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# University of Southampton

Faculty of Social Science

School of Economic, Social and Political Sciences

# *Negotiating Dementia Care within Informal Family Care Networks: Lived Experiences from Bayelsa State, Nigeria.*

by

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# University of Southampton

## Abstract

Faculty of Social Sciences

School of Economic, Social and Political Sciences

Doctor of Philosophy

*Negotiating Dementia Care within Informal Family Care Networks: Lived Experiences from Bayelsa State, Nigeria*.

by

Lilian Iluobe Odaro

The aim of this thesis is to understand how informal carers of older people with dementia negotiate everyday caregiving in Nigeria. Current literature on dementia in Nigeria has focused on dementia epidemiology, knowledge and understanding, and stigma. However, little is known about how carers negotiate dementia care. Existing literature from other countries may not be transferable to the Nigerian context due to socio-cultural differences. Therefore, it is important that approaches to supporting informal carers in negotiating dementia care are relevant and tailored to the socio-cultural context of Nigeria. Using qualitative methods, semi-structured interviews, and observations among eleven family care networks in Bayelsa State, Nigeria, were conducted. Data were analysed using reflexive thematic analysis aided by NVivo. The findings show that informal carers evaluate their caregiving and that of others by making positive and negative judgements; these judgements formed their conceptualisation of what 'good care' and 'bad care' are. Informal carers had diverse care arrangements that were either influenced by cultural scripts or were a natural extension of the previous relationship between the informal carer and the older person with dementia. Furthermore, Informal carers placed more value on support received from outside their family compared to that within their family. These findings broaden understanding of how informal carers in Nigeria negotiate everyday caregiving against the backdrop of unspoken expectations they hold of themselves, of others, and from the wider society. The findings offer two key practical and policy recommendations for healthcare organisations and the government. First, improving post-diagnostic support for older people with dementia and their carers, such as healthcare providers encouraging families to plan care, including discussions of what is expected from each member of the care network. Second, the Nigerian government should include guidelines on managing dementia in its national policy on ageing.

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# Research Thesis: Declaration of Authorship

Print name: Lilian Iluobe Odaro

Title of thesis: *Negotiating Dementia Care within Informal Family Care Networks: Lived Experiences from Bayelsa State, Nigeria*. I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signature: ..... Date: .....29 April 2026....

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# Definitions and Abbreviations

| | |
|---|---|
| ADLs | Activities of daily living |
| IADLs | Instrumental activities of daily living |
| EoC | Ethics of Care theory |
| SSA | Sub-Saharan Africa |
| LGA | Local Government Area |
| LTC | Long Term Care |
| UN | United Nations |

Older person ..... an individual aged 60 years or over (UN, 2019)

Social care ..... "both formal and informal care networks existing side by side and providing support for activities required as part of daily living" (Ngan, 2011:130)

Activities of Daily Living .... "skills required to manage one's basic physical needs, including personal hygiene or grooming, dressing, toileting, transferring or ambulating, and eating" (Edemekong et al., 2023:1)

Instrumental Activities of Daily Living....."include more complex activities related to the ability to live independently in the community" (Edemekong et al., 2023:1). Such as financial and medication management, preparation of food, laundry, and housekeeping."

Hands-on care ..... , active engagement of an individual in the care network of a person with dementia in caregiving or decision-making.

Informal carer ..... is an individual providing unpaid care for someone with dementia; they include family members, friends, neighbours, grandchildren, or other members of the social network of a person with dementia.

Care Organisation ..... the organisation of ADLs, IADLs and organising how to meet the care needs of a person with dementia by informal carers.

Paid help/Paid carer.....an individual hired by an informal carer to help with their caregiving tasks. They could either be living in the home of the person with dementia or not.

# Chapter 1 Introduction

## 1.1 Background

Globally, the population is ageing due to key drivers such as increased life expectancy and a reduction in fertility (United Nations Department Of Economic and Social Affairs, Population Division [UN DESA] 2020). Although population ageing signifies the success of social, economic, and medical advances, it still presents unprecedented challenges, including those regarding disease burdens. Dementia is considered to have a large impact on healthcare systems globally. According to Alzheimer's Disease International's [ADI] (2021) dementia statistics, over 55 million individuals in the world are living with dementia as of 2020. These numbers are projected to increase to 78 million by 2030 and 139 million by 2050. Of these projected estimates, by 2050, 71% will be in low- and middle-income countries (LMIC) such as those in Sub-Saharan Africa (SSA). It was also estimated that 2.13 million individuals in SSA were living with dementia, and this number is set to increase to 7.62 million by 2050 (ADI, 2017).

Of the countries in Africa, Nigeria is currently the most populous and the 6$^{th}$ most populous country in the world. It has a population of over 216 million individuals, and a life expectancy of 52 years for males and 53 years for females (UN DESA, 2022). Nigeria is also one of the poorest countries in the world, despite its abundant human and material resources (Uwakwe et al., 2009). An estimated 71.3 million individuals live in extreme poverty (living below $1.90 a day as measured by the World Bank), with over 36.1 million men and 35.2 million women living in extreme poverty (World Data Lab, 2023). Extreme poverty equates to undernourishment, inability to access basic services such as safe water to drink, electricity, education and healthcare (Hasell et al., 2022).

Although Nigeria currently has a youthful population, it still has the highest number of older people in Africa (Population Reference Bureau [PRB], 2019). The World Population Ageing [WPA] report has projected a percentage increase in the population of older people in Nigeria aged 65 years and older from 2.7% in 2019 to 4.0% in 2050 (UN DESA, 2019). This increase coincides with a projected rise in the cases of dementia in Nigeria. Adeloye et al. (2019) in their systematic review on the prevalence of dementia in Nigeria found that in 20 years, the number of dementia cases has increased by over 400% from 63,512 in 1995 to 318,011 in 2015. They also estimated an overall prevalence of dementia in Nigeria at 4.9%, with the prevalence significantly higher in women than in men.

However, it is important to note that there are very few studies on the epidemiology of dementia in Nigeria, most of the data are derived from two large studies in Ibadan, which is one of the 36 states in Nigeria (Burns et al., 2019). This covers a very small percentage of the overall population, meaning that the prevalence of dementia may be higher than currently thought. Nonetheless, the current diagnosis and capture of dementia in Nigeria have seen great improvements compared to the 1990s. This is also due to improved reliability and validity of instruments for screening dementia, and the enhanced reporting of dementia cases in medical records (Adeloye et al., 2019). Moreover, a rise in the number of people with dementia means an increase in the number of people requiring care and support (Ebimgbo et al., 2021).

The challenges resulting from the rapid rise in the number of people with dementia are exacerbated in low- and middle-income countries like Nigeria for many reasons. First, few resources are allocated to the healthcare system, so the infrastructure is inadequate and inaccessible (especially in rural areas where the majority of the older people reside) (Nwakasi et al., 2021, Gureje et al., 2011), resulting in a lot of health inequalities. Second, approximately 80% of individuals in Nigeria with severe mental health challenges cannot access the care they require to meet their needs (Nwakasi et al., 2021, Ugochukwu et al., 2020). Although these figures are not directly representative of older people with dementia, they do provide a glimpse into the current situation of mental healthcare in Nigeria. Third, there is a shortage of skilled mental health personnel (about 0.9 per 100,000 Nigerians) (Nwakasi et al., 2021), and a higher utilisation of privately owned services for mental health needs, resulting in more out-of-pocket expenses (Gureje et al., 2011, Ogunniyi et al., 2000).

These privately owned mental healthcare services are expensive, have limited scope and coverage, and are only available in a few major cities in Nigeria (Abdulmalik et al., 2019). Additionally, excessive out-of-pocket expenses for mental healthcare in Nigeria may often lead to some households relieving the financial burden by skipping expenses on other essential commodities, such as clothes and food (Agboola et al., 2018). Finally, there are no health insurance schemes for the general population, and the available pension schemes are contributory, which makes their coverage low, given the high levels of unemployment in Nigeria (Uwakwe et al., 2009).

In Nigeria, the healthcare system is not sufficiently equipped to meet the increasing needs of people with dementia and their families, which makes the role of informal carers essential. However, informal carers face significant psychological, physical, mental and socio-economic challenges (Dotchin et al., 2014). The burden of dementia care in Nigeria is exacerbated by factors such as inadequate knowledge about dementia, lack of formal care systems, very few

healthcare workers skilled in dementia care, as well as widespread poverty and social inequalities.

Although the burden of care among informal carers of older people with dementia in Nigeria has not been extensively explored, some studies in Nigeria show that informal carers, even with the majority of them living in extended-family households, still have high levels of strain (Dotchin et al., 2014, Prince et al., 2012). Baiyewu et al. (2003) also found significant emotional distress due to providing informal care for an older person with dementia. According to Schulz and Martire (2004:240) "caregiving typically involves a significant expenditure of time, energy, and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting".

Therefore, supporting carers is key to minimizing their health risks and preventing poor care for the person with dementia. This is also in line with the United Nations [UN] (2021) decade of healthy ageing that aligns with the Sustainable Development Goals (SDGs), which aim to improve older people's lives, those of their family, and the communities they reside in. To adequately support informal carers, there needs to be a better understanding of the nature of informal care provided for people with dementia. Very few studies in Nigeria have explored informal caregiving, such as care arrangements for people with dementia (Nwakasi et al., 2021, Ogunniyi et al., 2005) and the burden of dementia care (Baiyewu et al., 2003, Prince et al., 2012).

There is a lack of understanding of how informal carers negotiate everyday caregiving, who has the responsibility for care and how informal carers seek help and support with caregiving in Nigeria. Existing literature in Singapore, Italy, the United States, and the Netherlands (Koo et al., 2021, Cipolletta et al., 2023, Seaman, 2020, Wammes et al., 2021) also shows that informal carers frequently utilise paid assistance, often referred to as 'paid help' or 'hired help', to assist with daily caregiving tasks. This is an aspect of the care network that has not been explored by studies in Nigeria or Africa more widely.

This thesis aimed to fill this gap in the literature by investigating how informal carers of older people with dementia negotiate everyday caregiving in Nigeria. An investigation into how informal carers find their way through complex dementia care can help improve our understanding of what it is like for families living daily life with dementia. This understanding is crucial in ensuring that approaches to supporting informal carers in Nigeria to provide care at home for a person with dementia apply to their lived experiences and socio-cultural context. It could also help identify areas where improvements or adjustments can be made to make sure people with dementia get appropriate care. This will ensure that they enjoy their human rights to dignity, participation and autonomy (HelpAge International, 2023).

In the following sections, I provide an overview of dementia as well as an overview of the care needs of people with dementia and discuss the context of informal care for older people with dementia in Nigeria. I also discuss the rationale, purpose, objectives, and research questions of this thesis.

## 1.2 Dementia: an overview

Dementia is an umbrella term utilised in the description of a group of symptoms; it is progressive, and it is not a normal part of ageing. In the following paragraphs, I discuss dementia within two schools of thought, known as the biomedical and psychosocial approaches. The more dominant biomedical approach to dementia defines it as a pathological condition affecting cognition, with forgetfulness at the core of describing the cognitive symptoms. It is said to be a disease that progresses through stages, such as mild, moderate, and severe (World Health Organization [WHO], 2022). Dementia is typically diagnosed with neurological and cognitive tests, blood tests, genetic tests, and brain scans. Additional information involved in the diagnosis process entails taking a medical history and information about activities of daily living (ADL) (Desai et al., 2004). Diagnosis of dementia within the biomedical approach results in care centred on drugs to manage the symptoms and progression of the condition, which is dependent on the stage of the disease (Taft et al., 1997).

There are various types of dementia, and Alzheimer's disease (AD), accounting for 60-80% of cases, is the most prevalent type of dementia (Centers for Disease Control and Prevention [CDC], 2019). Other types include vascular dementia, Lewy body dementia (abnormal protein clumps that accumulate inside nerve cells), and a spectrum of disorders that lead to frontotemporal dementia (due to the frontal lobe of the brain degenerating). Additionally, multiple types of dementia can coexist in the brain, especially in adults over the age of 80. An individual may have both Alzheimer's disease and vascular dementia, for example. It is not always clear if an individual has mixed dementia because symptoms of one kind of dementia may overlap or be more enhanced than the others. Dementia progression may be faster when an individual has two types of dementia compared to one (Alzheimer's Association, 2022, CDC, 2019).

Generally, the symptoms of dementia vary according to the type of dementia an individual is said to have. However, people with dementia typically have challenges with attention, communication, memory, reasoning, judgement, changes in mood, problem-solving, and visual issues above the normal age-related decline in vision (CDC, 2019). More specifically, some of the symptoms include challenges speaking, idea expression and interpretation, reading and writing, getting confused in recognisable areas, challenges with money management and bill

payment, repeating questions, describing typical objects with unfamiliar terms, and taking more time to do routine daily duties. Lack of interest in routine activities or events, hallucinating or suffering delusions or paranoia, and making impulsive decisions are also some dementia symptoms (National Institute on Aging [NIA], 2022). One of the strengths of the biomedical approach in defining and understanding dementia, its types, symptoms, and consequences, is that it provides a label for the condition and potential pathways for the management of symptoms following the stages. It also offers ways to reduce the likelihood of getting dementia in later life, such as exercise, weight control, having a healthy diet, avoiding damaging alcohol use, not smoking, and sustaining healthy blood sugar levels, cholesterol, and blood pressure (WHO, 2022).

The biomedical approach has been criticised by various scholars who dispute it as placing emphasis on medical care, frequently utilising medications to alleviate behavioural symptoms, with pathology being the primary focus of treatment (Taft et al., 1997). More recently, social gerontologists Manthorpe and Iliffe (2017b:3) supports Taft et al. (1997) argument, as they claim that the biomedical approach characterises dementia as a one-size-fits-all condition, which may eventually have one cure. They assert that dementia is a 'fuzzy concept,' difficult to diagnose, even though it can be recognised, with a general cure being unlikely. Based on this, they call for a need to shift the emphasis of dementia discourse from the biomedical approach, which focuses on medical treatment, to the psychosocial approach, which emphasises psychological and social care.

The psychosocial approach defines dementia as a multiple-cause disability and not just as a disease, with the need for person-centred care at the forefront (Manthorpe and Iliffe, 2017a, Manthorpe and Iliffe, 2016). Moreover, epidemiology has played a significant role in bringing to light social influences that may have an impact on the onset and progression of dementia (Nicholson, 2020). This is because only biomarkers cannot explain the discrepancies between brain damage visible in a scan or under a microscope and the lived experiences of people with dementia, which is a challenge for research. For example, the symptoms of dementia can manifest in persons who do not have amyloid deposits in their brains or tangles inside their brain cells, which are hallmarks of AD (Manthorpe and Iliffe, 2017a, Vernooij-Dassen et al., 2021). The same brain alterations have been found in individuals without AD's symptoms (Manthorpe and Iliffe, 2017b).

Therefore, balancing the psychosocial approach within the biomedical approach could reduce the discrepancies between the pathology of dementia and people with dementia's lived experiences. Kitwood (1990:177) proposes what he terms a 'dialectical interplay' between neurological and psychosocial factors, with the neurological factors said to deprive an

individual of their personhood. This deprivation of personhood is what the psychosocial approach aims to remedy, by drawing the focus to the individual living with the condition and not just dementia's pathology. Taft et al. (1997:13) also claim that this approach 'validates the person with the illness, builds on strengths, and meets the person's needs, by focusing on a person with dementia's care on their independence level and everyday life.'

Looking past just the biomedical lens could facilitate a better understanding of dementia and how it is experienced, without neglecting the importance of the individual experiencing it. According to ADI's (2022:23) report, 'dementia has been traditionally viewed through a narrow biomedical lens [...] Relying solely on such a framework [...] can result in stigmatisation and disregard the reality that people with dementia are whole people, capable of participating in meaningful social connections!'. However, it is less a case of picking sides between the biomedical and psychosocial approaches to understanding and managing dementia. It is more a case of exploring connections between both approaches, and taking advantage of the connections to manage the symptoms and meet the needs of a person with dementia, irrespective of illness pathology (Nicholson, 2020).

Therefore, I argue that a combined approach drawing from both the biomedical and psychosocial approaches is important in addressing some of the challenges (symptom management, care planning, and predicting the disease progression) in understanding and managing dementia. According to Nicholson (2020) the biomedical approach assists with understanding the type of dementia an individual has, as well as any behavioural challenges that may arise. While the psychosocial approach helps in tailoring specific therapies that can facilitate effective person-centred management of dementia. Both approaches make significant contributions to understanding dementia and how it affects people living with it.

In terms of management, dementia cannot currently be cured by any medication. However, as of 2025, there are approximately 140 drugs being researched in various phases of clinical trials worldwide (Taylor, 2025). Recently, after decades of setbacks in drug trials, a drug known as lecanemab has been approved by diverse regulatory bodies in over 50 countries to treat people with early-stage Alzheimer's disease (ADI, 2025, Scheltens and Carrillo, 2024, University College London, 2024). Some of these areas include the United States, Japan, the European Union, the United Kingdom, China, Canada, and the United Arab Emirates. This drug is said to slow down patients' memory and thinking decline and improve ADLs in patients with Alzheimer's disease (Pinches, 2022). Like lecanemab, another drug known as donanemab has been approved in fewer countries for use in treating Alzheimer's disease (Taylor, 2024). This drug is said to tackle the underlying disease, compared to other treatments focusing on alleviating symptoms (Taylor, 2024).

Yet, The Lancet (2022) in their editorial, cautions about overstating the impact of drugs such as lecanemab, as it is not likely to be cost-effective for low- and middle-income countries, where the majority of the people with dementia live. There are also challenges with the cost-effectiveness and successful implementation of lecanemab even in high-income countries in the world. For example, in the United Kingdom, the National Institute for Health and Care Excellence [NICE] (2024) analysed clinical trial evidence for lecanemab, reviewed its benefits of slowing the progression of Alzheimer's, and the cost of the treatment. They concluded that the advantages of lecanemab are too minimal to justify the cost. Furthermore, a study in Japan reported significantly lower staff and treatment capacity compared to what was anticipated one year after the launch of lecanemab in Japan (Sato et al., 2025).

Therefore, the chances of the lecanemab and other different drugs in various stages of clinical trial in cost-effectively treating Alzheimer's disease are still far-fetched. Additionally, there is no indication that these drugs will be effective against other types of dementia. Of the countries where the lecanemab has been approved, countries in SSA are currently not part of that list. There is also an absence of infrastructure in the health systems of low- and middle-income countries to facilitate the massive roll-out of lecanemab (The Lancet, 2022). Based on this, the provision of adequate care and support is currently the best management for dementia.

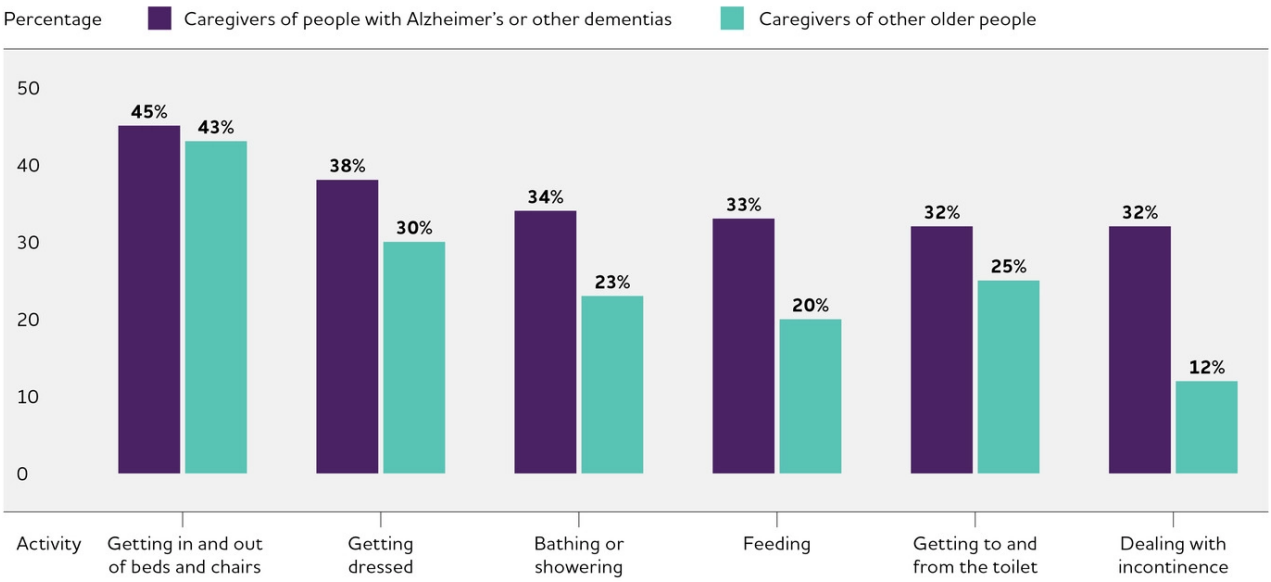
### 1.2.1 Dementia care needs

Due to the progressive nature of dementia and the cognitive and behavioural challenges that develop, there are a lot of difficulties in care and support. All forms of dementia progress, this means that the brain's structure and chemistry deteriorate with time. The rate at which it progresses is based on individual differences. As discussed earlier, dementia is experienced uniquely by diverse individuals, and many factors can influence this, including emotional resilience, genetic makeup, and the degree of assistance available to them (Alzheimer's Association, 2022). According to the Social Care Institute for Excellence [SCIE] (2020), once you know one individual who has dementia, you know one individual with dementia. This is to emphasise how dementia affects every person in unique ways, irrespective of the type of dementia the individual may have.

Although the care provided by informal carers of people with dementia is like that provided by informal carers of older people living with other conditions, dementia informal carers tend to provide more extensive assistance (Alzheimer's Association, 2022, Spillman et al., 2014). The 2011 National Health and Aging Trends survey in the United States shows that informal carers of people with dementia are more likely than carers of people without dementia to provide help

with mobility, self-care and feeding. Figure 1.1 below provides an illustration of the differences in care needs of older people.

Figure 1.1*: Differences in the percentage of assistance provided for older people with and without dementia*.




(Alzheimer's Association, 2022).

According to Alzheimer's Association (2022) some dementia caregiving tasks include:

- Assisting with IADLs such as housework, grocery shopping, meal preparation, transportation, scheduling doctor's appointments, overseeing financial and legal matters and taking phone calls.
- Assisting with medication taking, either by providing reminders or by giving the medication directly.
- Assisting with adherence to treatment guidelines for dementia or other guidelines.
- Assisting with ADLs such as transition from bed to chair, toilet use, managing incontinence, washing, clothing, grooming, and feeding.
- Finding and utilising the services of support, such as day service programs for adults and support groups.
- Setting up paid in-home care, nursing home, or assisted living.
- Managing behavioural symptoms such as disruptions of sleep, low mood, agitation, anxiety, and aggressive behaviours (biting, shouting, physical attacks, object throwing and destruction of personal possessions).

There are other caregiving tasks that informal carers also perform, such as addressing family concerns that arise from providing care for a person with dementia (making decisions, coordinating plans for care, and arranging breaks in caring). They also help with the management of comorbidities, including illnesses such as cancer, hypertension, diabetes, or arthritis. A study in Spain found that people living with dementia have four comorbidities on average (Poblador-Plou et al., 2014). Similarly, a scoping review of literature from Australia, Canada, Finland, Japan, Switzerland, the United States and the United Kingdom, found that comorbidity was high among people with dementia, with diabetes and stroke being the most prevalent conditions (Bunn et al., 2014).

Informal carers of older people with dementia who have other illnesses encounter significant obstacles in managing the various conditions while dealing with the psychological and behavioural symptoms of dementia in daily care. According to Wilder (2010) carers often face emotional and physical stress, poor health, low quality of life, and financial dependency. They are tasked with negotiating dementia care and sharing various care responsibilities with others in their care network. In other instances, the care responsibilities may rest on them as they could be the sole providers of care for the older person with dementia.

## 1.3 Context of informal care for older people with dementia in Nigeria

Informal carers are typically family members (spouse and children) providing unpaid care (Adedeji et al., 2022). Family members are the major contributors of support and unpaid care for an older person with dementia. Agyemang (2021:74), argues that care and support being seen as the responsibility of the family is because of reciprocation, which is related to an African adage translated to mean, ‘Because you [i.e., one’s older parent] have taken care of me [the child] to grow teeth, I will take care of you until your teeth fall out.’ However, other individuals close to the person with dementia could also be providing unpaid care, such as friends, neighbours, grandchildren, or other members of the older person’s social network (Ebimgbo et al., 2021). Uwakwe et al. (2009) in their study, they observed that impoverishment (not having enough to meet basic needs) was common among older people in Nigeria, as they also had to rely on the church and community for support.

According to Köhler et al. (2022), informal carers provide a range of support for people with dementia, including personal care such as washing, dressing, toileting, and other practical care such as cooking, helping with mobility, medication, and hospital appointments (as discussed previously). In addition, they also provide emotional support as well as practical supervision. They often function as liaisons between the formal and informal support systems, frequently

overseeing complex care arrangements. It is obvious that informal carers make and will continue to make a significant contribution to the overall sustainability of health and social care systems, through their practises of supporting daily life with dementia (Ceci and Purkis, 2021).

To date, there is no literature on the estimated amount of unpaid care carers in Nigeria provide for a person with dementia. This could be because of the problems associated with measuring the amount of time an individual spends providing unpaid care. On one hand, assessing and explaining basic ADLs across cultures and countries, such as toilet use, washing, dressing, feeding, and managing incontinence, may be quite easy. On the other hand, IADLs such as making meals, shopping, managing money and house chores, etc., are more particular to cultures; therefore, measuring such tasks could be more challenging. ADI (2018:5) argues that some IADLs are 'joint production' as it is carried out by more than one individual, for example, the carer and person with dementia preparing meals or shopping.

Despite the problems associated with measuring the amount of time an informal carer spends providing care, ADI (2018) estimates that globally, carers provide about 6 hours of unpaid care per day for a person with dementia. This unpaid care ranged from basic ADLs to IADLs and supervision. Yet, these estimates from ADI cannot be said to be an adequate representation of the hours of unpaid care a person with dementia receives for a few reasons. First, ADI (2018) estimated the global hours utilising available data from one or more nations in the same region, and those data were utilised to impute data for countries in the same WHO region (which had no data). Second, the worldwide approximations were created by weighting time estimates depending on how big the dementia population is in the countries from which the time studies originated. Finally, they utilised global statistics for all the regions in Africa. Contrary to ADI's report, Adedeji et al. (2022) in their scoping review of studies on dementia carers' practices and experiences in African countries found that informal carers spent an average of 13 hours daily providing care. Their estimates double that of ADI's (2018) report and are a more accurate depiction of the approximate number of hours informal carers, especially those in Africa, spend providing care.

In Nigeria, studies show that the majority of the individuals providing hands-on care for a person with dementia are daughters (Baiyewu et al., 2003, Uwakwe et al., 2009), with financial support most likely provided by the sons (Okoye, 2012). Similar findings were also noted by the 10/66 dementia research group, with 95% of the informal carers in Nigeria being women (daughters and daughters-in-law) with limited education (Uwakwe et al., 2009). These findings highlight deeply rooted gender roles with women mainly being primary carers for their families, while juggling other roles, and actively participating in the workforce. In some cases, women cut back on their working hours or give up employment to provide care for the person with dementia

(Uwakwe et al., 2009). This further complicates an already challenging issue in Nigeria, as a significant number of adult children who are dependent on their families to provide care face unemployment (Nwakasi et al., 2021). According to ADI (2018), although the increase in female workforce participation is a positive trend, it may also mean that there would be a reduction in the availability of women for informal carers. Such assumptions foster the idea that the provision of care for people with dementia is the responsibility of women (because they are said to produce more hours of informal care), and their active participation in the workforce will reduce informal care availability.

It is more than women's increased participation in the workforce that impacts informal care availability, Burns et al. (2019) argue that changes taking place in countries like Nigeria, such as rural-urban migration reduces the availability of informal care. Considering that most older people in Nigeria live in rural areas, the younger people migrate to the cities in search of better work opportunities. The ones that do not migrate may need psycho-social interventions, as mentioned earlier in Nwakasi et al. (2021) study where a large number of children were unemployed, relying on their families for support. Informal carers often have limited resources at their disposal to care for older people with dementia in Nigeria. They often lack financial resources to cater to the increasing needs of older people with dementia, whilst managing other duties related to their work, family, and personal life. According to NICE (2018) caregiving can be physically and mentally draining, especially when the behaviour of the person is challenging, and they require extensive care. Caring for someone with dementia was linked to high levels of anxiety and depressive disorders among carers (Schulz and Martire, 2004).

Many carers struggle to cope, and they often have feelings of isolation and loneliness while navigating the changes in the relationship between them and the person they care for as dementia progresses. Informal carers could also experience mobility and health issues due to their own health challenges, especially when the carer is older. The difficulties associated with coping with dementia care lead to high levels of physical and psychological strain, which can also result in secondary stress in other aspects of the informal carer's life, such as family, work and personal relationships (Zigante, 2018). When informal carers are not adequately supported, they may not be able to ensure sufficient quality of care.

Support for informal carers ranges from skill training, respite care, to programmes that provide information on how to manage difficulties related to living with dementia, psychotherapy, and support groups that are led by peers or professionals. Burns et al. (2019:19) argue for 'an urgent need for community support services for people with dementia and their carers in every primary healthcare centre, to provide friendly counselling and rehabilitative services as well as respite care and financial support services' in Nigeria. Although the roll-out of such support services

nationally in Nigeria may seem far-fetched, it is nonetheless an efficient way to go about providing adequate support for informal carers as they remain the major providers of long-term care at home (LTC) for older people with dementia.

However, scholars in Africa have argued against the dominant notions in SSA that support for individuals with long-term health challenges is provided by informal carers (Ananias and Keating, 2023). They argue that the sustainability of informal care with families at the forefront of providing this LTC is concerning (Keating, 2022). One of the UN's priorities for meeting the care needs of older people in their Decade of Healthy Ageing is a call for countries to develop LTC facilities for older people requiring such. LTC refers to a range of services meant to cater to an individual's personal or health care needs over a short or extended period. These services enable individuals who can no longer undertake daily activities without assistance to live as safely and independently as possible (NIA, 2017). LTC is based on an individual's need, and it is often provided by different carers in various locations such as nursing homes and day care centres. Very few countries in Africa have been able to achieve LTC facilities in the form of residential homes for all older people, provided by the government (which includes a level of financial support) (Agyemang, 2021). Such LTC facilities do not exist in Nigeria; there is a long way to go before LTC systems are implemented by the Nigerian government.

In Nigeria, there are about 13 nursing homes owned by NGOs and private investors, with the general population having limited access to them, and there are high financial implications of utilising these facilities (Burns et al., 2019). There are also challenges with the cultural acceptability of LTC facilities. Dementia is widely stigmatised in Nigeria; for some informal carers, collectively (within families) caring for the person with dementia is a way of 'hiding their shame' (Nwakasi et al., 2021:1453). This shame to them could be made public by having to institutionalise the older person with dementia. In addition to stigma, there is also the widespread cultural script that 'it is a taboo to abandon one's parents' in a home where the quality of care is feared to be inadequate, since they would be cared for by strangers' (Burns et al., 2019:18).

This cultural script is also due to the fear that the challenging behaviours expressed by people with dementia could foster abuse by carers not related to them. However, this may not always be the case, as abuse of a person with dementia could also be carried out by any individual in direct contact with the older person, irrespective of whether they are related to them or not. Elder abuse was found to be perpetuated mainly by children and grandchildren against older women in Nigeria (Cadmus et al., 2011, Oluoha et al., 2017). Therefore, there is a range of socio-cultural factors that impact the acceptability of LTC facilities in Nigeria.

Nevertheless, care for older people with dementia in Nigeria, in a sense, relies only on the informal care system, with very little to no effort currently being made by the government to establish LTC systems. Therefore, it is important to understand how care is negotiated by informal carers, what exists to support them (so that it might be strengthened), and what they might wish to receive in terms of support, which might inform the development of future provisions. This is the best course of action considering the current projections of a rise in the number of older people in Nigeria with dementia, and the lack of alternative LTC systems in the country.

## 1.4 Rationale for the research

Various strategies in managing dementia and its associated challenges championed by individuals and organisations push the need for early diagnosis to facilitate prompt treatment, which may slow the progression of dementia, and provide health organisations with time to prepare for future health service needs. In reality, early diagnosis is not always the case because changes in an older person's behaviour are mostly accommodated by their family members, who make adjustments to their everyday routine to reduce the impact of any observed changes (Ceci and Purkis, 2021). Most of the time, carers typically seek help from professionals only when a crisis (such as getting lost) happens, that signalled to them that there is a problem.

In Nigeria, late presentation to orthodox healthcare facilities (at tertiary healthcare level) is a standard, and this is directly linked to a lack of dementia awareness among policymakers and the general populations (Burns et al., 2019). Relatives are often hesitant to seek help from these orthodox healthcare facilities due to the widespread belief that dementia is caused by supernatural forces and thus untreatable, which causes significant delays in early diagnosis and management (Burns et al., 2019, Nwakasi et al., 2021). With the current unlikelihood of early diagnosis and treatments, scholars have argued the need to shift the strategies of managing dementia, from the emphasis on only pharmaceutical treatments and future potential cure, to also the provision of psychosocial support for people with dementia and their carers (Ceci and Purkis, 2021, Manthorpe and Iliffe, 2016).

The need for psychosocial support for carers and people with dementia is important because, unlike some countries in Africa, Nigeria currently lacks a social security system and a functional national policy for the welfare and care of older people (Tanyi et al., 2018). The social policy on care and support for older people in Nigeria established in 1989, assures that the care of the elderly will be the responsibility of the three-tier (federal, state, and local) government, who will encourage the establishment of day care centres and home visits for the elderly by healthcare

professionals, while discouraging nursing homes (Burns et al., 2019, Mbam et al., 2022). Most of the promises made by the Nigerian government that they will ensure adequate shelter, food, elderly care, and pensions for all older individuals have not been kept.

There is a significant policy implementation gap when it comes to the care of the elderly, and there is currently no national policy or plan for the care of older people with dementia (Burns et al., 2019, Mbam et al., 2022). The government's attitude towards older people and, by extension, older people with dementia is argued to be linked to the fact that older people make up a small percentage of the overall population, and the belief that care is the responsibility of the family (Mbam et al., 2022). However, there have been some steps in a positive direction, in 2021, the Federal Government of Nigeria approved the national policy on ageing for older persons. The objective of the policy is to 'have a society where senior citizens are guaranteed security, independence, participation, comprehensive care, self-fulfilment and dignity' (Lamai, 2021:1). This policy is said to cover all older people living in both rural and urban areas.

In addition to the above mentioned, Ugochukwu et al. (2020) and Saied (2023) also argue that the outdated mental health legislation (giving medical professionals and magistrates the right to detain people with mental health issues) in Nigeria, reinforces negative attitudes and inhumane treatment of individuals with mental health needs. As well as stigmatisation, this could also explain why there is limited belief in formal treatment for people with dementia in Nigeria (Baiyewu et al., 2003). Furthermore, there has been little progress in updating the Mental Health Bill, which was initially known as the 'lunacy ordinance', first passed in 1916, and later renamed the 'lunacy act' in 1958 (Ugochukwu et al., 2020:989). The act set out principles for care delivery and management for individuals with mental health problems but did not specifically include people with dementia.

Refining the bill governing mental healthcare in Nigeria has been a challenging journey for legislators. Starting with the National Assembly in 2003, receiving a bill to improve the shortcomings of the lunacy act, to the new bill being withdrawn in 2009. It was later reintroduced in 2013 but failed due to inadequate support (Saied, 2023). More recently, in 2023, the Nigerian president passed the National Mental Health Act 2021 to replace the lunacy act of 1958 (Saied, 2023). The new Act acknowledges mental healthcare as an integral aspect of primary care and aims to foster and safeguard the lives of individuals with mental health challenges. However, the newly passed national mental health act, just like the national policy on ageing, does not specifically include older people with dementia. There is a long way to go in terms of their implementations and effectiveness in improving the lives of older people in Nigeria.

Furthermore, there is a lack of social security as well as inadequacies with the national pension systems (which are contributory and only available to those who have worked in civil service for years). These pension funds have been known in the past to experience issues with mismanagement and embezzlement (Mbam et al., 2022). With the current policy and social security situation for older people in Nigeria, it is not surprising that the majority of care and support for older people is usually provided through traditional informal networks (Ebimgbo et al., 2021). Older people's care needs are met in traditional African households (made up of multi-generational extended families) and social networks (Adedeji et al., 2022, Burns et al., 2019).

For older people with dementia in Nigeria, getting care and support from their social networks is, in most situations, their only option for reasons mentioned earlier. It is also established that carers often lack adequate training to efficiently recognise and provide home care, and management of the behavioural and cognitive symptoms of dementia (Adedeji et al., 2022, Mushi et al., 2014). Informal carers often find themselves in their role as a dementia carer without knowing the demands and challenges that come with caring for a person with dementia. In many cases, caring is mainly because of filial responsibility and reciprocity (Agyemang, 2021).

Literature on how informal carers negotiate dementia care in Nigeria is sparse. Ogunniyi et al. (2005) found that there was a large tolerance of challenging behaviours such as hallucinations and euphoria among family members. This was to preserve the integrity of the family, even when these challenging behaviours were daily stressors for the informal carers. This was due to the stigma associated with dementia and resulting behaviours, making it easier for carers to tolerate it than seek help. Similar findings were also noted in Nwakasi et al. (2021) study were participant mentioned hiding the challenging behaviours to prevent the rest of their family from being ostracised from the community.

Other studies in Africa show that care for people with dementia, hospital visits, and assisted living (having a live-in paid help) are primarily managed by informal carers (Adedeji et al., 2022). Informal carers assisted with tasks like cooking, dressing, feeding, grooming, and bathing, as well as arranging for doctor's visits and prescription refills (Hendricks-Lalla and Pretorius, 2020, Mansi, 2014, Mushi et al., 2014). Younger family members assumed most domestic duties, and people with dementia were not permitted to partake in domestic duties (Baiyewu et al., 2003). Women (wives, daughters and daughters-in-law) were typically the main carers and were involved in carrying out ADLs such as bathing, food preparation, toileting, and dressing (Agyeman et al., 2019).

Evidence also suggests that caregiving was frequently a shared task, with distinct responsibilities delegated to various family members: in Ghana, typically children (Agyeman et

al., 2019) and in Tanzania, grandchildren (Mushi et al., 2014). Interestingly, a study in South Africa found that although day care was considered difficult (because they had to endure the guilt of leaving the person with dementia in day care), it was still an essential strategy to the participants, as they were able to gain respite from their caregiving role (Deist and Greeff, 2017). The decision between living with the guilt of utilising paid help and the respite that could be obtained from the caregiving role may not be easy, but carers in the study ended up feeling refreshed and ready to take on their role as carers. In Nigeria, day care centres and other LTC facilities are sparse or non-existent; therefore, how informal carers perceive the support they receive (or do not receive) from within and outside their care network remains unclear. Although the findings of Deist and Greeff's study highlight the importance of respite in alleviating the burden of caregiving for carers, much remains unknown about how informal carers evaluate their role as carers and the role of other carers. This is important as informal carers make meaning of their role as carers and may do the same for others in their care network, which could have a positive or negative impact on their caregiving practices and experiences.

## 1.5 Purpose of the research

Informal carers need to be supported as much as possible because they are the bedrock of dementia care provision (Ceci and Purkis, 2021). Informal carers could be sustained through a range of initiatives, such as improving access to training and counselling on managing and living with dementia, provision of cash benefits where possible, paid leave for informal carers, and healthcare professionals supporting carers and people with dementia to plan for care. Additionally, families living with dementia will benefit greatly from financial initiatives (where possible), considering the high levels of poverty, dependency, and unemployment in Nigeria (Uwakwe et al., 2009). This majorly impacts the care and management of dementia, especially in those with co-morbid conditions. Supporting informal carers means they would be better equipped in their role, which could improve their wellbeing and the quality of care they provide for people with dementia as they age in place (age at home). Adequate support hinges on approaches that are tailored to real-life challenges and situations of living with dementia.

