care giving relationships. Such meeting spaces could include churches, memory clinics, and dementia organised events. This would not interfere in the natural formation of neighbour relations but facilitate the natural trajectory of neighbour care giving relationships. The implication is that if more neighbours are facilitated to support their neighbours in need of care, and discuss their experiences amongst each other, it would help to sustain ageing in place. Again, the most important point is that any contact must be voluntary, freely made, and without external influence. However, there should not be any assumptions that highly motivated neighbour carers do not need support in facilitating care giving relationships. Although I found that neighbour care givers give support selflessly and voluntarily, with reciprocity tilted in favour of the persons living with dementia, the Alzheimer's Society programme like memory clinic has been a contact point and the start of neighbourly relations.

The above suggestion is anchored in the Alzheimer's Society IPSAF (Information Programme for South Asian Families) which was formed to facilitate and enable South Asian carers to gain a deeper understanding of dementia, adopt more effective copying styles and enable the persons living with dementia to live better (Parveen et al., 2018). The programme has four sessions which cover information about dementia, financial and legal issues, services, looking after someone with dementia, and looking after yourself (as a person caring for someone with dementia). The course was run between November 2014 and February 2015 in nine towns with a local South Asian organisation (Parveen et al., 2015). According to an evaluation of the programme, carers gained a better understanding of the condition of the persons living with dementia, and were able to change how they cared, were able to communicate better, planned a more organised routine, and maintained independence in helping the person living with dementia. (Parveen et al., 2015).

My recommendation is also anchored on the success of the programme, START (Strategies for Relatives); this is a carer’s psycho-education skills and training programme that is facilitated and sponsored by the Alzheimer’s Society at University College London, which was found to be effective with White British Carers (Parveen and Oyebode, 2018). START (2017-2020) was a successful eight session programme founded by Professor Gill Livingston at UCL, because of the dearth of interventions to help the mental health of carers of people living with dementia, who become anxious or depressed in performing their caring role. In other words, the programme aimed to support the development of coping strategies for carers of people with dementia (UCL, 2017). The programme (START) has eight sessions: stress and wellbeing, reasons for changes in behaviour, making a behaviour plan, behaviour strategies and unhelpful thoughts, communication, planning for the future, pleasant events and your mood, what works - using skills and strategies in the future (Livingston et al., 2019).

The evaluation of the programme showed that the intervention reduced depression and anxiety for carers of people with dementia “*when measured at eight months and two years after they had received the intervention*” (Kashimura et al., 2020; Livingston et al., 2019). I found that neighbour carer participants in this study have known their neighbour living with dementia for a very long time (average of 19 years) and understand their needs and how their needs can be adequately met. They also act as advocates for the person living with dementia, particularly in situations where they have lost the capacity to make important decisions about their life. For example, I found that some participants act as appointees for person living with dementia and act as attorneys under the lasting power of attorney programme.

I therefore recommend a neighbour dementia care advocacy programme managed by a voluntary organisation like the Alzheimer's Society, where neighbours who have known a neighbour living with dementia and who have lost cognition act as appointees or befrienders to manage their bills, bank statements, and benefit paper works, with the permission of the person living with dementia. This would be possible where there are no family members available to act in such capacities for the vulnerable adult living with dementia. The proximity of neighbours to their neighbours who live with dementia would help the advocate to facilitate and monitor paperwork, documents, bank statements and bills.

This recommendation is based on the model of “McKenzie Friends”, that gives free moral support in court for their “friends”. It is important to state that not all “McKenzie Friends” give free support, but my recommendation is modelled on the McKenzie Friends who provide free support in court. McKenzie Friends are generally family members, friends, or voluntary helpers attached to institutions or charities who generally do not charge for their help. McKenzie friends help with court proceedings by providing moral support, taking notes in courts, helping to complete case papers and quietly giving advice. However, they cannot speak in court, i.e., question witnesses or talk to judge (unless they get a right of audience with the permission of the judge) or manage cases outside the court (Legal Choices, 2022). According to Barrister Stephen Innes (2022) McKenzie Friends are only there to give support and assistance when presenting a case. The name “McKenzie Friend” derives from a legal case in 1970 called McKenzie v McKenzie. This was a divorce case and because the husband was unable to afford to continue using solicitors for free, someone was sent to represent him for free (Innes, 2022).

The services of “free” McKenzie Friends are not controlled, and anyone can call themselves a McKenzie Friend, although some have professional qualifications. Members of fee charging McKenzie friends could belong to professional institutions like the Society of Professional McKenzie Friends (SPMF). However, I am not recommending the fee charging model of McKenzie friends. This is because neighbour dementia care givers provide free support.

The implication of having an advocacy programme modelled on the form of McKenzie Friends, for neighbours who live with dementia is that the programme will represent a flexible and trusted way to support neighbours who live with dementia to manage their bills financial affairs and other paperwork. An advocacy programme like McKenzie Friends would be flexible, simple, and less laborious to put in place, unlike the process of appointing a lasting power of attorney and/or appointee. Moreover, it will ensure that they are supported by people they know and trust, especially in circumstances where family/kin carers are not available. A lasting power of attorney (LPA) is expensive to process and often the neighbours who lives with dementia would not have the capacity to give consent for a LPA due to the cognitive impairment caused by dementia. Applying for deputyship, when the person living with dementia lacks the capacity to give consent for LPA, is even more cumbersome and costly and involves very stressful court of protection processes. The advocacy programme would be a friendly, less stressful and person-centred arrangement, and would not disrupt the natural and person-centred way in which neighbour care giving relationships emerge. Instead, it will facilitate and make it safer, particularly if overseen by dementia service providers like the Alzheimer’s Society.

6.5 Recommendations and Implications for Neighbour Caregivers

I found that neighbour carers do not like talking about themselves or be seen to be addressing their own needs before attending to the needs of their neighbours who live with dementia. They are focused on the needs of their neighbours who live with dementia and express guilt about looking after themselves. This leads to passivity when seeking support, which thereby leaves them vulnerable to health-related risks.

I therefore recommend that dementia friends and voluntary organisations help to encourage them to talk about their needs and experiences. This could be achieved through befrienders and informal carer meetings organised by relevant voluntary organisations where they could be invited to tell their stories. This must be done in a person-centred manner. Neighbour dementia carers should not be made to attend meetings they are not interested in, even if such meetings are meant to benefit them.

I also recommend a neighbour carer only database where all the neighbour carers giving support to older people living in the community, and the nature of support they give are documented. The database could be developed in the form of a Joint Dementia Research (JDR) database that captures carers and persons who live with dementia in the community. JDR's database does not ask registrants to specifically self-identify as kin or non-kin (neighbour or friend) in their database. This is therefore why 3000 registrations on their database are just categorised as "carers", without any specification of the type of carers they are. The implications of a separate database for neighbour non kin carers is that they could be easily reached to tell their stories and experiences if they wish to participate in social care research. Their experiences are necessary for any improvements to services in the social care sector.

Neighbour participants in this study expressed that they would not want to be paid for their caregiving roles, and attributed motivations for their support to selflessness, friendliness, community service, and their culture. This means it is imperative not to attempt to integrate their roles with formal carers or begin to reward them with largely formalised incentives that involve huge financial benefits. This avoids diluting the very essence and flow of their roles. Their status and roles need to be kept flexible, informal, and selfless. The most important aspect of their role tends to be the satisfaction they have willingly contributed and the support to someone in need of care. According to Barker (2002), incorporating a naturally occurring friendship within a social care package is fraught with danger. I argue that one of the dangers is that the informal care dyad may repel formal care arrangements and view it as an invasion of privacy, particularly if they prefer more selfless and informal non-kin relationships.

I therefore recommend that non kin carers should not be offered carer assessments under the Care Act, 2014. The Act should be amended to reflect this. Such offers have the capacity to corrupt the non-kin care system and disrupt its natural pattern of emergence and sustenance. However, non-kin carers could ask for assessments or support if they want, but it should not be first offered to them. This will help to keep their support natural and selfless. I acknowledge this recommendation could be controversial.

6.6 Recommendations and Implications for Social Work Practice

The social work practice approach to assessments and reviews should be completed in a person-centred manner with older people living with dementia at the centre of the assessments. If the assessments are completed in a person-centred way, it would encourage persons who live with dementia to name the social networks they have in the community. Such social networks may include neighbour non-kin carers. Social Workers should work with older people living with dementia and with their families and communities to mobilise resources to meet needs. According to the School of Social Welfare (2021:1), “*this translates to having a helping relationship characterized by alliance, empathy, collaboration, and focus on clients and communities’ aspirations and goals*”. This includes understanding their choice or preference for carers and/or sources of support and means that the interests of the person who lives with dementia and the community they live in should be prioritised. Most importantly, the policy thrust should be directed towards steering social work professionals to mobilise the strengths of older adults in the community and their supporting resources including the relationships they forge in the community.

6.7 **Recommendations and Implications for Dementia Care**

I found that neighbour non-kin carers experience burden and stress. They, therefore, need support to deal with the emotional, social, and economic implications of caring for their neighbours living with dementia. I recommend the creation of a bespoke information bank where information about the support available to carers (including non-kin carers) is made available. Such an information portal could be managed by voluntary organisations like the Alzheimer’s Society, Age UK, Carers Trust or any other dementia friendly organisation. This has implications for enabling neighbour carers to have easy reach to a portal where they can access information about community care. The portal could be in form of a carer website.

However, it is worth noting that most neighbour carers do not ordinarily engage in the support of neighbours living with dementia due to (formal or informal) benefits they may receive. All neighbour carer participants in this study “laughed” at the idea of either being paid for their roles or referred as carers. They viewed themselves as belonging to a socially constructed family. Although the support available should be brought to their attention, the decision as to whether to access such support (like respite) should be theirs. My recommendations have implications for how the principle of partnership could be re-enforced to ensure that older adults living with dementia in the community are supported to manage care. However, such partnerships should be sensitive to the nature of non-kin care, and done in a person-centred manner, to ensure that the carers are at the centre of any decisions, and that decisions are not made for them.