Therefore, it is important to have a better understanding of what it is like for an informal carer negotiating everyday care for a person to live at home with dementia. It is in answering this question that the day-to-day care for a person with dementia is understood from the perspective of an insider (informal carer). This is crucial in ensuring the approaches to support do not only capture the informal carer’s voices but are also applicable to the socio-cultural setting of Nigeria. In addition, the emphasis on how they negotiate care could not only provide a holistic view of caregiving at home for a person with dementia, but it could also show how

families may seek assistance that is tailored to their circumstances, and the challenges they are experiencing at different times, or how they manage their circumstances and challenges alone without any assistance. This could be respite care, which would give the informal carer a break from 24/7 care, utilising paid assistance to help with caregiving tasks, or even being the sole provider of care.

Although the previously discussed studies make significant contributions to the little that is known about informal care experiences in Nigeria and across Africa. There is still a gap in literature on key areas such as how informal carers evaluate their role as carers and that of others, how the various responsibilities of care are shared or not shared, and how informal carers perceive the support received (or not received) and how the support impacts their caregiving experiences. These are important areas of focus because most of the research done on informal care in Nigeria tends to focus mainly on dementia knowledge and awareness, carers' burden, stigma, and only family carers of people with dementia. This neglects other sources of support informal carers may utilise or receive from within and outside their family network. Understanding how informal carers not only contribute to everyday caregiving but also how they evaluate their care and that of others, and how they share their responsibility of care in Nigeria, are unique contributions this thesis aims to make.

Based on this, the aim of this thesis is to understand how informal carers of older people with dementia in Nigeria negotiate care. To achieve this aim, I answer the objectives and research questions below.

## 1.6 Research objectives

To gain a comprehensive understanding of how informal carers in Nigeria negotiate dementia care, this thesis has the following objectives:

1. To investigate how informal carers evaluate the care they provide as well as that of other carers.
2. To examine how care responsibilities are shared (or not shared) among informal carers in the care network of an older person with dementia.
3. To investigate informal carers' perception of the support they receive (or do not receive) from within and outside their family network.

To achieve the above aim and objectives, this thesis has the following research questions.

## 1.7 Research questions

1. How do informal carers of people with dementia experience and evaluate caregiving, both their own and that of others?

2. How do informal carers of people with dementia arrange and share care responsibilities with others?

3. How do informal carers perceive the support they receive (or do not receive) from within and outside their family network, and how do these perceptions impact their care practices?

## 1.8 Outline of the following chapters

The outline of the next sections includes the literature review, methods, results (divided into four chapters), discussion, and conclusion chapters. In the Literature review chapter, I discuss the theoretical framework of this thesis, drawing on theories such as the Ethics of Care (EoC), Ubuntu philosophy and Finch and Mason's concept on negotiating family responsibilities. In addition, the existing literature on informal caregiving for older people with dementia in Nigeria and other parts of the world is discussed in detail. In the method chapter, I discuss the methods that were used to answer my research questions, known as qualitative methods, as well as the ethical considerations, and reflexive thematic analysis, which I used to analyse my data. The results chapter is divided into four chapters. In the first chapter of the results, I present a table summarising each family's case as well as a figure summarising the main themes in this thesis. I then discuss the developed themes and subthemes that answer each research question (with a separate chapter for each research question). In the discussion chapter, I discuss the overarching themes in this thesis and situate them within existing literature. In the final chapter, I conclude with the overarching points of this thesis and discuss the implications for policy, practice, and future research.

# Chapter 2 Literature Review

There is a paucity of studies on what it is like caring for a person living at home with dementia in Nigeria. In the following sections, care conceptualisation is discussed in general and in the context of Africa, drawing insights from the EoC and the Ubuntu philosophy. I also draw on Finch and Mason's concept of how care responsibilities are negotiated amongst families daily. Furthermore, existing literature on informal caregiving is presented under three major themes: meeting the care needs of an older person with dementia, negotiating, and sharing care responsibilities, and seeking help and support with caregiving, from studies in Africa and other parts of the world.

## 2.1 Theoretical framework

The theoretical framework of this thesis draws from three theories that capture the understanding of care and how care is distributed and practised in everyday contexts. They include the EoC theory, the Ubuntu Philosophy, and Finch and Mason's negotiating family responsibilities. The EoC provides a moral and relational basis for understanding care as a practice grounded in empathy and being responsive to the needs of others (Gilligan 1982, Noddings 1986). To conceptualise care within an African perspective, the Ubuntu philosophy provides a unique yet complementary moral and relational basis that deepens and reinforces the EoC. Although both theories highlight the value of connections, Ubuntu places emphasis on interdependency, shared humanity, and community (Nolte and Downing, 2019).

Furthermore, Finch and Mason's (1993) work complements the EoC and Ubuntu philosophy by shedding light on how caregiving tasks are allocated and distributed within families in everyday caregiving. These theories integrate philosophical, cultural, and sociological viewpoints in providing a comprehensive understanding of care by connecting ethics, culture, and the lived social experiences of caregiving.

### 2.1.1 Conceptualising Care: The Ethics of Care theory

How care is conceptualised is a complex topic that has been investigated and disputed by scholars from a variety of disciplines, often referencing the welfare regimes of advanced industrialised countries (Razavi, 2011, Thelen, 2015). Care is a fundamental part of human existence that encompasses a variety of practices, attitudes, and ideals. A prominent perspective on care is the EoC, which highlights the significance of empathy, relationships, and responsiveness in ethical decision-making. Simply put, ethical decision-making refers to

actions or choices an individual makes based on what aligns with their principles and moral beliefs (Botes, 2000). The EoC originates from feminist studies by Gilligan (1982) and Noddings (1986) in the 1980s. Their approach challenges traditional ethical frameworks such as deontology and utilitarianism, among others (see Norlock (2019)). These traditional frameworks prioritise duties and abstract rules above the unique contexts and relationships in which care occurs in ethical decision-making. According to these frameworks, moral agents (individuals with the capacity to make ethical decisions and judgements) are required or encouraged to be unemotional, and their decision-making should be logical and rational with a focus on universal and objective rules (D'Olimpio, 2019).

For example, men are deemed not to be as emotional as women and are said to pay more attention to rules rather than relationships, which makes them more ethical. Graham (1983) in Thelen (2015:501) argues that 'care constituted a process of female (in contrast to male) identity-building: 'Caring is "given" to women: It becomes the defining characteristic of their self-identity and their lifework. At the same time, caring is taken away from men: not caring becomes a defining characteristic of manhood.' However, such notions may downplay an individual's capacity to care, as caring is considered a key aspect of human nature and should be encouraged regardless of gender, even though it is typically attributed to women (D'Olimpio, 2019, Noddings, 1986, Thelen, 2015). Gilligan and Nodding's work highlight this historic undervaluation of the caregiving role; they argue that it is problematic and male-centric to associate certain roles, traits, and virtues specifically with women in contrast to men (Gilligan, 1982, Noddings, 1986).

Furthermore, in EoC, moral agents do not only include individuals with the capacity to make moral decisions and judgements, rather, it includes everyone irrespective of gender, cognitive abilities, and other factors. This is because moral and caring considerations towards other individuals can also be founded on feelings and empathy, in addition to rational thought (D'Olimpio, 2019). The EoC emphasises the role relationships play in ethical decisions and the moral obligation individuals have towards people who are important to them (Engster, 2005, Tronto, 1998). For example, an informal carer cutting down on their working hours to be able to meet the care needs of a person with dementia; according to abstract rules or principles, this can be seen as a poor decision that could have financial consequences for the informal carer and their family. According to the EoC, the informal carer's decision can be argued to be based on the emphatic bond shared between them and the person with dementia, as well as their desire to relieve the person's burden, even if it entails potentially suffering financial consequences. Such a scenario highlights the ethical dilemma of what is morally 'right' or 'wrong' in this situation, particularly if the informal carer is the sole provider of care for the person with dementia.

Furthermore, caring should be viewed as a fundamental moral principle that governs people's interactions and relationships with others, while taking their situations and contexts into account. Building on the work of Gilligan, Tronto (1998:15) presents 'a more complicated account of ethics' by broadening the way caring is thought about as well as the understanding of what is 'ethical'. This is to encompass many of the decisions that are made daily when individuals take care of themselves and others. Therefore, care has dual meanings as it refers to both a mental state of being concerned and the actual actions taken as a result of this (Buch, 2015, Tronto, 1998).

Earlier discussions on care did not capture these dual meanings, either by ignoring references to actual work through overemphasising the intellectual and emotional aspects, or they overstated care as work while failing to comprehend the deeper intellectual and emotional dimensions (Fisher and Tronto, 1990). Recognising these dual meanings of care, Fisher and Toronto highlighted in their earlier work, adds to the foundation of understanding how care is conceptualised. An examination of care's ethical dimensions, or how it relates to what is understood regarding the meaning of living as well as possible, can provide a useful framework for thinking about how specific caring activities are carried out. Based on this, Fisher and Tronto (1990) identified four phases of what they consider good caring to be, which include:

- Caring about: involves a recognition and responsiveness to the need for caring. This is achieved by listening to the care recipient's expressed needs, recognising their unspoken needs, and choosing which needs to prioritise.

- Caring for: involves taking responsibility for meeting the need that is prioritised. It is taking responsibility for the organisation, gathering resources or persons, and funding the care activity that would satisfy the prioritised need.

- Caregiving: involves the material fulfilment of the caring need. Individuals and organisations undertake the appropriate caring tasks when providing care. It entails understanding how to care for others.

- Care receiving involves a response from the person or group that has received the care. It considers whether the needs were satisfied, whether or not the caregiving was successful, as there will be some reaction to the care that was provided.

Although these phases of what good caring should be are very well articulated, I argue that they do not capture a realistic picture of what caring is for many carers daily. It also raises the question of whether these phases of 'good caring' will ever be achievable in the real world. For example, caring for a person with dementia is challenging due to their care needs; it is even more complicated in cases where a person with dementia has other comorbid conditions (as

discussed in chapter one). Conflicts could arise in deciding which care needs to be prioritised and met. For example, a person with dementia expressing aggression towards their carer can make it difficult for the carer to prioritise needs such as bathing, eating, or taking their medication. In managing all these, the carer could also be dealing with comorbid conditions like diabetes or hypertension. The nature of dementia care could mean just 'surviving the day' as opposed to successfully providing care, as the phases of care discussed earlier propose. This is in line with Tronto's (1998:17) later work, where it is argued that 'several aspects of care make it much more complicated than this account of phases might suggest.'

In the phases of 'good caring,' choosing which needs to be prioritised certainly means overlooking others. Carers must balance their own needs as well as the needs of those they are caring for. Selecting which needs to be prioritised may inadvertently put the care receiver at a disadvantage, as a need may be considered a priority by the carer but may not be one to the care receiver. This also feeds into the power imbalances in the carer/care receiver relationship. Not all care relationships have power imbalances, as caregiving also occurs among equals, for example, cleaning, cooking, and doing the laundry for others in the home who can perform such tasks for themselves (Tronto, 1998).

However, the majority of the care provided has such power imbalances as that provided for a person with dementia. The carer possesses knowledge, resources, and abilities that the care recipient does not possess. The phases of 'good caring' highlight some of these power imbalances, as it only captures the care recipient in the final phase, with the first three phases placing caregiving in the hands of the powerful (the carer). According to Thelen (2015), care recipients are too often portrayed as passive receivers and not actors. This means that individuals who receive care are frequently depicted or treated as if they have little to no agency, control, or involvement in their care; they are primarily viewed as passive objects that carers act on.

Some of the challenges identified with the phases of good caring by Tronto (1998) could be addressed by what Engster (2005:53-54) identified as the 'virtues of care'. Engster argues that without these virtues, the basic goal of caring, which is to help individuals to achieve at least a basic level of wellbeing, meaning, at a minimum, survival, and as much basic functioning as they can achieve, may not be adequately accomplished. These virtues include attentiveness, responsiveness, and respect. Attentiveness is being able to anticipate the care needs of an individual while possessing some measure of empathy. Without attentiveness, caring, according to Engster, is considered ineffective or limited because we might not be able to realise when others need care, or we could respond to their care needs inappropriately or partially. The second virtue is responsiveness, that is, engaging to understand the precise

nature of another person's care needs and observing how they respond to the care that is provided. This is to ensure that they are receiving the care they need. Engaging with the person for whom care is being provided is a critical aspect of care provision. The final virtue is respect, that is, the realisation that others are deserving of attentiveness and responsiveness, therefore, they should be able to express their needs and should not be considered lesser because they cannot meet those needs. Treating others in ways that are not degrading to them in their perspective and in the perspectives of others, while acknowledging their capabilities, is an essential part of caregiving.

Held (2005) further supports this by arguing that the EoC can provide a framework for making ethical decisions. Held highlights the significance of responsiveness, empathy and understanding interdependence in the ethical dimensions of care. For example, a carer deciding how to provide care for a person with dementia who has incontinence problems. The EoC framework could facilitate an understanding of the complex relationship between the person with dementia and their carer, and the context of the condition that is being managed, while also acknowledging the preferences and the individuality of the person with the condition. In this, collaborative decisions (on how to manage the incontinence problems) can be made where possible, while not negating ethical principles like beneficence and non-maleficence (Stone, 2018). This is doing what is in the best interest of the person with dementia (beneficence) and avoiding harm (non-maleficence).

In discussing the conceptualisation of care, it is important to acknowledge other powers and social structures that characterise care relationships, because they provide another perspective in understanding care relationships and caregiving. The intersectional aspects of care must consider race, class, gender, and other social identities, and how they impact caring and care distribution (Buch, 2015, Tronto, 1998). Intersectionality refers to how different aspects of diversity in people's lives interact with institutional structures, cultural beliefs, social practices, and power dynamics (Davis, 2008, Hengelaar et al., 2023). For instance, the importance of gender is extensively discussed in studies on care, which demonstrates the existence of gender hierarchies. Meaning that greater status and power are given to behaviours that are viewed as more male (Hengelaar et al., 2023). Therefore, in considering what care is, it is also necessary to examine how the different intersectional identities interact with one another beyond the consideration of a single category.

Furthermore, the EoC has often been criticised in the past by scholars for associating care exclusively with women, thereby emphasising traditional gender labels and roles (Davion, 1993, Jean, 1997). Scholars argue that focusing solely on care risks overlooking the relevance of fairness, autonomy, and other ethical considerations. Nevertheless, the conceptualisation of

care is a vast and expanding field of study, and it has contributed rich knowledge in understanding what caring is. Based on the discussions so far, I argue that care is an integral part of human existence, although it has been historically attributed to women. While relationships and emotions such as love, affection, and empathy play a key role in motivating care, the obligation to care is equally as important as the actions or choices an individual makes based on what aligns with their principles and moral beliefs. As Tronto (1998) puts it, care has dual meanings as it is more than just physical actions, but also the mental state of being concerned. Therefore, there is no universally accepted way of caring or providing care because of the unique contexts in which they occur. However, the virtues of care as highlighted by Engster (2005), which include attentiveness, responsiveness, and respect, are key in achieving the basic aims of caring (which again is context specific).

Nonetheless, studies have applied the EoC to investigate different topics related to informal care for older people with dementia (Brear et al., 2024a, Keyes et al., 2019, Smebye et al., 2016), this provides evidence for its relevant use in this current study. For example, Brear et al. (2024a) ethnographic study investigated the conceptualisations of ‘good care’ within informal caregiving networks for older people in rural South Africa. Their findings show that ‘good’ care conceptualisations were based on the informal carers' practical knowledge, with reciprocity being a norm in their motivations to care. Additionally, Smebye et al. (2016) in their hermeneutic study, they investigated ethical dilemmas concerning a person with dementia's decision to live at home. Their findings show that people with dementia embraced their reliance on others to maintain their true independence and align with their recognised values.

The above studies provide examples of how the EoC can contribute to the understanding of informal care for older people with dementia. By drawing on the discourse so far, this current study positions the EoC as one of the critical lenses through which the lived experiences of informal carers can be understood. The EoC also highlights the moral, emotional, and possibly critical dilemmas carers encounter in negotiating everyday care for a person with dementia. This is because emphasis is on relationships, with sensitivity to both the personal, familial, and systemic aspects of care provision.

### 2.1.2 Conceptualising care within the African context: The Ubuntu Philosophy

Thinking critically about the EoC in the context in which it was discussed in the above section, the importance of also considering the African perspective in terms of the EoC becomes clearer. Capturing the way ethical frameworks are understood within the moral framework of Africa is essential in understanding the values at play when analysing ethical decisions within the African context (Atuire, 2022). However, it is crucial to emphasise that the concept of care in Africa is

not homogeneous, as there are significant variations across the continent. Care may have different cultural ideas, practices, and standards in different countries, regions, and ethnic groups in Africa. Therefore, discussing the conceptualisation of care in the African context is not aimed at comparing Africa's perspective to the Western perspective of EoC, rather, it acknowledges that care in a continent like Africa is often a multifaceted concept firmly rooted in historical, social, and cultural contexts (Gyekye, 2011, Metz, 2013).

Before discussing the African concept of caring, it is important to briefly discuss the core beliefs of the African ethics. According to Gyekye (2011:1), 'African societies, as organised and functioning human communities, have undoubtedly evolved ethical systems—ethical values, principles, rules—intended to guide social and moral behaviour.' Humanism, the ideology that emphasises human interests and wellbeing as fundamental to people's cognition and behaviour, is the foundation of African morality. This idea, as understood in the African moral viewpoint, has given rise to the African society's communitarian (see Chang (2022)) principles. These principles emphasise an individual's connections with their communities, therefore, protecting the welfare and interests of all members of society is difficult to achieve outside a communitarian society (Gyekye, 2011).

African humanitarian ethics, as Gyekye (2011) further argues, gives birth to the morality of common good, social morality, and the morality of obligation, which is so broad that it includes what is known as moral ideals (such as love, virtue, and compassion), which are considered supererogatory in Western ethics. In African ethics, there is the predominant tradition of human beings being seen as brothers due to their common humanity, buttressing the importance of community in ensuring the collective interest of all, as opposed to individual interests (Nolte and Downing, 2019).

Coming back to the African concept of caring, the most predominantly cited notion on the concept of care in Africa is the philosophical principle of Hunhu/Botho/Ubuntu (a Zulu/Xhosa/Ndebele/Sesotho/Shona word), which has its origins in Southern Africa (Mangena, 2009, Mangena, nd., Nolte and Downing, 2019, Siniora et al., 2022). Many languages in SSA may have their own version of the Ubuntu phrase. According to Nolte and Downing (2019:9), 'the word is difficult to translate into English, but it roughly means 'humanness' or 'a person is a person through other persons.' 'Giving,' which is seen as a mutual act of exchanging resources, close connections, and solidarity, is the fundamental act of Ubuntu.

Prozesky (2003:5-6), as seen in (Mangena, nd.), highlights what is considered to be some of the distinctive qualities of the Ubuntu, which include: gentleness, hospitality, humanness, empathy, deep kindness, generosity, friendliness, vulnerability, toughness, and compassion. This philosophy is passed down from generations through diverse tribal practices, with

members of the family, community or village, tribe, and even ancestors thought to be involved in the African concept of caring (Nolte and Downing, 2019). Recognising oneself in others and demonstrating solidarity are essential elements for building communal bonds and affirming persons in Ubuntu philosophy (Siniora et al., 2022).

Care is often regarded as a key responsibility and duty of individuals in many African countries (Gurayah, 2015). This responsibility is towards their communities at large and narrowed down to cover an individual's family unit and extended kinship network. Similar to Tronto's (1998) earlier definition of care, in the African concept, care extends beyond the meeting of basic physical needs but also includes the emotional, psychological, and spiritual (connections between others and the universe) care (a concept not covered in Tronto's dual definition of care). The family and community at large not only play a key role in how care is conceptualised but also in how humanity is interconnected. According to Olare (2014:1) 'traditionally, in African communities, social needs and social problems were addressed by the family (nuclear and extended) or the clan. It is common for neighbours or religious organisations to assist.'

Thus, the community can be said to provide the relational framework and support individuals need to develop and live. This can foster feelings of pride and duty contextualised within the community, resulting in a sense of communal identity (Nolte and Downing, 2019). In Nigeria, it was found that native communities had procedures and practices in place that ensured the continuation of life and improved people's well-being (Olare, 2014). Some of these practices include name-giving and marriage rituals, indigenous banking systems (known as microfinancing), informal adoption of children, and care for the elderly by relatives. Olare (2014) further argues that these practices are influenced by strong beliefs in the spiritual components of human existence, and they regard caring as an obligation not just to individuals but also to the gods.

Furthermore, Ezulike et al. (2024) study in Nigeria on individuals' motivations to provide care for older adults found that motivations were rooted in cultural and religious underlying factors. This shows that in conceptualising care within the context of Africa, it is important to consider the role religion and spirituality play. According to Dhamani et al. (2011) and Mshayisa et al. (2024) spirituality is considered an essential aspect of both individual and kinship care. Masango (2009:916) relates the African care ethos to theological anthropology that people are created in God's image ('Imago Dei') and thus deserve respect and care. In this case, caring becomes a spiritual duty and divine call that goes beyond social and moral considerations. That is, while the motivation to care in the African context could be spiritually and religiously motivated, caring also extends beyond individuals to the community; as Ubuntu phrases it, 'I am because you are, you are because I am' (Masango, 2009:918, Siniora et al., 2022:262).

Based on this, I argue that where Toronto's definition of caring highlights dual meanings, in the African conceptualisation of care, spirituality introduces a third meaning that is as vital as the physical state of being concerned, and the actions taken because of that concern. This third meaning addresses the presence and needs of the human spirit, with a focus on the person's self-worth and purpose, particularly in times of illness. Simply put, while care has dual meanings which capture concerns and actions taken to address those concerns, the spiritual meaning of care in the African concept recognises how we are all connected (buttressing the care receiver's self-worth and existence in their family, and wider community).

Nonetheless, it is impossible to discuss the African concept of caring and Ubuntu without considering how these concepts, just like the EoC, feed into women traditionally being associated with care, nurturance, and empathy (Chisale, 2018, Mangena, 2009). Caring being seen as a defining characteristic of women's self-identity and life work is a universal notion, especially in traditional African societies, where there are persistent gender roles of women bearing an unequal responsibility for caregiving (Hall et al., 2013). Challenging this notion goes back to the importance of fostering care as an integral part of every human's existence. Based on the above discussions, in the African conceptualisation of care, I argue that it is not just about the ethical decision to care, but also the importance of an individual's interconnectedness to humanity, with caring being a communal obligation. This obligation is to those an individual is empathic towards or in close relationship with, and those 'within' their community.

Additionally, although the Ubuntu philosophy and the EoC are based on relational principles, one of their notable differences is that in EOC, the emphasis is often placed more on solidarity than on the act of identifying with others. Whereas in Ubuntu, both the identification with others and a sense of solidarity are essential for expressing Ubuntu (Siniora et al., 2022). Nonetheless, these theories are connected in that they reflect the ethical values caring possesses. Both theories do this by providing an understanding of the moral behaviour in the relationship between a carer and a person with dementia (Siniora et al., 2022).

The Ubuntu philosophy offers a useful theoretical perspective for understanding informal caregiving for individuals with dementia in Nigeria. Various studies have shown how Ubuntu principles influence motivations to care and caregiving behaviours in African settings, underlining respect, empathy, and collective accountability (Ezulike et al., 2024, Gurayah, 2015, Siniora et al., 2022). Specifically, Gurayah (2015) explored caregiving for people with dementia in rural South Africa, and they found that there was a strong sense of duty and kinship conveyed by participants in caring for their relatives. This was linked to an unspoken expectation in African culture of caring for your parents and family, as reflected in the principle of Ubuntu. The findings

of this study provide an example of how the Ubuntu philosophy supports the understanding of caregiving as a practice rooted in relationships and culture. This aligns with this current study's emphasis on how informal carers negotiate dementia care within their socio-cultural contexts.

### 2.1.3 Finch and Mason's concept of negotiating family responsibilities

Contemporary sociological methods for understanding family dynamics reflect the greater autonomy we possess regarding the structure of our family connections (Chambers et al., 2009). During the mid-20th century, functionalism was the prevailing sociological viewpoint for examining family structures (Chambers et al., 2009). Functionalism is the sociological viewpoint that considers society as an intricate system where various components, or institutions such as education, religion, and family, collaborate to foster stability and solidarity (Parsons, 1991). Although many scholars in sociology and anthropology played a role in shaping functionalism as a theoretical framework for understanding families, American sociologist Talcott Parsons is seen as its most contemporary promoter (Amoateng, 2007, Chambers et al., 2009). Parsons (1991) acknowledged that individuals do not exist in isolation, rather, they engage with broader social systems. He asserted that the family should not be viewed as an autonomous system but rather as a subsystem within society (Amoateng, 2007).

By the late 20th century, different perspectives began to emerge that emphasised the significance of individual agency in shaping family dynamics and practices, reflecting the increasing practical changes observed in family life (Chambers et al., 2009). Finch and Mason's (1993) work on negotiating family responsibilities is one of the dominant perspectives on how individuals are active agents in shaping dynamics and practices within their families. They argue that family relationships are not simply formed by individuals passively adhering to traditional cultural norms or expectations. Rather, family dynamics arise from interactive processes that, although influenced by societal norms, necessitate the ongoing independence of those involved, either directly or indirectly. That is, relationships gradually develop through a sequence of interactions within the different family contexts in which they occur (Chambers et al., 2009).

Finch and Mason (1993) further argue that family dynamics can only be comprehended within their unique context, indicating that responsibilities and expectations are influenced by much more than overarching cultural norms. While individuals certainly rely on shared ideas of familial roles, their actual conduct is affected by their specific situations and the past histories of their interactions (Chambers et al., 2009). Here, family members do not merely follow a fixed script; rather, they interpret what is appropriate based on considerations such as emotional intimacy, past instances of assistance, their personal capacity, and the actions of others within

the family network. Over time, family relationships unfold, with future expectations shaped by the interactions. Therefore, responsibilities are shared through a process of negotiations which are contingent and based on family members' personal history, context, and collective understanding, rather than customary norms or cultural guidelines (Chambers et al., 2009, Gillies, 2003).

One of the most significant points in Finch and Mason's understanding of how families negotiate responsibilities is the concept of negotiation. These negotiations are not merely a series of independent occurrences; instead, the practical and moral aspects of present negotiations are transferred into future negotiations. They argue that how individuals negotiate can have a lasting impact, which is parallel to the tangible results of the negotiations (Finch and Mason, 1993). This happens because, during the negotiation process, individuals create social interpretations that assist them and others in understanding the past, present, and future.

Different forms of negotiation could take place; these negotiations could either be explicit or implicit. On one hand, explicit negotiation entails open discussions between two or more individuals seeking to commonly understand where the balance of responsibility to receive and give help should lie. (Finch and Mason, 1993). On the other hand, implicit negotiation does not involve open conversations, but people have methods of communicating with each other regarding what kind of responsibilities are deemed reasonable for other people and themselves. Negotiations may continuously occur over time in response to changing demands, circumstances, and relationship dynamics.

Another key point that can be taken from Finch and Mason's definition of negotiation is that it is often indirect, and it is not a single event, but a continuous process, proceeding through assumptions, emotional cues, and routines, rather than formal conversations. Furthermore, much of family negotiations occurs in different forms such as 'open discussions', 'clear intentions' and 'non-decisions' (Chambers et al., 2009:5). Where open discussions involve explicit conversations, clear intentions involve one individual making a decision that is accepted by others without dispute. However, in non-decisions, outcomes emerge naturally as an obvious choice to everyone (Finch and Mason, 1993).

Amongst informal carers, specifically family carers, reciprocity can play an important role in understanding the exchange process within kin groups regarding caring responsibilities. However, Finch and Mason (1993) argue that reciprocity is only one way of understanding an individual's commitment to offering help to their relatives. According to them, 'responsibilities between kin are not straightforward products of rules of obligation but also a product of negotiation' (Finch and Mason, 1993:60). This suggests that people actively work out their course of action while consulting with others. Here, negotiation is a social, moral, and relational

process in which family members decide and manage duties, particularly those involving care and support, either explicitly or implicitly.

However, Finch and Mason's work is not without criticism, one of the criticisms of their work is the tendency of their concept to depict negotiation as a largely collaborative undertaking. Yet, literature shows that family relationships in general could often involve a degree of ambivalence, conflict, and tensions (Bengtson et al., 2002, Connidis and McMullin, 2002), including among families caring for older people (Shrestha et al., 2024). Yao (2023) defines ambivalences as a common blend of sweetness and bitterness, harmony and conflict, love and hate, a longing for closeness, and a fear of losing independence that occurs in both different relationships within a family. These complexities could obscure negotiation, as what may appear to be a negotiated resolution may actually stem from unaddressed expectations, rather than a genuine agreement, even where the negotiation is implicit.

Another criticism of their work is that although they significantly emphasise agency, variability, and diversity in family behaviour, focusing on agency and interactions within families may downplay the influences of power dynamics and larger structures of inequalities, such as gender. For example, in societies, there is the persistent gender role of women carrying an unequal responsibility for caregiving (Hall et al., 2013). Therefore, where 'non-decisions' in negotiations explain how outcomes emerge because the choice was obvious or natural, women could be disproportionately affected in such implicit negotiations due to the predominant gendered role associated with caregiving. This is because different social identities not only impact caring but also care distribution (Buch, 2015, Tronto, 1998).

Although Finch and Mason's concept is key in conceptualising and understanding how families negotiate their care responsibilities, the application of their work may be limited across different family and cultural contexts from late 20$^{th}$-century British society. For example, some aspects of their concept may not apply to the Nigerian society. This is because negotiating care for an older person may be seen as disrespectful or confrontational, especially when a younger family member initiates the conversation. While Finch and Mason argue that families do not strictly adhere to established cultural guidelines or inflexible standards when negotiating responsibilities and sharing care tasks, I argue that this view is narrow because it downplays the ongoing influence that normative and socio-cultural expectations play in shaping family actions.

Nonetheless, Finch and Mason's concept played a crucial role in moving family sociology away from rigid, rule-based perspectives towards a deeper acknowledgement of agency, variability, and diversity in the behaviour of families. Their work also provides an understanding of how the 'insider knowledge' family members have about their life stories and circumstances can determine what they expect from one another in different contexts (Chambers et al., 2009:6).

Although Finch and Mason's concept have not been extensively utilised in literature on informal care for people with dementia in SSA, it can still provide a critical lens for analysing how informal carers divide and share their care responsibilities.

In the following sections, existing literature on the experiences of informal carers providing dementia care in SSA and globally is discussed in detail.

## 2.2 Informal care for older people with dementia

The dependency of a person with dementia increases as the condition progresses (Lindeza et al., 2020, Darling, 2007) and their care needs are shaped by how dependent they are. For example, a person with dementia may be able to carry out ADLs such as washing, shaving, brushing hair, and getting dressed with little to no assistance. However, they will eventually require more assistance as the condition progresses. Several studies have shown that informal carers meet the care needs of the person with dementia either by themselves or by negotiating and sharing the care responsibilities with others in the care network (including paid helpers).

Informal carers craft care and manage care in challenging circumstances and shifting relationships (between the person with dementia and the informal carer) (Cipolletta et al., 2023, De la Cuesta, 2005, Nielsen et al., 2021b, Seaman, 2020, Köhler et al., 2022), while negotiating the care responsibilities with others in the care network (Agyeman et al., 2019, Berdai Chaouni and De Donder, 2019, Mayston et al., 2017, Nielsen et al., 2021a). In some cases, they provide care alone (Hendricks-Lalla and Pretorius, 2020), in other cases, they get assistance from a paid helper (Cipolletta et al., 2023, Deist and Greeff, 2017, Seaman, 2020, Wammes et al., 2021).

In the following sections, I review the existing literature on informal care practices under three sub-themes: organising care to meet the needs of older people with dementia, meeting care needs in shifting relationships and challenging times, and day-to-day caregiving for older people with dementia in Africa.

### 2.2.1 Organising care to meet the needs of older people with dementia

According to De la Cuesta (2005:885), caring for someone with dementia is not a rational process because dementia is a 'disorganised' and complicated condition that does not follow stages, even though dementia is categorised in stages. As discussed in chapter one, dementia is experienced differently by diverse individuals; though it is categorised in stages, it does not always follow that linear progression. De la Cuesta (2005) further argues that caregiving is invented and tailored to suit the person care is provided for. In their study in Colombia, they

found that care is a craft that family members intelligently and creatively utilised to adapt in their care environment. For example, a son used a ruse of asking his dad to look for his pyjamas inside the drawers of a room to get his father inside the room and identify the room as his. This son's ethical decision-making could be based on his desire to prevent harm and do what is best for his dad given the circumstances. In addition, his responsiveness and empathy towards his dad made it easier for his father to maintain his identity, despite the cognitive limitations of dementia.

Nonetheless, the various ways the family carers crafted care only lasted for a few days, this means that they were constantly inventing new ways to meet the care needs of the person with dementia. Additionally, a carer in the same study also invented a bottle to feed the person with dementia because they kept their mouth shut, making spoon feeding challenging. These crafts of care are complex skills developed by the family carers in De la Cuesta's study while providing care for a person with advanced dementia. Crafting of care is arguably due to the carer's experience/professional background in dealing with everyday caregiving issues, which may not be related to the stage of dementia the individual has. Kontrimiene et al. (2021) study in Lithuania found that some informal carers utilised logic-based organisation of care, such as segmenting hygiene processes (washing their mother's head one day, and her body the next day) to manage leg ulcers. Such crafts of care not only reveal how some informal carers organise care but also the skills and knowledge these carers possess in negotiating care for the person with dementia.

However, caregiving may not always be a craft, as seen in De la Cuesta's study; it may often be a case where informal carers make spontaneous decisions that are not crafted uniquely. Some informal carers could face challenges in meeting the care needs of a person with dementia, even with the use of persuasion. Araujo et al. (2020) in Brazil, carried out a participant observation study looking at the materiality of care (bringing visibility to the mundane and overlooked aspects of care), such as adult diapers with one participant, and how it influenced daily care practices in the home. For example, the family carer's desire for her mother to be in diapers affected other practices such as meal routines. This was because of her mother's consistent refusal to wear or take off a full diaper (after eventually wearing it), leading to the carer struggling to take it off. This is an interesting finding that highlights how objects such as adult diapers could have a significant impact on other aspects of care provision. It is important to note that the person with dementia in Araujo's study had an existing urinary incontinence problem alongside her dementia. This may have exaggerated the importance of the adult diaper and the impact it had on negotiating everyday care.

Additionally, other objects not directly involved in the care of a person with dementia could play a significant role in everyday caregiving. Koo et al. (2021) looked at intergenerational Singapore-Chinese families' everyday caregiving experience. They found that objects and nature hold great traditional and cultural values and meanings in everyday care and living with dementia. For example, an acrylic painting of Chinese mandarin oranges, Koi Chinese fishes, and a sunrise was hung on the wall facing the person with dementia's bed by her son, so she sees it daily when she wakes up. According to the participant, 'the oranges symbolise a happy occasion; the sunrise symbolises a new beginning every day, and the fishes symbolise prosperity and abundance' (Koo et al., 2021:1905).

Cultural values and norms play a significant role in everyday life and have existed before the diagnosis of the person with dementia. The paintings utilised by the family carers in the study above were a way the carers communicated their shared cultural Chinese heritage to the person with dementia, which is vital in maintaining personhood. This further buttresses the importance and role of different objects in supporting the continuity of identity, which is a critical aspect of caring for a person with dementia (Hennelly et al., 2018).

### 2.2.2 Meeting care needs in shifting relationships and challenging times

Organising and carrying out care activities by informal carers is also influenced by how they understand their relationship with the person with dementia. For example, in a participant observation study in the United States, a family carer providing care for their spouse experienced a shift in the once intimate relationship between spouses towards a more parent-child-like relationship (Seaman, 2020). Similarly, a qualitative study in Australia investigated the experiences of informal carers, and they found that informal carers experienced a shift in their bond with the person with dementia. Carers in the study mentioned how their relationships transitioned from an intimate to a more friendly and companionable one (Engel et al., 2022).

This shift in relationships was also experienced in a German study amongst parent-child relationships. The family carers, particularly children, saw themselves as the parent and the person with dementia as the child (Köhler et al., 2022). Relating the person with dementia to being childlike may be seen as infantilisation and ageism, which dehumanises the person with dementia (Jongsma and Schweda, 2018). However, Seaman (2020) argues that this way of seeing people with dementia as being childlike can be a way families make sense of the shifting relationships. This is because carrying out caregiving activities such as bathing, feeding, dressing, movement, and management of the household are activities a parent typically does for their child. Therefore, seeing the person with dementia this way makes it easier for them to carry out their daily care practices, while making sense of the shifting relationship.

However, infantilisation of a person with dementia is a challenging concept to reconcile because the way families may cope with this shifting relationship does not negate the fact that it is not ageism or infantilisation. Instead, what becomes clearer is the carer's reality providing dementia care, and the reality the person with dementia must endure as the care receiver. Here, power dynamics as discussed earlier in critiquing Toronto's phases of good caring come to play. This is because care lies in the hands of the powerful (the carer), and they decide which care needs to be prioritised and met because they see the person with dementia as a child. This strengthens the need for support interventions for informal carers tailored to improve their skills on how to provide person-centred care for their relative with dementia.

Spouses could find it easier to adjust to the shifting relationship between them and their spouse, compared to children and their parents. The provision of basic care needs such as bathing, toileting, and brushing hair and teeth are intimate task. There is already a level of intimacy that exists in spousal relationships, which could make the transition from spouse to primary carer easier. Zhang (2021a) in their study in China found that husbands did not regard gender norms when providing care, whereas son carers frequently considered the line between 'appropriate' and 'inappropriate' behaviours in care provision. The caregiving tasks the husbands and sons performed ranged from manual labour-intensive tasks to all aspects of care, such as shopping, transportation, medication management, housekeeping, cooking, bathing, and toileting.

Apart from the shifting relationships between the person with dementia and their informal carer, challenging times such as the COVID-19 pandemic also influenced how care was negotiated by informal carers. The pandemic led to a lot of uncertainty, confusion, and worry in navigating typical care activities. In Italy, a study found that it was difficult to respect rules such as wearing face masks (in cases where the informal carer did not live in the same home as the person with dementia) and maintain distance during mundane tasks like eating, cleaning, and other activities at home (Cipolletta et al., 2023). The pandemic also affected the use of day care centres, with very few family carers able to make up for the lack of physical activities by taking walks in their private garden or on the streets where possible. This was because of the fear and uncertainty that characterised the lockdown period. Family carers felt it was much better to have the person with dementia indoors in a safe and controlled environment. This finding is similar to that of a study in the United States on dementia care during the lockdown phase of the pandemic. They found that 62% of the family carers precisely followed the COVID-19 guidelines to ensure the person with dementia was safe.

Cipolletta et al. (2023) also demonstrated how the typical challenges family carers experience were amplified by the COVID-19 pandemic. This led to heightened burden in terms of practical

challenges, difficulties in accessing help, and emotional stress. Similar findings were also noted in Collins et al. (2024) study in England on the experiences of carers of people with dementia from the British IDEAL cohort. They found that the increased demands of caregiving, the deterioration of the person with dementia, and the decrease in formal assistance resulted in greater stress and burnout for carers. Carers expressed difficulties with their own health challenges, financial strain, and insufficient personal time, with many carers mentioning that training, tailored support, and regular assessments would be beneficial for them.

Despite challenging times like the pandemic, some family carers' preexisting mindful approach to caregiving meant that they were able to evaluate the situation and utilise other strategies to meet the care needs of the person with dementia (Cipolletta et al., 2023). For example, the lockdown rules meant that there were a lot of communicative and physical limitations, resulting in discomfort and aggressive behaviour from the person with dementia, which had a negative influence on care routines. However, family carers in Cipolletta et al.'s study were able to find other cognitive and physically stimulating ways, such as in-house exercises, organising walks and keeping in constant contact with loved ones, to meet the needs of the person with dementia.

This demonstrates that carers negotiate care in an ever-changing care environment that can also be affected by external circumstances that the informal carer has no control over. While some informal carers can adapt to these challenging circumstances and prioritise the care needs of the person with dementia, others do not. This highlights imbalances that could be created based on how an informal carer negotiates care provision in their care environment. Such imbalances could be remedied by improving equal access to support and training programmes (where possible) for carers, which may remedy such imbalances.

### 2.2.3 Day-to-day caregiving for older people with dementia in Africa

In Africa, most of the literature focuses on day-to-day care practices of family carers. Agyeman et al. (2019) study on the experiences of living with dementia in Ghana found that caregiving was a collective effort of both immediate and extended family networks. Organising day-to-day activities such as bathing, cooking, dressing, toileting, and ensuring that the person with dementia was not left alone was done by the primary carer, typically wives, daughters, and daughters-in-law. Men (husbands and sons) were central in making decisions regarding healthcare, finances, and hospital visits. Commonly, grandchildren carried out household tasks such as cooking, which was also seen in a Tanzanian study on social representation and practices related to dementia by Mushi et al. (2014). These findings also echo those of Baiyewu et al. (2003) study in Nigeria, where younger children were responsible for household tasks and

people with dementia were prevented from participating. This could be due to beliefs in African households, where younger children are expected to perform certain tasks out of respect for the elderly person, irrespective of a medical condition.

However, Bayiewu et al.'s study did not consider who performs the other caregiving tasks within the multi-generational household identified among the participants. Organising care for people with dementia goes beyond who performs IADLs, such as household chores, but also considers the importance of ADLs. These tasks are essential in meeting the basic needs of people with dementia and cannot be overlooked. This links to the earlier discussion on the conceptualisation of care, particularly the Ubuntu philosophy, where care is a collective effort of the traditional African communities, which includes nuclear and extended family networks.

In some circumstances, caregiving tasks such as ADLs were carried out by only an immediate family member, such as daughters in South Africa. This was due to other family members being insensitive and having differing opinions about caring for the person with dementia (Mahomed and Pretorius, 2022). Differing opinions among family members could be a significant hindrance in negotiating dementia care. This could be due to tensions that are created in trying to reach an agreement. In another South African study, a male (husband) carer mentioned how there were conflicts and tensions as other members of the family, originally expected to be involved in care provision, severed ties with the person with dementia and the primary carer (Hendricks-Lalla and Pretorius, 2020). Family tension, dating way back before dementia diagnosis, was also evident in Araujo et al.'s (2020) study. According to Ananias and Keating (2023), an individual being the sole provider of care could also be due to the preference for that particular carer by the person with dementia, or the person with dementia being overly critical when it comes to how care is provided for them.

Although people with dementia were prevented by family carers from participating in household tasks in Baiyewu et al. (2003) in Nigeria, Agyeman et al. (2019) study in Ghana found that some family carers organised alternative activities such as helping to sort maize for the poultry, to compensate for the person with dementia's inability to perform IADLs such as going to the market or farming. This also highlights the African concept of care, where emphasis is placed on ensuring collective interests as opposed to just the interest of an individual, which will ultimately exclude the person with dementia.

Interestingly, Brear et al. (2024b:469) in their study on everyday dementia care practices in rural South Africa, emphasised the crucial role of mundane activities, particularly 'sitting in wait' plays in enhancing the well-being of people with dementia receiving home care. Sitting in wait is a concept the researchers used to describe the mindful practice of allowing the person with dementia to freely perform productive and meaningful activities that they are able to complete.

Although power dynamics exist in the carer and care receiver relationship, in this study, the care practices of the informal carers placed power back in the hands of the person with dementia.

The above finding is in contrast to the infantilisation of people with dementia discussed in Seaman (2020) study where power lay in the hands of the carers, as seeing the person with dementia like a child could mean that everything is done for them without them contributing to meeting their needs. The concept of 'sitting in wait' also placed the act as both a means of providing care, and a physical expression of systemic helplessness the carers experienced due to government polices that unfairly position women as carers.

Therefore, what is evident in the studies discussed so far is how individual families negotiate everyday dementia care, providing care based on their knowledge and skills, and to suit their unique circumstances and contexts. They do this while adapting and adjusting to the constantly evolving dementia care environment as dementia progresses.

## 2.3 Negotiating and sharing care responsibilities among informal carers

The negotiation of care responsibilities focuses on how informal carers decide who is responsible for the different caregiving tasks. The forms of negotiations (as discussed in Finch and Mason's concept of negotiation) that informal carers utilise in sharing their care responsibilities with others in the care network are influenced by their family dynamics as well as other factors. According to Zhang (2021b) some of these factors include the socio-economic status of the informal carer and the availability of women to help in caregiving. This fosters the ideology that caring for an older person is the responsibility of the women in the informal care network (discussed earlier in chapter one). An overarching theme in the majority of the studies was the traditional role of women being the primary carer of the person with dementia. These primary carers are, in some cases, responsible for organising care. Particularly, wives, daughters, and daughters-in-law provided most of the day-to-day care for the person with dementia.

Other members of the extended family network, such as grandchildren, also got involved in care responsibilities when the need arose (Nielsen et al., 2021a, Koo et al., 2021). This could mean that the responsibility of being the primary carer falls on the immediate family, typically spouse and children, with extended families taking up responsibilities on an as-needed basis. This supports Baiyewu et al. (2003), who argue that care provision for people with dementia is the responsibility of the primary carer (spouse or children) even in multigenerational households.

These primary carers function as the care coordinators for the families, with the responsibility of organising and sharing the day-to-day care activities with others in the informal care network.

Furthermore, there were strong patterns of keeping care within the family; these patterns were common among ethnic minority groups (Arabic-speaking communities, Turkish and Pakistanis). A study on minority ethnic groups in Denmark (Nielsen et al., 2021a) found that keeping care within the family was not only attributed to cultural norms of reciprocity, but also the fear and stigma associated with putting a family member in a care home. In their study, care was rotated amongst family carers on a day-to-day, week-to-week or month-to-month basis between different members (children) of the family. The person with dementia either moved in with her children during the rotation, or the children moved in with her temporarily. This afforded the carers flexibility with other responsibilities outside of caring. Sharing care responsibilities this way was seen as a way to minimise the burden of caregiving being on just one member of the care network, which could avoid the need for formal care. However, this may lead to discomfort and instability for the person with dementia, impacting their overall well-being.

Similar findings were also noted among minority ethnic groups in Belgium and the Netherlands. In Belgium, the majority of the family carers in the care network worked together, showing a strong commitment to meeting the care needs of the person with dementia (Berdai Chaouni and De Donder, 2019). The family carers often assumed roles that were explicitly or implicitly negotiated. For example, the wife of a person with dementia was the sole provider of care, while their children were there whenever their mother needed assistance. In the Netherlands study, eldest daughters or wives of the eldest sons had the responsibility of providing personal care, while some men provided personal care, typically for their fathers or uncles. (van Wezel et al., 2016). Family care was considered ‘superior’ to formal care services due to the negative views of residential care, and also care being seen as the obligation of the family (van Wezel et al., 2016:79-80). This aligns with the EoC, where emphasis is not only on empathy and the relationship between the carer and care recipient in the decision to care, but also the carer’s moral obligation to care.

However, other forms of formal care services may be more acceptable to family carers compared to care homes. Koo et al.'s (2021) study in Singapore found that cultural norms of reciprocity and filial obligation among families in inter-generational Chinese households played a significant role in ensuring a shared home space for the person with dementia to live in. Meeting the care needs of a person with dementia was negotiated among members in these intergenerational households. Unlike the above discussed studies, fear of stigma did not prevent the family carers in Koo et al.'s study from assessing some sort of formal care services (such as using a live-in maid). This was irrespective of how difficult the decision was due to the

widespread notion among Chinese people that the home is for family members to live in, not strangers (live-in maids) (Matondo, 2012). I argue that the family carers in Koo et al.'s study acceptability of the live-in maids, despite the notion of them being strangers, could be due to how common live-in maids are in Singapore, with one in every six households with care responsibilities hiring a live-in maid (Thang and Mehta, 2009).

Moreover, the gendered role of females frequently researched as primary carers is being challenged (Zhang, 2021b). This inequality in research approach to studying informal carers has led to an increase in studies exploring male caregiving roles in various parts of the world. Similar to female informal carers, male informal carers taking up the responsibility of care for the person with dementia was either the only option to them or a decision they made from choice (Frelih, 2019). In such situations, the male carers still played their role as 'decision makers' but in different circumstances, such as being the only child of the person with dementia, therefore taking up the care responsibilities. In Chinese culture, men taking up the responsibilities of providing care for a person with dementia is seen as unusual, as this is typically considered the responsibility of women. Male carers have been referred to as 'Cinderella men' (Zhang, 2021a), which is a female fairy tale character. In this way, the society tries to make sense of the male carers' roles by attributing them to a popular female fairy tale character but still retaining their identity as men.

In studies in Africa, as is seen in other parts of the world, traditional gendered roles of women being involved in the day-to-day caregiving still exist; this is highlighted in both EoC and the Ubuntu philosophy. A study looking at the cost of caring for dependent older people in SSA found that even in households where the females were working, the males were still the decision makers and financial providers (Mayston et al., 2017). Although there is the gendered role of females being the hands-on carers, in some cases, they could occupy a dual position of being both hands-on carers and decision makers. This is supported by Agyeman et al. (2019), who found that some female carers (usually the older person's daughter) were both decision-makers and hands-on carers. The female carers made unilateral treatment decisions and only involved family members who financially contribute to the care of the person with dementia, after the decision was made and treatment was accessed. The responsibilities and roles in the provision of ADLs, IADLs and making treatment decisions may be jointly decided by immediate and extended family networks. This is an explicit form of negotiation where discussions take place, and the family members decide and agree on who will accept which caring responsibility.

Based on the literature on informal caregiving reviewed so far, families share their care responsibilities by negotiating (often implicitly) with others in their care network. This negotiation is done while taking into consideration their existing family dynamics, what they

have agreed to, or based on the circumstances of things, which is in line with some of Finch and Mason's (1993) theory. However, in some cases, sharing care responsibilities for a person with dementia could lead to tension and friction between members of the family (Hendricks-Lalla and Pretorius, 2020). Leading to the primary carer becoming solely responsible for the care of the person with dementia, as discussed previously.

I argue that in certain cases and contexts, negotiations (as Finch and Mason theorised) on who shares what aspects of care responsibilities may not always be successful or even occur. This is because of complexities like tensions and conflicts that could obscure negotiation, as what may appear to be a negotiated resolution may actually stem from unaddressed expectations, rather than a genuine agreement, even where the negotiation is implicit. In instances where negotiation occurred and was unsuccessful or where caregiving responsibilities are not shared, family carers may decide to seek other sources of help and support with caregiving within or outside their social networks.

## 2.4 Seeking help and support with caregiving

Family carers frequently utilise diverse sources of help and support with caregiving for a person with dementia, even in scenarios where care is predominantly provided by the carer. The help and support could either be from other members of the care network or paid helpers who may live within or outside their home. Paid help was sought by informal carers to help with a range of caregiving activities such as personal care, housework, grocery shopping, or cooking (Koo et al., 2021, Zhang, 2021a). In most cases, the primary carers of a person with dementia, such as their spouse, are typically advanced in age. Therefore, when caregiving became physically difficult, getting a paid helper or relying on other members of their social network was the only option for them (Cipolletta et al., 2023, Frelih, 2019, Zhang, 2021a). In the Netherlands, a study found that the informal carers utilised paid help for IADLs such as household tasks, shopping, managing finances and medication (Wammes et al., 2021).

The number of paid individuals' informal carers utilised to help with caregiving tasks could vary depending on their needs. A study in Singapore on families living in intergenerational households found that participants employed between one and two paid helpers to meet the basic needs of the person with dementia (Koo et al., 2021). This is interesting because intergenerational households constitute extended family networks that could help with caregiving. But this is not always the case, as using paid help could be because of full-time employment or the family carer having challenges with their health. Similar findings were also noted in Seaman's (2020) study in the United States, where a family carer utilised more than one paid individual to keep his wife company and meet her daily needs. For these families, hiring

one or two individuals to help with caregiving tasks could be quite feasible, as they were of middle-class socio-economic status, or in full-time or part-time employment, which could explain their ability to afford up to two paid individuals.

However, hiring someone to help with day-to-day caregiving activities may not relieve the primary carer of their responsibility. They may remain actively involved in caring for the person with dementia at home (Seaman, 2020). Having paid help could be an informal carer's way of reducing the burden of caregiving associated with living everyday life with dementia. In addition, the unacceptability of care homes and the need to keep care within the family could play an important role in their decision to settle for paid help. Although paid help also constitutes a level of financial obligation, as does care homes, to some informal carers, it could be worth it to ensure the person with dementia remains at home. However, the extent of the paid helpers' involvement in daily care, or whether the family carers fully utilised them, remains unclear.

Furthermore, previous studies have shown that friends, neighbours, and other members of the social network were rarely involved in the care organisation (Köhler et al., 2022, Zhang, 2021a). Support from family members was considered the main and most valued source of care provision for people with dementia in their studies. That is, the more the support provided by family members, the more relieved the primary carer felt in their role. Contrarily, a study in South Africa found that families take advantage of adult day care facilities or respite care to allow them a break from caring (Deist and Greeff, 2017).

Respite care is an important aspect of the support available for family carers, though carers experience guilt and shame for leaving their relative with dementia there temporarily. This could be due to the cultural views within African societies, where the family is seen as the ideal provider of care, and carers should provide care as it is their duty. So, a break, irrespective of how long it was, may seem like an inadequacy on the carer's part and a lack of Ubuntu. Nonetheless, the carers did come back to their role feeling more motivated. Therefore, adequate support for carers could have a significant impact on their overall health and well-being. However, it could become challenging for families of low socio-economic status to afford respite care or other forms of paid help in assisting with day-to-day caregiving activities.

Financial constraints were found among male carers of low socio-economic status to have a major impact on their ability to provide care in South Africa (Hendricks-Lalla and Pretorius, 2020). Low socio-economic status correlates with poor health, low education levels, and poverty, which has an impact on the availability of resources. Families of low socio-economic status could struggle with care provision for a person with dementia. For example, a participant who lived on his pension in Hendricks-Lalla and Pretorius (2020) study mentioned how they could not afford paid help that would free up time for him to get a job, so he had to be strict with

his budget and adapt to the situation. In such cases, any form of help or support the carer receives from their social network, including support from friends, is considered very valuable.

Apart from the use of paid help or respite care, external support groups were also very important for family carers. In Norway, Singapore, and South Africa, studies show that support groups were very useful for sharing advice and practical tips that helped the carers better handle care for someone with dementia at home (Deist and Greeff, 2017, Koo et al., 2021, Nordtug et al., 2021). Although support groups for carers of people with dementia are increasingly being established, there are still issues with their acceptance in certain societies. In Nigeria, the external support available for a person with dementia and their carers was found to be hampered by stigma associated with dementia (Nwakasi et al., 2021). The stigma associated with dementia is a significant challenge for family members in SSA. Recent systematic reviews in SSA on awareness of mental health disorders and dementia (Spittel et al., 2019), and contemporary views on dementia (Brooke and Ojo, 2020), found that people with dementia were frequently accused of witchcraft, satanism, and considered to be possessed by evil spirits. Dementia was also often thought to be a punishment from God.

Such notions are widespread and have been attributed to the misunderstandings caused by a lack of awareness and understanding of dementia (Adebiyi et al., 2016, Ogunniyi, 2018). A study conducted by Adebiyi et al. (2016) among six community groups in south-west Nigeria found that enacted stigma was apparent, with 36% of the participants linking dementia with disgrace and shame in the community. 28% of the participants believed that people with dementia should not be taken seriously. Similar findings were also noted from a survey in eastern Nigeria among leaders of religious organisations, which showed that the majority of the participants did not believe dementia can be cured, nor did they believe in orthodox care for a person with dementia; rather, they believed evil spirits were the cause of dementia. (Uwakwe, 2000).

According to Ogunniyi (2018:9), ‘such a misconception within the community by professionals that should counsel others has resulted in the individuals with dementia being taken to at least 2 other service providers (churches, native healing centres, homoeopathy, private hospitals, patent medicine stores, etc.) before proper assessment by experts on the disease.’ However, people with dementia being taken to diverse places before receiving a formal diagnosis may not only be due to the existing misconceptions about dementia. I could also the attributed to the inadequacies of mental healthcare in Nigeria, amongst other factors such as the shortage of skilled mental health professionals as discussed in chapter one.

Apart from stigma and misconceptions about dementia, other factors could influence how external support is received in countries like Nigeria. Similar to Nwakasi et al. (2021), Hendricks-Lalla and Pretorius (2020) also found that most of the carers in their study did not attend

support groups because they considered their challenges too private to be discussed in a group setting. There was a larger reliance on women, such as wives, daughters, female relatives, and female partners, for such support. It could be safer for the carers to discuss with people they could trust than have their challenges discussed openly with others. Nonetheless, support groups, when structured based on the socio-cultural settings of the informal carers they are tailored for, could prove to be very useful in fostering community, safety, and a sense of belonging among informal carers.

Furthermore, the decision to use paid help was more prominent in studies in other parts of the world than in Africa. The 10/66 Dementia Research Group investigated care arrangements for people with dementia in developing countries (China, Africa, the Caribbean, Latin America, Southeast Asia, India) (Prince, 2004). Their findings show that informal carers in Nigeria and India did not utilise as much paid help as in other countries, such as China, Latin America, and the Caribbean. In the few African studies where paid help was utilised, it was usually because the household's care needs had increased (more than one person in the house required care), or because the primary carer could no longer cope as the person with dementia had declined (Mwendwa et al., 2022). While in other studies, such as that in Singapore (Koo et al., 2021) and the United States (Seaman, 2020), paid assistance was frequently used because the male carer felt that carrying out intimate care needs was unsettling. This resulted in them hiring a female paid helper to carry out such tasks (typically ADLs such as bathing, grooming and toileting amongst others) which they considered women to be better at.

In addition, Deist and Greeff (2015) in their study in South Africa, found that there were very few family carers utilising paid help. I argue that family carers deciding against using paid help could be due to a few reasons, such as traditional African households functioning with great reliance on the family for help and support. Second, the findings could be particular to the circumstances and living situation of the families in the study. Third, it could be because of the socio-economic status of the family carers, as previously discussed. Finally, the availability of paid help in some African countries could also be an important factor. Although paid helpers may exist as a concept in some countries in Africa, family carers in countries like Nigeria, for example, may result in asking their domestic staff to help with caregiving tasks. This means that domestic staff could take on a dual position of carrying out domestic and caregiving tasks, which may or may not have been a part of the paid helper's agreement with the informal carer.

## 2.5 Summary

This thesis engaged with three key theories, such as the EoC, Ubuntu philosophy, and Finch and Mason's negotiating family responsibilities. In different ways, these theories emphasise

relationships and their significance in shaping care conceptualisation and negotiation of responsibilities within families. First, the EoC emphasises the importance of caring for others with responsiveness, empathy, and commitment to the relationship. Second, Ubuntu provides a communal African-centric viewpoint rooted in the belief that an individual's identity and welfare arise from their shared humanity. Finally, Finch and Mason's theory illustrate how families share their responsibilities, which they argue are not based on strict guidelines but shaped through different forms of negotiations. These negotiations occur against the backdrop of their histories, practical realities, reciprocity, and expectations. These theories offer robust viewpoints by demonstrating that caring and care responsibilities are dependent on a variety of contexts and relationships, thus providing a critical lens for this thesis.

Furthermore, the studies reviewed so far in SSA and globally contribute significant, rich, and varied knowledge to what is known about the experiences of informal carers (specifically family carers), and how they meet the care needs of a person with dementia, but little is known about this in Nigeria. Very few studies were conducted in Nigeria on how informal carers negotiate dementia care, how they arrange and divide care responsibilities and how they seek help and support with caregiving. As shown in this review, only two quantitative studies have explored some of these areas in depth: Baiyewu et al. (2003) on carers' behaviour and reaction to dementia, and Ogunniyi et al. (2005) on experiences living with dementia in Nigeria. A more recent qualitative study looked at carers' attitudes about dementia and caregiving (Nwakasi et al., 2021).

However, there is a gap in the literature on how informal carers in Nigeria negotiate dementia care, specifically how they evaluate their role as carers and that of others, share their care responsibilities, and seek help and support with caregiving. These are areas that have not been fully explored by previous studies in Nigeria but are essential in understanding everyday care for people with dementia. Additionally, many of the existing studies tend to focus only on family carers, thereby neglecting other sources of support from the care network a person with dementia receives. This thesis aimed to fill these gaps by investigating ` how informal carers of older people with dementia negotiate everyday caregiving in Nigeria.

Unlike most countries in Africa, Nigeria does not have a functional national policy for the welfare and care of older people (Tanyi et al., 2018). Only in 2021 has the Federal Government of Nigeria approved the National policy on ageing for older persons, however, this policy is yet to be fully implemented, and it does not include older people with dementia. This means that the care needs of older people in Nigeria mainly rely on and are met by their families and social networks (Adedeji et al., 2022). Therefore, an investigation into how carers find their way through complex dementia care can help improve knowledge on what it is like for families living every daily life

with dementia. It can also enhance an understanding of what exists to support informal carers who are the main providers of LTC in Nigeria (so that it might be strengthened), and what they might wish to receive in terms of support, which might inform the development of future provisions.

# Chapter 3 Methods

The aim of this thesis is to understand how informal carers of older people with dementia negotiate everyday caregiving in Nigeria. To achieve this aim, I used qualitative research methods because it is best suited to answer my research questions. In the following sections, I discuss the research paradigm, approach, design, area, participants, and data collection methods. Additionally, I also discuss the ethical considerations of this thesis and the data analysis method I used.

## 3.1 Research paradigm

In discussing the research paradigm of this thesis, I first define what the term 'paradigm' is. From a research viewpoint, the term paradigm means 'the basic belief system or worldview that guides the investigator, not only in choices of methods but in ontologically [viewpoints on reality] and epistemologically [how reality is learnt] fundamental ways' (Guba and Lincoln, 1994:105). In this thesis, I use the term paradigm to discuss my research perspective and broader research approach. According to Shah et al. (2013:2375) the paradigm a researcher builds in their mind has a strong influence 'on the lens through which they see the world.' Based on this, I adopted the interpretivism paradigm, also known as naturalistic, anti-positivist, humanistic, alternative, and constructivist research paradigm (Bryman, 2016, Shah et al., 2013, Ritchie et al., 2014). The interpretivist paradigm argues that the understanding and interpretation of a phenomenon cannot be separated from each other. That is, it seeks to comprehend the meanings, values, and implications of a social phenomenon in order to gain insight into human social interactions and experiences (Shah et al., 2013).

Coming back to Guba and Lincoln's (1994) earlier definition of the term paradigm, all research is shaped by ontological and epistemological positions. On one hand, ontology is concerned with 'the nature of reality and what there is to know about the world' (Ritchie et al., 2014:4). Interpretivism in terms of ontology adopts the relativist assumption that objects exist because of the viewer's perception, and reality is based on cultural and ideological beliefs, which individuals construct and interpret (Scotland, 2012). Simply put, a single occurrence might have diverse meanings and interpretations to individuals. This means that reality is complicated, local, specific, and multi-layered. On the other hand, epistemology 'is concerned with ways of knowing and learning about the world and focuses on issues such as how we learn about reality and what forms the basis of our knowledge' (Ritchie et al., 2014:6).

Interpretivism in terms of epistemology adopts the interpretivist assumption. The emphasis is on how humans interpret their social world, as well as the importance of both the participants‘ and researchers’ understanding and interpretations of the phenomena being studied (Bryman, 2016, Ritchie et al., 2014). Furthermore, in interpretivism, the participant’s social world is understood by the researcher through the observation and interpretation of lived experiences from the perspective of the participants. The philosophical assumptions of interpretivism govern my understanding of the nature of reality and how individuals come to know and learn about it. There are diverse ways individuals interpret and understand a phenomenon; therefore, I argue that knowledge is historically situated and derived culturally, and an understanding of an individual’s social world can only be from the point of view of the individual partaking in it.

Shah et al. (2013) argue that all research seeking to understand the social world is interpretive because it is guided by the desire of the researcher to understand and therefore interpret social reality. This means that even though facts exist, understanding the social world necessitates an observation and interpretation of it. Wilhelm Dilthey is an important contributor to the establishment of the interpretivist position. His literature (during the 1860s and 1870s) highlighted the necessity of ‘understanding' (‘verstehen’ in his native German) and researching people's lived experiences within a specific historical and social context’ (Ritchie et al., 2014:11). This is because human beings, their contexts, and interrelationships are at the centre of interpretive research as it facilitates an innate understanding of the phenomenon through the build-up of elaborate and rich descriptions.

Furthermore, interpretivism is considered an alternative to the positivist position, which promotes the use of natural science methods in the study of social realities. However, it is important to acknowledge the role positivism played in influencing social research and forming the foundation on which social enquiries developed over the course of several centuries. Researchers adopting the positivist position are expected to distance themselves from the analytical process of the research. That is, data should be collected based on direct observation and in an unbiased and objective way. This direct observation leads to the formation of invariant and universal laws used to identify human behaviours (Ritchie et al., 2014, Shah et al., 2013). The division between positivism and interpretivism is what Von Wright (1971) in Bryman (2016:26), terms as ‘epistemological clash’. Positivism emphasises an explanation of human behaviours with the researcher being completely objective, while interpretivism emphasises an understanding of human behaviour, taking the subjectivity of the researcher into account.

Resolving the ‘epistemological clash’ necessitates a focus on what the research aims to achieve in order to decide between interpretivism and positivism. I argue that, although the observation, recording, and explanation of data are essential, they cannot adequately provide a

comprehensive understanding of people's lived experiences. It is important for the meanings of social actions to be understood within the context of the participant's perspectives and culture. In doing this, it is unrealistic for a researcher to completely distance themselves from the analytical process and take on an objective, value-neutral position in investigating social actions. Furthermore, I also argue that the majority of social science research does not limit itself purely to the observation of participants, but instead elicits the thoughts, beliefs, and justifications by directly asking participants.

Therefore, the interpretivism paradigm is more appropriate for this thesis, as the focus of social sciences (people and their institutions) differs significantly from that of natural sciences. Thus, studying the social world requires that researchers respect the differences between objects of natural sciences and people. Respecting these differences will facilitate a better understanding of the 'subjective meanings of social actions' (Bryman, 2016:26). Taking an interpretivist (epistemological) and relativist (ontological) position enabled me to understand and make interpretations on how informal carers negotiate care for older people with dementia in Nigeria, as opposed to positivism where emphasis is placed on just describing their caregiving in relation to numerical data.

## 3.2 Research approach

According to Bryman (2016), phenomenology is one of the main academic schools of thought responsible for the anti-positivist position (ensuring individuality is captured in research that studies the social world) and a methodological approach to interpretivism. The term 'phenomenology' refers to the study of a phenomenon as it appears in an experience, the perception and understanding of the phenomenon, and the significance that the phenomenon has for an individual's lived experiences. (Manen, 1997, Woodruff, 2018). Simply put, phenomenology is the study of a person's lived experience of the world. According to (Neubauer et al., 2019:92), examining an experience as it is lived subjectively can result in the development of 'new meanings and appreciations that can inform, or even re-orient how we understand that experience.' This implies that the research participant's experiences are taken on, and by focusing on them, we learn to understand them.

There are two main approaches to phenomenological studies by Husserl and Heidegger, these are the transcendental (descriptive) and hermeneutical (interpretive) phenomenology. The field of phenomenology was founded by philosopher Edmund Husserl (1859–1938), his methodology, called transcendental phenomenology, is also known as descriptive phenomenology (Alison and Joanna, 2018, Neubauer et al., 2019). Husserl believed that in transcendental phenomenology, experiences should be described while leaving the researcher's perceptions

out or ‘bracketing’ them in order to enter the study participant's world free of preconceptions. His beliefs on phenomenology are not surprising considering his background as a natural scientist, with his initial work focused on the objective study of mathematics, before moving on to explore other phenomena (Neubauer et al., 2019). Additionally, Husserl argued against positivism's exclusive emphasis on making objective observations of the outside world, instead, he favoured studying a phenomenon as it is experienced from a person's perception. In his ontological and epistemological assumptions, reality is internal to the knower, and it is what appears in their consciousness’ (Neubauer et al., 2019:92), so, to achieve a transcendental state, the observer must separate themself from the world, including their being. This will help them analyse the phenomena in a bias-free manner.

The above notion was rejected by a student of Husserl, known as Martin Heidegger, in his work (1889-1976). This formed the origin of Heidegger’s work called hermeneutic phenomenology, also known as interpretive phenomenology (Alison and Joanna, 2018, Neubauer et al., 2019). Hermeneutic phenomenology was formed using hermeneutics (philosophy of interpretation) (Ritchie et al., 2014). Like Husserl, Heidegger’s background in theology (before moving to philosophy) played a significant role in his conceptualisation of phenomenology. According to Heidegger’s understanding, ‘an individual’s conscious experience of a phenomenon is not separate from the world, nor from the individual’s personal history. Consciousness is, instead, a formation of historically lived experiences including a person’s history and the culture in which he/she was raised’ (Neubauer et al., 2019:94). That is, an individual cannot separate themself from the realities influenced by the world they live in (which he refers to as lifeworld).

Therefore, hermeneutic phenomenology investigates people’s narratives to comprehend what they experience in their lifeworld (Alison and Joanna, 2018, Neubauer et al., 2019). In Heidegger’s ontological and epistemological assumptions, the lived experience of an individual is an interpretive process that takes place in the individual's lifeworld. The observer is a part of the world and is not devoid of prejudice (Neubauer et al., 2019). Therefore, as an observer, I understand the lived experiences of informal carers negotiating dementia care through interpretations.

I decided on hermeneutic phenomenology over transcendental phenomenology for three main reasons. First, the epistemological assumption of hermeneutics stipulates that the observer is not objective, they are part of the world, and their understanding of the phenomena is based on interpretation. While transcendental epistemological assumptions stipulate that the observer must separate themselves from the world to have an unbiased descriptive understanding of the phenomena (Neubauer et al., 2019). As the researcher, I am part of the world of the informal carers, and for me to understand how they negotiate care, I did so by observing and making

interpretations of their experiences, as opposed to just describing their experiences in a detached manner.

In describing, I am simply stating the fact without any analysis or personal perspective, for example, 'the informal carer walked away when the other carer tried to talk to her.' However, in observing and interpreting, there is a personal perspective of what is observed, which interpretation takes a step further by offering an explanation or analysis. For example, the informal carer ignored the other carer when she tried to talk to her, and the other carer expressed disappointment with her behaviour. This is due to the unresolved conflicts between the carers, as one of them mentioned how they disagreed about who was supposed to bathe their mother in the morning.'

Second, in hermeneutic phenomenology, I play a key role in the data collection, this is by reflecting on key themes from the participants' experiences with negotiating and providing care, while also reflecting on my own experiences (Neubauer et al., 2019, Ritchie et al., 2014) dealing with, and knowing informal carers providing care for a person with dementia in Nigeria. Contrarily, in transcendental phenomenology, the researcher is expected to bracket their subjectivity during the collection and analysis of the data (Neubauer et al., 2019). I argue that my subjectivity is an essential tool that I am conscious of and is beneficial in my analysis of the data.

Finally, in analysing and interpreting the data of hermeneutic phenomenological studies, the researcher reflects on how the data contribute to developing an understanding of the phenomena. This is done through 'Iterative cycles of capturing and writing reflections towards a robust and nuanced analysis' (Neubauer et al., 2019:92). In transcendental phenomenological studies, the phenomena are considered from various angles, identifying units of meaning, and grouping them into themes to form textual descriptions (the 'what?' of the phenomenon) and creating structural (how?) description, using imaginative variations. However, the overall goal of this thesis is to go beyond just providing a description of how informal carers evaluate their caregiving and that of others, share their care responsibilities, and seek help and support with caregiving. Rather, I aimed to find patterns across the dataset, and how the participants' lived experiences are situated within the larger socio-cultural setting of Nigeria.

## 3.3 Research design

I selected qualitative research methods, specifically hermeneutic phenomenology, as it is best suited to answer the research questions of my thesis. On a broad level, qualitative research is typically defined as an interpretative, naturalistic approach aimed at studying a phenomenon

from within, with the accounts of the research participants and their perspectives as a starting point (Ritchie et al., 2014). Qualitative research's key feature is that the data steer the research process. Therefore, emphasis is placed on the detail-rich data from each participant, rather than the number of participants (Bryman, 2016, Ritchie et al., 2014). This thesis used qualitative methods such as face-to-face semi-structured interviews as the main method, and observations as an additional method for data collection. The design of the interview questions is open-ended and informed by current literature on the lived experiences of informal carers reviewed in chapter two. I made the questions relatable to the socio-cultural context of the participants (see Appendix B and C for the detailed interview guides for the participants).

Furthermore, in my engagement with literature, researchers typically conducted one-off interviews. However, carers discussing their experiences providing care for a person with dementia may require reflection and thinking into what they could have considered an 'everyday scenario' or typical 'day in their life.' These reasons fostered my decision to utilise repeat interviews, also known as follow-up interviews, as opposed to one-offs. Repeat interviews provide an opportunity to follow up on lines of enquiry that were missed in the first interview or clarify some topics discussed previously (Vincent, 2013).

However, during fieldwork, it became clear that the majority of participants rarely agreed to schedule or attended follow-up interviews even after agreeing to do so previously. For example, I contacted a participant after my initial interview with her to schedule a repeat interview, but she kept insisting that she had nothing more to say, as she had said everything she wanted to say. I tried to clarify the goal of the follow-up interview and how she could schedule it when it was convenient for her, but she still declined. So, I had to respect her wishes and accept the fact that she wanted just one interview. I had anticipated that not all individuals might want to participate in repeat interviews, as it was not an inclusion criterion for participants to take part in this research. Therefore, this had minimal effects on the data collected as I ensured I covered the interview questions in the majority of cases, where one-off interviews were conducted within the time limit the participants' allowed.

Nonetheless, the semi-structured interviews were guided by the six stages described by Ritchie et al. (2014:186). Before I started each interview, I ensured rapport was established between the participants and me to enable a friendly interaction. For example, I noticed one of my participants on first contact with her had identical twins. I complimented her children and mentioned how rare such an occurrence is. This made her laugh and provided an opening into the question of 'please tell me about yourself.' Although I followed the semi-structured interview guide, it was also important that the participants took the lead in terms of the questions they answered, when they chose to answer them, and how they answered them.

Emphasis was placed on ensuring the participants were comfortable and encouraged to share as much as possible about their experiences caring for a person with dementia. I used various probes and prompts (Bryman, 2016) at different times during the interviews to elicit more detailed answers from the participants. For example, when a participant mentioned how her sister had cut ties with her and her mother with dementia, I probed the participant by asking her if she could share what happened with me if she was comfortable doing so. This was because an understanding of the conflict between her and her sister is useful in understanding why the participant was caring alone. These approaches to the interview process also served to minimise the likelihood of social desirability bias in qualitative research occurring (Bergen and Labonté, 2020)

After the semi-structured interview guide was covered, I allowed the participants to discuss or share any other information they wanted to. However, semi-structured interviews are not without disadvantages, as they are known to take time, are labour-intensive, and necessitate interviewer sophistication. According to Adams (2015) Interviewers must be knowledgeable about the pertinent fundamental issue as well as smart, sensitive, poised, and efficient. My experience in structuring and conducting semi-structured interviews of family carers of older people with dementia in Nigeria provided a good foundation for me. During the data collection, I planned my time and ensured that I carried along printed consent forms and participant information sheets for every interview. I arrived ahead of time at the location agreed with the participant to ensure I could write some fieldwork notes before the participant arrived.

Additionally, when the participant arrived, I ensured I greeted the participant respectfully (greeting with courtesy), which is an incredibly significant aspect of the Nigerian culture. I also referred to the person with dementia the same way the participants did. For example, where the participant called the older person with dementia ‘mama,’ I referred to her as ‘mama’ in our conversations. Sometimes, participants abruptly had to reschedule an interview due to various reasons or left me waiting for hours without showing up. In such situations, I remained calm and gave them options to reschedule at their convenience, while being aware of my own time and limitations. My understanding of the time, labour, and sophistication required in conducting semi-structured interviews helped me mitigate these disadvantages. According to Bryman (2016), interviews continue to be an effective method for investigating how participants experience and understand their lives.

Besides interviews, observations were another method I used to collect data for this research. Outside its use in ethnographic studies, observation is used variably in social research. The nature of this qualitative method increases the likelihood of uncovering unexpected issues (Bryman, 2016). Regardless of whether nothing unexpected happens, visual data on care

practices provides richer depth and details to the participant's accounts. According to Ritchie et al. (2014), observations aim to capture interactions, insights, behaviours, and processes that go beyond the understanding communicated by verbal accounts. In this thesis, I used selective observations aided by an observation guide (see Appendix D), focusing on finding additional examples and evidence of practices or processes that are essential to my research questions.

For example, during an interview with a participant, she mentioned how she uses her 'sixth sense' to perceive her mother's needs and meet those needs because her mum cannot communicate. After the interview, I was writing fieldwork notes, then I observed that her mother woke up from her sleep and tried to step out of her room, just opposite the living room where I sat with the participant. The participant got up as soon as she saw her mother and took her back inside the room to the toilet, after which she brought her mother back to the living room to sit down. This provided a good example of what she described as using her 'sixth sense' during her interview, which occurs in practice.

The focus of my observation was on the organisations and interactions that occur during daily caregiving for the person with dementia. Observations were based on the family's decision to be observed, as not all participants were comfortable with being observed. However, Ritchie et al. (2014) argue that researchers must immerse themselves in the community they are seeking to understand. My familiarity with the communities I recruited participants from made this systematic observation (record of interactions and actions, exchange and dialogue, and rituals and routines) among the participants achievable. I lived in the research area for a significant part of my life, and I am conversant with the cultural norms, behaviours, and beliefs that characterise individuals in my research area.

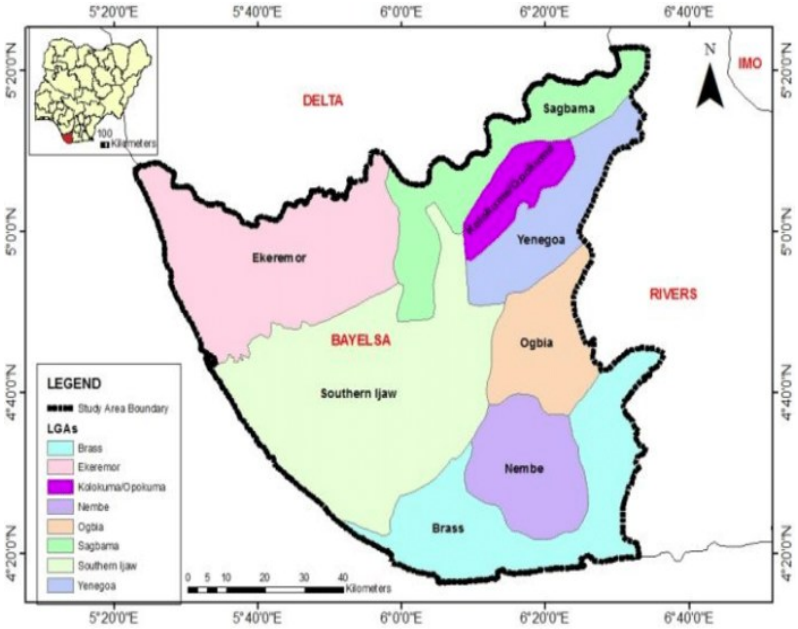
Nevertheless, while I was in the field, I realised that the practical difficulties of observing intimate care and care arrangements within Nigerian households were evident. Participants were not very enthusiastic about the idea of observation, even after clarifying what I planned to observe. To remedy this challenge, I often had to bring out a copy of the observation guide to show some participants exactly what I planned to document. This made observations more successful amongst participants who agreed to be observed. As was the case with repeat interviews, agreeing to take part in observations was not a criterion for participation in this research. Therefore, participants were able to decline observations if they did not want to be observed.