6.8 Limitations of the Research

The limitations of this study have been grouped around recruitment and sampling via gatekeeper organisations; limitations related to interviewing at a distance; and limitations around generalisability. The recruitment strategy for this study was approved by the ethics committee of the School of Health and Society, and the sources for recruitment included newsletters, dementia study websites including JDR (Join Dementia Research), and social media and community organisations. Of the 3,000 carers registered on the JDR website for dementia research, none identified as a neighbour carer. This is potentially related to the fact that neighbours do not consider themselves as carers although many in caregiving relationships meet all the criteria to be considered a carer. They believe that they are engaged in community service and fulfilling moral and/or social obligations. Consequently, they fail to register in dementia care research websites. This created limitations as I did not have direct access to neighbours who give care to their fellow neighbours who live with dementia, which made it more difficult for me to identify neighbour caregiving participants for the study. This was remedied because some kin carers registered with the dementia care website notified me of possible neighbour non-kin carers who were likely to meet the advertised criteria. I followed these referrals up and sourced some of my neighbour carer participants.

Another limitation of this study is that it was originally designed to include face to face interviews in participants' preferred places. Due to the emergence of the COVID19 pandemic in 2020, the plan was amended to include interviews via video and voice calls; this aligned with COVID19 guidelines and helped to protect participants and me from the virus. The amendment was approved by the School of Health and Society at the University of Salford, but the re-application process delayed my study. The amendment made it impossible for me to meet some of the participants for interview in their environments; hence, I could not capture their body language and the nature of the places in which they lived which would have constituted sources of vital unspoken data.

The situations described above were remedied because first, I made sure that interviewees living with dementia had kin or their non-kin carer present throughout the interview session. This helped to build their confidence and prompt them during the conversation. I also applied to the School of Health and Society for an extension of the timeline of my study by three months, which was granted. This gave me time to re-adjust and plan.

Finally, I always reflected in action as I worked daily on the research as per my aims and objectives. I had daily quiet times at the end of the study and reflected on feedback received after supervision. Although I would have had more time to reflect if the study time had been longer, I do not think it has significantly limited the quality of the outcome.

6.9 Recommendations for Future Research

In the introductory chapter and literature review of this research, I argued that non-kin informal care giving is not adequately understood and there is a need for research to fill the gap in knowledge. I have presented evidence that could help to address the gap in knowledge regarding neighbour informal care giving, but my research has raised more questions regarding neighbour dementia care relationships that need further study. None of the persons living with dementia raised any issues about being abused in any form by their neighbour carers. However, there are instances of safeguarding enquiries concerning allegations of financial abuse of people living with dementia in the community by their neighbours. This research has therefore raised the following questions of safeguarding in relation to the abuse of people who live with dementia and their neighbours:

- Do people who live with dementia in the community experience abuse by their neighbours?
- If, yes, what is the nature of the abuse and how could it be minimised?

Although this study has helped to fill some gaps in knowledge about the motivations for non-kin care giving, it would be useful to better understand the motivations behind neighbour informal care giving, especially as it relates to neighbour dementia care relationships. I therefore recommend further exploration of the motivations for informal neighbour care giving because it lies at the core of the non-kin care system and is central to understanding the relationships between the neighbour care giver and the person living with dementia. The focus of further research could be to explore the drivers influencing the motivations of unpaid non-kin carers in the community, and how these impact the reciprocity of support.

Another area of my study that could benefit from further research is the circumstances of people living with dementia. While I found that all persons living with dementia live alone, it is believed, for example, that in Southeast Asian and African countries most older people in need of care live with kin family members (Parveen et al., 2018). It would be interesting to test this in a further study to compare outcomes.

Furthermore, there is no indication in the study that carers provide any support because of their level of education, but this warrants more study to investigate how the level of education of non-kin carers motivates or is linked to their caregiving experiences. Other factors that need study regarding their influence on the caregiving relationship include age and gender. There is also no indication from my research that the age or gender of the person living with dementia influenced the level of care they received from their neighbour carers. The common determinant of care provided was respective individual needs arising from their dementia conditions (Lapierre & Keating, 2013).

Moreover, while I conducted in-depth interviews in this study in the United Kingdom, I suggest that a further study should apply a focus group discussion as a method of data collection in the same context (the United Kingdom) to check whether there are any differences in outcome because of a difference in method. A difference in method would also help to determine reliability and consistency of the outcomes of this study.

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8 List of Appendices

Appendix 1

Recruitment Flyer

University of Salford
MANCHESTER

PhD Research on DEMENTIA Care

Are you over 65

Living in the Community, and

Living with DEMENTIA

OR

Are you a NEIGHBOUR of an Older Person Living with DEMENTIA and You Care for Him/Her

If YES, you are invited to participate in a PhD Research Project aimed at understanding the experiences of support provision by NEIGHBOURS to older adults living with DEMENTIA in the Community.

For more information – please email Austin – a.aneke.edu@salford.ac.uk

Or Call- 07881767878

Appendix 2

Personal Information Sheet (Persons Living With Dementia Arm)

School of Health & Society, Mary Seacole Building, Salford, M6 6PU

Personal Information Sheet for older adults living with dementia

Study Title

An Exploration of the role of Neighbours in Providing Support and Care to Older People Living with Dementia in their own Homes.

Invitation

You are being invited to take part in a PhD research study. This research is being undertaken by me – Austin Aneke PhD student of the University of Salford. Before you decide whether you would like to take part, it's important for you to understand why this study is being undertaken and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

This study aims to better understand the experiences of providing support provision by neighbours to older adults living with dementia in their own homes, in the community. I am undertaking this study as part of my PhD research programme at the University of Salford.