## 3.4 Research area

The country of focus in this thesis is Nigeria, located in Western Africa. It is the most populous country in Africa with a population of over 200 million people (The World Bank, 2021). It comprises 36 states divided into six geopolitical zones, which are north-east, north-west, north-central, south-east, south-west and south-south (Federal Republic of Nigeria, 2021a). The categorisation of the states in geopolitical zones in Nigeria is primarily based on areas with comparable ethnic compositions rather than on geographic location. The majority of the population of people in Nigeria are Muslims (51%), Christians (47%), with traditional religion accounting for the rest of the population. Christianity is the predominant religion in the southern part of Nigeria, while Islam is predominant in the northern part of Nigeria (Minority Rights Group International, 2018). My research area is the south-south zone in Nigeria, also known as the Niger Delta region. It consists of six states: Akwa Ibom, Bayelsa, Cross River, Edo, Delta, and Rivers, with a population of over 24.6 million. This zone makes up about 12% of the nation's population (Bassey et al., 2018).

In this thesis, informal carers were recruited from one of the states in the south-south region, known as Bayelsa state. Bayelsa State is bordered on the north by Delta State, on the east by Rivers State, and on the west and south by the Atlantic Ocean. In both Nigeria and Africa, Bayelsa state possesses one of the largest oil and natural gas accumulations, contributing more than 30% of Nigeria's oil (Federal Republic of Nigeria, 2021b). Bayelsa state is made up of eight local government areas (LGAs), namely Brass, Ekeremor, Kolokuma/Opokuma, Nembe, Ogbia, Sagbama, Southern-Ijaw and Yenagoa (which is the capital city of the state). Figure 3 below shows the map of Nigeria in the top left-hand corner, with Bayelsa state zoomed in, showing the various LGAs.

Figure 3.1: A map of Bayelsa State in Nigeria and the eight Local Government Areas in the State




(Ok et al., 2019).

Although English is the official language in the state, the four other main languages include Epie-Atissa, Izon, Ogbia, and Nembe. Christianity is the major religion in the state, and the enormous amounts of creeks, lagoons, rivers, and wetlands in the Bayelsa region make commercial fishing the main activity of the locals (Federal Republic of Nigeria, 2021b, Niger Delta Budget, 2023). Participants from various LGAs were recruited to take part in the research through my existing networks (healthcare and religious organisations) in the state. These networks were established during my master's research on family carers of people with dementia, and the period I was resident in the state. This made participant recruitment more feasible, considering the difficulties associated with accessing informal carers of people with dementia in Nigeria.

Although I planned to recruit participants from all the LGAs in Bayelsa state, the Foreign Commonwealth Development Office (FCDO) advised against all travel to the riverine areas of Bayelsa state (GOV.UK, 2023). These areas (parts of Brass, Southern-Ijaw, Ekeremor and Nembe) are considered red zones because of some attacks and targeted killings that occurred in the zones. These riverine areas are inaccessible by roads, and there are also high levels of pirate activities in the rivers. Due to these reasons, I was not able to travel to these locations to recruit or visit participants.

Moreover, participants from the listed red zones and all zones were still eligible to take part in the research even though they resided in areas that are unsafe and inaccessible to me. As I have lived in Bayelsa state for years, I was fully aware and conversant with the safety measures and precautions in the communities. I also completed a risk assessment form as part of my plans for fieldwork. During fieldwork, I ensured that I visited areas that I was not familiar with an

indigene who is conversant with the area. This involved the indigene assisting me with locating areas where I had arranged to meet my participants.

## 3.5 Research participants

A purposive sampling strategy (Bryman, 2016) was used to select participants for this research. I selected this sampling method because it is a non-probability sampling method where participants who are relevant to the research are strategically sampled. For example, an informal carer is defined as an individual who provides unpaid care for a person with dementia. Such individuals are typically family members but could also include friends or neighbours and church members. Although the Informal carers are the main participants in this research, one goal was to interview different people in the care network who were happy to be interviewed; this included a person hired to provide help with caregiving. Several studies in various parts of the world identified the use of paid helpers in assisting with everyday tasks and caregiving at home (Cipolletta et al., 2023, Frelih, 2019, Koo et al., 2021, Seaman, 2020, Zhang, 2021a). However, studies on caregiving in Nigeria and Africa at large tend to focus on only family carers, thereby ignoring other sources of support in the care network an older person with dementia receives.

Recruiting participants for this research was more successful by purposively selecting them through hospitals and private clinics, and other existing professional networks in Bayelsa state, compared to religious and cultural organisations. Both formal and informal approval were obtained from organisations where required. This involved meetings with the heads of departments or managing directors of the private clinics. They then referred me to a member of their team who provided me with the contact details of those who could be eligible to take part in research. I contacted these individuals, scheduled a face-to-face appointment to discuss the research further, and provided them with the participant information sheet and consent forms (see section 3.7 for more details on this). I found that people with dementia and their carers were not easily accessible, and the condition was not something that was talked about in society, particularly in places like religious organisations and cultural centres. Although I tried to recruit participants via these networks, it was unsuccessful; this challenge was expected, and before my data collection, I had decided on an alternative sampling strategy known as snowballing.

Snowballing (participants recruiting other participants) was another sampling strategy (Bryman, 2016) I used alongside purposive sampling; this was to ensure that enough participants were recruited due to the stigma associated with dementia in Nigeria. Stigma affected my initial recruitment strategy because carers frequently put off getting assistance because they fear

negative attitudes due to the challenging behaviours the person with dementia may have (Burns et al., 2019) or are not comfortable talking about the condition due to the shame it may bring to their families (Nwakasi et al., 2021). It can also be due to their disbelief in traditional medicine for managing dementia, as discussed earlier in Chapter One. This may have led to their reluctance to visit hospitals or clinics, even during their clinic days, from which I had aimed to recruit participants. In addition, the widespread notion of dementia being caused by supernatural forces (Adedeji et al., 2022) could have deterred participants in the religious and cultural centres from openly identifying as someone caring for a person with the condition. Therefore, participants felt more at ease connecting or communicating with those who knew what it is like living everyday life caring for a person with dementia, which made snowballing an effective strategy for recruiting participants.

During the course of data collection, each family was given a crate (consisting of 24 330ml cans) of a popular beverage in Nigeria known as 'Maltina', offered as a courtesy for participation. In Nigeria, it is customary in certain areas for people to bring drinks when visiting a person or family for the first time, it is also a sign of respect and hospitality. It was often the case that participants were very excited and appreciative of the gesture, some participants were even surprised that I gave them such a gift. For example, one participant informed me on my second visit to her community that the Malt is what her mother drank in the morning because she had planned to buy the drink due to the belief that it has health benefits.

Of the twenty-four families living with dementia that I contacted in Bayelsa state, seven families informed me that the person with dementia was deceased, and they were not comfortable revisiting the past events, while the other five families declined participating in the research. I also contacted two members of another family, the man informed me that he did not have dementia, but was diagnosed with depression in the hospital, and therefore declined to participate. A total of twenty-three participants from eleven families (pseudonymised with letters A to K) of people with dementia in Bayelsa state agreed to take part in the research. Of the eleven families, observations occurred in six families; the other families either declined observation or the person with dementia was in the hospital or in a care home (see chapter four for a summary of each family's case).

As discussed earlier in Chapter One, the data on the current prevalence of dementia in Nigeria show that the prevalence is higher among women. Nonetheless, this did not play any active role in my recruitment strategy; I successfully recruited carers providing care for a total of five males and six females living with dementia. That is, where a person with dementia was identified as part of 'family A,' at least one informal carer was interviewed and categorised as belonging to family A. However, of the eleven families, only one family utilised a paid helper categorised as

belonging to 'family B,' and another family utilised a paid carer categorised as belonging to 'family E.' The remaining families at the time of the interview did not have any paid helpers or paid carers. There was, however, one family where the person with dementia had five nurses on rota assisting with his care (outside the nurses on shift in the hospital where he was admitted). I was unable to interview these individuals because they were beyond the scope of my research.

### 3.5.1 Inclusion and exclusion criteria

For a participant to be recruited in this research, they met all the following criteria adapted from Hendricks-Lalla and Pretorius (2020) and Nielsen et al. (2021b) to suit the context of this research. The inclusion criteria were adapted from their study because their methodological approach is similar to that of my research. Hendricks-Lalla and Pretorius (2020) used the phenomenological approach to investigate care practices of male informal carers in South Africa. While Nielsen et al. (2021b) investigated care practices of minority ethnic groups in Denmark, using the hermeneutic phenomenological approach. Any individual who did not meet these criteria was not eligible to take part in this research. The inclusion and exclusion criteria are presented below in Table 3.1.

Table 3.1: A table of the inclusion and exclusion criteria for the thesis

| **Inclusion criteria** | **Exclusion criteria** |
|---|---|
| The participant must be an informal carer of an older person with dementia or hired to assist with caregiving in Bayelsa state. | Individuals providing informal care or hired to assist with caregiving for older people living with other conditions in Bayelsa state. |
| The participant must be involved in the care of the person with dementia but must not be the primary carer. | Individuals who are not involved in the care of the person with dementia. |
| The participants must be able to communicate in Pidgin (broken English) or English. | Individuals who only speak native languages in Bayelsa state. |

## 3.6 Data collection

Data was collected in 2024 in Bayelsa state via semi-structured interviews and observations. There was no specific time limit for the interviews, as the participants were fully informed of their right to pause or stop the interviews whenever they wished (Bryman, 2016, Byrne, 2001,

Ritchie et al., 2014). The interviews were conducted in English, which is the official language of Nigeria, spoken by the majority of people in the country. However, pidgin (broken English) is frequently spoken by most people in Nigeria, and it is a language with which I am very conversant. So, I allowed participants to speak freely in both English and the pidgin languages as they saw fit. The majority of the interviews took place during the day in the homes or private offices of the participants, which was very secure and safe for both the participants and me. While one interview occurred in a private garden, which was the choice of the participant.

A total of twenty-three interviews and six observations were conducted during the period of data collection in Bayelsa State. Although I had initially planned to carry out repeat interviews as discussed previously, a lot of participants were not open to this. To overcome this challenge, I let the participants lead in terms of the frequency of my contact, and I stopped contacting them for any follow-up interview after they declined. Based on this, I was only able to successfully revisit and have repeat interviews with two of the eleven families that took part in the research.

At the end of the interviews, I reflected on ways the interview can be improved, and if the interview questions can be adjusted moving forward, as well as noting my impressions of the interviews. During my first set of interviews, I noticed that participants were more likely to share more information after I had thanked them for their time, announced to them that the interview had ended, and had stopped the recording. Based on this, I decided to utilise my field notes to record relevant information after the interviews had ended. In reflecting further after each interview, I found that when the male participant was the provider of hands-on care, they were less likely to provide in-depth details on how they provide care for the person with dementia. This could be due to existing gender roles of caregiving, seen as what women typically do (Christian, 2024) so, some of the male participants were not confident discussing the topic with me. To mitigate this, I allowed pauses between questions and used prompts to elicit more detailed answers.

Additionally, reflecting on my interview with the paid helper in this research, I realised that there was a lot of hesitation and reluctance in her response to my questions, probes, and prompts. However, this was not surprising as I anticipated that there could be difficulties interviewing the paid helpers, because they may fear that the information they provide could cause them to lose their jobs (although I had assured the participant that it would not be the case). It was also not possible to interview the paid helper outside the house of her employer because her working hours made this unachievable.

Furthermore, the observations occurred only in the houses where the person with dementia lived. I used the observation guide to record occurrences that I observed during my visits, such as any changes in the location, body language, emotional expression, and any other noteworthy

behaviours (Kawulich, 2012), that took place during and after the interviews. It was easier to stay back a few minutes after the interview to record my observations. In situations where that was not feasible, I completed the observation guide as soon as I returned to my accommodation based on what I recorded in my field notes. In addition, observations on how daily care is performed, particularly in the morning and evenings, were not possible. This was because participants were not comfortable with me being present during such moments. I expected this due to the practical challenges of observing intimate care within Nigerian households.

## 3.7 Ethical considerations

Ethical approval was obtained from the University of Southampton's (UoS) ethics committee (see Appendix A), and I also completed the mandatory ethics training for PGRs. Furthermore, in discussing the ethical considerations of my research, I used the ethical values endorsed by the University of Southampton's ethics committee. This comprises consent of individuals, beneficence and non-maleficence, and fairness (University of Southampton, 2019). As my data collection took place in Bayelsa state, I also obtained approval from the hospitals and clinics, which were happy to help with recruiting participants for my research. This was done by having formal or informal discussions with the relevant heads of department (HOD), such as the HOD of mental health and medicine and other medical professionals. I printed the gatekeeper letter, as well as the ethical approval from the University of Southampton, and the documents used to obtain it. During my meetings with the HODs and other healthcare professionals, they asked me questions about my research. Once satisfied, I completed the ethical approval process in their hospital. After which, they proceeded to introduce me to members of their team who provided me with the contact details of potential participants.

After getting the contact details of the potential participants, I proceeded to call them to discuss the research and whether they were willing to participate in the research. Once they agreed to meet up with me, I scheduled a meeting with them and on arrival, I discussed the research further and provided them with the participant information sheet and consent form. The information sheet specified my thesis background, objectives, the voluntary nature of involvement, and the ability of participants to withdraw and destroy any record of their interviews/observations within the week. It also endorsed the safety and privacy of the participants, with a promise to make available a printed brief of the thesis findings or an electronic copy via email if they are interested. After they read the participant information sheet and were happy to proceed, I asked them to sign the consent form before the interviews began. In the consent forms, there was a box where participants could tick if they were comfortable

with being observed in their home during the interviews (participants who did not tick this box were only interviewed). All participants provided fully informed consent (Bryman, 2016, Byrne, 2001) before participating in the research.

For participants with a lower level of literacy, the information sheet was read and explained to them in Pidgin English by me. When they understood and were willing to participate, I asked them to sign the consent forms by putting an "X" in the allocated space or by printing their full names. As I was able to interview one paid helper and a paid carer, I sought consent from the informal carers first. When the informal carer consented and introduced me to the paid helper and paid carer, fully informed consent was sought before they participated in the research. While conducting the interview with the paid helper part of 'family B,' I noticed her reluctance to divulge certain information. I reiterated her rights at different times during the interview. These rights included being able to choose not to answer any question, pause or stop the interview at any time. I also informed her of the voluntary nature of participation and that there would be no consequences for her job if she decided not to participate.

Although I aimed for the interviews to take place in private areas where the carers would be comfortable discussing their experiences without the person with dementia being present, it was not always the case. The person with dementia was on a few occasions either close to the room where the interview was taking place, moving around the house, or present (typically sleeping or sitting down) in the room during the interview. Although I endeavoured to greet the person with dementia, introduce myself, and explain why I was there, some of them had advanced dementia (this was the case in most of the families), so they could not provide informed consent. As the informal carers are the main participants and the persons with dementia are passive participants, proxy consent was sought from the surrogate decision maker (either their spouse, adult children, or siblings) before data collection (Hegde and Ellajosyula, 2016, Lepore et al., 2017).

Throughout the interviews, I was conscious of any forms of objections, including non-verbal objections that the person with dementia made during my visit. In one case, the carer of the person with dementia informed me that her sister could provide informed consent; therefore, I enlisted the carer's help as she is someone the person with dementia knows and trusts, to further discuss the nature of participation. The person with dementia was able to provide informed consent (with the support of the carer) after reading the participant information sheet and consent form (which was simplified to accommodate their cognitive impairment) with an 'X' before participation.

At all times during the data collection process, I ensured that I respected all the participants' wishes regarding how their families participated in my research and to what extent, including a

participant's decision not to introduce me to another member of the person with dementia's care network. The participant declined my request, asking me to provide the contact details of his mother (the primary carer of his father), to discuss her experiences providing care for him. This was because his father and mother had separated before his father was diagnosed with dementia. In the participant's bid to make caring for them easier, he asked his mother to move back in with his father. Although discussing with his mother could have provided a more detailed understanding of their family's case, I had to respect his decision not to connect his mother and me.

In addition, as I was filling out and collecting papers containing personal data in communities, I ensured extra care at all times when transporting such documents by placing them in my secure bag. After which, they were transferred to a secure locker in my accommodation. Seeing that Nigeria is still in the process of establishing a data protection bill, I complied with the general data protection regulation (GDPR) principles throughout my research. Therefore, as I transcribed the interviews, all of the participants were given culturally appropriate pseudonyms, and the transcribed files and audio recordings are stored on my university laptop. The completed observation guides and signed consent forms are stored in my home locker.

Additionally, an automatic file backup system using the University of Southampton OneDrive backed up my files automatically on a regular basis. I completed the two cybersecurity training courses (email security and phishing and working securely away from campus) to ensure that my systems were adequately secured. I manually checked that my data was up to date every Friday of the week. After the end of my research, I will destroy all the primary data, and the processed data will be kept for 10 years according to the UoS policy on research data management (University of Southampton, 2019).

Due to the sensitive nature of the research topic, informal carers, paid help, or a person with dementia could have become distressed during the interviews or uncomfortable during observation. This was mitigated by establishing a culturally suitable rapport from the onset of participant engagement. This helped with building trust and ensuring the participants were comfortable sharing their experiences in an environment that was sensitive and safe for them (Pinto et al., 2022). However, a participant became distressed and began to cry during the interview as she narrated how she lost her mother while her husband with dementia was rushed to the hospital. I offered that the interview be put on hold, provided tissues for her, and gave her some time to recover until she was comfortable to begin again. I also referred another participant to the dementia friend's program organised by a dementia charity known as 'Dementia Nigeria,' which provides support and guidance for people with dementia, their relatives, and friends. This charity aims to encourage positive thoughts and talk about dementia.

Thus, helping the carers feel less alone as they will have the opportunity to meet other carers, people with dementia, and individuals interested in dementia during events organised by the charity in Nigeria.

Furthermore, in cases where participants had a low level of literacy, I communicated these support mechanisms to them in 'Pidgin English', and where they did not have internet-enabled phones, I assisted them in saving the phone numbers and address of the charity on their phones, for them to contact at will. This protocol to refer participants and minimise harm was set in place for every contact I had with the research participants to ensure that they were comfortable and supported to share their experiences. Also, some participants were not enthusiastic about engaging with the charity as they did not see how it could help their current situation. In such cases, I provided the contact details for them in the eventuality that they would decide to engage with the charity at a later time.

Additionally, as I am researching a sensitive topic and had multiple contacts with the participants, the data collection also had an impact on me, this known as vicarious trauma (Moran and Asquith, 2020). For example, what I gathered during the interviews and observations stirred up feelings of helplessness in me, considering that I am a Nigerian who is part of the communities I was researching, making some of the participants' challenges very relatable. However, I was conscious of this during the data collection as I aimed not to become overly involved, at the same time empathising with the participants. I also gave myself time to deal with pleasant or unpleasant emotions that arose during data collection. This was done by reflecting on my position as a subjective researcher in my field notes and observation guides.

## 3.8 Data Analysis

After I transcribed the data, I used thematic analysis (TA) to analyse the data, aided by NVivo. TA is a method used frequently in various academic literature and disciplines to analyse qualitative data (Ritchie et al., 2014). The approach has been widely employed in the social, behavioural, and more applied sciences (clinical, health and education). The goal of TA is to create conceptual patterns (or 'themes') that provide answers to a research topic throughout a dataset. This is achieved through a meticulous process of data familiarisation, data coding, theme formulation, and theme revision, which leads to the generation of patterns (Kiger and Varpio, 2020). According to Braun and Clarke (2019) the best way to think of TA is as an umbrella term for a group or family of techniques for qualitative data analysis. TA's primary objective is the development of themes (patterns of meanings) from qualitative data. Although they frequently have a handful of theoretical flexibility in common, their underlying philosophies and methods for developing themes might be quite different (Braun and Clarke, 2021b).

However, Braun and Clarke (2019) have extensively written about their previous approach to TA (Braun and Clarke, 2006). They clarified and revised some of the terms they utilised to conceptualise TA, as well as the components and procedures surrounding the technique that they refer to as reflexive TA (Braun et al., 2022). In reflexive TA, the role of the researcher is a key aspect of the data analysis process. However, previous literature on dementia caregiving frequently utilises Braun and Clarke's (2006) conceptualisation of TA with hermeneutic phenomenology. For example, Nielsen et al. (2021b) investigated the care practices of minority ethnic families managing dementia in Denmark, using hermeneutic phenomenology and thematic analysis. Hendricks-Lalla and Pretorius (2020) also utilised hermeneutic phenomenology and thematic analysis to investigate male familial carers' experience caring for a person with AD in South Africa.

I opted for reflexive TA over other forms of TA such as coding reliability approach and code book approach, because the 'researcher subjectivity is the primary "tool" for reflexive TA; subjectivity is not a problem to be managed or controlled, it is a resource for research' (Braun and Clarke, 2022a:8). Additionally, reflexive TA was more appropriate in the context of my study's underlying interpretivism paradigm. It allowed me to ensure that the qualitative data I gathered and analysed was done in ways that express and respect the subjectivity of my participants' accounts of their caregiving experiences. While also recognising and accepting the reflexive impact of my analyses as the researcher.

### 3.8.1 My approach to using reflexive TA

In my approach to using reflexive TA, I used the 'experiential (reflexive TA) framing of language, data and meanings' (Braun and Clarke, 2021b:331). I used this approach because experiential TA answers research questions concerning the lived experiences, opinions, perspectives and behaviours of participants (Braun and Clarke, 2022b), which my research questions are based on. This approach allowed me to deeply analyse the data with a focus on the patterns of meaning across the experiences of the participants in this thesis. Experiential TA was also used with a combination of both an inductive and deductive analytical coding process. On one hand, the inductive process allowed me to open-code the data and emphasise the participant/data-based meanings. On the other hand, the deductive process ensured that the open coding contributed to themes relevant to answering my research questions while highlighting participant/data-based meanings.

The combination of inductive and deductive analytical processes is in line with the epistemological (interpretivism) and ontological (relativism) assumptions of the interpretivism paradigm. That is, as an insider researcher (collecting data within my community), I am part of

the social world and not free of bias, so, for me to understand the experiences of the informal carers, I made interpretations of participants' narratives while reflecting on my own subjectivity as the researcher. I was also aware that my experiences, skills, knowledge, research values, and training mediated the data engagement process, and the themes that are generated from the data cannot completely exist separately from me. Therefore, I examined and utilised the value of my subjectivity during the data analysis process by continuous reflection, making the process more credible and transparent.

In conducting reflexive TA, I followed the six-phase process discussed by Braun and Clarke (2022a). These phases were not followed rigidly by me, rather, they provided guidance to assist me in conducting a pattern-based analysis of my data methodically and reliably. The six phases include familiarisation with the transcripts, coding, initial theme generation, reviewing and developing themes, theme defining, refining, naming the themes and writing up (Braun and Clarke, 2021b). In the first stage of the analysis, I took some time off after the data collection and transcription process. This was because I wanted to approach the data with 'fresh eyes' after fieldwork, supporting a more reflexive and deeper analytical approach.

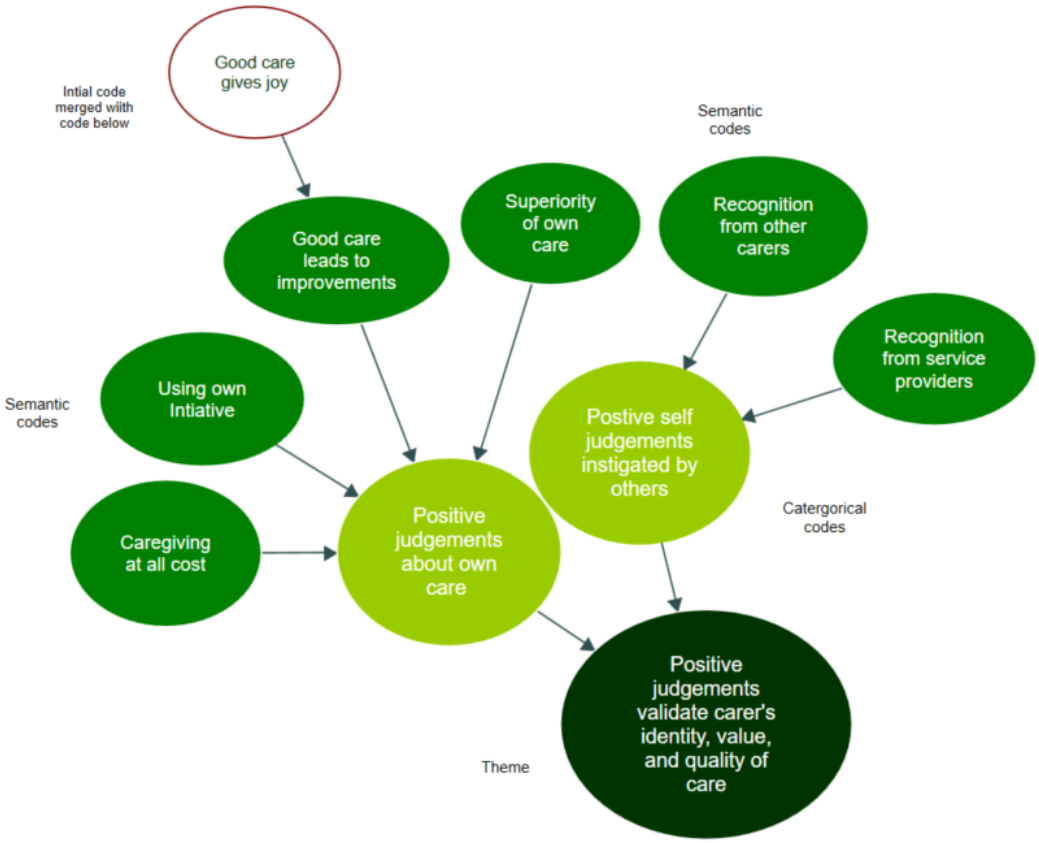
After my time off, I read the transcripts multiple times to become more familiar with them and fully immerse myself in the data. My goal was not to notice patterns or themes but to deepen my knowledge of the data (as seen in Braun et al., 2022:28). I also made notes on aspects of the transcript that were developing points of interest in the entire transcript and the individual dataset. For example, I noticed that participants were critical of the care provided by others and sometimes their own caregiving. After reading and familiarising myself with the transcripts, I began the first stage of inductive coding, developing a range of semantic codes capturing different relevant parts of the data.

For example, I coded participants' statements referring to their care as being good compared to others as 'superiority of own care.' For instance, parts of a larger coded texts such as 'I mean my own [approach] is good, I must be strong with her, if not [there is] no way', and 'since we came, he has really improved, the improvement is very big, now he is really happy', were coded as 'superiority of own care'. Additionally, I coded statements where participants referenced their ability to use their initiative, such as 'I must use my head' or 'I must be extremely alert' as 'using own initiative.' Furthermore, it became clear as my analysis progressed that participants were evaluating their care and that of others by making judgements, and these judgements were either positive or negative. In some instances in the transcripts, the judgments participants made were instigated by statements made by either other carers or service providers, such as traditional physical therapists. An example of this is reflected in parts of a statement of what a participant said, which was 'one or two times [my siblings] come to check [on us], and they see

the way [my mother] is behaving, they will say 'HA! You are really trying,' they see what is happening.' This statement was coded as 'recognition from other carers.'

Based on the realisations that participants were making judgements, I began to categorise the codes into broader categories of codes. So, codes where participants made judgements of their care as positive were categorised as 'positive judgements about own care.' The codes ('recognition from other carers' and 'recognition from service providers') reflecting the judgements participants made of themselves, which were instigated by statements of others in their care network, were categorised as 'positive self-judgements instigated by others.' Moreover, I read the transcripts again to see if some judgements were neutral, however, the majority of judgements made were either positive or negative, with little to no instances of neutral judgements. Figure 3.2 below provides a visual example of some of the codes discussed above and their categories.

Figure 3.2: A concept map showing the links between codes and a theme




During the data analysis, I continuously reflected on the analytical process using my research diary. This process involved what Braun et al. (2022) referred to as immersing oneself into the data, analysing, contemplating, inquiring, envisioning, pondering, documenting, withdrawing, and coming back. This resulted in my movement between the analysis phases as they were not

meant to be rigidly followed. Rather, they were approaches that facilitated a thorough process of data examination and engagement that led the analysis. For instance, in reading the excerpts and contemplating codes such as ‘good care gives joy’ and ‘good care leads to improvements,’ I realised that it was less a case of participants’ judging their care as good because it gave the person with dementia ‘joy.’ Rather, participants were essentially communicating that the care they were providing led to their observed improvements in the overall well-being of the person with dementia. Based on this, I merged the code ‘good care gives joy’ with the code ‘good care leads to improvements.’

After reading the excerpts of the codes on positive judgment of self and reflecting on their categories, I noticed that participants were not only making these judgements, but they were also communicating deeper meaning through their statements. For instance, participants communicating the ‘superiority of their care,’ the recognition they received from others, how the care they provided led to improvements, and how they provided care irrespective of the cost to them, had deeper meanings of validation-seeking. Seeking validation from me, the researcher, could be due to reasons such as the knowledge they believed I have about dementia, as I was researching the topic. Therefore, they portrayed themselves as ‘good carers’ providing ‘good care’ by judging aspects such as their identity, value, and quality of care. This led to the renaming of the developed theme from ‘positive judgements reflect carer’s identity, value, and quality of care’ to ‘positive judgments validate carer’s identity, value, and quality of care.’ Through my analysis and reflections (including reflecting on the EoC and the Ubuntu philosophy in terms of conceptualising care), I was able to create a more comprehensive story of the data and answer my research question on how informal carers evaluate their caregiving and that of others.

Moreover, an example of the deductive coding process I used in my analysis was in thinking about my second research question. Looking through the transcripts and thinking about my second research question on how carers divide and share their care responsibilities, I reflected on my experiences of being a Nigerian who has also researched families living with dementia, as well as my understanding of Finch and Mason's theory on negotiating family responsibilities. This allowed me to subjectively examine the data while thinking about how my experiences and knowledge shape the analysis process. Thus, I realised that how care responsibilities within families are divided and shared is determined by socio-cultural factors, such as the eldest child having greater responsibilities within the family. Therefore, I employed deductive coding of the data indirectly or directly reflecting on this, for example, where a participant said, ‘I could say that I took it upon myself because I am the oldest’, I coded it as a latent code called ‘eldest child’s responsibility’.

As my analysis developed, I found that this eldest child's responsibility was not the only socio-cultural factor that could determine care arrangements. There were also parts of the data where participants directly or indirectly mentioned how they had the responsibility of care because they were the youngest unmarried child. Based on this, such parts of the data were coded as 'unmarried child's responsibility.' Furthermore, in reflecting on the code excerpts, I saw that the codes were not just a reflection of socio-cultural factors, but scripts that influenced how care for the person with dementia is divided and shared amongst families. Based on my experience of being a Nigerian, I started to ponder on other scripts within the Nigerian society that existed and could also influence care arrangements. An example of this script is that care should be provided by the family and not formal institutions or paid carers. So, I reread the transcripts and coded instances where participants directly or indirectly used the script as 'preferences for family care.' One of such instances is when a participant said, 'even if we say we want to bring someone to take care of him, the person will not be able to take care of him personally, the way the children will take care of him.'

Additionally, after withdrawing and coming back to the above codes, I read their excerpts again and found that these scripts not only exist, but they also influenced how different care arrangements across the families 'emerge.' That is, care arrangements developed through participants' unknowingly or knowingly using or working against the scripts to justify their different care arrangements for the person with dementia. These reflections led to the development of the theme known as 'emergence of care arrangements.' This meant that care arrangements emerged not as a result of explicit negotiations but were influenced by cultural scripts that exist within the Nigerian society. Additionally, other semantic codes like 'division of labour' contributed to how I understood care arrangements as emerging through influences of cultural scripts. Appendix E provides a detailed concept map showing the links between codes, sub-themes, and themes that resulted from my deductive analysis process.

In summary, my approach to reflexive TA was rooted in a repetitive and interpretative interaction with the data. Instead of viewing coding and theme development as a rigid process, I approached the analysis as a dynamic and thoughtful journey shaped by my growing insights, understanding of theories, positionality, and analytical choices. I intentionally reflected on how my experiences academically and as a Nigerian researching communities I am part of influenced the meanings I focused on during coding and the development of themes. This reflexive approach enabled me to transcend superficial categorisation of the data to develop nuanced, relevant themes that reflected the complexity of my participants' narratives while enabling me to answer my research questions. Thus, the final themes presented in this thesis embody not only the pattern across the participants' accounts of their lived experiences negotiating dementia care but also the interpretive lens through which I interacted with the data.

However, the question could arise as to why I decided against using other methods of data analysis, such as interpretive phenomenological analysis (IPA), which is typically associated with phenomenological studies. This method of analysis was not chosen for a few reasons. First, the research samples of studies using IPA are typically small (not more than 10) (Braun and Clarke, 2021a). In this thesis, I collected data from informal carers, a paid helper, and a paid carer belonging to eleven families living with dementia. This resulted in a total of twenty-three semi-structured interviews and six family observations.

Second, my research questions do not focus on just sense-making and subjective experiences of the participants in providing care for someone with dementia at home. It also focused on how the informal carers seek help and support with caregiving, such as using paid help, for example. Third, I used more than just semi-structured interviews to collect data, as I collected data using observations, for which I was given consent to do so by the participants. Fourth, I did not only focus on the distinctive characteristics of the individual participants, but rather, my analytical focus was also on finding patterns across the dataset, and how the participants' subjective experiences are situated within the larger socio-cultural setting of Nigeria. According to Braun and Clarke (2021a:42), 'we recommend the use of reflexive TA instead of IPA when the requirements or focus of IPA are not well met by a study'.

## 3.9 Summary

Qualitative research methods are the chosen methods for this thesis because they are best suited to answer my research questions on the experiences of informal carers negotiating dementia care in Nigeria. The hermeneutic phenomenological approach of this thesis is rooted in the interpretivism paradigm, which emphasises understanding and interpretation rather than a description of the phenomenon being studied. My subjectivity as a researcher, based on my past experiences and knowledge, is recognised as valuable in guiding the analytical process. Furthermore, the research design consisted of semi-structured face-to-face interviews as the main instrument of data collection. Some participants were also observed in their homes during the interviews. The participants were recruited from Bayelsa state, located in south-south Nigeria. A total of twenty-one informal carers, one paid carer, and one paid helper were interviewed from eleven families living with dementia. The data was collected at times and locations that were convenient and safe for the participants and me, the researcher. Before participating, all individuals provided fully informed consent, and their data is managed using the GDPR principles governing data protection and the UoS research data management policy. During the transcription of the data, all identifiable information was replaced with culturally appropriate pseudonyms, and the data was analysed using reflexive TA aided by NVivo.

# Chapter 4 Introduction to the results

This thesis sought to understand how informal carers experience and evaluate their caregiving and that of others, how they divide and arrange care responsibilities, and how they perceive the support they receive (or not) from within and outside their family network. Themes were generated from the data through iterative circles of coding and thematic analysis, informed by the hermeneutic phenomenological approach of this thesis, rooted in the interpretivism paradigm. This paradigm emphasises understanding and interpretation rather than just a description of the phenomenon being studied. The resulting themes are presented in this results chapter, which is divided into four chapters. In chapter four, I present a summary of each family's case, the pseudonyms they have been assigned, and a map summarising the themes and subthemes for each research question. In chapters five, six and seven, the themes and subsequent subthemes that answer each research question are presented and interpreted within the socio-cultural context of Nigeria.

Table 4.1: A table showing the families, participant's pseudonyms, and a summary of each family's case

| **No.** | **Family Pseudonym** | **Participant's Pseudonym**<br><br>****: Indicates main carer***<br><br>***Underlining: indicates co-resident with the older person with dementia*** | **Summary of the family's cases**<br><br>***Note: Family members who were not interviewed are mentioned in this table to illustrate the household context*** |
|---|---|---|---|
| **1** | Family A | Person with dementia – Mr Afini<br><br>P1- Alero (daughter)<br><br>*P2- Boma (wife)<br><br>P3- Ebiye (daughter)<br><br>P4- Atima (son) | Family A consists of a man living with dementia (Mr Afini), his wife (Boma), and their seven children. Boma was the main carer, assisted by Atima, Alero, Ebiye and Afini's younger son and daughter (resident with Afini and his wife) where needed. Ebiye, Afini's eldest daughter, is married, but she occasionally visits them. Afini's other adult children were either away at University or too young to be interviewed. |

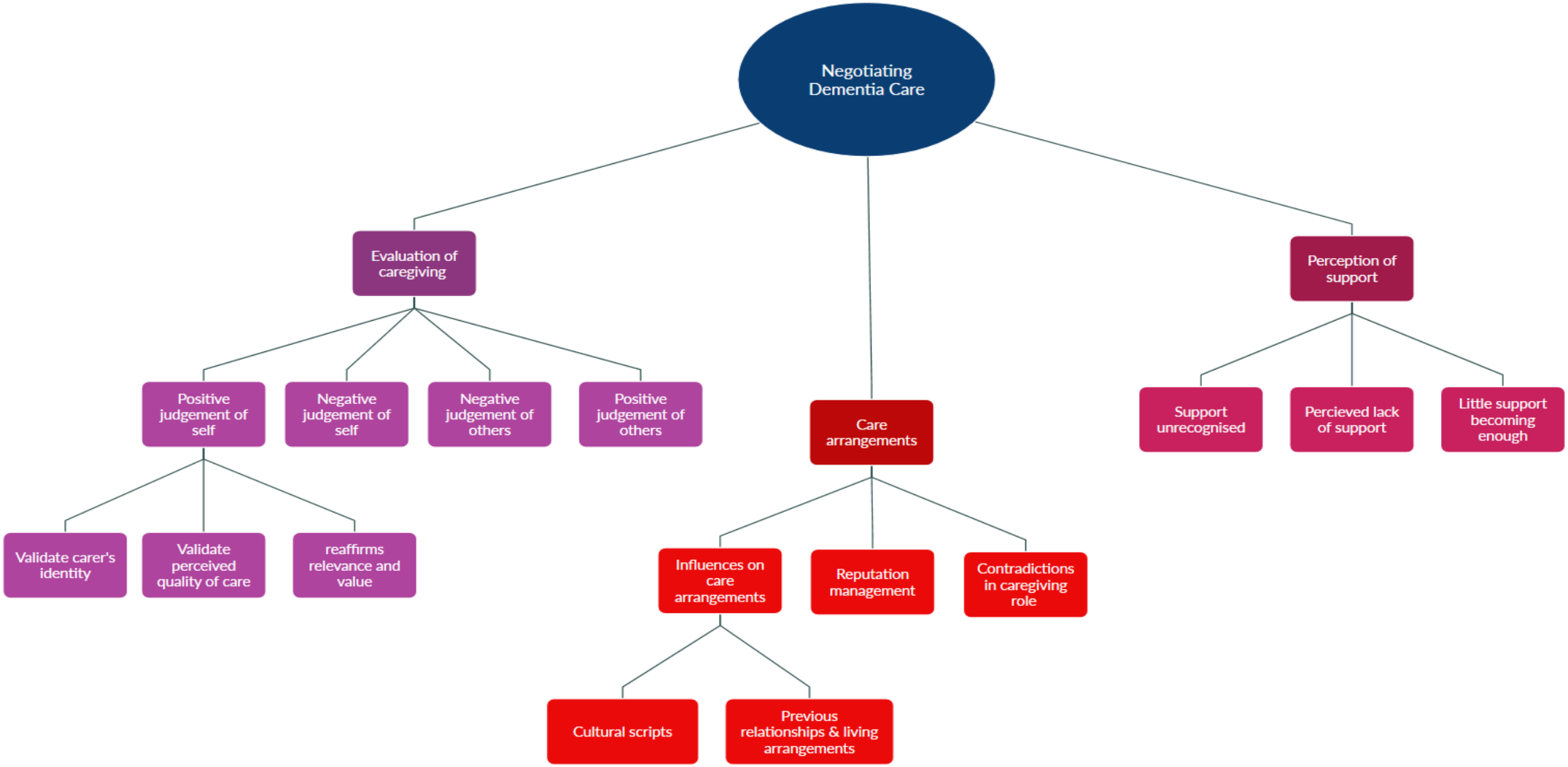
| No. | Family Pseudonym | Participant's Pseudonym<br><br>**: Indicates main carer*<br><br>***Underlining: indicates co-resident with the older person with dementia*** | **Summary of the family's cases**<br><br>***Note: Family members who were not interviewed are mentioned in this table to illustrate the household context*** |
|---|---|---|---|
| **2** | Family B | Person with dementia- Mrs Ibiso<br><br>*P1- Tamara (daughter)<br><br>P2- Fila (paid helper) | Family B consists of a widowed woman living with dementia (Mrs Ibiso) and her two children. Her daughter (Tamara) and paid helper (Fila) were interviewed, but her son, who is co-resident with them, was not interviewed. Tamara was the main carer, and she was occasionally supported by her brother and aunt. Fila, the paid helper, comes weekly in the morning and leaves in the evening every Monday-Saturday. Fila conducted whatever task was requested of her. |
| **3** | Family C | Person with dementia- Mr Sele<br><br>P1- Tokoni (son)<br><br>[The ex-wife is the main carer, but was not interviewed] | Family C consists of a man living with dementia (Mr Sele), who has four children with his ex-wife. Only his son (Tokoni) was interviewed. Mr Sele lives with his ex-wife, who is his main carer, providing the hands-on care. Tokoni, who is married and living with his family, manages all other aspects of Sele's care. |
| **4** | Family D | Person with dementia- Mr Owei<br><br>P1- Idala (son)<br><br>*P2- Iso (daughter-in-law)<br><br>*P3- Derima (son) | Family D consists of a widowed man living with dementia (Mr Owei) who has four children. His two sons (Idala and Derima) and his daughter-in-law (Iso) were interviewed. Mr Owei lives with Derima, Iso and their young children (Under 10 years old). Derima and Iso are Owei's main carers, while Idala, who is married |

| No. | Family Pseudonym | Participant's Pseudonym<br><br>*: Indicates main carer*<br><br>*Underlining: indicates co-resident with the older person with dementia* | Summary of the family's cases<br><br>*Note: Family members who were not interviewed are mentioned in this table to illustrate the household context* |
|---|---|---|---|
| | | | and living with his family, supports them when possible. |
| **5** | Family E | Person with dementia- Mr Binatu<br><br>P1- Erebi (son)<br><br>*P2- Ake (paid helper) | Family E consists of a man living with dementia (Mr Binatu), who is married with four children. His son (Erebi) and paid carer (Ake) were interviewed. Mr Binatu lives with Ake, who is the main carer, in a separate flat from his wife's. Erebi assists with IADLs when possible. |
| **6** | Family F | Person with dementia- Mrs Inemo<br><br>*P1- Ekiye (daughter) | Family F consists of a widowed woman living with dementia (Mrs Inemo) who has two children. Of her two daughters, only one of them (Ekiye), who was interviewed, was involved in her care. Ekiye was providing care alone for Mrs Inemo until Ekiye recently decided her mother should move to a care home, without Mrs Inemo having a say in the decision. |
| **7** | Family G | Person with dementia- Mrs Ebi<br><br>P1- Alali (sister)<br><br>*P2- Ogola (son) | Family G consists of a widowed woman living with dementia (Mrs Ebi) who has five children. Her younger sister (Alali) and Mrs Ebi's son (Ogola) were interviewed. Mrs Ebi lives with Ogola and his two children in their village. Although Mrs Ebi was able to do some things herself and provide care for her grandchildren, Ogola was her main carer, supported |

| No. | Family Pseudonym | Participant's Pseudonym<br><br>*: Indicates main carer<br><br>Underlining: indicates co-resident with the older person with dementia | Summary of the family's cases<br><br>Note: Family members who were not interviewed are mentioned in this table to illustrate the household context |
|---|---|---|---|
| | | | occasionally by Alali. Mrs Ebi frequently went to Alali's house for short- or long-term visits. |
| **8** | Family H | Person with dementia-Mrs Kalaya<br><br>*P1-Loila (daughter) | Family H consists of a woman living with dementia (Mrs Kalaya) who has six children and is one of the three wives of her husband. She lives with her daughter (Loila), who is her main carer, and young grandchild (who was not interviewed). Loila was mainly supported with a few tasks by her niece (Mrs Kalaya's grandchild). |
| **9** | Family I | Person with dementia-Mrs Yinkeye<br><br>*P1- Funere (daughter)<br><br>*P2- Enemo (daughter)<br><br>P3-Oyinbra (Sister-in-law)<br><br>P4- Suoton (daughter) | Family I consists of a widowed woman living with dementia (Mrs Yinkeye) who has seven children. Her three daughters (Funere, Enemo and Suoton) and her sister-in-law (Oyinbra) were interviewed. Mrs Yinkeye stays in a room on her own, divided by the wall of Enemo's room (where Enemo stays with her young children). Suoton stays in a bungalow directly opposite her mother and Enemo's rooms. Oyinbra stays in another room with her husband (Mrs Yinkeye's brother) and young children, which is very close to Mrs Yinkeye's room. Funere and Enemo are the main carers, while Oyinbra assists when necessary. Suoton does not provide care for Yinkeye, although she lives directly opposite Yinkeye's house. |

| No. | Family Pseudonym | Participant's Pseudonym<br><br>**: Indicates main carer*<br><br>***Underlining: indicates co-resident with the older person with dementia*** | Summary of the family's cases<br><br>***Note: Family members who were not interviewed are mentioned in this table to illustrate the household context*** |
|---|---|---|---|
| **10** | Family J | Person with dementia- Mr Ebitimi<br><br>P1- Tekena (daughter)<br><br>P2- Ini (niece) | Family J consists of a man living with dementia (Mr Ebitimi), his wife and six children. His daughter (Tekena) and his niece (Ini) were interviewed. Though Mr Ebitimi lived with his wife, cook, gatekeeper, and niece (Ini), he was also cared for by five nurses running a shift pattern. Tekena is married and living in a city close by with her family. She and her siblings visited Mr Ebitimi when they were in town and available, while one of her brothers recruited and managed the nurses. |
| **11** | Family K | Person with dementia- Mrs Ibinado<br><br>*P1-Funebi (daughter) | Family K consists of a widowed woman living with dementia (Mrs Ibinado) who has four children. Her daughter (Funebi) was interviewed. Mrs Ibinado lived with Funebi and her family (husband and son). Funebi was her main carer and was occasionally supported by her younger brother. At the time of the interview, Funebi had recently moved her mother to a care home. The decision to move Mrs Ibinado to the care home was made by Funebi, her husband, and her supported younger brother. |

Figure 4.1: A map summarising the themes and sub-themes that answer the research questions.



# Chapter 5 Informal carers' experiences and evaluations of caregiving

Participants experienced caregiving in diverse ways. They evaluated the care provided by themselves and other carers by making positive and negative judgements. It is important to note that participants' evaluation of their care and that of others is, in most cases, based on their self-report of care rather than actual observed care. Nonetheless, these self-reports enable an understanding of the informal carers' lived experiences and why they view specific actions as suitable, acceptable, or difficult, thus uncovering how care is discussed, understood, and emotionally felt within families.

Across all the families, participants often made more positive judgements about themselves as carers than they did about other informal carers. In this section, I will argue that this stems from their desire to seek the validation they feel they do not get from other informal carers, while also asserting their relevance in the care provided for the older person with dementia to me as the researcher. The findings also highlight unspoken expectations participants feel society and their family have of them, and expectations they have of other carers. When the participants believe they or other carers meet or exceed these expectations, it often results in positive judgements. When these expectations were not met by themselves or other carers, it often resulted in negative judgements.

On one hand, participants' negative judgements of other carers are associated with what they conceptualise as bad care. On the other hand, their positive judgements of themselves and other carers are synonymous with good care. Participants understand good care as care that leads to reported (both by themselves and others) improvements in the older person with dementia's overall health, while bad care leads to reported or self-observed deterioration. In some instances, the positive and negative judgements participants made were instigated by statements of others, some of whom were not involved in the care of the older person with dementia.

In the following sections, the findings are discussed under four themes. First, positive judgements validate the carer's identity, value, and quality of care. Second, a negative judgement of self reflects an inability to meet care needs. Third, positive judgements of other carers reflect exceeded expectations. Finally, negative judgements of other carers confirm their inability to provide care.

## 5.1 Positive judgements validate carer's identity, value, and quality of care

The findings show that participants' positive judgements of themselves often validate their identity as carers and affirm their value and the quality of care they believe they provided. This theme is divided into three sub-themes: first, care provided as a positive validator of carer's identity; second, care provided compared to that of others validate perceived quality of care; finally, external validation reaffirms carer's relevance and value.

### 5.1.1 Care provided as a positive validator of carer's identity

Positive judgement of self related to care provision was not only based on the day-to-day caregiving but also on everyday actions (related to decision making despite limitations brought on by dementia symptoms) taken to meet the needs of the person with dementia. For example, a participant placed emphasis on her ability to 'use her head' and be 'extremely alert' in providing care despite the barriers in communication between herself and her mother.

> *She cannot communicate, that is the issue we are having with the dementia, something, it is when she is in pain, and I really do not know exactly where is paining her, I must use my head, I must be extremely alert.* ***FB, Tamara.***

Even in circumstances where a lack of communication was not a barrier, some participants reported they had to employ patience or be firm to manage the person with dementia's challenging behaviours.

> *She is that person that when she says it is like this, that is how it will be. So, when I talk multiple times and even shout, she will not want to [listen], I just leave her, that is endurance and patience, I just thank God, it is not by my power, it is just God.* ***FH, Loila.***

> *I check his blood sugar [regularly}, but suddenly early in the morning he is calling me that he wants to go to a lab [to have his blood sugar checked], and I am like "but we have [the blood sugar equipment] in the house why can you not just do it in the house" and he is like he wants to go to the lab. I must be firm and say, "no do it in the house I am not coming."* ***FC, Tokoni.***

In the statements above, the participants positively judge their ability to provide care despite the opposition from the older person with dementia. Where Tamara and Tokoni judged themselves as individuals who possess the intellectual skills to assertively manage behavioural challenges, Loila judged her abilities to be from God and not by her power. Their communication of this can

be their way of validating their identity as efficient carers, who figure out what to do despite the challenges posed by dementia symptoms.

In some other instances, participants portrayed themselves as individuals who endured the discomfort that came from providing care despite what it would cost them financially or otherwise.

> *Like the other day I told you [the paid carer] called me, and I dashed down there, I had to leave everything to make sure [my dad] was stable, it was already dark at that time, I was supposed to travel that day, in fact I missed what I was to do, I can live with that because it is one of those things, I do not really mind.* ***FE, Erebi.***

For Erebi, reflecting on the discomfort he endured to ensure his father got the care he needed validates his identity as a carer. Sacrificing plans and comfort to meet the needs of the older person with dementia was the norm for another participant. Alali from family G expressed how she advised her elder sister with dementia (Mrs Ebi) to spend more time in her house for visits, even if Alali and her family have nothing to eat.

> *[Mrs Ebi] is always down [low in mood], but [Mrs Ebi] started coming [to my house] last year or the year before when she complained [about feeling low in mood]. I told her that she should come home, I told [Mrs Ebi] to come to my place, even my husband said she should come, anyhow, [the situation in the house is] we will manage, even if there is nothing [to eat].* ***FG, Alali.***

It is worth noting that Alali mentioned that Mrs Ebi always comes from the village with food items, which the family eats. Although Alali portrayed herself as a good carer who goes the extra mile to ensure Mrs Ebi is supported regardless of the circumstances ('we will manage, even if there is nothing [to eat]'), she at the same time admitted that Mrs Ebi often brings food items when she visits. This also shows that the contributions the older person with dementia may make to meet their needs could easily be overlooked due to the perceived (and emphasised) burden of caring for someone with their condition, or the economic circumstances of the informal carer. This is because the informal carer may place more emphasis on monetary support compared to other forms of support that are still of importance.

In addition to the above, participants' identity as carers is positively validated by the care they provide for the older person with dementia. it. Ekiye positively described herself as a "one-man squad," who is a person that gets things done on their own, irrespective of how difficult the task is; this was an integral part of her identity as a carer.

*I have been taking care of her. I do not wait for somebody to bring money to do anything for me; I always encourage myself: 'my dear, you are a one-man squad, oh, do this thing, if you do not do it, nobody will do it for you', that is how I have lived my life.* ***FF, Ekiye.***

However, at the time of the interview, Ekiye had moved her mother to a new care home that had just opened because she could no longer manage her mother, despite mentioning that her mother is independent and does most things herself. Such conflicting portrayals highlight participants' positive representation of themselves in words, while their communicated actions convey a different reality. This shows that for participants, maintaining their identity as good carers to me as the researcher is important. In this context, being a good carer represents sacrifice, determination, and endurance. To the participants, maintaining their identity as good carers, to me as the researcher, confirms that they meet the expectations they had of themselves as carers and their obligation of care towards the older person with dementia. Therefore, admitting that they are no longer carers means that they are unable to meet their expectations and obligation to care, which they may feel highlights failure on their part.

### 5.1.2 Care provided compared to that of others validate perceived quality of care

Participants made positive judgements of their care provision when comparing it to the care provided by other informal carers. This formed their evaluation of what good care is. To them, the good care they provided often led to self-reported improvements in the well-being of the older person with dementia, while the bad care provided by others often led to self-reported deterioration. Additionally, participants built their understanding of good care and bad care based on what they consider important to the older person with dementia, and what is important to themselves as the carers.

Often, participants judged themselves to be better carers than other carers, which the other carers contradicted. For example, one participant associates good care with her ability to control her mother and prevent her challenging behaviours from escalating. To her, being 'strong' with her mother [Mrs Yinkeye] was the only option she had, which was successfully working until her mother left to live with her sister.

*Here [in my house] I was trying to protect [my mother], keep [my mother safe], talking to her. I mean, my own [approach] is good, I must be strong with her, if not, [there is] no way. So, when [my mother] left to stay in that kind of [home] environment [of Enemo] that is open and free, everything changed [for the] worse.* ***FI, Funere.***

Her use of the word 'strong' can be understood to also include physical abuse. From an interview with her sister (Enemo), Enemo divulged that Funere's care involved the beating and

slapping of their mother, as observed by her children. Where Funere perceives her mother's care to be worse when provided by Enemo, Enemo was of a different opinion. She believed her mother to be 'lost,' that is, no longer the person she used to be. Therefore, Enemo tried to do all she could without abusing her, irrespective of how difficult and challenging her behaviour is.

> *I cannot beat my mother, no matter what, because this condition she found herself in; she does not know what she is doing, she is not herself.... I cannot beat her, I feel very bad when [Funere] treats her like that.* ***FI, Enemo.***

Funere's judgement of Enemo's care provision reflects her defensiveness and desire to validate the quality of care she provided for her mother as better than that provided by Enemo. While Enemo also validates the quality of care she provided for her mother as better than Funere's. Enemo's statement highlighted the deep respect she feels for her mother, which she believes Funere does not possess. This is not surprising, as I observed tension and witnessed disagreement between the sisters about the way they each provided care for their mother. This shows that informal carers' perceptions of how they provide care, its quality, and their existing relationship with other carers, influence how critical they are of themselves and other carers.

Other participants drew attention to the value of an older person with dementia being around people, especially grandchildren, which is an important aspect of good care to participants. To participants, grandchildren in the family play an important role in combating loneliness and are a source of happiness to the older person with dementia.

> *Since we came, he has really improved, the improvement is very big. Now he is really happy, sometimes when [the children] come back, he would carry [his grandchild] and be dancing. Whenever we carry [the] baby and give him, he would be happy, he would be dancing.* ***FD, Iso.***

Iso statement highlights the importance of intergenerational relationships, which she believed results in good care ('now he is really happy'). For her, the connectedness of having children around the older person with dementia has improved the quality of life of her father-in-law.

Similarly, Alali in family G highlighted the importance of keeping families connected. Alali provided care for her elder sister (Mrs Ebi), she considered her mother (as her mother died when she was young), and Mrs Ebi became a mother to her. Alali asked Mrs Ebi to spend more time with her and her children, and she believed the result of this had positively improved Mrs Ebi's quality of life.

> *The loneliness always kept [Mrs Ebi] on her own. But I thought of it that [Mrs Ebi] can be playing with the [my] children, and she will not be thinking [about her problems], so, [I*

> *told her] that she should be coming to my [house]…I am seeing improvements…. There are improvements, she is sleeping, and she is eating.* ***FG, Alali.***

To Alali, asking Mrs Ebi to come around had a positive outcome, as Alali's children are like grandchildren to Mrs Ebi, so her having them around is essential to combat loneliness and isolation. However, during an interview with Ogola, the son of Mrs Ebi (with whom she lives), he revealed that Mrs Ebi is a carer of his two children, even when he goes to the farm for extended periods. Therefore, where Alali believed she encouraged Mrs Ebi to spend time with her children to reduce loneliness and isolation, Ogola believed he sent Mrs Ebi to his aunt's house for respite from caring for his children.

> *So, from time to time, if I have money, I will decide that [my mother] should go for one week to [Alali's place] to rest, and I will stay with the [my] children…. that is just it oh.* ***FG, Ogola.***

This is an example of certain conflicting ideas some participants had about their roles as carers and their contributions to the older person with dementia's care. Though Alali believes herself to be thoughtful and perceptive of her Mrs Ebi's need for companionship, Ogola believes himself to be thoughtful enough to allow his mother respite from caring for his children. Ogola's statement is an example of how the contributions an older person with dementia makes to support their families may be overlooked because of the perceived burden of caring for someone with their condition. Furthermore, the positive judgements carers make of themselves show their need to validate themselves as provider of quality care, which is based on what is important to them as carers. In the case of these participants, it is spending time away or with grandchildren.

### 5.1.3 External validation reaffirms carers' relevance and value

Positive judgements of care were sometimes instigated through statements made by others that validated what the carer believed to be true about their caregiving. This external validation was either from other family members or service providers. Their communication of this during their interview is a way of affirming their relevance and value despite how challenging caregiving is for them.

> *Even my siblings, they all know, they are even saying that I am really trying because they [know] themselves, they cannot do it. One or two times [my siblings] come to check [on us], and they see the way [my mother] is behaving, they will say 'HA! You are really trying,' they see what is happening.* ***FH, Loila.***

In Nigeria, HA! is often used as a form of exclamation to express surprise for a variety of reasons. Loila uses "HA!" in her statement above to describe the surprise her siblings felt when

they saw the reality of everyday caregiving for their mother. Her sibling's surprise and consequent acknowledgement of the challenges she experiences providing care for her mother served as an external validation of Loila's relevance and value. Participants' positive judgement of themselves in other cases was instigated by service providers, which fed into participants' ideas of good care. For example, in Nigeria, a traditional physical therapist often provides a full-body massage to help a person recover from an illness or maintain good health. These service providers meet a lot of older people, as they are their frequent customers. A participant expressed how a traditional physical therapist praised her care for her mother.

> *Sometimes when I call somebody to come and massage [my mother's body], they will ask me if I am taking care of my mother. I will ask them what they mean by that, they will say that I should not worry that they will come. By the time they come [to my house], they will start greeting me, they will say "HA! God will bless you." They will tell me that the reason they asked me that question is because sometimes when they get to the homes to massage these [older] women, [their carers] do not bathe them, they do not take care of them. I bathe my mother every morning, she is the first to bathe.* ***FK, Funebi.***

Her communication of this information is her way of reaffirming her value and relevance as a provider of quality care, particularly in terms of hygiene, which is an essential aspect of caregiving to her. Similarly, another participant's positive judgement of herself, instigated by a service provider, was also her way of reaffirming her value and relevance as a provider of quality care. To her, the ability to control her mother's challenging behaviour was an essential aspect of caregiving. For Funere, comparing her own caregiving as more favourable than Enemo's shows that she placed emphasis on not only being a good carer but a better carer than Enemo.

> *The first day [Enemo] took [my mother] to where they are massaging her, it was a fight, [Enemo] was crying [laughs], the [massage woman] said 'where is your senior sister [Funere], it is her that understands your mum better.' For [my sister] to [persuade] my mum [to lay down] on the mat for her to be massaged it was a big problem.....So the day I said let me take [my mum] down there, the [massage woman] said 'okay [your mum] really understands you better oh, she has laid down and started the massage and nothing happened, your sister cried'.* ***FI, Funere***

Although Funere's statement shows the external validation (of being a good carer) she received ('your mum really understands you better'), it also shows her competitive element of being closer to her mother, and therefore a better carer. Funere and Enemo's situation highlights some of the complexities of sibling dynamics in Nigeria, which is majorly influenced by birth

order, that is, an older child assumes they do things better than their younger sibling because they know better, therefore, they are better qualified.

## 5.2 Negative judgements of self reflect carer's inability to meet care needs

Participants' negative judgements of themselves are based on the care they provided, which they did not consider ideal but was a compromise given the situation. For example, a participant decided to use a peppery hot ointment on her mother, which is commonly used to relieve colds in Nigeria, to get her mother to sleep. When this substance meets an individual's eye, it forces the eyes to shut, as opening them will lead to intense pain and tears.

> *She bit my breast and my hand while I was calming her down, she tore my chair, … I forced her to sleep, I gave her drugs [to aid sleep], it did not work, she did not sleep that night. I turned off the light thinking that if the place is dark, she will sleep, oh Jesus! It was the worst… May God have mercy on me, I brought out a pepperish ointment and rubbed it into her eyes, thinking that it would hurt her, and she would sleep. My mother did not sleep, she was disturbing [us] till the early morning. This made her eyes red and painful. So, I took her to the hospital the next day, and they gave her an eye drop and some other things to clear the eye.* ***FI, Funere.***

However, Funere expressed remorse about the situation as she did it as a last resort because she felt she had no other option. Additionally, her disclosure of the situation shows that she did manage to 'learn' something from it. This supports the fact that caregiving is often a learning experience for carers, especially when dealing with challenging behaviours. Their decisions are often made due to a lack of knowledge of other ways the situation can be managed. Tokoni is another example, as he felt that he was not experienced because he used to comply with his father's constant desires to leave the house to either go shopping, to the hospital or t for a change of environment, even when it was not necessary for him to.

> *Last year, I used to really fall for it a lot [smiles], I would send someone to pick [my dad] up and drive him [around]. But I was thinking of it, and I knew that as I kept doing it, it became a lot more frequent, every time he kept calling for me. Then, he [stopped] asking for me again he started asking for the person [that drove him around], he will say 'send the person to come and pick me up,' and I am like no, it [does not work] like that.* ***FC, Tokoni.***

Tokoni and Funere's statements above are examples of some of the inabilities participants felt because they believed that they were performing below the expectations they had of

themselves as carers. These feelings result in their negative judgement of themselves, which was often characterised by the participants' thinking about the caregiving situation and realising that they could have performed better. In both Funere and Tokoni's statements, it is evident that their handling of the challenging behaviours of the older person with dementia could have been better if they had more knowledge on how to manage such behaviours. This shows that for informal carers in Nigeria, experiencing everyday caregiving is their only way of learning how to provide better care for the older person with dementia, even though this may have detrimental effects on the well-being of the older person and the confidence of the informal carer as a caregiver.

Sometimes, the negative judgement participants made of themselves was because of the responsibilities they believed they had as an eldest child within their family. A participant expressed this in her statement below.

> *[It is] a lot of stress, because I have been thinking, calculating, because I am the first daughter. So, by right I am supposed to do some kind of things, even if my mum does not ask…When I see that things are not going well, I feel concerned.* ***FA, Ebiye.***

Culturally in Nigeria, there are certain expectations that individual families have of the eldest son and daughter, and they are meant to fulfil these expectations. When the expectations are not met, the eldest child is either considered a failure by the family and society, or the eldest child judges themselves to be one. Ebiye believes she has failed in her responsibility as the eldest daughter in fulfilling what she considered the most important part of her father's caregiving, which was providing physical and financial support (which her mother was providing). This highlights the impact societal expectations and perceptions have on how informal carers evaluate their caregiving, and the decisions they take as a result of it. Similarly, another participant's negative judgement of himself was instigated by his perception of what other people in the neighbourhood may say about the lack of care they believed his father was not receiving, which was showcased as an inability on his part.

> *I was not [living] close to [my dad], I was not around. People will be talking about how nobody is there to take care of him.* ***FD, Derima.***

Derima's quote reflects his negative judgement of himself because he was not providing hands-on care for his dad. He expressed that his decision to move close to his dad was because people might say that nobody was there to take care of his dad. Therefore, Derima moving close to his dad with his family is his way of combating accusations of abandonment. Although nothing was directly said to him by his neighbours, it is typical in Nigeria for people to talk when they see an older person living alone when they have relatives (especially children). His decision

to move close to his dad might not have been to provide good care but rather to satisfy societal expectations, even though, to him, being a good carer was ultimately a result of the decision.

## 5.3 Positive judgements of other carers reflect exceeded expectations

Participants' positive judgements of other informal carers were often based on their observations of the care provided by other informal carers. For participants, their judgement was facilitated by the informal carer's ability to exceed care expectations given their gender, family circumstances, and other expectations. Exceeding expectations often resulted in increased trust and confidence for the other informal carer. For example, it is a predominant cultural expectation in Nigeria that women are the ones who provide hands-on care. This expectation was understood by Tamara, who describes her brother as an 'open soul' because he is not limited by this expectation.

> *My brother bathes my mum, he cleans up her poo, he cleans up her wee. My brother is 'open,' he is an 'open soul,' as in he cares, he cares for [my mum]. The care he shows her, I find it amazing, let me put it that way…When I am not there, I am very sure, I am very confident that she is in good hands.* ***FB, Tamara.***

Tamara had assumed that her brother, who lives with her, might never provide care for their mother, particularly personal care. But his deviation from her belief warranted her description of him as an open soul because of how he cares for their mother, which is not typical of the male gender in Nigeria. Men are typically expected to be the financial providers, while women are the ones who provide hands-on care, particularly when the person with dementia is of the same sex as the informal carer. This shows that participants' positive judgement of other carers is often facilitated by the other carer's ability to supersede the uncommunicated expectations they had (or expectations the society had) of them.

Similarly, another participant commended his mother's ability to provide hands-on care for his father, considering the fact that they are separated. He requested that his mother move back with the father, so it would be easier for him to 'keep an eye' on both.

> *I had my conversation with [my mum], I was like, the way it is, it will be better for [both] to be under one roof, because [my parents living separately] was another stress [for me]. I had my dad [to visit], and I had to see my mother somewhere else, which was very stressful. So, now that they are [living] together, it is a lot easier.* ***FC, Tokoni.***

However, his mother's willingness to move back in with a man she had separated from was not due to her own volition, but rather, it was more convenient for Tokoni. Although his mother may not have willingly become her ex-husband's carer, Tokoni appreciated the difficulty that came with her decision.

> *It is stressful for her; I will not lie…It is not easy for someone [who has separated] to come [ back to care for the person] and she is the one doing the [daily care].* ***FC, Tokoni.***

Tokoni plays a role as the decision maker of his family, who makes tough decisions regardless of the implications, as long as it makes care provision easier for Tokoni. Tokoni's statement above shows he recognises that it is not easy for his mother to care for someone that she is emotionally distant, with potentially unresolved feelings. Although Tokoni might have communicated in his statements that his expectation of his mother was to move in with his father to make supporting them easier. However, he also expected her to take over the caregiving tasks that he did not want to do. His admission of this to me as the researcher will make him look incompetent, which he did not want. Despite Tokoni's reasons for asking his mother to move in with his father, he still judged her positively for exceeding his expectations, as he recognised that she could have refused to care for his father given the circumstances.

For another participant, his wife's willingness to provide care for his dad was commended by him, as he believed his dad's care to be his responsibility and not hers.

> *[Iso] too is willingly doing it, it is not her own responsibility, but for the fact that she is married to me too [she is doing it], she is not the type [of person] that look at things like they are very high, she too takes it [like] it is common, if I am not here [and] he poops, she will clean it, she is trying in her own part.* ***FD, Derima.***

In Nigeria, it is not always the cultural expectation that the daughter-in-law will provide care for her in-laws when they are ill. Care provision is most often expected from the children and not the in-laws. It is also dependent on the husband's perspective of whose role it is to provide care for his parents. For example, Derima commends Iso for willingly providing care for his father, but he also mentions that she is doing it because she is his wife. This unspoken expectation of his wife and her ability to take things as 'common' (normal) and not 'high' (difficult) resulted in his positive judgement of his wife.

However, where the quality of care provided by another carer was not observed by participants, the other carer's communicated desire to provide care was crucial for the participant's positive judgement of their caregiving. Idala's uncommunicated expectations of his sister-in-law (Iso)

were superseded, leading to his positive judgements of Iso's caregiving. Idala mentioned a conversation he had with Iso during one of his visits to his father's house.

> *So, one of [Iso's] sisters was telling her to relocate to …. and she was [like] no oh! if I relocate, who will take care of [my father-in-law] for me. It means she is okay taking care of him, and she is happy doing it. So, when she told me that, me too deep inside of me, I was happy. I felt relaxed because he is in good hands, and she is doing it perfectly, [including] her family.* ***FD, Idala.***

Iso's statement during her and Idala's conversation played a crucial role in reassuring the doubt that he had while highlighting the expectations he had about Iso's care for his dad. This shows the importance of words and not just actions, in positively reassuring feelings of undisclosed doubt and uncertainty that carers may have of other carers. This was also evident in a statement made by Funere below.

> *Our last-born [sibling], that one is a caring person. [My] last-born [sibling] because he grew up with [my mother, he was taking care of her] till he brought her to my house, he was the one there seeing all [her symptoms]. He is feeling her pains every time… he will ask me …'how is mama's body?'* ***FI, Funere.***

To Funere, classifying her younger brother as a caring person was based on his checking up on their mother (Mrs Yinkeye) and communicating the pains he feels for Mrs Yinkeye, even though he was not involved in her daily care. His ability to not only call frequently but also express his discomfort with Mrs Yinkeye's challenges, exceeds the familial expectation Funere had, which is expecting her siblings to call frequently to check on their mother, even though they live far away.

Furthermore, the existing relationship between participants and other informal carers plays an important role in how they evaluate their caregiving. For example, Tekena and her cousin (Ini), who she mentioned was like a sister to her, had a very good relationship. She always referred to her Ini's ability to manage everything in their home, including providing hands-on care for Mr Ebitimi.

> *Ini was really hands-on… [although] the carer was around, she was managing their activities, making sure they were doing things properly, even when we are not around.* ***FJ, Tekena.***

Another participant positively commended the work of his father's paid carer but made it clear that it is what he expected, as the carer is paid to do the job.

> *For the [paid] carer, he is doing the best, but it is his job. But each time I go there, the place is neat, he takes his drugs, he eats, basically, the place is just okay.* ***FE, Erebi.***

The transactional nature of the relationship between Erebi and his father's paid carer may have made him trivialise the effort that goes into caring for a person with dementia, especially with the limited resources and lack of regular payments the paid carer faced. To Erebi, his father's house being 'just okay' meant that it met the standards that are expected of someone who is doing the job of being a carer, which to him was a positive. However, Ake, the carer, complained that his payments, including the one he needs to look after Mr Binatu, often came late.

> *The payment was not good enough, sometimes I will not see the money, sometimes when the money eventually comes, it will not be complete.* ***FE, Ake.***

Ake's statement shows that even when a paid carer is used by an informal carer, there are still significant barriers that impede the paid carer's ability to meet the person with dementia's care needs. Nonetheless, Erebi's judgement of Ake's care for Mr Binatu was positive because Ake not only exceeded his expectation on providing hands-on care for Mr Binatu but also did so even with limited financial resources.

## 5.4 Negative judgements confirm other carers inability to provide care

Participants' negative judgements of other informal carers were often based on information they 'found out' or their observations. Participants' judgements often affirmed the perceived inabilities they had of other carers. Additionally, participants' negative judgements formed their understanding of what bad care is, which led to decreased trust, disappointment, or pity for the older person with dementia. In some cases, once the bad care was found out by the participant, they took drastic steps to improve the situation. Some of these steps included becoming the main carer or restricting the other carer's access to the older person with dementia.

> *I found out that [my elder sister] was not taking good care of [my mother], at that time, my mother was washing her clothes by herself, and she was bathing herself. I said HA! When she fell ill that time.... I found out that [my mother] was not taking her bath very well....and secondly again, I found out that she had an infection. So, I said, "mama you are not going back there [to my elder sister's house]." I had to stay in the hospital for two weeks to make sure that my mother's infection had completely cleared.* ***FK, Funebi.***

> *Then my husband's brother was living with [Mr Owei, my father-in-law], he was not always around, so he would give him food in the morning and go to work, before he came back, it would be night. So, the hunger, stress, and the loneliness [contributed to*

*how Mr Owei was looking], sometimes he would poop and if my brother-in-law does not come throughout that day, [that is] how he would [stay all day].* ***FD, Iso.***

The resulting realisation of the 'bad care' provided for Mr Owei shifted the approach Iso and her family employed. This meant Iso and her family moved very close to Mr Owei (as opposed to their previous occasional visits), so they could provide 'better care' compared to what Iso's brother-in-law was providing. Similar to participants' positive judgements of themselves and others, their negative judgements of others centred on the aspects of caregiving they considered the most important. For Funebi, it was hygiene, while for Iso, it was having grandchildren around and looking well. In some cases, negative judgements were made based not just on the participant's observations, but also of those who were present during their absence.

*One thing that [Funere] does in the secret [is] when feeding my mother, [she] will slap [my mother] when feeding her, if she refuses to eat, she will slap her mouth, the children have seen [it]. ...[When] the children told me I was surprised, how can [she] be beating our mother because she refused to eat, she will tell [my] mother "you already know me, if you don't [eat] the food I will slap [you]" and she will slap her.* ***FI, Enemo.***

However, in family I, there was a lot of observed tension between the siblings as well as conflicts on their different roles and responsibilities for caregiving. For example, Enemo believed Funere neglected their mother and physically abused her, while Funere believed that she 'educated, directed' and took better care of their mother.

*Where they are staying does not look good to be sincere, it is a "basher" [local house built with wood or mud]. So, [it is] a village concept because of the environment, and the way they are taking care of her, [the illness] became worse. Nobody to educate [my mum], nobody to tell her, "this thing you are doing, do not do it again," nobody to shout at her, nobody to direct her. Now she is kind of very, very free, using her brain to do whatever she wants to do. It became so [much] worse.* ***FI, Funere.***

Although both sisters negatively judged each other's approach to caregiving, one of the very few things they seemed to agree on was their distaste for their younger sister's (Suoton) behaviour, because Suoton refused to care for their mother. For example, Enemo described a situation that occurred between her and Suoton over the phone, which she found dissatisfactory.

*One day, [Suoton] was calling me on the phone, and I asked her why she is calling me when she is there [at home], [Suoton] said that 'please, I cannot do it' that [my mother] has pooped on her body, I just ended the call [hisses], I told [Suoton] that I do not blame her [for refusing to care for our mother].* ***FI, Enemo.***

Enemo sarcastically criticised Suoton for not wanting to provide personal care for their mother, despite their mother's immediate need. In this context, Enemo telling Suoton that she 'does not blame her' means she actually blames Suoton, but Enemo used sarcasm to say it indirectly. This form of communication is not unusual in the Nigerian settings, as difficult conversations, especially about caring, tend to occur indirectly, resulting in a form of soft reproach. Therefore, Enemo directly telling Suoton that she blames her could have led to a confrontation between the sisters, which Enemo wanted to avoid. Funere also expressed a similar view to Enemo, evident in her quote below.

> *It got to a period that Suoton said from her dirty mouth, 'if she wants to die, she should die, I am tired.' When she is not even taking care of the woman in any way [laughs].* ***FI, Funere.***

Funere found it funny that Suoton expressed how she truly felt about being a relative of an older person living with dementia. To Funere, Suoton is not in a position to wish their mother dies nor complain about the burden of caring, because she is not deserving of that position as she refused to provide care. This shows that Funere and Enemo's negative judgements of Suoton confirm Suoton's inability to provide care for their mother. It is evident that existing conflicts between informal carers within a family play a role in how they evaluate the care provided by themselves.

In another instance, the friction that developed between a participant and another informal carer outside her family network confirmed the informal carer's inability to provide care for her mother. This was the case for Ekiye, who lost trust in her mother's (Mrs Inemo) neighbour, whom she had previously trusted due to the neighbour's occupation as an auxiliary nurse. She asked if the neighbour could help her take care of Mrs Inemo, which she agreed to do. The neighbour was responsible for managing Mrs Inemo's money to ensure she did not spend the money on sugary things, which would make Mrs Inemo's diabetes worse. The neighbour was also in charge of giving Mrs Inemo drugs, amongst other things. However, things became worse than Ekiye had anticipated.

> *I found out that instead of me taking care of my mother, I was taking care of that nurse and her family. I transferred the weekly money to her, but this woman was not doing anything. I did not know that I would talk to my mother on the phone, but she would not even allow my mother to explain. I will ask my mother how she is, but the woman will talk in the call, and I was thinking my mother was fine. After two to three weeks, when I went back, my mum was just looking like a caricature [a distorted version of herself].* ***FF, Ekiye***.

To Ekiye, she realised that placing Mrs Inemo in the hands of her neighbour, who was also Ekiye's friend, resulted in a difficult, unexpected situation. This situation turned out to be a significant determinant in her final decision to move her mother to a newly opened care home. For some other participants, their negative judgements of other carers were passed even though the other carer did not have an opportunity to show themselves to be dependable.

> *No. They can do it oh! I believe that I understand my mum very well. [My siblings] might not understand her the way that I have understood her. So, that is why I said that they should just leave her [with me], they might not understand her, they will do things the wrong way.* ***FH, Loila****.*

To Loila, bad care would be the result of letting her siblings provide care for their mother (Mrs Kalaya), because she believed she understood Mrs Kalaya better. Loila positions herself as the only suitable carer who provides good care for Mrs Kalaya, leading to her limiting other carers' access to their mother. This highlights the role preconceived ideas (not only existing frictions) within families play in carers' evaluation of other carers. Additionally, participants sometimes made negative judgements of other carers because of their inability to provide what they deemed to be the barest minimum when it comes to providing care.

> *[My sibling] hardly picks up their phone to call her and find out how her health is. Some of them, it is their wives that is calling [my mum], sometimes [my mother] calls them, they will call her back, but if she does not call them, in a month they will not call [my mother].* ***FG, Ogola.***

Although Ogola had expectations of his brothers to check on their mother, these expectations were not communicated to his brothers. This is an example of where families expect more frequent social contact from other informal carers. Most times these expectations lie with the main carer and often go unsaid because it is something the other carer 'should know to do,' if only they cared. To the main carer, not doing it is a form of neglect of the older person with dementia. The perceived inabilities of the other carer, the main carer has could make the main carer feel undervalued and underappreciated because they believe they are putting in all their effort, with little to no effort from the other carer. This shows that the negative judgements participants make are often based on their perceived inabilities of the other carer, not the other carer's inability to meet the care needs.