Why I have been invited to take part?

You have been identified as a possible participant for this study due to being a person living with dementia.

Do I have to take part?

You do not have to take part; participation is completely voluntary. If you would like to take part please contact the researcher (to insert my name and picture following approval). You will then be provided with a consent form which you will sign to say you have agreed to take part. If you have difficulties signing a consent form you will be asked to verbally give your consent. This will be recorded on an audio device and kept safely in a password-protected file. You do not have to answer any questions you don't want to.

What will happen to me if I take part?

Your participation in this research for the interview will last for about 60 minutes or less, and it is likely to take place in your own home, unless you choose a different venue. You will need to meet the researcher sometime before the interview starts to explain to you details about the interview and for example where you want the interview to take place and whether you want anyone to be around during the interview. This contact with the researcher will be for approximately 30 minutes. The final time you will see the researcher will be during the interview period which will last for about 60 minutes. You will be asked questions about your experiences being supported by your neighbour. We will also wish to have access to your personal information including age, your needs, and the nature of the support relationships. You may decide to be interviewed alone or with someone of your choice.

With your permission the interview will be digitally recorded to ensure that the researcher fully captures all the conversations during the interview, to facilitate proper transcribing of the conversations. The audio recording will be deleted after all the data have been transcribed.

You will not be identified in any way in the final publications as one of the interviewees of the research.

Expenses and Payments

No payments or expenses will be made to participants for taking part in the research.

What are the possible disadvantages and risks of taking part?

It is unlikely, but you may be asked questions that could because you distress. Every effort will be made to take a sensitive line of questioning by the researcher.

You may be asked questions that could cause distress. This is unlikely, but every effort will be made to take a sensitive line of questioning by the researcher. You will be advised as to what the questions will be before being asked to answer them. You do not have to answer any questions you do not want to and are free to withdraw from the interview at any time.

If you reveal any difficulties during the interview that cannot be dealt with by the researcher, they will be referred to appropriate local authorities or voluntary organisations for necessary action.

What are the possible benefits of taking part?

I cannot promise the study will help you, but the information from the study may help to improve the support for people who live with dementia. It may also help to increase understanding of how neighbours provide support for people living with dementia.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do his best to answer your questions. If you remain unhappy and wish to complain formally you can do this by contacting the research supervisors (Professor Andrew Clark- a.clark@salford.ac.uk or Professor Anthea Innes- A.Innes@salford.ac.uk).

If the matter is still not resolved please forward your concerns to Dr Stephen Pearson, Deputy Chair of the Health Research Ethical Approval Panel, Allerton Building, Fredrick Road Campus, University of Salford, Salford, M6 6PU. Tel: 01612952673 Email- S.Pearson@salford.ac.uk.

Will taking part in the study be kept confidential?

All information that is collected about you during the research will be kept strictly confidential and any information about you which leaves the university will have your name and address removed so that you cannot be recognised.

Your data will be collected and stored t under GDPR, and data received through face-to-face interviews will be anonymised and given a research code known only to the researcher. A master list identifying participants to the research codes data will be held on a password-protected computer known and accessed only by the researcher, and all hard paper and recorded data will be stored in a locked cabinet, within a locked room accessed only by the researcher. All electronic data generated in the course of the research will be stored on a password-protected computer known only by the researcher and all data generated in this study will not be used in any future studies. My supervisors for this study may view the data generated for this study for monitoring the quality of the research, but the data generated will be destroyed/securely disposed of immediately after the publication of the research findings around May 2021.

What will happen if I don’t want to carry on with the study?

You can change your mind about taking part or continuing to take part in this study, at any time during the interview or data collection stage. You do not need to answer any questions you do not want to answer. If you withdraw from the study all the information already collected from you if any, will be used up until the point of withdrawal. Though very unlikely, if you become distressed during the time of the interview, you will be advised to withdraw from the interview. You will be signposted to relevant supportive organisations like Alzheimer’s Society or Age UK if after we talk, your distress persists.

You can withdraw from the research at any point in time during the process of the research.

If following the interview, you wish to withdraw from the research and also withdraw information already given, you shall contact me (the researcher) within one month of the interview.

What will happen to the findings of the research study?

The main purpose of this research is to create a published thesis. The findings of this study will also be published in journal articles and conference papers. I will let you know of any findings that are published by writing to you. You will not be identified by name in any report/publications.

Who is organising or sponsoring this research?

This research is being sponsored by the University of Salford, Manchester

How Long is the Data Storage?

I will keep all the data for five years after the end of the award.

All paper works will be carried inside a locked bag and all digital materials will be saved in encrypted USB Flash drive/s during transport from one place to the other using car, or train. The data on the encrypted USBs will also be used to transfer data over a secure computer unit.

Further Information and contact details

The researcher has been trained and is also a social worker and experienced in the field of dementia research. He will also have the contact details of other organisations that may be able to help you if this is needed. Details of the two organisations are given below.

For support with dementia or caring with someone with dementia please contact 'DementiaUK'. Dementia UK runs a national helpline and email service, called the Admiral Nurse Dementia Helpline, for family and professional careers, people with dementia and those worried about their memory. It is the only nurse-led dementia helpline in the country. Their nurses are ready and waiting to answer your questions about what support is available for people with dementia. You can call on 0800 888 6678 from 9 am to 9 pm from Monday to Friday, and 9 am to 5 pm during the weekend. You can send an email to helpline@dementiauk.org.