## 5.5 Summary

The findings show that although informal carers in Nigeria had some similar experiences, how they perceive and position themselves within those experiences varied greatly. This also had an

impact on how they evaluate both their caregiving and that of other carers. Being an informal carer in Nigeria is often characterised by unspoken expectations, both that the carers had of themselves but also those of their families and society. These expectations fed into their desire to validate themselves, their quality of care, and reaffirm their relevance and value in their care network. Participants' evaluation of themselves was in the form of positive and negative judgements they made of themselves as carers and those of other carers. The judgements participants often made fed into their conceptualisation of good care and bad care. Understanding of good care and bad care is based on what participants considered important to the older person with dementia, and what is important to them as the carers.

According to the findings, most participants evaluated themselves positively, while being critical of other carers. I argue that this is due to their desire to seek validation and assert their relevance in the care provided for the person with dementia. The participants had expectations of themselves to care for the older person with dementia, regardless of how challenging dementia caregiving is. Their positive judgements of themselves reaffirm what they believe to be true about their identity as carers, while also asserting their relevance in the care provided for the older person with dementia to me as the researcher.

The positive judgement participants made of themselves was either based on their care provision, the quality of the care they provided compared to that of other carers, or, in some cases, based on statements instigated by other individuals. Furthermore, their negative judgements of themselves were often based on situations they believed could have been managed differently, had they known better. While participants' positive judgements of other carers were based on their observations, their negative judgements were often based on information others told them (which may be subjective) as well as what they observed. These positive judgements participants made of other carers reflect the carer's ability to exceed the unspoken expectation the participants had of the other carer.

Participants sometimes had different views about each other's roles and responsibilities. Existing dynamics and family friction play a role in how carers evaluate other carers. In some cases, participants' varying ideas on their different roles and responsibilities for caregiving did not come to a resolution, due to the existing friction between the carers. When the friction between the participants was not brought to a resolution, it often resulted in negative judgements, and the participants perceived the other carer as unable to meet the care needs of the older person with dementia.

# Chapter 6 Arranging and sharing care responsibilities

Care responsibilities were arranged and divided similarly amongst the majority of participants in this thesis. Care arrangements for the older person with dementia often 'emerged', and it was rarely the case that explicit negotiation had occurred between informal carers. Participants' care arrangements were commonly a natural extension of previous relationship with the older person with dementia or influenced by cultural scripts. Participants either justified their actions with the script or worked against the script. In the Nigerian context, age, family hierarchy, cultural norms, and gender often determine who makes decisions or has authority in the family. Therefore, discussing care arrangements for an older person or the burdens of caregiving may be seen as disrespectful and often confrontational, especially when a younger member of the family starts the conversation. This can explain why decisions concerning who takes on the distinct aspects of care for the older person are often decided through indirect channels rather than direct bargaining between the informal carers.

The findings also highlight the importance of gathering the perspectives of different members of the care network of an older person with dementia, where possible. This is because participants made contradictory statements about their caregiving role, especially in relation to other carers. These contradictory statements were often in relation to how care responsibilities for the person with dementia were shared amongst the carers. Furthermore, the concept of reputation management within the caregiving role is a key finding in this thesis. Participants often tried to manage their reputation as carers by portraying themselves (to me, the researcher) as the main or only individual providing care for the older person with dementia, when this was not always the case. Participants managing their reputation could not just be their way of seeking validation from me, the researcher, but it could also highlight an interstate of overwhelm due to the caregiving burden, despite the support they sometimes received from other carers.

In the following sections, the findings are presented under three themes: the emergence of care arrangements, contradictions in caregiving roles amongst care network members and the concept of reputation management.

## 6.1 The emergence of care arrangements

This theme explores how care arrangements developed over a period of time amongst the families in this thesis. This emergence of care arrangements is categorised under two sub-themes. First, care arrangements were often based on cultural scripts that exist within the

Nigerian society, particularly associated with the responsibility and (often unspoken) expectations of the eldest child or the youngest unmarried child in the family. Second, care arrangements were sometimes a natural extension of the previous relationships and living arrangements between the participants and the older person with dementia.

### 6.1.1 Emergence of care arrangements influenced by cultural scripts

How informal carers of older people with dementia arranged care was frequently influenced by cultural scripts that are dominant in the Nigerian context. Examples of some of these scripts include the eldest child having the greatest responsibility for decision-making, financial provision, coordination, and collaboration within the family, unmarried children taking precedence as carers over married children, and that care should be provided by the family and not formal institutions or paid carers. These scripts play a key role in participants' decision-making, significantly influencing how care for the older person with dementia is arranged. The findings show participants either used the cultural scripts to justify their actions or conversely did things that do not fit within these cultural scripts, and therefore, they had to work harder to justify their actions. An example of the eldest child script is seen in Family A, where the eldest son's (Atima) position in his family made him a decision maker in terms of his father's (Mr Afini) care arrangement.

> ***LO**: So, in a typical day of caring for [Mr Afini], what do you do after putting him on the chair, bathing him, feeding him, are there any other things you do, like taking him out?*
>
> ***Atima**: [long pause] because of his condition, we do not take him out, but like his clothes, I used to wash them then, but now it is my younger ones because I am steady [monitoring] him.*

In Nigeria, clothes are typically hand-washed outside or in places like the bathroom or corridor. Because of this, an individual could spend the duration of the clothes washing away from parts of the house, like the bedrooms and living rooms. This explains why Atima stopped washing Mr Afini's clothes, as he could not afford to spend that time away from him, but rather put that time towards the task he considered more important.

> ***LO**: From talking to your mum and sisters, your family always come together to take care of your dad. I am interested in how you all came to that agreement, is it something you decided as the first son, or did your family just know that it is what is expected?*
>
> ***Atima**: I personally decided that I was going to stay with [Mr Afini] basically in the night, but… I stayed with him almost every time [at night]. My younger ones are the ones that*

*will go and buy drugs, but I stay with him to observe him and to also pray for him, that was my own decision*.

Atima is the firstborn of Mr Afini, and he saw himself as the person who manages the aspect of Mr Afini's care that is the most meaningful to him, which is observing and monitoring him, especially at night, and praying for him. He left his siblings to handle the more mundane tasks like buying the drugs and washing Mr Afini's clothes. This was not explicitly negotiated between him and his siblings, but their silence and compliance with the arrangements reflect their tacit agreement with it. This is also in line with the cultural script where younger siblings are less likely to bring up conversations regarding certain topics like elderly care, or challenge the decisions made by their eldest siblings. This is evident in a quote by Enemo below.

*We overlook many things because she is our eldest sister, nobody [challenges] her, but when it is me, they [ask questions] because I do not have a job and I do not have a husband*. ***FI, Enemo.***

Enemo's statement above highlights the position younger siblings occupy in terms of challenging or questioning the decisions made by the eldest sibling. Additionally, having a husband and a job is associated with a status of competence and respect in the Nigerian society, which warrants a level of respect from family members. Therefore, for Enemo, her lack of a job, husband, and being a younger sibling, intertwine to make her more likely to be challenged. Thus, placing her in a position where she is less likely to speak up, even as a younger sibling.

Furthermore, family A is a good example of a collaborative care arrangement where different members of the care network chip in at different capacities, with Atima, Boma and Alero handling the majority of the tasks. This was due to the fact that some of Atima's siblings were sometimes away at the University, which limited their capacity to help with caregiving. Although this was not explicitly negotiated within the family, the cultural script, as well as their existing familial hierarchy and dynamics, plays a significant role in shaping this arrangement.

Another similar case of the cultural script influencing care arrangements can be seen in family D. Derima saw himself as a decision maker in his family who sorts out challenges and does what has to be done without involving his family.

***LO**: I know you mentioned earlier that you are doing it alone, but is this a decision you made yourself without involving your other siblings?*

***Derima**: I do not need to know. Already they know, I did not talk to them, I just came*.

Derima indirectly gives insights into why explicit negotiation was not needed because his siblings already knew.' According to him, there was no negotiation between him and his siblings, as moving in to take care of his father (Mr Owei) was a decision he took after considering the circumstances. This circumstance included what people would say, seeing that Mr Owei had nobody around caring for him. Derima may not have explicitly mentioned his role as the eldest child, but his statement later in the interview provides a clearer insight into his thought process in the care arrangement for Mr Owei.

> *I just love him, I love him, so it is my duty to him, not only my duty but all his sons, it is everybody's duty too, but since they cannot do it, I took it upon myself, so let me play my own role, it is my own role I am playing.* ***FD, Derima****.*

To Derima, his love for Mr Owei naturally extends as his duty to him, therefore, Derima expects this same love and duty from his brothers. He expects that his brothers should have the same love and duty to Mr Owei, which is not unusual, because in the Nigerian society, it is strange for children not to love or have a duty of care to their parents. His 'role' mentioned above reflects the ingrained expectation that the eldest children have of themselves, as it is their responsibility to step up irrespective of what others do (not), which is echoed in his decision to 'play his own role' due to a lack of alternative.

The eldest child's role in the Nigerian society already carries expectations, these expectations are further amplified when other siblings are not forthcoming in fulfilling their own responsibilities. Some of these expectations of other siblings include supporting financially, being available to help with caregiving, and checking in regularly with the main carer to ensure everything is well. As in the case of Derima, Funere, in family I, mentioned taking on the responsibility of her mother's (Mrs Yinkeye) care because her other siblings did not live up to Funere's expectations.

> *I could say that I took it upon myself because I am the oldest. From the start [of the interview], I told you, I took it upon myself. It was when the thing was [too] much, I called for [help]. But when I called, did I [get] any good response? Did I? Rather, anyone who has maybe ₦0.10, they will send it to my account, maybe for one or two days. But to be sincere, it is me that is taking care of [Mrs Yinkeye]... I am the only one that everybody is looking up to. To be sincere, I am not proud to say it, but that is just the truth.* ***FI, Funere.***

Although Funere's care arrangement for Mrs Yinkeye emerged as a result of the cultural script of it being her responsibility as the eldest child, it does not change the fact that her perceived shortcomings of her siblings are still an issue for her. In Funere's statement above, she

expresses discomfort in the fact that 'everybody is looking up to her' and she is not 'proud to say it' because it is something she considers shameful. However, from the interviews with Funere's sisters and my observations, it was less a case of everybody in the family 'looking up to her.' Rather, the family had an imbalanced care arrangement where Enemo was providing the hands-on care (sometimes supported by Oyinbra), with Funere supporting with things like food, drugs, taking their mother to the hospital, and cash. This is similar to the case of family A discussed earlier, where the eldest child is in a monitoring role, and the mundane tasks are delegated to the younger siblings.

In some instances, participants did things that did not fit the cultural script of the eldest child. For example, in family J, Tekena challenged the expectations of the eldest child as opposed to agreeing with them. Tekena believed that her family's care arrangement for their father (Mr Ebitimi) was explicitly negotiated amongst her and their siblings (Ini included).

> *[It] is more or less a joint effort, as much as [I] am [the] eldest, I do not take any decision without informing them, I do not impose anything on them, it's a collective effort, we agree on something before we do it and they also suggest [things] and make me see reason with them.* ***FJ, Tekena.***

Ini, who provided the hands-on care, was not aware that any form of negotiation with Tekena and her other cousins had occurred in terms of providing care for her uncle. Tekena's statement highlights her desire not to portray herself as the typical eldest child in Nigeria, who makes decisions without considering their younger siblings' input simply because they are the eldest child. Tekena's desire to break away from the cultural script could be due to the existing views that other siblings may have of the eldest child. The eldest child may often be viewed by their younger siblings as inconsiderate or enforcing decisions on them that they do not agree with, especially when the younger siblings' perspectives were not considered.

From my observation and conversation with Ini, Tekena does break away from the cultural script (with very few challenges) with her approach to decision-making in their family. However, Tekena's success in breaking from the script could be exacerbated by their family's care arrangement for Mr Ebitimi, which involved five nurses providing around-the-clock care for him. Perhaps the decision-making process and the navigation of this process have been cushioned because the burden of care on Tekena and her siblings is not immense.

Another example of a participant breaking the cultural script is seen in family C, where Tokoni breaks the cultural script of the eldest child by assuming authority despite not being the eldest child. Considering the cultural script of the eldest child having the greatest responsibility compared to younger siblings, existing family dynamics could also determine who takes on this

responsibility, and not just the 'age' of the child. Tokoni may be the youngest amongst his siblings, but he functioned with the authority of the eldest child and often positioned himself as the decision maker of the family. However, during the interview, he communicates his actual position within the family in his statement below.

> *I am not someone who will say [to my siblings], "see what I have done", if it comes up. I have done my part; if there is something [my siblings] can do, then [they] do it as well. Everybody has what they are going through, that is just the truth. No matter what it is, what you can do you do, you cannot force anybody, even when you have good intentions, you cannot [force anybody].* ***FC, Tokoni.***

Tokoni's statement highlights his feelings about the part he plays in his father's (Mr Sele's) care arrangements. He believes he plays his part quietly, regardless of whether his older siblings recognise it or not, and he does not force them to do more, no matter how good his intentions are. His feelings could also be exacerbated by the fact that he is the only one of his siblings living in the same state as Mr Sele. So, while he may be functioning as and carrying the responsibility of the eldest child, when it comes down to it, he is only playing the part he thinks he is responsible for ('you cannot force anybody'), whilst signalling disapproval with what his siblings are (not) doing. Although Tokoni does not negotiate more with his siblings, his statement signals that he thinks his siblings should be doing more. This shows that the role of the eldest child is not easily assumed by just any sibling, especially the youngest ones. While the role can be taken up, limitations exist in terms of the autonomy and power the individual can exert, especially when the eldest child is still present in the family (even though they have not fully assumed that role).

In some instances, the cultural script of unmarried children taking precedence as carers over married children is evident. The previous and current circumstances of the participant (living arrangements and being unmarried) played a role in how care was arranged implicitly between them and others in the care network. For example, Loila mentioned that because she remained unmarried, she is still providing care for her mother, considering all her siblings are currently married.

> *I am the one who is staying with her right now, so I have to do it… I am still single, I will continue to do it till when my own [husband] comes, then maybe my elder sister will take over; my other siblings are all married. I will say that I decided to [provide care for my mother].* ***FH, Loila.***

Although Lolia communicates the pressure (I have to do it) of having to care for her mother because she was staying with her before the dementia diagnosis, compared to her siblings,

Lolia also acknowledges the choice she had (I decided to), even if it is partial agency. Loila may have control over her choices, but her control is greatly influenced by her family. To Loila, her siblings being married meant that they could not care for their mother, but she had to do it as the only single person. This perception could also be because of the notion that single individuals have more time on their hands; this will, however, change if she gets married. At that point, her eldest sister will become the most appropriate choice, because within the cultural script, the eldest child is expected to carry the greatest responsibility of care provision in the family if there are no single siblings remaining.

Similar to Loila, Idala from family D is another case of the cultural script of an unmarried person getting married and no longer being able to care, yet the eldest married sibling steps in.

> *It is a shared responsibility, but for now it is basically under my elder brother and his wife, because he voluntarily said he wants to take care [of our dad], but I was with [my dad] from 2017 till 2019 before I got married. So, [my wife and I] had to relocate to [a place further away] …. so, my elder brother said since [my wife and I] are married now, he would come with his wife to stay [with our dad]****. FD, Idala****.*

Although Idala mentions that the responsibility of his father's care is shared by all his siblings, he also admits that he had to take a step back because of the responsibilities that he and his siblings believed came with being recently married. Within the cultural script, the eldest child still holds the greatest responsibility and authority, irrespective of whether other siblings are married or not. However, the unmarried child takes on the care provision knowing that it will ultimately rest upon them, and they are not in a position to negotiate a different arrangement until they are married. Being married in this case functions as a rite of passage, which allows the provision of care to fall back on the eldest child, although the responsibility never left them (while care was being provided by their unmarried sibling). A similar finding was noted in Ogola from family G, as seen below.

> ***LO****: Okay, how did you decide that you would be the one to stay with your mum?*
>
> ***Ogola:*** *I did not decide it on my own, I am the last [born], my four [brothers] are older than me. They are married.*

Ogola's statement above supports the cultural script of the youngest unmarried child taking precedence as a carer over their married siblings. Although Ogola hints that some form of negotiation had taken place ('I did not decide it on my own') between him and his siblings, it became clearer from his statement that his actions were based on the cultural script, which he used to justify his actions.

Another existing cultural script is that care should be provided informally by the family and not formally by individuals and institutions. Interestingly, the findings in this thesis showed that there were very few instances where participants fit within this cultural script. This cultural script was only evident amongst carers in family D, where Iso and Idala had the same views of keeping care within the families, but justified it very differently.

> *Even if we say we want to bring someone to take care of him, the person will not be able to take care of him personally, the way the children will take care of him; outsiders will not be able to take care of him because of the things he does. Sometimes the things he does can be annoying; if he is not your father, you can walk away and leave him. Sometimes, you can be angry [enough to want] to beat [him] but despite everything [he is doing], he does not know [what he is doing].* ***FD, Iso.***

Iso believes that the care provided by an 'outsider' (a non-family member) will not be as good as that provided by the children of an older person with dementia. She associates being related to a person with patience to care for that person, however, that is not always the case. Dementia care is complex, and even the children of the person with dementia may not always be patient, especially when dealing with challenging behaviours. Although Iso uses this cultural script, she justifies the need for care to be provided by the family with the ability of the family to 'accept whatever they see' as carers. This is because they have no option, but a formal carer does have options because of their lack of familial ties to the care receiver. Idala also had the same views but with a different justification for the use of the cultural script.

> ***Idala****: I am very close to my dad, most times when they say they want to take him outside [to the elderly home], I have this guilt in me, like how will I go and be paying someone to take care of him when I can do it.*
>
> ***LO****: Can you please tell me why you feel guilty about thinking of paying someone to care for him?*
>
> ***Idala****: …this is very personal, my dad took care of me, I lost my mum, I did not know my mum, yeah, but this very man, my dad, took care of me, he just took me personally. So, I am seeing it as the time to pay back, and he did not allow anybody to touch me, his care for me was too much…Anytime I hear 'take him to the home of the elderly', I will say no, let me do this for my dad, let me pay back.* ***FD, Idala***

For Idala, his justification for keeping care within the family was that he wanted to pay his father back for the 'too much care' he received from him, even after the death of his mother. Idala's use of the words 'too much care' highlights the gendered stereotype (that still exists) where women are associated with being the ones to provide care for their families. Therefore, when

men provide care, it is considered unusual, hence, his use of the term 'too much.' However, his statement also highlights that the guilt informal carers feel is one of the massive influences and propagators of the cultural script of family care preferred over institutional care.

Contrary to the above, some participants did things that did not fit this cultural script; therefore, they worked harder in the interview to justify their actions. For example, Erebi employed a carer (Ake) and rented a space for Ake to live with his father (Mr Binatu).

> *I am busy. I am not usually around, but it became necessary for us to get someone… [Ake] does practically everything, the only role I play for now is making funds available. At least I do all that coordination, then I take him to the hospital, always on his check-up days, at least I coordinate that.* ***FE, Erebi.***

In Erebi's statement above, he highlights the positive aspect ('at least I do all that coordination') of the situation he considered difficult (which was the necessity of getting a paid carer to provide care for Mr Binatu), given his busy schedule. However, later in the interview, he provides more details about his reason for employing a paid carer.

> ***LO****: Your decision to use a paid carer, it may be the case for some people, there is an obligation to do it themselves, even with their competing responsibilities.*
>
> ***Erebi****: I believe that for those people, it boils down to the availability of cash. If you cannot muster the cash, then you have to do it yourself. It is not possible for me to be there every day, I cannot even. For me, washing poop is the most difficult thing, to wash something belonging to an old man stained with poop and all that is not simple. I did it initially, at least I tried, but at some point, I just really could not continue*

Erebi communicates that he does not have to provide care himself because he can afford not to. Although his reason is legitimate, Erebi also communicates the advantage he believes he possesses by being able to afford a paid carer. Additionally, he goes on to admit that he found the provision of personal care difficult, particularly dealing with incontinence. This is not surprising as men are typically expected to be the financial providers, while women provide the hands-on care. Erebi fits into this stereotype and unintentionally uses it to justify going against the cultural script of care being provided informally by the family.

Contrary to Iso's above perspective on not being able to trust 'outsiders' to provide care for her father-in-law with dementia, Ekiye in family F believed that trust for 'outsiders' (as Iso puts it) was not a relevant criterion in her decision to move her mother to a care home.

> ***LO****: Are you more confident that the people in the elderly people's home can better care for her?*

> ***Ekiye**: You see, in being confident or trusting someone, you might not really know unless you give the person a task. There are some people you feel you can trust, but at the end of the day, you just find out that they cannot really do anything, they cannot deliver [on the task you asked them to do]... **FF***

Ekiye's decision to move her mother to a care home did not fit the cultural script of family care being preferred over formal care. To Ekiye, it was not a case of being able to trust the carers before letting them provide care for her mother, rather, she believed that a carer can only be proven to be competent when they have been given a task and have completed it. However, Ekiye's above view on arranging care for her mother reflects her experience when she trusted her neighbour (an auxiliary nurse) to provide unpaid care for her mother. Although she believed the neighbour was competent enough to achieve this, how the neighbour managed the situation was very disappointing to Ekiye, and was the main reason she moved her mother to a care home.

This shows that for informal carers, moving the person with dementia to a care home or using other forms of formal services as opposed to just family care, could be a result of the carer's belief that they are either not competent enough to provide complex dementia care, or that they have trusted others close to them to provide this care, but they failed. Therefore, it was easier to trust a more structured system that may be more successful at meeting the person with dementia's care needs.

### 6.1.2 Emergence of care arrangements as a natural extension of relationships and living arrangements.

Amongst the majority of the families in this thesis, care arrangements naturally developed from previous relationships that existed before the dementia diagnosis. In these cases, participants were not aware that some sort of negotiation had taken place. Instead, it was often implied or subtle, reflecting their past, future, or current circumstances. The case study of family J (see table 4.1 for a summary of their case) provides a good example where care arrangements emerged as a natural extension of previous relationships (between the informal carer and person with dementia)as well as some explicit negotiation. Ini began living with her uncle, Mr Ebitimi, and his family when she was young. Although Mr Ebitimi has six children (Ini's cousins), Ini mentioned that he was very fond of her, and she became like a daughter to him. Tekena (Ini's cousin) is Mr Ebitimi's eldest daughter, who lives in a different state with her family. Tekena mentioned that she and her other siblings are not always around, and when they come around, they do not stay for long. Tekena also mentioned that she viewed Ini as a sister because of her ability to do certain things for Mr Ebitimi.

> *I took [Ini] r as a sister, she went as far as, when [my dad] urinates on himself, she will wash [him]. There were times when my dad would wet himself, [even] if I were there, my dad would prefer [Ini] to clean him, that is how close they were. She is one of us.* ***FJ, Tekena.***

Ini later went into higher education [away from home], so Tekena's brother had arranged nurses, who work a shift pattern to care for Mr Ebitimi. Even with the nurses present, Tekena mentioned that her father always requested Ini and preferred her to take care of him when she was back from her university. The care Ini was providing for her uncle before his diagnosis did not involve personal care but more of support with some activities of daily living, like laying out his clothes, taking him for appointments, serving him food and medication, etc. Ini's providing support to a certain capacity for Mr Ebitimi before the diagnosis of dementia, alongside their existing living arrangements and the quality of their relationship, influenced her decision to provide care.

> ***LO****: Did you decide to take on the responsibility of his care, or was it something you decided with your sisters?*
>
> ***Ini****: [laughs], no oh we did not discuss anything. It is just that when I came, [Mr Ebitimi] always called me for everything, so I was just used to do[ing] things for him, I did not find it difficult. Whenever he called, I was always there. We would normally sit down and talk about things, but we did not decide anything; I just did it from my heart.*

Ini's laughter could be her way of confronting the topic, as it may have been the first time such a conversation had come up. Nonetheless, to her, the transition from being a person who provided a level of support while living with her uncle before the dementia diagnosis, to being his full-time carer (before she went to the University) was not difficult for Ini. Ini did not think classic negotiation occurred ('we did not discuss anything') as the decision came from shared practices, routines, and a close relationship ('I just did it from my heart') which had developed over time. However, when asked how the decision-making had been so far for her and her cousins, her response painted a different picture.

> ***LO****: [Tekena] mentioned that you all always make decisions together regarding him, how has that been so far for you?*
>
> ***Ini****: We have to make decisions together concerning him. I do not have a problem with that. We always talk about things, [like] how to help him, and maybe look for somebody who would treat him. We will just come together and talk about it and look for a solution.*

For Ini, the aspect of care that involved medical arrangements, such as taking her uncle to the hospital, and financial management, required explicit negotiation with her cousins. This shows that in care arrangements; different aspects warrant explicit negotiation and more consultation from active members of the care network. Given the status of Mr Ebitimi and the finances he was receiving from a certain organisation in the State, it was not surprising that explicit negotiation occurred in terms of the medical decisions and financial management.

> *We have this aunty that feels we are spending our father's money on ourselves, that he spent so much [money] to [educate] us, but we left him to rot, and we are selling his properties to enrich ourselves. For example, I have been called a thief [by her] because I sold [my father's] property to build myself a house to live with my husband. But when my siblings hear, they just laugh, because they know you can't access my dad's account without all of us.* ***FJ Tekena.***

Although the part that had to do with the hands-on care for Mr Ebitimi did not warrant explicit negotiation, explicit negotiation for financial issues was demanded by the situation ('they know you can't access my dad's account without all of us'). The bank in this case study functioned as an outside force, which set the need for Tekena and her sisters to explicitly negotiate. This was particularly important as the money was given by a notable organisation, and there was an existing lack of trust as well as disputes between Mr Ebitimi's sister and his children. This shows that the need for negotiation is often set by external forces like the bank or the law, which explains why it is the exception to the 'eldest child' or 'natural extension of previous relationship' script.

Similarly, in family B, for Tamara, care arrangement was a natural extension of her relationship with her mother (Mrs Ibiso), however, the gendered expectation that exists with caregiving was prominent in family B's case. For Tamara, there was an awareness of the influence of her existing living arrangements as well as other circumstances, which played an important role in her transition from living with Mrs Ibiso to becoming her carer.

> ***LO****: In terms of who provides which part of your mum's care, did you just decide that is the part you will do?*
>
> ***Tamara****: Definitely, I have been the one staying with her before this, so it is something that has to be continuous. It is just I and my brother, when this issue started, it brought a lot of problems, [my mother's family] were like my brother and I were too young to understand what was going on, we should move her to [her] elderly [sibling] house, so we ourselves were not comfortable with that. So, we had that kind of meeting and said*

*"no," we cannot do that, we have to take care of our mother ourselves, and if we need your assistance, definitely, we will ask for it.*

Tamara's statement above highlights a key issue that often happens amongst some Nigerian families. Similar to the eldest child script, there is the belief that complex care should be left in the hands of more senior people within the family. This is because these individuals are considered more experienced and wiser, and by extension better placed to provide complex care, compared to younger individuals. Here, the different values contradict each other, that is, the value of being cared for by adult children/coresident relatives versus the value of seniority. Nonetheless, Tamara and her brother were able to stand their ground in terms of their preferences for Mrs Ibiso's care through explicit negotiation with Mrs Ibiso's extended family members.

In addition, Tamara's brother has also been living with her and Mrs Ibiso while helping out occasionally, but he did not naturally take on the role as Mrs Ibiso's primary carer.

***LO**: I do not know if you mind me asking, but the decision you made, for example, bathing her, is it something you and your brother agreed on, or did you know you would handle that aspect?*

***Tamara**: Yes, I am in Africa, I am an African girl, my mum is a loving person, my mum is good, like she is a good soul, not because I am her child, naturally she is. So, it is not something I am doing as a burden, I am doing it like it is something I must do, it is a duty, I owe her that, I have to do it, … I knew that yes; I would be the one to definitely carry it.*

Tamara saw it as her natural role as 'an African girl' and her duty to provide hands-on care for Mrs Ibiso. In this case, different solutions would have been possible, but the one that emerged was seen as natural, which is Tamara becoming the primary carer. This sheds light on the gendered expectations of caregiving, which did not even have to be discussed within the family or justified to me as the researcher, but naturally occurred in Tamara's case. Family B's care arrangement shows a strong element of collaborative care with Tamara's brother and her aunt chipping in, even though it is not in equal capacities. This was brought about by both implicit and explicit negotiation between them and other members of their care network.

Furthermore, amongst some participants, there is the belief that care responsibilities should be naturally delegated to specific individuals within the care network, because of the nature of the relationship that exists between them and the person with dementia. For example, Alero in Family A believed that her mother (Boma) should be responsible for certain parts of her father's (Mr Afini's) care because she is his wife.

> *It is mainly my mum since she is the one married to him; she takes care of him, like changing his diaper. He was able to do all those before, but after a while, he could not, so when my mum is not around, my elder brother and I would change his diaper and carry him.* ***FA, Alero.***

For Alero, aspects of Mr Afini's care, such as personal care, were only completed by her and Atima when her mother (who she thinks is naturally responsible for that task) was not around. Nonetheless, it is not unusual for the relationship between spouses to naturally evolve to a carer and care receiver relationship, which Alero affirms in her statement above. However, in the case of Boma, she not only made the natural transition to being her husband's carer, but she also had to assume the position of the breadwinner of the family (which she mentioned her husband had been doing for years) because of how great the needs of their family were.

> *Since he has retired, once the salary [pension] has not come, the food I sell daily is what I use to feed [my family]. When I have finished selling, I will cook, sometimes I buy food and give it to [Mr Afini] to eat, so that he can eat that one before I finish cooking... Sometimes he will say no oh, why is it only me doing all this? I will say you are not well now. If you recover, I know how you struggle to feed us, now I am taking care of you...When he knows himself, he normally says that, so I would tell him not to worry, that if he recovers well, he will take care of the family. That is the way we have been managing.* ***FA, Boma.***

Boma also carried the burden of Mr Afini's care with the hope that he would recover and be able to take back the responsibility. Throughout the interview, Boma conveyed this hope that her husband will recover, which may have made it easier for her to take on his responsibility without explicitly delegating it to any of her children.

> *I did not share any responsibility with anybody oh, I took it as a burden, if they have, they help me. I take it, I did not share any responsibility with anybody, I manage myself.* ***FA, Boma.***

Boma's perception of her children's role is that they support her with their discretion, even though she did not ask them, it is still her expectation. Culturally, parents expect their children to assist them without the parents asking directly, especially when the need is evident for them to see, in Boma's case, it was care for her husband with dementia.

The relationship between spouses does not always evolve naturally into the carer and care receiver relationship, especially when this transition is halted by the children. For example, Erebi (from family E) and his siblings halted their mother from naturally becoming Mr Binatu's carer against their mother's judgement to preserve her health.

***LO**: How did you decide who is responsible for his care? Or was it something that you and your siblings decided?*

***Erebi**: Yes, we all decided, including my mother, at some point, my mother wanted to run this whole thing herself, she would go there, especially when [my dad] was in the hospital, she would go there and stay the whole day. [When] she does it two [for[ two to three days [by] the fourth day, we are taking [my mum] to the hospital, [because she was falling ill]. So, we had to stop her, so she has not seen him for about two years now.*

Interestingly, there was explicit negotiation involved in the decision on how care was provided for Mr Binatu by Erebi, his siblings, and their mother. But Erebi's mother was not involved in the decision-making when Erebi and his siblings decided to separate their mother from Mr Binatu. Although this decision was to protect his mother's health, it also stripped her of the opportunity to provide care for her husband. This shows that, despite previously agreed decisions explicitly negotiated between informal carers, another decision could be made by others, in the assumed best interest of those they deem vulnerable and in need of protection, even when the person is not the older person with dementia. However, it also became clear that the care arrangements Erebi made for his father were influenced by an external authority, such as a medical doctor.

***LO**: How do you navigate the feeling of knowing you have separated them, and she would love to see him, but she cannot?*

***Erebi**: It was actually one of the doctors [that] suggested it, it is not like I brought up the idea, if it is working for [my mum], then it is okay by us. There is nothing I can do because I am the one [close by]. Imagine me running to … then from … I go to… where [my mum] is based, it is not easy in an average day before I start going about my own normal things, so I think it is working for me…*

Erebi, in his above statement, separated himself from the decision and communicated powerlessness when asked how he deals with the feelings that arise from separating his parents. This is his way of navigating the decision, as it is easier to handle it knowing that the idea was not from him but from a medical professional (who is considered trustworthy). Nonetheless, Erebi made peace with the decision even though he was unsure whether it was a successful decision.

Where in family E, Erebi separated his mother from his dad (Mr Binatu) to make the living arrangements more convenient and to preserve his mother's health, Tokoni in family C explicitly negotiated with his mother, who had separated from his dad (Mr Sele), to move back in with him. Tokoni's main reason for asking his mother to move back with Mr Sele was because he wanted

them to be in the same place, which would make it easier for him to care for both of them, but she 'ended' up being the father's carer.

> *I had my own conversation with [my mum], I was like, the way it is, it will be better for [both] to be under one roof, because [them living separately] was another stress.* ***FC, Tokoni.***

While Erebi (in family E) and his siblings separated their parents to ensure their continued health and well-being, Tokoni brought his separated parents back together to make it easier for him to look after both of them. This shows that when care arrangements are negotiated (or not) amongst participants in this thesis, it was often a 'do whatever it takes' situation to ensure that care is provided. This was sometimes irrespective of how the arrangements could affect the person with dementia.

In some instances, care arrangements were not just an extension of previous relationships and living arrangements but also the current situation of the participant. For example, Enemo came into the caregiving role based on her living arrangements and lack of a job.

> ***LO****: Are you the one who decided that you would be the main person taking care of your mum?*
>
> ***Enemo****: I did not decide, but I am not doing anything… things are hard, we all waited for month end [to get money, but] I do not sell anything… I am at home, not doing anything, so that is why. , And again, as they brought her from the village, she is close to me I cannot leave her, and I am not doing anything so I decide to take care of her, others are far away from her me, I am close to her, so I said let me do it and she is my mother, what will I do.*

Enemo views herself as an individual who has the free time to provide care for Mrs Yinkeye because she does not have a job, which to her means she did not have much of a choice. At the same time, she also admits her agency in her decision ('I decided to take care of her'). Additionally, for another participant in family I, Oyinbra, living in proximity to her sister-in-law (Mrs Yinkeye), resulted in her providing around-the-clock care, because Mrs Yinkeye had very challenging behaviours.

> *When they are not around, I take care of her, when they are around, I still support her every time****. FI, Oyinbra.***

Oyinbra helped her niece-in-law (Funere and Enemo) to provide care for Mrs Yinkeye (who is her sister-in-law), and Oyinbra functioned as a standby care provider. Although Funere and Enemo did not necessarily delegate the caregiving task to her, she always made herself available to

them whenever the need arose. This can be attributed to the nature of Oyinbra's living arrangements, as she, Enemo, and Mrs Yinkeye lived in bashers as previously discussed. As these bashers are situated so close to each other, it is not surprising that Oyinbra supports her nieces-in-law as the need arises, especially when she is mostly around the premises running an oil-making business from home. Therefore, the quality of Oyinbra's relationship with Mrs Yinkeye also played a role in the care arrangement, as she sees it as her role to help out.

> ***LO**: Do you help them because she is your husband's sister?*
>
> ***Oyinbra**: Yes, that is why I help them. God will help us.*

Where caregiving was often a natural extension of previous relationships and living arrangements, there is an exception to this rule, which is an individual refusing to provide care even though they have a relationship with the older person, and they live in proximity to them. This was influenced by an external authority, such as a religious leader, this is similar to the case of Erebi in family E, where a medical professional influenced his decision to separate his parents.

Suoton, who is the youngest sibling of Funere and Enemo, lived in proximity to Mrs Yinkeye but refused to help out with the majority of Mrs Yinkeye's caregiving, even when it caused issues between her and her sisters (especially Funere).

> *[Funere] always asks me why I do not assist in bathing my mother or wash her clothes; I told her I am not doing anything other [than] cooking for her when I can, she said why? I told that I cannot do anything [more] than [I am] already doing. I feel it, I feel very sad and pained, but I cannot bathe her…* ***FI, Suoton.***

During one of my visits, while talking to Suoton, Funere came, walked past us to check on Mrs Yinkeye, and proceeded to ask Suoton and me to come and see the condition of Mrs Yinkeye, which Suoton refused. Out of respect for Funere and seeing that the situation was escalating, I got up and went to check on Mrs Yinkeye, who I found lying on the floor in urine. Suoton, who was behind me, refused to look inside the room but was peeping from the door and instead asked me, 'Is she dead?' This really upset Funere, and Suoton, noticing how bad the situation was getting, decided to look inside the room, and later assisted Funere in lifting their mother to the bed. Suoton was very firm and clear in her decision on what she will not do. However, from her statement above, she communicates pain and sadness as though the decision was not entirely up to her, and she wishes it were different. Later in the interview, she revealed the reason.

***Suoton**: [When] I go to church, there are so many prophecies coming, anytime they [see] prophecies, it [is] always related to my mother.*

***LO**: Can you please tell me any of the prophecies?*

***Suoton**: For example, of all my mother's children, I was the richest, but after [a certain] time, I could no longer get money. There was a time I was seeing about ₦2,000,000, sometimes ₦1,000,000, but now I do not get money like that anymore. When I go to church for prayers, they say the problem is from my mother's side. Some people [said] I need to ask my mother why I [do not] get money anymore, [and] what she did when she was young [that caused her current condition].*

Suoton believed that Mrs Yinkeye is the cause of the misfortune that has befallen her. The prophecy from the religious leader greatly influenced why Suoton refused to provide care for Mrs Yinkeye aside from giving her food when she could, even when Suoton lived opposite Mrs Yinkeye. This highlights how much impact external authorities could have on the care arrangements of informal carers. Family I's care arrangements highlight long-term conflicts that have existed between the sisters, especially between Suoton, Enemo and Funere, which have gone unresolved, these conflicts contributed to creating an imbalance in their care arrangements. This imbalance, although communicated and presented differently to me (as the researcher) by the family members, was always centred on existing conflicts, which they were all aware of.

## 6.2 Contradictions in caregiving roles amongst care network members

Participants s in different care networks sometimes contradicted each other in relation to their care arrangements or caregiving roles. These contradictions could be a way participants made sense of the overwhelming nature of dementia care as well as its emotional, psychological, and physical cost. For example, Derima from family D denied that any negotiation had taken place between him and others in his father's care network, as he believed that he had decided on his own (as discussed previously); meanwhile, other members of his family believed it was explicitly negotiated.

*So, I had to call my husband [Derima], and I told him that this man [my father-in-law] needs people around him, it is as if he does not have any [family]. So, that time I had to talk to my husband about how we should come and stay with daddy because of his condition. **FD, Iso***

Iso's report of how negotiation occurred between her and her husband paints a completely different picture from what was previously stated by Derima. I observed during my visits to their house that Iso played a more significant role in the care of her father-in-law than Derima often portrayed. In conversations with Derima, he painted his wife as a more passive than active individual in his father's care, while he said he is the main carer, with her only assisting him. Specifically, during one of my visits, I noticed that both Derima and Iso provided care in partnership with each other, supported by their children. For example, while Iso was cleaning his father's room floor, Derima was changing the mattress cover, and their children were helping them fetch water while doing other relevant things necessary to complete the work. Their partnership may not have been explicitly negotiated, but it might have been facilitated by their existing family dynamics.

For another participant, Funere, emphasis was placed on the emotional cost of the caregiving role, which she highlighted in her statement below.

> *I am just trying my best, and my younger sister, too, is helping me, trying her best to bathe her in the morning because they are close there. Except she is not around, I go there and bathe her before I leave, that is how we are living.* ***FI, Funere.***

Although Funere portrays herself as the one making the biggest sacrifice to care for her mother, with occasional help from her sister (Enemo), Enemo contradicts the above statement.

> *The last time I travelled to the village to plant cassava, when I came back, my children were telling me that my elder sister [Funere] did not do anything to take care of [my mother]. The last [time] I travelled, I went on Friday and came back on Wednesday. [Funere] did not take care of [my mother], she did not bathe her mother till the day I came back, she did not wash her clothes.* ***FI, Enemo.***

Family I's case provides an example of some of the challenges that could occur when care arrangements are not explicitly negotiated within families. During my different visits to their home, I often noticed a lot of friction between the three sisters interviewed in family I (as previously discussed). Although Enemo was the hands-on carer, Funere often had issues with Enemo for different reasons, especially when Funere believed Enemo did not meet the care needs of Mrs Yinkeye. This is interesting as Funere, in her statement above, mentioned that Enemo was 'helping her' and Funere is the main carer.

For example, when I visited their home (they live very close to each other) one early morning to interview Enemo, I was informed that she had gone to do a temporary job. A few minutes later, Funere came around, went to check on Mrs Yinkeye, and found her on the floor of her room, soaked in urine (this occurred frequently during my visits). Funere was infuriated by this and

asked Oyinbra (her uncle's wife) if Mrs Yinkeye had had her bath, to which she replied that she had not. She then proceeded to complain bitterly to me about the things Enemo does that she does not like. During this period, she did not proceed to bathe her mother, although I had told her I could wait, she lifted her up from the floor to the bed, and we both waited for Enemo to come back. It was interesting that she waited for Enemo to come back while complaining about the condition Mrs Yinkeye was left in. Even after Enemo arrived, although Enemo knew I was waiting for her, she asked me if I could wait for her to give her mother a bath. I agreed and informed her that I would come back later. This shows that Funere's statement, where she earlier said that she bathes her mother when Enemo is not around, can be contested.

Furthermore, the findings show that when an informal carer does not play an active role in the care for the person with dementia, they tend to exclude themselves from the care network even when they are part of it. In Family A, Ebiye, who does not live with Mr Afini, mentioned that care provision for Mr Afini was something that her family shared between themselves.

> *They decided they shared it themselves.* ***FA, Ebiye*****.**

However, this was portrayed differently by her mother and elder brother, who disagreed that explicit negotiation occurred. Rather, they believed everyone in their family just played their part, which was largely influenced by the cultural script and existing family dynamics. In addition, Ebiye often excluded herself from the care network (even though she was part of it) when asked questions about how care was arranged for Mr Afini and the challenges that occurred as a result of it.

> ***LO****: Have you and your family faced any challenges in terms of sharing who cares for him?*
>
> ***Ebiye****: Lots of challenges, oh, but I would say that I am not directly involved in it, honestly [laughs].*

Although Ebiye mentions that there are a lot of challenges her family faces in sharing care responsibilities for Mr Afini, she declined to disclose any of the challenges. However, when Atima, her elder brother, was asked the same question, he contradicted Ebiye, as seen in his statement below.

> *There are no challenges; every person just knows what to do. We do not have challenges in that area.* ***FA, Atima****.*

For Atima, caring for Mr Afini is like a performance where everyone knows their role and plays it without any challenge. On one hand, Ebiye's perspective on care arrangements for Mr Afini seems to be influenced by how she sees herself and her role within the care network (this

explains why she often distances herself from the caregiving role). Ebiye sees herself as an extended member of family A because she is married with children. Therefore, Ebiye does not think she plays an active role in the caregiving and its resulting challenges, rather, she has an obligation and duty to her family to support them when she can. On the other hand, Atima's perspective was influenced by how he sees himself within the care network and also their existing family dynamics. Atima sees himself as an active and key member of his care network, and as such, he brings a level of stability by ensuring the most important aspects of his father's care get done.

These findings show the value of gathering the different perspectives of members in the care network to better understand how care is arranged and care responsibilities shared for the older person with dementia. These contradictions are not a sign of confusion or failure amongst members of the care network, but rather they provide some insights into the emotional, physical, and psychological realities of caregiving in Nigeria. That is, informal carers are constantly making sense of their experiences providing care and their role as carers. This is within the backdrop of their human reactions to their experiences providing care and dealing with other carers in the care network. Informal carers carry the burden of care alongside unspoken expectations they have of themselves, as well as those from their families and the wider society. These expectations could explain why their statements were sometimes contradictory, as they tried to 'live up' to the expectations while discussing their lived experiences providing care.

## 6.3 The concept of reputation management in care arrangements

Throughout the interviews, I noticed a frequent need for participants to portray and assert themselves as the 'main carer' to me, as the interviewer, who represents an outside observer. Individual participants often mentioned that they either made the decision to care without discussing it with others or that they did not receive any help from anyone. I conceptualised this as reputation management, that is, when participants made statements where they not only portrayed themselves as the 'main carer,' but also one caring alone, even when that was not the case. The interview was a tool that participants used to manage their reputation to me as the researcher.

Reputation management was a way participants sought validation from me as the researcher and asserted their role by ensuring that they were portrayed in the best light possible. Additionally, the participant's portrayal of themselves as the 'main' carer asserts their relevance and value in the care network. Their depiction of themselves as the 'only' carer when that was not the case could highlight an internal state of overwhelm and their need for sympathy (given

their caregiving challenges), even when they had others around supporting them (although this support may be limited).

The participants' need to present themselves as the main carer/one who is providing care alone was an unexpected encounter. However, my position as a PhD student coming from an institution abroad, as well as the knowledge the participants believed I have about their relative's condition, could have played a role in why the participants saw the need to validate and assert their role as the main and only carer. This power imbalance between me (the researcher) and the participants could explain why they needed to portray themselves in the best light possible.

Nonetheless, reputation management was used by some participants to justify the care arrangements they made for their relative with dementia, especially when the decision was unusual, such as institutionalisation. For example, some participants' portrayal of themselves as lone carers acted as a justification to support their decision to move their relative with dementia to a care home, which does not fit the cultural script that care should be provided by the family and not by an institution (as discussed previously).

In Nigeria, care homes for older people are not yet a widely supported option for elderly care. There is the societal and familial expectation of care staying within the family. In order to justify their decision, some participants used reputation management (that they do not receive help from anyone) in defence of their care arrangements. The case studies of family K and family F (see Table 4.1 for a summary of their cases) below are examples of reputation management being used as a justification for the care arrangements that were made.

Funebi in family K was providing care for her mother (Mrs Ibinado) at her home, where Funebi lived with her husband and son. A dispute between Funebi and her sister led to her sister taking Mrs Ibinado to live in her own house for about three months, after which Mrs Ibinado ended up in the hospital ill with an infection. After the situation in the hospital, Funebi then mentioned that her husband advised her to move Mrs Ibinado to the care home as she had deteriorated, and it became impossible for Funebi to manage Mrs Ibinado alone.

> ***LO**: How long did she stay with you after you came from the hospital before taking her to the care home?*
>
> ***Funebi**: It was that same week, we did not waste time, which is when my husband said that the load would be too much [on me]. Previously, I just held her, and we would be strolling inside like I was a walking stick, but this time around, I had to carry her HA!…it was just one or two days before she left [to the care home]. I begged the doctor and told him that I would like to talk to my husband first [before she is discharged], as I*

*cannot just take her to my house like that because of the first incident that happened. So, I begged [the doctor], and he agreed, so my mother stayed in the hospital for one extra day before I came the next morning.*

***LO**: Which incident are you talking about?*

***Funebi**: When I brought my mother [to our home] without telling him, and I told you he was not happy about it, so I do not want that to repeat itself.*

Funebi's statements above communicate a deeper reason for her mother's care arrangements, which is related to her relationship dynamics with her husband. During the interview, it became clear that Funebi's decision to move her mother to the care home was mainly influenced by her relationship with her husband. She had initially desired a different form of care arrangement where someone would come around to support her (like a paid help/carer), but this decision was rejected by her husband because he was concerned with a 'stranger' coming to their house. Meanwhile, Funebi communicated that she was the only one caring for Mrs Ibinado immediately after mentioning the issue with her husband, but this was not the case, as her brother was helping out.

***LO**: Are you the one who decided to take up the responsibility of your mother's care?*

***Funebi**: There is nobody now, and I am the one suffering from it. My own [role] is to just pray that God should bless me, God should make a way for me to get that money. If I look at the money, my salary is not enough compared to the money. It is God who created my mother, she has brought me into this world, and the bible says, "take care of your parents," so if I am obedient, my God will bless me.*

Funebi, describing herself as 'suffering from it' without anyone helping her, was her way of managing her reputation and seeking validation for her decision, especially with the increased demand of her mother's needs, and her husband's influence in the care arrangements. Funebi may not have had much room for manoeuvre in her situation but considering the cultural script of care being provided by the family (irrespective of how challenging it is) and not an institution, she goes against this script. Funebi tried to manage her reputation (as an obedient daughter willing to go the extra mile, who will be blessed by God if she takes care of her mother) to me by highlighting her suffering and the challenges of caring alone. This justified her unusual decision to take Mrs Ibinado to the care home even when this decision contradicts Funebi's reputation. Although Funebi said that nobody was helping her, she later admitted that her brother does help her as much as he can, even with his limited resources.

> *Except this [my brother], who is helping me. His salary is not too much; he has a wife and three kids, and they are all going to school. His own [belief] is that whatever thing [arises], he is there to take care of her, and I should go and look for the money….He is helping me in every way I need assistance.* ***FK, Funebi.***

In her statement above, Funebi makes 'legitimate excuses' for her brother, and admits the constraints he had, after stating earlier that she is suffering alone and there is nobody helping her.

A similar case was also noted in Family F, where Ekiye also took her mother (Mrs Inemo) to a care home after deciding she could no longer provide care for her. Ekiye has only one sibling (a sister), whom she explained to me that she had a falling out with, which ended up in a severance of their relationship. Ekiye also believed that the issues her sister had with her impacted the sister's relationship with Mrs Inemo because her sister cut contact with them both. Ekiye portrayed herself as an organised and determined individual who does what has to be done, even when there is no one helping her. She believed strongly in doing things herself because if she did not, no one would help her.

> *I came to the decision on my own because I was not seeing anybody help her… I always encourage myself, 'my dear you are a one-man squad oh, do this thing, if you do not do it, nobody will do it for you.'* ***FF, Ekiye***

However, Ekiye's decision to take Mrs Inemo to the care home does not support her reputation as a 'one man squad.'

> *Do you know why I made this decision to take her there? It is because while she was staying alone, there was this auxiliary nurse who was staying close to her that I asked to take care of her. Like, helping me to give her the drugs and other things. But I found out that instead of me taking care of my mother, I was taking care of that nurse and her family [because the nurse took Ekiye's money without caring for Ekiye's mother].* ***FF, Ekiye***

Ekiye admitted that she relied on her friend (who is also an auxiliary nurse), whom Ekiye was not paying, to care for Mrs Inemo, and this ended up in a disappointing situation. Based on her statement above, the 'natural' thing that she may have done was to do it herself, considering she said that nobody would do it for her. Instead, she decided that it was better for her to pay someone that she can hold accountable and not a friend, to provide care for Mrs Inemo. Although she tries to manage her reputation as the only carer, she uses the situation with her friend to justify why she had to make the care arrangements she did. Nonetheless, for Ekiye, her role as an informal carer does not end even with her Mrs Inemo in the care home.

> *I will go there and pay bills; I will also buy her drugs and take her to the hospital.* ***FF, Ekiye.***

It is interesting that Ekiye still takes Mrs Inemo to the hospital, considering that there is another clinic directly opposite the care home Mrs Inemo is in. This was an aspect of Mrs Inemo's care that Ekiye believed held the greatest importance and required the most attention. Therefore, Mrs Inemo being in a care home that caters to her needs did give Ekiye less to do and worry about, but it did not change her functionality as an informal carer. Ekiye's statement also communicates her desire to preserve her identity and functionality as a carer and perhaps manage the guilt that she may feel about taking her mother to the care home.

In considering the two families' cases, on one hand, Funebi's mother's care was physically demanding due to a decline in her health; on the other hand, Ekiye's mother was more independent but had a lot of challenging behaviours. This highlights that the care needs of the person with dementia do influence how care is arranged for them by the informal carers in the care networks. These care arrangements did not involve any form of negotiation, but rather decisions were made by the 'main carer' in reaction to what others in the network were not doing.

Furthermore, for another participant, Funere, her reputation (her status in her community) justified why she is the 'main' person providing care for her mother, even when this was not the case.

> *She is my mother, it is too shameful that somebody like me, my mother, is like this, it is too shameful. So, I would not want her to be like this till she dies, that is why I took the responsibility and the pains [providing care], that is just the gospel truth…I cannot let her be like this, I have to try my best, even if other people will not come [to care for her], let me try my best and leave the rest for God.* ***FI, Funere.***

To Funere, her description of 'somebody like me' depicts how she sees herself in the community, which is as an educated and respectable person. Mrs Yinkeye had many challenging behaviours, such as going into an open drain to pick the dirt inside and pack it in a massive bowl (because she believed that she was fishing as she did in her past). Such behaviours in Nigeria are typically associated with people who are mad, so, to Funere, she feels ashamed that her mother behaves in that manner, while also thinking of the perception of those in the society. Additionally, Funere's use of the term gospel truth is to describe her extreme honesty. The gospel is known as the truth, so, to Funere, she is telling me the truth of exactly how she perceives the situation. Funere believes that she took up the responsibility ('and pains providing care') to avoid the damage it would cost her reputation if she did nothing. Funere used

the interviews and observations to constantly manage her reputation and assert her role as the main carer, whilst seeking validation from me, an outsider researcher.

For some other participants, reputation management was used to emphasise the priority they placed on providing hands-on care for the older person with dementia, which they believed trumps everything else. For example, Derima portrayed himself as the main and only carer because he was providing the majority of his father's hands-on care.

> *I am the one taking care of him now, so there is [no one else], I do not share any responsibility. I am the one here now, so no need, they can just come and [ask him] how are you doing, check on him, and they go back. I am the one here, when his clothes are dirty, I wash them, [I do] everything.* ***FD, Derima.***

Derima's portrayal of himself as the main and only carer was his way of managing his reputation and societal expectations, as discussed earlier in this chapter, where he was worried about what people would say about the fact that there was nobody taking care of his father. He asserts his role as the main and sole carer to combat accusations from others that he abandoned his father. Therefore, he uses the interview to manage his reputation and validate the fact that he is there with his father doing everything without any help, even when interviews with his brother and wife paint a different picture. When I visited their home, I observed that caregiving tasks were divided within his family, and he works in partnership with them to get things done. This is evident in Derima's wife's (Iso) statement below.

> *When he urinates, [my children] will mop, they will help me to do those things when I am not there, that's why I do not always leave the house, because if he poops, they would not be able to clean it, they are small children… But when he urinates, they mop it, they carry his foam [mattress] to dry it [when he urinates on it], yes, they do those, but the clothes it is my husband and me that washes it, my husband also bathes him, I bathe him sometimes when my husband is not around, when he poops on his body.*
> ***FD, Iso***

Iso statement highlights the position children often play in the provision of care for an older person. They are often not allowed to handle certain caregiving tasks because of their complexity and sensitivity, even when this will result in the limitation of movement and the cancellation of plans for the informal carer. Nonetheless, Iso's statement paints a clearer picture of how she and her family provide care for her father-in-law. Although Derima portrays himself as the main and only carer for his father, Iso's statement reveals that this was not the case. Derima's attempt to manage his reputation showcases his attempt to assert his relevance in his father's care network. Derima's statement could also highlight an internal state of

overwhelm and desire for sympathy (given his father's challenging behaviours), even though he had his wife and children around supporting him. This indicates that informal carers may portray themselves in the best light possible to others because they do not want to come across as inadequate while navigating complex dementia care, which can lead to feelings of overwhelm coupled with the unspoken expectations from themselves and their family.

## 6.4 Summary

Participants in this thesis often discussed *how they arrived at* their diverse care arrangements, when directly asked *how they decided on* the care arrangements with other carers. Their 'decisions' were more often made through indirect channels rather than direct bargaining between themselves, or they naturally evolved from previous relationships and living arrangements. Some of these indirect channels include compliance, silences, unspoken expectations, and even actions taken. Relationship and family dynamics, as well as diverse cultural scripts, influenced how participants came into their various roles as carers with different care arrangements. These cultural scripts that exist include the eldest child having the greatest responsibility within the family, unmarried children taking precedence as carers over married children, and that care should be provided by the family and not by an institution. The findings show that participants often used these cultural scripts to justify the actions they took or did not take.

Although some form of negotiation occurred amongst care network members, it was often unspoken and implicit, with one or both parties not being aware that any negotiation had taken place. In the very few cases where explicit negotiation occurred, it was due to external forces like the bank or the law, or conflicts between care network members, which explains why it is the exception to the 'eldest child' or 'natural extension of previous relationship' script.

The concept of reputation management was also an important finding in this thesis. That is, participants, portraying themselves to me, the researcher, as the 'main carer' or the sole provider of care, to manage their reputation. This was a way they sought validation whilst also maintaining their reputation for diverse reasons. Some participants used this reputation management to justify the decision they made, particularly when their decisions resulted in the older person with dementia being moved to a care home, which is not a widely accepted option for care in Nigeria.

Based on the findings, participants across care networks often contradicted each other in terms of their caregiving roles. This highlights two essential considerations in dementia care research in Nigeria. First, the importance of gathering the different perspectives of members in the care

network, to better understand how care is arranged, and care responsibilities shared for the older person with dementia. Second, it provides some insights into the emotional and physical realities of caregiving in Nigeria, as informal carers carry the burden of care alongside unspoken expectations they have of themselves as carers, as well as those from their families and wider society.

# Chapter 7 Informal carers' perceptions of support within and outside their family network

Participants' perception of the support they received from members of their family was often negative, with very few instances of positive perceptions. Support was recognised, but its impact was commonly minimised by the participants, especially when it did not lessen or relieve the primary source of their caregiving burden. Furthermore, financial support was the most desired amongst participants as opposed to other forms of support, like emotional or physical support. On one hand, the support participants received from within their family network is characterised by a lot of unspoken expectations, which explains why the support commonly goes unrecognised. On the other hand, the support received from outside the family network is not part of familial expectations, which made it easier to be recognised by the participants.

Additionally, the burden of dementia care in Nigeria is very financially heavy, especially when the participants experienced significant financial constraints alongside other competing responsibilities. The financial burden was also the greatest when the older person with dementia frequently visited (or was admitted) to the hospital due to other comorbid conditions or severe symptoms. In the very few instances where physical and emotional support was not received from within the family network, the findings showed that participants were disappointed, but they accepted the situation because they had no other options.

In contrast, support received from outside the family network was often recognised and received with gratitude from the participants, especially when it was financial. This shows that expectations are often greater when it comes from the participant's family, considering the burden associated with dementia care. Therefore, there is the expectation that the burden should be shared with those who share in the responsibility. This means that when those who should not carry this responsibility provide support, it is more likely to be recognised and appreciated.

Participants' perceptions of the support they received (or failed to receive) from within and outside their family network had a ripple effect on their caregiving experiences, but very little effect on their care practices. That is, where a participant had a negative perception of the support provided, it tended to result in negative experiences, such as the participant feeling unsupported and underappreciated by others in their care network.

In the following sections, the findings are presented under four themes: support unrecognised due to caregiving burden and unspoken expectations, perceived lack of support exacerbated by negative views of other carers, when 'little' becomes more than enough for informal carers, and thoughts of having more support versus the reality of the support.

## 7.1 Unrecognised support due to caregiving burden and unspoken expectations

Participants were less likely to recognise support received from within their family network when they were overwhelmed by the caregiving role and had unspoken expectations of those within their family network. The majority of participants were more likely to mention financial support when directly asked if they received any form of support with caregiving, especially those who had the greatest financial burden of care alongside other responsibilities. For example, Boma in family A had a greater need for financial support, as a result of her husband being hospitalised due to dementia-related health complications, resulting in a greater financial burden.

> ***LO**: Apart from your children, is there anyone who supports you with daddy's care while you were at home?*
>
> ***Boma**: [My husband's] younger brother now, sometimes he sends money, ₦50,000, ₦20,000. Before [my husband's] younger brother was [living with us] in our house before he [moved away], he said, if he sits down at home not doing anything, where will the money [to care for my husband] come from? So, I let him go back [to the village], [my husband's family] contributed ₦80,000 to give to me, that money, it is two days to finish it [silent].*

Boma communicates how she gave her husband's younger brother 'permission' (I let him go back) to find money to support their family. Despite this, she still expresses dissatisfaction with the fact that the money did not last as long as she needed. Boma had other major responsibilities aside from her role as her husband's carer, such as caring for her younger children and grandchildren, caring for her sick mother (who eventually died while her husband was in the hospital), and running a food business. These responsibilities, coupled with the burden of dementia care and her expectations of financial support from her family network, made the support she eventually received insufficient. This shows that the greater the burden of care alongside other competing responsibilities, the more overwhelmed the informal carer may feel and the greater the need for support, especially from those within their family.

A similar view was expressed by Erebi in family E, where their financial needs were great because of their family's use of a paid carer, including renting a separate house for the paid carer and Erebi's father (Mr Binatu) to live in.

> *[My father's] immediate family [my father's brothers and sisters] will only come once in a while. For the [past] five years, [my father's] immediate family has only brought ₦150,000. So, does it add up? No, it does not, so if we are waiting for [my father's] family to do something, then I am sure he would have passed on long ago. It all boils down to cash... **FE, Erebi.***

To Erebi, finances were an important aspect of support that he believed preserved his father's life. Erebi had expectations of financial support from Erebi's father's siblings (which he expressed great disappointment for not receiving), even when this need was not communicated to them. This is because it is the expectation in Nigeria that the siblings of a person living with a terminal illness should provide support for the family where possible. For Erebi, he is better off figuring things out himself instead of waiting for support (that does not add up) from Mr Binatu's family.

This shows that where expectations for support are not communicated, informal carers risk waiting for the other carer to 'realise' that they need the support, or they find their own way. Additionally, there is the assumption that the need for financial support should be obvious to other family members, irrespective of how closely related the family members are. The findings showed that participants rarely communicated or updated other members of their family on the care needs of the person with dementia. This is because of the belief that they should not have to communicate a burden that is so apparent.

Aside from financial support, there were instances where emotional support was provided, but went unrecognised because its impact was not obvious to the participants. Some participants, particularly male participants, were less likely to admit that they received emotional support, even when they were directly asked about it. For example, Tokoni struggled to answer my question on whether he appreciated having an outlet in his elder brother to deal with the burden of caregiving.

> ***LO**: Do you think emotional support is important, because you mentioned earlier that you vent to your elder brother on the phone? Would you say you are happy with that outlet?*
>
> ***Tokoni**: Yes, but I think [it is emotional support] for [my brother] as well...I think you [should] direct the question to [my brother and ask him] how the emotional support is for him. The truth is, I already know what to do, I just need someone to just vent [to] and*

> *that is all. So, if [my brother] calls me, I might still end up doing [what I want to do], but at least you can just have somewhere to be like "this is how it is, this is the pressure, this is where the thing is bothering me." You just have that [outlet] and once you are done [with the conversation] all you get is the encouragement, but that one helps too.*

Tokoni's statement highlights a dominant societal perception of males where they are socialised to see emotions as a sign of weakness. This is because Tokoni saw himself as a person who provides emotional support to his brother, not the other way around ('if you direct the question to my brother and ask him how the emotional support is for him'). Therefore, Tokoni admitting to receiving emotional support will oppose his identity and ideology of self-reliance and emotional control, which he portrayed in his interview. On one hand, Tokoni disagreed with receiving emotional support; on the other hand, he admitted that the encouragement his brother provides helps. This emotional outlet and support Tokoni received from his brother was unrecognised because it also did not align with his definition of emotional support (which is not knowing what to do and being vulnerable).

Another participant, Erebi in family E, echoed Tokoni's perspective. Erebi communicates that he shares the challenging days with his elder brother. However, in Erebi's case, the cultural script of the eldest child occupying a position of strength in the family is evident.

> ***LO**: What other kinds of support, apart from financial support from your family and the paid carer, do you receive for caring with your dad?*
>
> ***Erebi**: There is none. In fact, it is just us; [my dad] does not have much [support]. I share the things particularly with my elder brother; I do not speak to my younger ones, as they get very emotional when I try talking to them. I only share the good days with them.*

Although Erebi does not explicitly mention getting emotional support from his elder brother, he does admit that he 'shares things with him,' including the good and bad days, which is an outlet for Erebi to deal with the burden of caregiving. Here, Erebi positions his elder brother as more stable and unemotional, which made him a stronger source of support than his younger siblings. For Erebi, it was easier to share the good days with his younger siblings to prevent them from getting 'very emotional,' which means he will have to be a source of support to them, thereby losing the support he may have aimed to receive from the conversation.

## 7.2 Perceived lack of support exacerbated by negative views of other carers

The findings show that the majority of participants had negative perceptions of why others within the family network were not supporting as much as they expected. Some participants' perceptions of other carers were based on the locations where the other carer was living and the reason behind why they did not support with caregiving. For example, Ogola described why he believed his brothers were not supporting him to care for their mother, which had to do with their location and his brothers' claims about a lack of money.

> ***LO**: Did they explain why they cannot support you?*
>
> ***Ogola**: No, oh, they will just say no money, but some of them are building houses, but they will say no money. Where I am from [in Bayelsa], honestly speaking, this [behaviour] is typical of the people there. Some of them have plenty of money, they can buy a house in Abuja, but their mother and brothers have nothing.* ***FG***

Building or buying a house in Nigeria (especially in Abuja) is a significant milestone that some individuals in Nigeria use to judge wealth and status. Abuja is the Federal capital of Nigeria, and buying or building a property there is extremely expensive. Therefore, some individuals believe that when a person builds or buys a house in such states, and later says they do not have money, they are not being honest. However, when I (as the researcher) directly asked Ogola whether his siblings have money and do not want to help, his views about them became clearer.

> ***LO**: so, you feel that they have money to help, but they do not just want to support?*
>
> ***Ogola**: I do not know, it is the way they behave, maybe they do not have plenty of money, but even that little self [that they have], I just feel like they do not want to help. They do not have oh but the little that they have to manage [they do not support us from it], I just think that they do not want to help.*

His earlier perception of why his brothers refused to support was out of Ogola's disappointment with their behaviour. Additionally, Ogola's statement above supports the narrative that is often dominant amongst individuals, even in the Nigerian context, where family members are expected to help because it is their duty and obligation, this is sometimes irrespective of the family member's circumstances. Ogola's expectation of his brothers was that they should support their mother even with the 'little they have to manage.' To him, his brothers' support despite having 'little' would be a show of sacrifice and commitment to their mother and wider family, as it is what is expected (especially as his brothers are all older than him). Ogola's

situation with his brothers shows how unspoken expectations for support amongst carers within a family influence how they perceive the person who does not provide that support.

Ekiye in family A expressed some similar views to Ogola about her elder sister, who lived in Lagos (the former capital city of Nigeria), which is also a major and expensive city in Nigeria.

> *My eldest's [sister] she is in Lagos with her children. You see, these people in Lagos do not care about people in Bayelsa, so for many years, I have been the one taking care of my mother...* ***FA, Ekiye.***

Ekiye attributed her sister's not supporting her to care for their mother to the location she is staying, and what that particular location implies (namely, wealth), in addition to a past grievance between her and her sister. Furthermore, Ekiye's use of Lagos versus Bayelsa highlights how she believes her sister views her and their mother. 'People in Lagos' not caring about 'people in Bayelsa' can be interpreted to mean her elder sister is looking down on her and their mother, because they are located in a place that is considered unimportant in comparison to Lagos, which is known also known as the land of opportunities. Additionally, Ekiye, at different times during the interview, painted her elder sister as hostile and unforgiving, particularly related to an incident involving Ekiye's love interest and her elder sister.

> ***LO****: Did anything happen in the past?*
>
> ***Ekiye****: Even though [my sister and I] had a problem, can she not forgive as the [eldest] daughter in the house? And yes, something happened, but it is not something that [should] bring a problem to the house, [to the extent] that at the end of the day you will not have anything to do with your younger [sister], no now.*

Ekiye brings the eldest child script into play, but here, she highlights the expectation that it is the eldest child's responsibility to forgive grievances and not allow problems to fester in the house (which signifies the family). Ekiye found it difficult to reconcile the fact that her sister refused to support her in caring for their mother because of an issue she considered trivial (and lying in the past). This shows that informal carers' perception of support is influenced by not just unspoken expectations but also existing family dynamics.

Similarly, Funebi brought another aspect of the eldest child script to play, which is the expectation that the eldest child should 'accommodate every character' in the family.

> ***LO****: How are you managing with your siblings not contributing?*
>
> ***Funebi****: This my younger sister is the problem, if I am not exaggerating, her salary will be bigger than mine. It is not that she has many little children, her children are [grown],*

> *so it is [only] her. If four of us [sisters] combine and bring different amounts [it will help]… I will say that I have sisters [meanwhile] they are not assisting me in any way, and I feel bad.* ***FK.***

From Funebi's statement, she has subjectively assessed her younger sister's financial status and familial responsibilities, which she used to conclude that her sisters should be in a position to support their mother better, as this was not the case, Funebi felt dissatisfied with the situation. This shows that the negative perceptions participants have of other carers in the family could make the lack of support they did not receive from the other carers more disappointing.

## 7.3 When 'little' becomes more than enough for informal carers

Amongst participants in this thesis, support received from outside the family network was often considered meaningful even when described by the participants as 'little.' This shows that the lack of expectation for support from outside the family network made it more likely for a participant to recognise (and appreciate) the support, irrespective of how trivial it might seem. Additionally, seeking support from outside the family network (specifically publicly) was also associated with shame and vulnerability among some participants. Ebiye in family A is an example of this, as she decided to reach out to a page on an online platform to request financial support for her father's care.

> *Like yesterday, I was on an international [social media] group, I just "picked up courage," I know there are many scams there, so I posted my dad there because my mum was complaining [about the situation]…So, I told them they can come [to the hospital to] verify even if I am not around, so, [a woman] came and when she checked, she saw that it was my dad, they now transferred some money to my mum…I just did the little I could. I am not proud that I came out publicly to look for money, but I have to do what I have to do.* ***FA, Ebiye.***

For Ebiye, she needed to summon courage to do the unusual (reaching out publicly for help) as her hands were forced by the situation, and she was moved by her mother's complaints. Although Ebiye's family received different amounts of money from diverse individuals from an online group due to her efforts, she still considered her efforts, despite the shame she endured, to be little. This highlights Ebiye's vulnerability as an informal carer as well as the expectations she has of herself as the eldest daughter of her parent (discussed in previous sections). Ebiye's expectation of herself is that she should be in the position to provide the financial support for her family, but instead, she had to 'publicly look for money,' which can be considered shameful.

In the Nigerian culture, bringing your family's challenges to public spaces can be perceived as disgraceful by some individuals. The person can also be viewed as incompetent, as they are seen as being unable to manage their family's challenges privately. This shows how cultural perceptions could have an influence on how informal carers seek support with caregiving (especially outside their family network), and how they feel as a result of help-seeking.

Although Ebiye did not see her 'little' efforts as enough, she mentioned later in the interview how the little support from different individuals contributes to a greater impact.

> ***LO:*** *So, will you say the financial help has made a difference for your family?*
>
> ***Ebiye****: It has gone a long way, at least people heard our cry. They say a little drop of water makes a mighty ocean. At least people heard our cry, and they came in their masses to help, and they are still coming. Even as I am talking now, they are still commenting that the money should get to a reasonable amount before they send it to my mum [again], instead of sending small amounts of money [separately], they would [rather] gather [the money]. I am grateful, first of all, to God and to many people around I am grateful.*

For Ebiye, the little from the different people online became more than enough for her family. This served as a compensation ('at least people heard our cry') to her due to the shame of having to publicly ask for money, which amounted to something significant, resulting in feelings of gratitude to God and the individuals.

In other instances, some participants drew attention to another important area in which individuals outside the family network support them, which is by bringing the older person with dementia back home when they wander off. Tamara in family B, highlighted how her neighbours 'help in their own little ways.'

> ***LO****: You mentioned your neighbours, how do they help you out?*
>
> ***Tamara****: They helped because the gate [used to be open], they had to start locking the gate, they understood [the situation]... There was a day I was doing something in the kitchen, one of my small baby sisters [my relative] was around, so I told her to brush her [teeth]. All of a sudden, [my mum left the house] and I was not aware. It was the neighbours on the road that now brought her back [to the house]. When I realised [she had gone], I was going to look for her in a different place [before they found her]. So, yes, they are aware, and they help in their own little ways.*

Tamara's neighbours played a key role in supporting her by ensuring that her mother (Mrs Ibiso) is always safe within their community and making sure they bring Mrs Ibiso home safely when

she wanders off. For Tamara, her neighbours' awareness of her mother's challenging behaviour of wandering off is them supporting Tamara and Mrs Ibiso in their little ways. This reinforces the fact that informal carers are more likely to view support from those outside the family network positively because they have little to no expectations of the individuals providing the support.

Additionally, bringing lost individuals home may seem trivial, but it is crucial because the identification and tracking of missing persons in Nigeria is still not adequate. An older person with dementia can be missing for days, never to be found, and if they are found and taken to the police station, it is often very challenging to identify them. This was noted amongst a few participants, where the person with dementia wandered off, and the participants struggled to find them. In these cases, individuals in the community played significant roles in helping the lost person with dementia find their way back home. For example, Idala recounted his experience trying to find his dad, who went missing for a few days.

> *[My dad] just walked [away], and we could not find him for three days. Do you know where we found my dad? In [another] state, somebody that we did not know [helped us]... Before then, we had even gone to the police station [to report that my dad is missing]. So, when [my father and the man] arrived at ..... luckily [the person they] asked knew who [my dad] was, that was how they brought him to the house.* ***FD, Idala***.

Even with Idala reporting to the police in the state his family was in, there was no inter-state communications between the police, which could have facilitated the tracing of Idala's father in the other state where he was found. This seemingly little act of kindness from the man who helped Idala's father was more than enough to safeguard Idala's father's life. This shows that some informal carers in Nigeria may face what can be termed as a ' double-edged sword.' On one side, they have to deal with the emotional and psychological distress of their relative with dementia being lost. On the other side, if and when the person with dementia is found, they have to deal with emotional and often financial stress from law enforcement to get the person with dementia home safely.

The findings above were also echoed by Ekiye in family F, who shed light on the challenges some participants in this thesis experienced with law enforcement officers.

> *[The police officer] now said "you people should come and get her because if you do not come, we are not going to release her." I said HA! Is it up to that [extent], he said yes, so I said okay I will come... By then I was in church, so I went to meet my pastor, and I told him, he prayed for me and gave me [money] for transport... So, at the end of the day, [the police] said I should go and meet their boss, that there are some reports they have to take concerning [my mother], and I have to pay for something. But by the*

*time I looked at their papers and everything, it was ₦50,000, so I said wow! I do not have ₦50,000 to pay. The woman just said that I should relax, that I would still pay for something, at the end of the day. I paid for something, and I took [my mother].* ***FF, Ekiye.***

Although the support ('he prayed for me and gave me money for transport') provided by Ekiye's pastor encouraged her in her journey to bring her mother home, the situation at the police station discouraged Ekiye in her journey. According to the law in Nigeria, bail (for people arrested) is granted free of charge, which buttresses the challenge the person with dementia and their families face. For a person with dementia who did not commit a crime but only wandered off, and was found and taken to a police station, releasing them to their family for that amount of money highlights a key issue with some law enforcement officers in Nigeria. This poses the question of what individuals in Nigeria who cannot afford to pay the 'something' Ekiye referred to in her statement above will do when they encounter similar issues. In Idala's and Ekiye's case, the 'little' support provided by those outside the family network might have been more than enough for them, but the external support that should be provided by the law enforcement system made their positive experiences with receiving support from their community turn negative.

Additionally, amongst the participants in the study, there was an openness in sharing about their challenges providing care for a person with dementia, including when the individual had challenging behaviours. Some participants shared the diagnosis with their church members, neighbours, friends and even work colleagues. This resulted in them receiving a range of support from the church, friends and even their workplace. For example, Idala from family D mentioned how his former manager told him to 'go and take care of your dad.'

***LO****: Do you get any support from others around you because you mentioned that all your colleagues know about your dad's condition?*

***Idala:*** *Yes, they are aware. In fact, most times, if they hear me say my dad is ill, they are also not comfortable. Like my former manager will say, 'go and take care of your dad.' Like the church, too, they are trying, they are aware, my pastor is aware, so most times they send things like cleaning products, food stuffs, and [they] send people to go check on him, he was an elder in the church before the illness started.*

For the Idala, the awareness of his office and church about his father's condition was instrumental in providing the support he and his family required, even if it seemed little. From the moment I approached Idala, he was very comfortable discussing his father's condition; he was even happy to tell his office colleagues that I came to interview him about it. Considering

dementia is very stigmatised in Nigeria and Africa at large, his approach and that of his colleagues were very different. His statement later on in the interview shed more light on why he approached things the way he did.

> ***LO**: I am also interested to know your comfort level talking to those around you about how your dad's condition came about.*
>
> ***Idala**: It is stigmatising, but a problem shared is a problem half solved.*

However, Idala's case highlights the barriers some informal carers face in getting support, especially from those outside their family network. This is because the stigma associated with dementia often functions as a barrier that prevents informal carers from sharing information, and by extension, it hinders the chances of the carers being supported by those around them. Nonetheless, the support received had a positive impact on the participants' caregiving experience, even if it was seemingly little. It is evident that when barriers that hinder the accessibility of support for an informal carer are reduced or removed, the chances of the informal carer receiving adequate support to meet the care needs of the person with dementia improve.

## 7.4 Summary

Participants in this thesis were often dissatisfied with the support they received from within their family network. The forms of support provided from within the family network that were more likely to go unrecognised were financial and emotional support. This was either because of the burden of providing care alongside other competing responsibilities or the expectations they had of other carers within their family network. This shows that although support is provided, it could often go unrecognised by informal carers because the burden is great, and their expectations are high. Furthermore, where support was not provided to the older person with dementia from those within their family network, it was often perceived negatively by the participant, with them giving extreme views as to why they believed the support was not provided by other carers.

Additionally, support provided by those outside the family network was often recognised and associated with gratitude by the participant. It was also the case that where the individuals outside the family network provided 'little' support, it was more than enough for the participant. This shows that support is more likely to be recognised by an informal carer because their expectations are low (for those outside the family network), therefore, the 'littlest' support seems large considering the circumstances of the informal carer. However, while this 'little' support led to positive perceptions amongst participants, their experiences quickly became

negative when they had to tackle external systems that are meant to protect individuals and enforce the law in Nigeria, such as the police.

# Chapter 8 Discussion

Despite the critical role informal carers play in providing everyday care for a person with dementia in Nigeria, not much is known about how they negotiate dementia care. This thesis aimed to fill this gap in the literature by investigating how informal carers of older people with dementia in Nigeria negotiate care. The emphasis on how they negotiate care not only provides a holistic view of how carers find their way through dementia care, but it also shows how families may (or may not) seek support that is tailored to their circumstances and the challenges they are experiencing at different times (Ceci and Purkis, 2021). Investigating how informal carers negotiate dementia care could facilitate an understanding of areas where improvements or adjustments in informal care can be made, so people with dementia can get appropriate care. This understanding is crucial in ensuring that approaches to supporting informal carers in Nigeria to provide care at home for a person with dementia apply to their lived experiences and socio-cultural context.