We hope you find the sessions sociable, relaxing and enjoyable, however, if you are feeling stressed because of taking part in this study or experiencing high levels of stress regularly in general it is suggested you contact Alzheimer Society- 03002221122.

Appendix 3

Personal Information Sheet (Neighbour Arm)

School of Health & Society, Mary Seacole Building, Salford, M6 6PU

PERSONAL INFORMATION SHEET FOR NEIGHBOURS

Study Title

An Exploration of the role of Neighbours in Providing Support and Care to Older People Living with Dementia in their own Homes.

Invitation

You are being invited to take part in a PhD research study. This research is being undertaken by me – Austin Aneke PhD student at the University of Salford. Before you decide whether you would like to take part, it's important for you to understand why this study is being undertaken and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

This study aims to better understand the experiences of providing support provision by neighbours to older adults living with dementia in their own homes, in the community. I am undertaking this study as part of my PhD research programme at the University of Salford.

Why I have been invited to take part?

You have been identified as a possible participant for this study due to being a person caring for a Neighbour living with dementia.

Do I have to take part?

You do not have to take part; participation is completely voluntary. If you would like to take part please contact the researcher (to insert my name and picture following approval). You will then be provided with a consent form which you will sign to say you have agreed to take part. If you have difficulties signing a consent form you will be asked to verbally give your consent. This will be recorded on an audio device and kept safely in a password-protected file. You do not have to answer any questions you don't want to.

What will happen to me if I take part?

Your participation in this research for the interview will last for about 60 minutes or less, and it is likely to take place face to face (if the lockdown and social distancing emanating from COVID-19 Pandemic are lifted); or via telephone contact or Video Call or both depending on your choice. The technology to be used for the video call depends on your choice and may include- Skype Video Technology, Google Meet Video technology' Microsoft team Video technology or Zoom Video Technology.

The interview will be audiotaped using a Dictaphone and there will also be manual note-taking of the interview.

You will be asked questions about your experiences being supported by your neighbour. We will also wish to have access to your personal information including age, your needs, and the nature of the support relationships. You may decide to be interviewed alone or with someone of your choice.

With your permission the interview will be digitally recorded to ensure that the researcher fully captures all the conversations during the interview, to facilitate proper transcribing of the conversations. The audio recording will be deleted after all the data have been transcribed.

You will not be identified in any way in the final publications as one of the interviewees of the research.

Expenses and Payments

No payments or expenses will be made to participants for taking part in the research.

What are the possible disadvantages and risks of taking part?

It is unlikely, but you may be asked questions that could because you distress. Every effort will be made to take a sensitive line of questioning by the researcher.

You may be asked questions that could cause distress. This is unlikely, but every effort will be made to take a sensitive line of questioning by the researcher. You will be advised as to what the questions will be before being asked to answer them. You do not have to answer any questions you do not want to and are free to withdraw from the interview at any time.

If you reveal any difficulties during the interview that cannot be dealt with by the researcher, they will be referred to appropriate local authorities or voluntary organisations for necessary action.

What are the possible benefits of taking part?

I cannot promise the study will help you, but the information from the study may help to improve the support for people who live with dementia. It may also help to increase understanding of how neighbours provide support for people living with dementia.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do his best to answer your questions. If you remain unhappy and wish to complain formally you can do this by contacting the research supervisors (Professor Andrew Clark- a.clark@salford.ac.uk or Professor Anthea Innes- A.Innes@salford.ac.uk).

If the matter is still not resolved please forward your concerns to Dr Stephen Pearson, Deputy Chair of the Health Research Ethical Approval Panel, Allerton Building, Fredrick Road Campus, University of Salford, Salford, M6 6PU. Tel: 01612952673 Email- S.Pearson@salford.ac.uk.

Will taking part in the study be kept confidential?

All information that is collected about you during the research will be kept strictly confidential and any information about you which leaves the university will have your name and address removed so that you cannot be recognised.

Your data will be collected and stored t following GDPR, and data received through face-to-face interviews or phone interviews or Video Call interviews will be anonymised and given a research code known only to the researcher.

A master list identifying participants to the research codes data will be held on a password-protected computer known and accessed only by the researcher, and all hard paper and recorded data will be stored in a locked cabinet, within a locked room accessed only by the researcher. All electronic data generated in the course of the research will be stored on a password-protected computer known only by the researcher and all data generated in this study will not be used in any future studies. My supervisors for this study may view the data generated for this study for monitoring the quality of the research, but the data generated will be destroyed/securely disposed of immediately after the publication of the research findings around May 2021.

What will happen if I don't want to carry on with the study?

You can change your mind about taking part or continuing to take part in this study, at any time during the interview or data collection stage. You do not need to answer any questions you do not want to answer. If you withdraw from the study all the information already collected from you if any, will be used up until the point of withdrawal. Though very unlikely, if you become distressed during the time of the interview, you will be advised to withdraw from the interview. You will be signposted to relevant supportive organisations like Alzheimer's Society or Age UK if after we talk, your distress persists.

You can withdraw from the research at any point in time during the process of the research.

If following the interview, you wish to withdraw from the research and also withdraw information already given, you can contact me (the researcher) within one month of the interview.

What will happen to the findings of the research study?

The main purpose of this research is to create a published thesis. The findings of this study will also be published in journal articles and conference papers. I will let you know of any findings that are published by writing to you. You will not be identified by name in any report/publications.

Who is organising or sponsoring this research?

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I will keep all the data for five years after the end of the award.

All paper works will be carried inside a locked bag and all digital materials will be saved in encrypted USB Flash drive/s during transport from one place to the other using car, or train. The data on the encrypted USBs will also be used to transfer data over a secure computer unit.

Further Information and contact details

The researcher has been trained and is also a social worker and experienced in the field of dementia research. He will also have the contact details of other organisations that may be able to help you if this is needed. Details of the two organisations are given below. For support with dementia or caring with someone with dementia please contact ‘DementiaUK’. Dementia UK runs a national helpline and email service, called the Admiral Nurse Dementia Helpline, for family and professional careers, people with dementia and those worried about their memory. It is the only nurse-led dementia helpline in the country. Their nurses are ready and waiting to answer your questions about what support is available for people with dementia. You can call on 0800 888 6678 from 9 am to 9 pm from Monday to Friday, and 9 am to 5 pm during the weekend. You can send an email to helpline@dementiauk.org.

We hope you find the sessions sociable, relaxing and enjoyable, however, if you are feeling stressed as a result of taking part in this study or experiencing high levels of stress regularly in general it is suggested you contact Alzheimer Society- 03002221122.

Appendix 4

<u>Consent Form</u>

CONSENT FORM

Title of study: An Exploration of the role of Neighbours in Providing Support and Care to Older People Living with Dementia in their own Homes.

Name of Researcher: Austin Aneke

Please complete and sign this form after you have read and understood the study information sheet. Read the following statements and select ‘Yes’ or ‘No’ in the box on the right.

1. I confirm that I have read and understood the study information sheet V3, dated 27/05/2020, for the above study.

Yes/No

I have had the opportunity to consider the information and to ask questions which have been answered satisfactorily.

Yes/N

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my rights being affected.

Yes/N

3. If I do decide to withdraw I understand that the information I have given, up to the point of withdrawal, will be used in the research.

Yes/N

4. I agree to participate and give consent to be interviewed, either face to face, by phone or via video call including –Skype, Google Meet, Microsoft Team, or Zoom.

Yes/N

5. I agree for the interviews I am involved with to be audio recorded using a Dictaphone, and also to be recorded through note-taking.

6. I always agree to respect the right to confidentiality and anonymity of my fellow participants and will not disclose any information about them gained through participation in this study.

Yes/N

7. I understand that my details will be kept confidential and will not be revealed to people outside the research and the Secretarial Services and transcription teams. *However, I am aware that if I reveal anything related to criminal activity and/or something harmful to myself or others, the researcher will have to share that information with the appropriate authorities.*

Yes/N

Yes/N

8. I understand that my anonymised data including notes taken in the course of the interview and audio recording data will be used in publications, reports and presentations produced by the Research Team. No information that could lead to me being identified will be used in any reports, papers or other presented material.

Yes/N

9. I agree to take part in the study:

Name of participant	Date	Signature
Austin Aneke	27/05/2020	
Name of person taking consent	Date	Signature

Appendix 5

Task/Activity/Environment: **Title** An Exploration of the role of Neighbours in Providing Support and Care to Older People Living with Dementia in their own Homes. **In-depth Interview of participants living with dementia; and neighbours who care for people living with dementia; in their home environment.**	**Location:** **The Home environment of the Participants or any other nominated location by the participant.**	**Date of Assessment: 4/12/2019**

Identify Hazards that could cause harm:		**Identify risks = what could go wrong if hazards cause harm:**	
No.	**Hazard**	**No.**	**Risk**
1	Remembering distressing past experiences	**1**	The participant may experience stress and distress remembering experiences during the interview.
2.		**2**	
3.		**3**	
4		**4**	
5		**5**	
6		**6**	
7		**7**	
8		**8**	

List groups of people who could be affected: 1. Participants who live with dementia 2. Neighbour participants who support participants who live with dementia.	**What numbers people are involv** 14 (Fourteen)

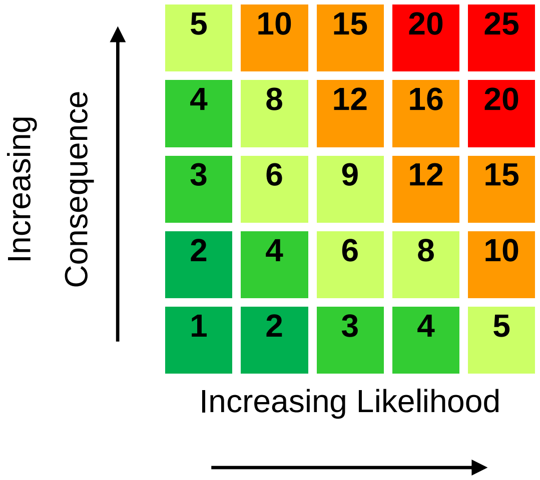
What risk controls are in place to reduce risks?		**Risk level with controls**
No.	**Risk Control**	
1	Details of plans for the interview will be listed on the Participant Information Sheet to ensure that every participant and researcher agree concerning the conditions for the interview session. All the hazards and risks as listed above will be considered in the PIS (Participant information sheet), and ways to mitigate the risks enumerated.	**2**

2	There will also be a consent form, and the consent of the participants will be sought to ensure that they agree to be involved in the interview.	**3**
3	Though very unlikely, if any participant becomes distressed during the time of the interview, he/she will be advised to withdraw from the interview. As the researcher, I will be there to listen to you and attempt to find a solution to your distress. You will be signposted to relevant supportive organisations like Alzheimer's Society, Age UK, or The Samaritans if your distress persists. Moreover, the researcher will be very sensitive with his line of questioning	**2**
4	There is risk associated with Lone Working, as the researcher is likely to be entering participant's homes alone, at different times. The risk will be mitigated as follows: I will inform my supervisors, my friends, and members of my family whenever I am on any visit to the participants for interviews in this research and will intermittently advise them about my progress and that I am safe or in any difficulty as the case may be. I will communicate with them with my phone and will also leave my phone numbers with them to contact me if they do not hear from me over some time.	
No.	**What additional actions are required to ensure risk controls are implemented/effective or to reduce the risk further?**	**Risk level additional controls**
	Researcher to discuss arrangements for the in-depth interview with regards to the timing, and the interview environment, with the participants to ensure that all dangers and risks are further mitigated with the controls to be put in pace. Such controls include not holding the interview during mealtimes, immediately after taking medications, and giving the researcher permission to ensure that there are no furniture or obstructions on the way of participants during the interview period; and to ensure that the interview period do not exceed 60 minutes.	**2**

Is health surveillance required? **NO**	**If YES, please detail:**
Who will be responsible for implementing risk controls: **Austin Aneke (PhD Student),.**	**By When:** Before during the interv sessions.

Completed by: **Austin Aneke** **Signed:**

Record of annual review:



5	10	15	20	25
4	8	12	16	20
3	6	9	12	15
2	4	6	8	10
1	2	3	4	5

17-25 **Unacceptable** – Stop activity and make immediate improvements/seek further advice

10-16 **Tolerable** – look to improve within specified timescale

5-9 **Adequate** – Look to improve at next review

1-4 **Acceptable** - No further action, but ensure controls are maintained

Guide to using the risk rating table:

Consequences	**Likelihood**
1 Insignificant – no injury	**1 Very unlikely** – 1 in a million chance of it happenin
2 Minor – minor injuries	**2 Unlikely** – 1 in 100,000 chances of it happening
3 Moderate – up to three days absence	**3 Fairly likely** – 1 in 10,000 chances of it happening
4 Major – more than three days absence	**4 Likely** – 1 in 1,000 chances of it happening
5 Catastrophic – death or disabling	**5 Very likely** – 1 in 100 chances of it happening

Appendix 6

Ethics Approval Letter

From: Health-ResearchEthics <Health-ResearchEthics@salford.ac.uk>
To: Austin Aneke <austinvital@aol.com>; Aneke Austin <A.Aneke@edu.salford.ac.uk>
CC: Clark Andrew <A.Clark@salford.ac.uk>
Sent: Mon, 9 Mar 2020 11:42
Subject: Ethics Application HSR1920-047_Approval Letter_09.03.20
Hi Austin,

I am pleased to inform you that your ethics application **HSR1920-047** has now been approved, and a copy of the approval letter is attached for your records.

If there are any changes to the project and/or its methodology, then please inform the Panel as soon as possible by contacting Health-ResearchEthics@salford.ac.uk

Best wishes,

Steve

STEVE AINSCOUGH, PhD
RKE Support Officer / Doctoral & Research Support
Research and Knowledge Exchange, Room 827, Maxwell Building, University of Salfo
Manchester M5 4WT
T: +44(0) 0161 295 2280
s.ainscough3@salford.ac.uk / www.salford.ac.uk

Appendix 7

Amended Ethics Approval Notice

From: Health-ResearchEthics <Health-ResearchEthics@salford.ac.uk>
To: Austin Aneke <austinvital@aol.com>; Austin Aneke <A.Aneke@edu.salford.ac.uk>
CC: Andrew Clark <A.Clark@salford.ac.uk>; Anthea Innes <A.Innes1@salford.ac.uk>
Sent: Thu, 28 May 2020 20:37
Subject: Amended Ethics Application HSR1920-047_Approved_28.05.20
Dear Austin,

I am pleased to inform you that your amended ethics application **HSR1920-047** has now been approved, and a signed copy of the amendment notification form is attached for your records.

If there are any further changes to the project and/or its methodology, then please inform the Panel as soon as possible by contacting Health-ResearchEthics@salford.ac.uk

Thanks, and best wishes,

Steve

Due to the Coronavirus situation, I am now working remotely, and I do not currently have access to my university phone. Therefore, please keep all communications to email and Teams. If you would like to hold a Teams meeting, please send me a calendar invite including a Teams meeting link.

STEVE AINSCOUGH, PhD
RKE Support Officer / Doctoral & Research Support
Research and Knowledge Exchange, Room 827, Maxwell Building, University of Salfo
Manchester M5 4WT
s.ainscough3@salford.ac.uk / www.salford.ac.uk

Appendix 7

Join Dementia Research (JDR) Confirmation of Research on their Website

On 12 Jun 2020, at 13:51, James Grassom <james.grassom@nihr.ac.uk> wrote:

Hi Austin

I hope you are well.

I have opened up your study, and I would suggest that you wait until Tuesday, to let those most interested contact you first. Then follow up with those who you think are the most appropriate.

I am on annual leave next week, so if you have any queries, do contact my colleague Sara Magari.

Best wishes

James

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Appendix 12

Appendix 9

Interview Guide - Older Adults Living with Dementia

1. How do you feel today?
2. Can you tell me about yourself?
3. Can you tell me about your neighbour?
4. How did you meet your neighbour?
5. How did you begin to relate with or him/her?
6. Do you have immediate family members? If yes, do you know where they live?
7. In what ways do you receive support on a daily basis?
8. What things can you do for yourself?
9. If you do not receive support from your neighbour, if you do, how would you cope?
10. Who would you prefer to support you?
11. Do you give support to anyone, yourself?
12. How would you consider your general wellbeing?
13. What would you consider as making you happy or making life worth living?
14. When did you start receiving support from Mr/Mrs A?
15. Are there things you want to change?
16. Tell me about your experiences so far about the support you receive?
17. Would you like the support to continue?
18. Do you have other friends? Do you have family relatives?
19. How would you want government to support your care plans?

Appendix 10

Interview Guide: In-Depth Interview of Neighbour Carers

1. How do you feel today?
2. Can you tell me about yourself?
3. Can you tell me about your neighbour?
4. How did you start to support him/her?
5. How did you begin to relate with or him/her?
6. What do you do for him/her?
7. How does your support for him/her impact on your own life/family?
8. What do you think will happen if you are not supporting him/her?
9. Would you prefer not to be giving the support?
10. Do you give support to anyone else?
11. How would you consider your general wellbeing?
12. What would you consider as making you happy or making life worth living?
13. Please tell me more about the relationship.
14. What would you like to change about the relationship?
15. How would you want government to support the care arrangements?

Appendix 11

Thematic Analysis

Themes	Sub Themes	Coding
1. Origin of Neighbourly Support Relationships	Motivation to support	Proximity
		Neighbourhood
Relationship between persons living with dementia and neighbour care givers		Relationship before care
		Neighbourly relationship
		Perception of older people/neighbour before the need to care
		Natural Inclination to care and offer of support
		Consistent verbal contacts
		Mutual confidence and trust-building
		Consistent face to face family contacts
		Contact via third party groups (Memory Clinic)
		Immediate needs and wellbeing
		Neighbours as family
		Dearth of kin relationships
		Migration of kin relations
		Need to socialise
		Death of a partner
		Dearth of living friends
		Involvement of extended kin relations
		Need for physical help

		Familial conflicts & frictions
		Zeal and passion to help
		Satisfaction in meeting others’ needs
		Unilateral assessment of care receiver’s needs (he/she needs help)
		Natural instincts to help
		Perception of what community is about (giving care without pay is what the community is about)
		Feeling of serving community
		Onset of dementia
		Confusion resulting from memory problems
2. The Nature of Care Given		Tendency to be involved in ALL types of support
		Medical/specialist support
		Personal care
		Financial support
		Nutritional support
		Referral support
		Shopping
		Festive periods/exchange of gifts
		Strengths in the face of need for support
	Intensity of Support	Having chat, conversation, and reminiscences
		Emotional and psychological support
		Companionship
		House-keeping
		Prompting
		Offer to help
	Quackery and Unqualified Professional Roles	Administration of medications
		Errands

		Paperwork
		Emergency support
		Playing games/cards (leisure times together)
		Opinion on wide issues
		Observation, monitoring, alert, and reporting
3. Vacuum of Kin Care. Lone Living		Filling gap of filial relationships
		Reliance on neighbours
		Joint travel and holiday
		Withdrawal of support (COVID-19)
		Diverse degree/level of support (kin & non-kin).
		Average no of years, overall
4. Complexity of care		Bridge between support networks
		Preferences of persons living with dementia
		Low reliance on specialist support
		Other informal networks
		Formal carers/support
		Friends or neighbours
		Support from a distance (over the fence)
		Impact of neighbourly care
		Ageing in place
		Making choice of carer.
		Financial barriers to formal care and support
		Management of finance by non-kin carer
		Supporting two or more recipients
		Multiple care givers supporting one persons living with dementia
		Care needs of the carer

		Perception of care being delivered
		Break down, emotional, physical and psychological wellbeing of care givers. (care giving is tiring)
		Need for respite, for partner carer/kin carer
		Condition of kin carer- disability.
		Protection against infection by neighbours
		Care boundaries
		Cultural boundaries (culturally sensitive support)
		Power relations
		Respect of wishes and values
		Breaking of perceptions and prejudices (race)
		Ageing in space (object to residential care)
		Attitude to different support networks
		Guilt amongst the care dyad
		Guilt of longevity
5. Reciprocity of support		In cash and kind?
		Exchange of affection and protection
		Motivation of support
		One sided support
6. Tensions in relationships		Reconciliation of relationships
		Background and historical acts
		Complaints by neighbours
		Involving the police
		Ending carer relationship
		Neighbour, not being friendly
		Male/female
		Dementia
		Neighbour carer

		Age of volunteer
		Level of education, and whether working
		Recognising the importance of the research finding to social work practice