To achieve this aim, this thesis sought to answer the following research questions:

1. How do informal carers of people with dementia experience and evaluate caregiving, both their own and that of others?

2. How do informal carers of people with dementia arrange and share care responsibilities with others?

3. How do informal carers perceive the support they receive (or do not receive) from within and outside their family network, and how do these perceptions impact their care practices?

In the next sections of this discussion chapter, I interpret the key findings of this research that answer the research questions and situate the findings within the existing literature. Finally, I discuss what the findings say about how informal carers negotiate dementia care in the context of Nigeria.

## 8.1 Understanding how informal carers of people with dementia experience and evaluate their caregiving and that of others.

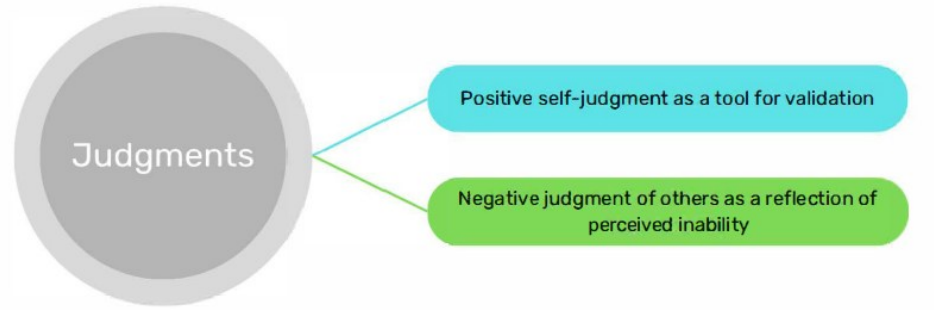
In response to the research question on how informal carers of people with dementia experience and evaluate their caregiving, and that of other carers, the findings show that although the participants interviewed had similar experiences, how they perceived and positioned themselves within their experiences varied. This illustrates the complex and subjective nature of caregiving, highlighting that it extends beyond a set of tasks to a process

shaped by the carer's expectations, values, and socio-cultural context. Caregiving is a subjective process of sense-making, and an important way the participants do this is by making positive and negative judgements about their care and the care provided by others. This process of judgements forms their definition of 'good care' versus 'bad care.'

Participants frequently made positive evaluations of their own care provision, while being critical of other carers in their care network. I argue that their positive and negative judgements stem from the participants' desire to seek the validation they feel they do not get from others in their care network, while also asserting their relevance in the care provided for the person with dementia to me, as the researcher. Participants' seeking validation from me as the researcher shows a desire for their caregiving to be seen as valuable and important. Being an informal carer in Nigeria is characterised by unspoken expectations; these include those the informal carers have of themselves, those they have of others, and their families have of them. As these expectations regarding caregiving are often unspoken, informal carers may feel that their efforts in providing complex dementia care are not acknowledged or appreciated by others in their care network, prompting them to seek validation from me, the researcher.

In the following section, the key findings that answer the above research question are presented under two overarching themes as displayed on the right in Figure 8.1 below.

Figure 8.1: The two overarching themes that answer the first research question




### 8.1.1 Positive self-judgement as a tool for validation

Participants predominantly made positive judgements about themselves while being more critical of others. This is their way of seeking validation and asserting their value within the family care network. That is, they were essentially telling me (the researcher) and themselves, 'I am a good carer,' to counteract a perceived lack of recognition from others. This need for validation stems from the unspoken expectations and pressures of caregiving in a Nigerian cultural context. Seeking validation from me, a researcher and outsider to the family, by making judgements about their care provision, confirms their identity as 'good carers.' Participants may believe I can recognise what good care looks like because I am researching their experiences

providing care. Therefore, I am in a position to identify that they are 'good carers' providing good care despite their perceived inabilities of other carers provide good care.

For participants in this thesis, being a 'good carer' is associated with providing 'good care' despite the challenges and limitations brought by living with dementia. Some of these include difficulties communicating with the person with dementia, managing challenging behaviours, and providing day-to-day care despite financial constraints. Furthermore, participants were not aspiring to an objective measure of 'good care,' but they positively judged their behaviour based on what they thought others were doing. That is, participants were not aiming to provide care that can be measured as good, rather, they judged their caregiving as good in relation to what others did (or did not) do. Therefore, participants associated good care with their observed improvements in the well-being of the person with dementia. Their positive self-judgement served as a tool to validate themselves as good carers, their identity as providers of good care (which was influenced by the care needs of the person with dementia), and their value in the care network.

Furthermore, in this thesis, the reality of 'good care' is that it is disorganised and laden with pressures (mainly financial), as participants frequently went beyond their limits to ensure that 'good care' was provided. Where the findings of De La Cuesta's (2005) study in Colombia identified caregiving as a 'craft' that family members intelligently and creatively utilised to adapt in the care environment, this findings show that caregiving in this context does not meet the definition of a craft. It is very rarely a skill and often unorganised, even when participants use different means to adapt to their care environment. Therefore, the theoretical models of 'good caring' (following Fisher and Tronto's phases discussed in chapter 2) do not fully capture the practical realities of caregiving within the Nigerian settings. In this context, 'good care' is more realistically defined as identifying and meeting a care need, rather than progressing through idealised stages. As Alali in family G mentioned, 'anyhow [the situation in the house is] we will manage, even if there is nothing [to eat].' They decided to provide 'good care' for the person with dementia despite the consequences to themselves and their immediate family.

My findings align with Tronto's later critique of the phases of good caring, where they argued that 'several aspects of care make it much more complicated than this account of phases might suggest' (Tronto, 1998:17). While Toronto's earlier phases of good caring depict a linear progression through phases, in this thesis, the experiences of participants reveal a more complex reality. In this context, 'good care' was realistically understood by participants as 'doing their best' to meet the care needs despite the pressures and challenges associated with dementia care. These findings reflect a more practical and situated understanding of care, shaped by everyday realities and constraints. Therefore, in conceptualising care, the

complicated nature of dementia care, accompanied by the lack of specialised skills informal carers possess, should be considered. Based on this, care conceptualisation must account for the complex and messy nature of providing care alongside a carer's motivation and obligation to care.

This thesis is the first to show how positive self-judgement (good carer providing good care) can be used as a tool by informal carers to validate their identity as carers and their care provision in Nigeria. This tool is grounded not only in the completion of everyday tasks, nor an ability to provide care based on knowledge of dementia, but on relational dynamics, peer comparisons, and unspoken expectations carers have of themselves and others. Currently, no previous study in Nigeria has documented this finding of informal carers evaluating their caregiving as good compared to others, which emphasises the originality of this finding.

Previous studies in SSA have predominantly focused on dementia understanding, stigma, burden of caregiving, unmet needs, and support experiences of carers in Ghana, South Africa, Tanzania, and Nigeria (Baiyewu et al., 2003, Hendricks-Lalla and Pretorius, 2020, Mahomed and Pretorius, 2022, Mushi et al., 2014). Although these previous studies provide valuable insights into the challenges informal carers face in SSA, the subjective frameworks that the informal carers use to assess their practices and those of others have not been captured. Nonetheless, Nwakasi et al. (2021) study in Nigeria found that participants referred to their caregiving as 'good care' to prevent negative views from others outside their care network. Brear et al. (2024a), in their study on the conceptualisations of 'good care' found that good care to participants involves providing consistent and frequent care, having the right motivations, and the hope that the well-being of the person with dementia will improve due to a range of care practices.

However, this current study shows that participants judging their care provision as 'good' was not just to avoid negative views from other carers (Nwakasi et al., 2021), or the right motivations, frequency of care, and hope that the care provided will have a positive outcome (Brear et al., 2024a) rather, providing good care serves as a tool the informal carers use to seek validation and assert their relevance within their care network. This is due to the unspoken expectations that characterise caregiving in Nigeria. For example, an informal carer did not communicate with those in their care network about what expectations exist in terms of who provides the different aspects of caregiving for the older person with dementia. Where the informal carer takes on the position of the main carer without communicating with other carers, this could result in a lack of validation and acknowledgement for said main carer, resulting in the carer's desire to portray themselves as a good carer providing good care.

The shows that informal carers are not only dealing with the burden of dementia caregiving (and other aspects of providing dementia care), but they are actively evaluating their caregiving role

and that of other informal carers within their care network. This evaluation occurs against the backdrop of the socio-cultural context of caregiving in Nigeria. The absence of these findings in previous studies highlights possible emerging trends in dementia caregiving in Nigeria and SSA at large, where the focus shifts from just carers' experiences providing dementia care to how they evaluate their role as caregivers (and that of others), which may or may not be specific to Nigeria.

### 8.1.2 Negative judgement of others as a reflection of perceived inability

Participants were more critical of the care provided by other carers in their care network. Where 'good care' in this thesis is defined as identifying and meeting a care need, bad care is linked to an inability to meet the care needs of the person with dementia. As is the case with good care, participants negatively judged the behaviour of other carers based on what they themselves believed they were doing right (compared to other carers), or to justify the caregiving decisions they made. In addition, participants often associated bad care with a perceived deterioration in the well-being of the person with dementia. For example, a participant associated 'bad care' provided by her sister as letting her mother be 'very very free' and 'using her brain to do whatever she wants to do' which made her mother become 'so [much] worse.' This was in contrast to the good care she was providing, which was 'educating,' 'shouting at,' 'directing,' and not allowing 'freedom.' The excerpts provide an understanding of the subjectivity of bad care versus good care.

Previous studies in SSA have not captured this idea of bad care, which is based on participants' perception of others' care provision as inadequate compared to their own. This thesis highlights how 'bad care' is perceived and experienced by informal carers. The findings of this current study present a more detailed and contextual understanding of patterns noted in McClendon and Smyth (2013) quantitative study in the United States. They found that poor care quality is associated with 'expressing anger in a punitive fashion, which increases the tendency to blame and punish others', termed as 'punitive caregiving', and 'efforts to control the behaviour of the persons with dementia', termed as 'controlling caregiving' (McClendon and Smyth, 2013:1008 &1009).

While McClendon and Smyth (2013) study quantifies these patterns of 'poor quality' of care, this current finding sheds light on the familial dynamics and emotional reasoning underlying the behaviours of participants. For example, participants expressed various forms of perceived bad care they believed other carers provided, and they framed their responses as emotionally justified. This suggests that what might seem as 'controlling' or 'punitive' in quantitative research can also reflect a carer's attempt to provide care despite the lack of skills in providing

specialised dementia care. This highlights complexities not captured in the study by McClendon and Smyth (2013).

Furthermore, the negative judgements participants made of other carers revealed conflicts and tensions that were made worse or developed as a result of caregiving. Rather than seeing conflicts and tensions as only a result of the caregiving role, as in Hendricks-Lalla and Pretorius (2020) study in South Africa; this current study shows that the caregiving role also served to escalate tensions and conflict that had existed within the care network before the participants became carers. This finding extends that of Araujo et al. (2020) study in Brazil, where existing family tensions worsened after diagnosis of dementia by highlighting that the conflict is not only between the person with dementia and the informal carer, but also other care network members. This shows that the negative judgements participants made of other informal carers not only reflect the carers' inability to meet the care needs but also that these judgements are heightened by existing tensions and conflict between the participants and the other informal carers.

Based on this, it is important to consider how the relationship a carer has with others within their care network influences their evaluation of their own caregiving (and that of others). When thinking more broadly about what constitutes 'good caring' (as seen in Toronto and Fisher) and by extension 'bad caring,' it is important to understand that the definition of these concepts occurs within a dynamic relational interplay between carers. Caregiving often happens alongside others in the care network, and it is rarely ever an event that happens in isolation within the Nigerian context. This means that informal carers' evaluation of themselves and others could change as the care environment changes, and as conflicts and tensions increase or subsides, particularly as dementia deteriorates over time, leading to more demands on care network members.

## 8.2 Understanding how informal carers of people with dementia arrange and share care responsibilities with others.

In response to the research question on how informal carers of people with dementia arrange and share care responsibilities with others, the findings show care arrangements often 'emerged' through indirect channels or they naturally evolved from previous relationships and existing living arrangements. Some of these indirect channels included compliance, silences, unspoken expectations, and even actions taken. This reveals the complex nature of care arrangements for people with dementia, which is influenced by culture, family dynamics, and individual differences.

Amongst the majority of families, care arrangements were rarely an outcome of explicit negotiation involving open discussions; this is a key finding in this thesis. Explicit negotiation only occurred where the situation demanded it, as opposed to it being what naturally occurred amongst informal carers providing complex dementia care. Such situations include medical and financial management for the person with dementia, conflicts between family members, or when it becomes necessary to make alternative arrangements for care provision.

The findings of this current study can be situated within Finch and Mason's (1993) work on how family responsibilities are negotiated among informal carers. Some of Finch and Mason's ideas of negotiating family responsibility, such as one individual making an independent decision on what they will do and acting accordingly, or caregiving roles emerging as natural due to circumstances or relationship history (Chambers et al., 2009) resonates with the findings of this current study. Explicit and deliberate conversations (which are typically associated with classic negotiation) involving family members talking through responsibilities were rarely found in this thesis. This could be because discussing care arrangements for an older person or the burdens of caregiving may be seen as disrespectful and often confrontational in Nigerian society, especially when a younger family member starts the conversation.

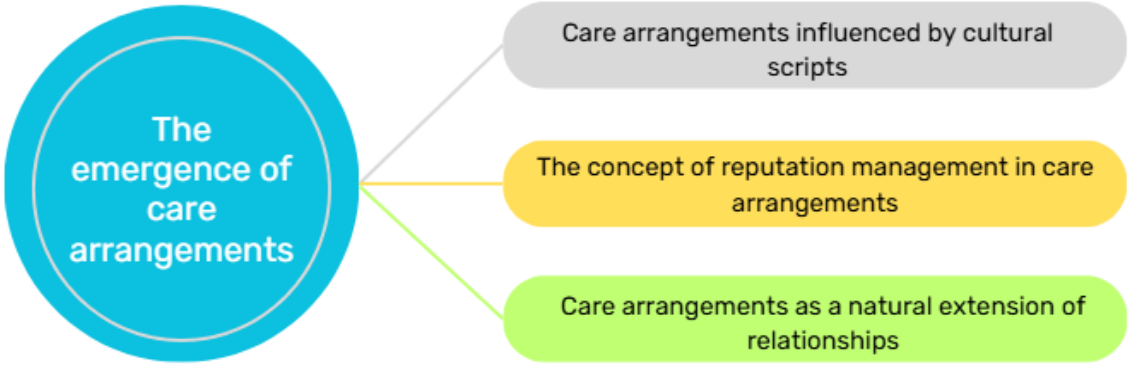
Based on this, I argue that although Finch and Mason's work offer in-depth insights into negotiation and moral reasoning amongst families, their context is different from the context of informal caregiving in Nigeria. Their work, which is situated in late 20th-century British society, is very different from the current Nigerian society, where kinship, obligation, authority, and cultural scripts are structured differently. For example, one of the key points from Finch and Mason's work is that family members do not merely follow a fixed script; rather, they interpret what is suitable based on considerations of personal capacity, emotional intimacy, past instances of assistance, and the actions of others within the family network. However, the findings of this thesis highlight the influence of socio-cultural norms and expectations in shaping how care responsibilities are divided and shared within families providing dementia care in Nigeria, which Finch and Mason's work did not account for.

An interesting finding in this thesis was the use of diverse cultural scripts as a justification for how care arrangements were arrived at. These scripts include the eldest child having the greatest responsibility within the family, unmarried children taking precedence as carers, and care should be provided by the family and not by an institution. Furthermore, a unique contribution of this thesis is the concept of reputation management in the caregiving role. That is, the informal carers' portrayal of themselves to me (the researcher) as the 'main caregiver' or the sole provider of care to manage their reputation. Some informal caregivers used this reputation management to justify the decision they made, particularly when their decisions

resulted in the older person with dementia being moved to a care home, which is against the cultural script of family care preferred over formal care in Nigeria. This has significant implications for the current reliance on family care as the only option for LTC in Nigeria.

In the following section, the key findings that answer the above research question are presented under one overarching theme (on the left) and subsequent subthemes (on the right) as displayed on the right in Figure 8.2 below.

Figure 8.2: The overarching theme and subsequent subthemes that answer the second research question




### 8.2.1 Care arrangements influenced by cultural scripts

Some cultural scripts that are dominant in the Nigerian context influenced how participants arranged care. The findings show that the majority of participants either used the cultural scripts to justify their actions or conversely did things that do not fit within these cultural scripts, and therefore, they had to work harder to justify their actions. This finding underlines the importance of recognising the broader influence of culture on how care for people with dementia is arranged, and the care responsibilities shared among their carers. One of these cultural scripts is the responsibility and (often unspoken) expectations of the eldest child in the family or the youngest unmarried child in the family. In the Nigerian context, age, family hierarchy, cultural norms, and gender often determine who makes decisions or has authority in the family.

Several participants used the eldest child script to justify their actions when asked how they arrived at their different care arrangements. The cultural script of the eldest child was associated with another cultural script, which is that of the youngest unmarried child taking precedence as carers over older married children. That is, the informal carers' decision to care was because they were unmarried, and this was still influenced by their family. Although this

script exists in the Nigerian caregiving context, participants still had different approaches to decision-making and navigating complex care arrangements. This shows that the cultural script of the eldest child and the youngest unmarried child is not consistently used in the same way amongst carers. Rather, it is a backdrop on which their decision-making occurs, even though the script is not obvious to the participant during the decision-making process.

Across all the participants, the eldest child script was notably independent of gender, as both male and female carers used this script in this thesis. Gender was rarely a justification for care arrangements and sharing care responsibilities (unlike many contexts where care is seen as a female's responsibility) within the eldest child and youngest unmarried child cultural script. This suggests a flexible, yet important cultural norm rooted in family hierarchies. In their cross-cultural research on Japanese and American male caregivers, Harris and Long (1999) discovered that the birth order, particularly being the eldest son, played a significant role in motivating Japanese men to assume caregiving duties. Although their emphasis is on male carers, both their findings and those of this current study highlight how cultural scripts associated with sibling order can significantly influence not only the desire to provide care but also the allocation and rationale of caregiving responsibilities.

Similarly, Leichtentritt et al. (2004) found that in Arab and Muslim households in Israel, the eldest sons frequently played a central role in decision-making regarding care. While van Wezel et al. (2016) demonstrated that in Dutch families, the duties of personal care often fell on either the eldest daughters or the wives of the eldest sons. In Nigeria, Ezulike et al. (2024) study on informal carers' motivations to provide care for older people found that an individual's birth order within their family was a distinct factor that imposed caregiving duties on participants. That is, being the eldest son, eldest daughter, youngest son, or youngest daughter meant that they had the primary responsibility for the informal care of their parents; this was dependent on the prevalent customary practices of the participants' local village communities.

These studies indicate that while patterns associated with birth order are common, their expressions differ across cultural settings. This current study contributes to the existing body of literature by indicating that in Nigeria, it is more than just birth order; rather, the cultural script for the eldest and youngest unmarried child is flexible. That is, it is not restricted by gendered norms, suggesting a potential separation between traditional caregiving gender roles and family hierarchy. Furthermore, it is not a case of birth order surpassing gender roles; rather, they intersect. This is because the order in which a child is born could have an influence on their caregiving roles within their family, resulting in dynamics that could defy gender roles. For example, the eldest child or the youngest unmarried child, irrespective of their gender, has the greatest responsibility of care for their parent with dementia. However, these influences cannot

overshadow established gender roles, which dictate behaviour and expectations across families and societies; for example, women often assume the role of the providers of hands-on care. Therefore, birth order may impact how care responsibilities are shared and enacted within families, but it does not override the wider influences of gender roles in caregiving.

Another dominant cultural script evident in this thesis is the script of care being provided informally by the family and not formally by individuals and institutions. The findings show that there were very few instances where the participants in this thesis fit within this script. However, some participants used this script to justify their decision to provide care for the person with dementia at home. This highlights the fears that some individuals associate with living in a care home in Nigeria. Here, not putting the person with dementia in a care home is not only associated with the moral obligation to care, as highlighted by the EoC theory (Noddings, 2013), but also the cultural script of family care being preferred over institutional care. This shows that being a relation (especially a close relation) of a person requiring care is still associated with being able to provide better care in Nigeria.

Within the cultural script, the family is expected to provide care, with family care preferred over institutional care. However, participants in this thesis did (or planned to do) things that did not fit within this cultural script. From the findings, it is evident that paid help/carers were used among some families and considered by the majority of the participants. The use of paid helpers in Nigeria is common as individuals have typically been employed to support with a range of household chores, and other activities within the household that are deemed relevant by the employer. However, it is unusual for paid helpers to perform caregiving tasks for an older person with dementia, as these tasks are deemed 'private' and 'reserved' for the relative of the older person. Additionally, the use of (and consideration to use) a paid carer by participants in this thesis is also unusual in Nigeria, as care provision is often the family's sole responsibility.

Similar findings on the use of paid helpers were noted in studies in Singapore, Italy, the United States, and the Netherlands (Koo et al., 2021, Cipolletta et al., 2023, Seaman, 2020, Wammes et al., 2021). They found that 'paid help' or 'hired help' to assist with caregiving tasks was a key part of informal carers' care arrangements. These previous studies highlight the role paid helpers and carers play in the care arrangements for a person with dementia. This current finding shows that the acceptance of these forms of formal support with caregiving in Nigeria not only goes against the cultural script, but rather it shows that the script is being challenged.

Participants justified going against this script by admitting that they had initially provided care for the person with dementia but had stopped due to reasons such as managing dementia symptoms or comorbid conditions. Studies in South Africa and the 10/66 dementia research on care arrangements found that paid carers were used as extra help, especially when the care

needs of the house increased, or the main carer could not manage due to deterioration in the condition of the person with dementia. (Deist and Greeff, 2015, Deist and Greeff, 2017, Mayston et al., 2017, Prince, 2004).

However, where the previous studies show a supplementary role of formal care being used by informal carers, this current study shows that this established cultural script of unpaid family care being preferred to formal care is being challenged in the Nigerian context. This demonstrates that practical issues with caregiving and limitations of the informal carer are beginning to take precedence over the moral framework of keeping care within families. These findings have implications not only for the state of family care in Nigeria (as discussed previously) but also for the predominant views of how care is conceptualised in Africa, particularly within the Ubuntu philosophy. Care for others, such as elderly care, is a key part of confirming one's own identity; that is, an individual cares because they are connected (Nolte and Downing, 2019). Caring is towards others within their communities and is narrowed down to cover the extended kinship network and the individual's family unit.

However, a recent study by Venter et al. (2025) in South Africa shows that extended family members and younger generations can no longer provide informal LTC because of the changing structure of extended families and the perceived attitude (attributed to a lack of care) of the younger generation. Although Gumbo (2014) argue that values of Ubuntu are eroding in current African society, with older people reporting neglect by the younger generation who prioritise materialism and individualism over communal responsibilities. I argue that the shifts in communal responsibilities and living do not signify an erosion of Ubuntu values (as these values are not fixed), rather, they are being reinterpreted by individuals in the current African societies within the social and economic environments that are quickly evolving. Based on this, the findings of this thesis add to the previous literature by showing that it is not only changing family structures but also a case of informal carers becoming increasingly aware of their limitations and ability to provide complex dementia care. This means that informal carers are negotiating dementia care in light of their everyday realities of providing care for their relatives with dementia.

Therefore, it is important to reconsider the tenets of Ubuntu in the current realities of care provision. Although this philosophy is still quite dominant and applicable to the African context, the use of this philosophy in understanding dementia care needs to consider its complex nature, the resulting burden of providing such care, and the limits of the carer in ensuring communal responsibility. This is especially important because of the belief that another individual's well-being is connected to their own and helps them in achieving the goal of communal responsibility (of care being a shared family and community duty). Within the

confines of the Ubuntu philosophy, formal support for caregiving can still be incorporated. That is, care can still remain as a shared familial duty with family-inclusive care plans. This is because the majority of the participants were still actively involved in their relatives' care arrangements, even with the use of a paid helper or carer.

Furthermore, care can take different forms; therefore, the EoC theory can also extend to allow the expressions of familial responsibility of care for older people to go beyond traditional caregiving roles. For participants in this thesis, placing the person with dementia in a care home or using a paid carer (even though it is against the cultural script) was not a failure to provide 'good' care but a different illustration of 'caring for.' This expression highlights the participants' recognition of their limitations as well as the quality of care they could provide because of it. As Brear et al. (2024a) in their study has found that 'good care' can be provided by individuals who are not related to the older person with dementia.

Similar findings were noted in studies in Canada, the United States, Finland, Germany, and Sweden. (Kadi et al., 2022, Kokorelias et al., 2021, Midgette and Ferreira, 2024, Peacock et al., 2020). They found that caregiving encompasses various dimensions such as organising paid care, providing emotional support and decision-making, which goes beyond providing hands-on care. The findings of this current study in Nigeria add to previous literature by supporting the increasing recognition of the non-physical aspects as legitimate and significant forms of caregiving. Thus, challenging the predominant understanding of care within the EoC as being hands-on or direct.

### 8.2.2 Reputation management in care arrangements

A unique contribution of this thesis is the concept of reputation management. Reputation management in the context of this thesis is defined as the informal carer's portrayal of themselves to me (the researcher/interviewer) as the 'main' or 'only' carer during the interview. This was an unexpected finding that emerged from the analysis of the data. Participants often mentioned that they either made the decision to care without discussing it with others or that they did not receive any help from anyone. For the participants, the interview served as a tool they used to manage their reputation. Participants' need to manage their reputation is centred around their desire for validation as well as an assertion of their role and identity as 'good carers' because they portrayed themselves in the best light possible.

The informal carers' portrayal of themselves as the 'main' carer asserts their relevance and value in the care network. Their portrayal of themselves as the 'only' carer (when that was not the case) could also highlight an internal state of being overwhelmed, and a need for sympathy (given their caregiving challenges). These further strengthen the point made in the previous

section about dementia caregiving in the Nigerian context. There are unspoken expectations (both familial and societal) and financial constraints associated with caregiving in Nigeria. This means that carers often push themselves beyond their limits. Additionally, the majority of informal carers globally are plunged into their role with little to no skills/knowledge on how to handle complex care for a person with dementia.

Participants positively portraying themselves in research is well recognised in literature as impression management and social desirability bias (Bergen and Labonté, 2020, Bispo Júnior, 2022, Goffman, 1971). According to Goffman (1971), individuals consciously or unconsciously manage how they are perceived by others in social situations, like actors on a stage. Goffman further argues that individuals employ a 'dramaturgical' perspective in handling how they publicly and privately display themselves to fulfil social norms and attain particular objectives (Goffman, 1971:154). In this context, 'dramaturgical' is when social interactions are likened to performances on stage. This entails individuals thoughtfully choosing actions, expressions, and engagements to craft their desired perception in social situations.

Although impression management and this thesis's concept of reputation management are related, there are also distinct differences. In the context of informal caregiving, on one hand, an informal carer may manage their impression in social situations by hiding their stress or frustration or being extra patient when completing a caregiving task. On the other hand, an informal carer's need to manage their reputation may be more concerned with an ongoing desire to be seen as a 'good carer' providing 'good care' with less focus on their immediate caregiving actions. Also, in reputation management, the focus is more on contrasting themselves favourably with other members of the care network.

Furthermore, social desirability bias provides a methodological perspective in understanding individuals' desire to positively portray themselves in qualitative research. Social desirability bias refers to the tendency of a study participant to depict themselves or their social environment in a manner that is socially acceptable, yet not entirely reflective of the truth (Bergen and Labonté, 2020, Bispo Júnior, 2022). The presence of this type of bias arises from individuals' tendency to reject socially undesirable characteristics and assert other socially favourable ones. My positionality as an 'outsider' researcher to the families in this thesis may have influenced the data collection process. As a PhD student coming from an institution abroad (as well as the knowledge participants believed I had about their relative's condition), my position could have played a role in why the informal carers saw the need to validate and assert their role as carers to me. This could explain why reputation management was used by carers to justify the care arrangement they made, especially when the decision was unusual, such as institutionalisation, which goes against the cultural scripts discussed earlier.

Nonetheless, steps were taken to minimise social desirability bias in the interview process (as discussed in section 3.3 of the methods chapter), such as building rapport, asking open-ended questions, ensuring the interview guide was not rigidly followed, scheduling repeat interviews where possible, and introducing the study in a neutral tone. For example, when I asked a participant if he shared care responsibilities with others, he said he did not; however, after discussing with his wife, it became clear that his answer did not convey the entire picture. So, during my second visit to their home, I asked both participants probing questions and made some observations to have a clearer picture of how they share their care responsibilities.

However, social desirability bias is hard to control due to the complicated nature of the psychological processes that drive individuals' behaviours (Bergen and Labonté, 2020). Although participants' portrayal of themselves as the main or only carer could be associated with the need to be socially desirable, this finding extends our understanding of social desirability bias. The participants' use of the interview as a tool to manage their reputation was a conscious (and subconscious) process, which is centred on their identity as good carers. Participants were not just trying to avoid negative judgements about their caregiving from me as the researcher, but they were also engaging in a representation of themselves that is aligned with their perceived roles in society as carers.

Participants worked to defend their reputation as good carers at different times, like one participant, Ekiye, who said she always encourages herself by saying, 'my dear, you are a one-man squad oh do this thing, if you do not do it, nobody will do it for you.' Her statement was in support of her decision to provide care alone; however, she eventually took her mother to a care home. While Ekiye tried to portray herself positively, she was also trying to maintain her identity as a good carer who provides good care despite the apparently contradictory action of taking her mother to the care home. Ekiye also mentioned how she still performed certain tasks like taking her mother to the hospital and paying bills, which is her way of maintaining her reputation as a good carer despite acting against the cultural script of keeping care in the family.

Therefore, the concept of reputation management goes beyond participants just wanting to provide good answers or socially desirable answers, as established in literature (Bispo Júnior, 2022), but it is also an expression of their identity as carers. That is, participants were not only saying they provide good care but also that they are good carers (which is an expression of their identity). There are currently no published studies highlighting this concept of reputation management in Nigeria. A similar pattern was found in a longitudinal study in the United Kingdom, where carers actively construct and express their caregiving identity, modifying how they present themselves over time based on changing personal and social expectations (Stapley et al., 2025).

However, this current finding supports previous findings by not only showing how carers present themselves to outsiders but also showing that carers use the interview as a tool to manage their reputation as carers for diverse reasons. From the findings, participants' perception of themselves as 'good carers,' often in relation to the shortcomings of others in the care network, was a reputation they ensured they maintained during the interview. This was even the case when others were assisting, and sometimes the other carer they spoke about was arguably the 'main carer' providing the hands-on care.

This shows a gap in literature considering the emotional and relational nature of qualitative research. In the context of this thesis, researching dementia caregiving in Nigeria places participants in a position where they have to recount different aspects of their practices, which include aspects they are unsure about. This highlights the use of the interview as a tool where participants highlighted their moral commitment and responsibility to provide care for their relative with dementia, while framing some of the decisions they made as a result of caregiving in a way that strengthened their identity as good carers.

Nonetheless, this finding could be attributed to the sample and geographical context of the participants in this thesis; this could explain why this concept has not been found in previous studies on dementia caregiving in Nigeria and SSA at large. Taking into account the influence of cultural values tied to family reputation, community status, or gender-based expectations of care on how informal carers present themselves explains why reputation management is a grounded extension of what is known about impression management and social desirability bias. While the concept of reputation management has not been established in academic literature, it does show that in researching lived experiences providing care, the research data could be influenced by the carer's intention to manage their reputation, to seem affectionate, valued, capable, and morally right. Therefore, my findings suggest that in researching dementia caregiving in Nigeria, there are diverse forms of reputation management that may occur alongside impression management. Researchers investigating dementia care in Nigeria in the future could consider this when analysing their interview data.

### 8.2.3 The emergence of care arrangements as a natural extension of previous relationships

It was frequently the case that care emerged as a natural extension of a carer's previous relationship, and/or living arrangements with the person with dementia before the diagnosis. This shows that sometimes, existing relationships and living arrangements are a foundation on which care arrangements naturally occur. The findings reveal that amongst some participants, there is the belief that care responsibilities should be naturally delegated to specific individuals

within the care network, because of the relationship that exists between them and the person with dementia, such as the relationship that exists between spouses. Although spouses play a significant role in caregiving because of the level of intimacy and obligation in the relationship, the role of a spouse was not predominant in this current study.

Amongst the majority of the families in this thesis, persons with dementia were mainly widows/widowers. Where a living spouse was present, they were unable to provide care due to sickness or being part of a polygamous home. In a polygamous family, a man rarely lives with all his wives in the same house. In most cases, the different wives live in their separate residences, either close to or far from each other. Therefore, if one of the wives becomes ill, the man may not see it as his responsibility to provide care for his wife, as he has other wives; rather, it may be seen as the responsibility of his children or the wife's extended family.

Nonetheless, the findings show that, on one hand, care arrangements were typically an extension of previous relationships, but on the other hand, the relationships were often profoundly altered as a result of caregiving. For example, a wife experienced a role reversal from her husband being the 'breadwinner' of the family, to it becoming her role. This finding supports patterns noted in previous studies in the United States and South Africa, where there was a shift in the intimate relationship between spouses to a parent-child relationship (Hendricks-Lalla and Pretorius, 2020, Seaman, 2020). Similar shifts were also documented in studies in Australia, South Africa and Germany, where they found that informal carers experienced this 'role reversal' with children assuming the care responsibilities of their relative, who typically provided care for them (Engel et al., 2022, Köhler et al., 2022, Mahomed and Pretorius, 2022).

The findings of this current study support those of existing literature, as the findings suggest that the implications of these role reversals go beyond functionality. Rather, they highlight emotional implications, especially in the Nigerian context, where the identity of an individual is linked to their role and responsibilities within the family. For example, when a child takes on the role and responsibilities of their parent, there are emotional and societal implications as the parent (often seen as the provider and protector) previously occupying the position of the one who cares, to becoming the one cared for. This could signify a breakdown in the carer's family structure as the parent has lost that authority, which could have implications for their family dynamics and the carer's emotional state.

For some other carers, living close to the person with dementia was an important determinant in them becoming carers by extension. These living arrangements involved children either living with or near the person with dementia. A similar finding was also noted in Agyeman et al. (2019:906), where the proximity to the person with dementia resulted in individuals becoming 'de facto' carers. This reveals that care arrangements for a person with dementia are not solely

formed from pre-existing relationship/emotional bonds, but also the geographical location of the eventual carer.

The findings of this thesis and those of previous literature support Finch and Mason's (1993) arguments of proximity are often used as a sensible and valid reason amongst informal carers when negotiating care responsibilities. They found that participants tended to refer to how geographically close they are, which was not just a justification for them being the main carer but also to suggest that another member of the family takes on the main carer role because they live nearby, therefore, they can provide immediate support.

Here, Finch and Mason's terms are 'non-decisions' (Chambers et al., 2009:5) comes to play. That is, care arrangements emerged both 'naturally,' based on circumstances that seemed obvious to those in the care network; these circumstances include previous relationships and living arrangements. However, such an implicit form of negotiation can obscure power dynamics and foster traditional gender roles. This is because in such circumstances, women may 'naturally' be positioned to take on the caregiving role due to socio-cultural norms without explicitly agreeing to it, creating uneven distributions of caregiving responsibilities.

Nonetheless, while the emergence of care arrangements as a natural extension of previous relationships and living arrangements in this thesis is not a novel phenomenon, this finding can offer important contextual contributions. It highlights how patterns identified in previous literatures (Agyeman et al., 2019, Hendricks-Lalla and Pretorius, 2020, Köhler et al., 2022, Mahomed and Pretorius, 2022, Seaman, 2020) occur within the Nigerian context, thus providing a more in-depth understanding of how these dynamics unfold in practice within another socio-cultural context.

In this case, care arrangements become a technical requirement that is triggered by a variety of reasons, including family dynamics, relationships, proximity, and cultural scripts. Therefore, understanding care should go beyond moral obligations to include the structural positioning of the 'default' carers. From an EoC and Ubuntu perspective, these caregiving arrangements show 'who cares' can be motivated by both the moral obligation to care and the proximity of the carers to the person with dementia.

## 8.3 Understanding how informal carers perceive the support they receive (or do not receive) from within and outside their family network.

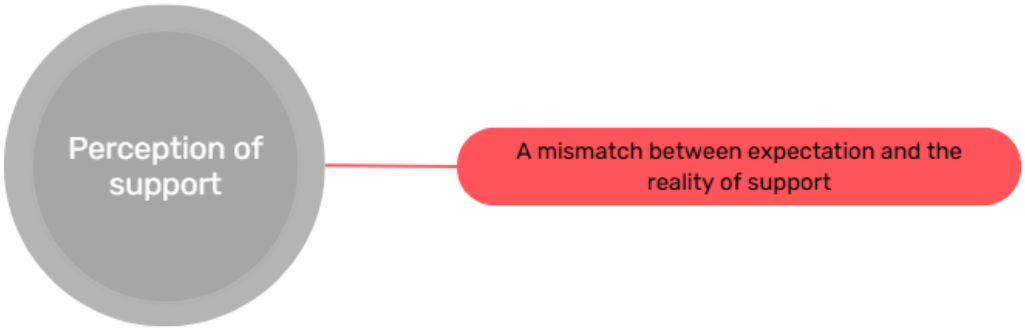
The final research question posed by this thesis is to investigate how informal carers perceive the support they receive (or do not receive) from within and outside their family network, and how this support impacts their experience and care practices. The findings show that, on one hand, support received from within the family network was often perceived as insufficient. When support was not received from within the family network, it was frequently perceived negatively, and this was made worse by the views participants had on the reason other carers did not support. On the other hand, participants perceived the support received from those outside the family network as 'more than enough' even when the support was described as 'little.' This reveals that external support can be considered more valuable because of its voluntary nature (as others outside the family network do not have to help), as opposed to the obligatory/culturally expected support from within the family network.

Furthermore, there was a greater reliance on financial support, compared to physical and emotional support amongst participants. This finding highlights the economic realities of caregiving in Nigeria. Other forms of support were important to participants, but without finances to meet the daily needs and demands of dementia caregiving alongside competing responsibilities, those other forms of support are more likely to be overlooked. Participants in this thesis were more likely to mention financial support even when directly asked what other forms of support they received or would like to receive as carers.

Perceived support from others (or lack thereof) had a diverse impact on participants' experiences of caregiving and their care practices. In cases where the person with dementia was moved to a care home, their informal carers often mentioned that they would have continued caring if they had received more support from within their family network. For other participants, they continued to care despite insufficient support from other family members, even when they had expectations of support.

In the following section, the key finding that answers the above research question is presented under one overarching theme as displayed on the right in Figure 8.3 below.

Figure 8.3: The overarching theme that answers the third research question




### 8.3.1 A mismatch between expectation and reality of support

The findings reveal that there is a mismatch between the support (mainly financial) participants received from within their family network and their expectations. Although financial support was provided (especially to support the carer providing hands-on care), it was often the case that the carer had to make do with the financial support, as it was not sufficient. This shows that financial support is viewed as the most practical form of support, which will enable the provision of care and alleviate the burden of caregiving. In light of the current economic challenges in Nigeria, it is not surprising that financial support played a more significant role for participants. This could also account for this mismatch between participants' expectations and the reality of the support they received, because family members were unable to provide the level of financial assistance the participants expected.

Amongst the majority of participants in this thesis, there was the assumption that the need for financial support should be obvious to the family, with money being provided without the participant asking. When these needs were not met, the participants felt disappointed. The assumption of the need for financial support to be obvious to other family members is irrespective of how closely related the family members are. The participants rarely communicated or updated other members of the family about their needs because of the belief that they should not have to communicate a burden that is so apparent.

These unspoken expectations for support within families reveal practical and emotional consequences. This finding supports previous studies by Hendricks-Lalla and Pretorius (2020) and Gurayah (2015) in South Africa, where financial constraints among carers of low socio-economic status were found to strongly impact their ability to provide care. Similarly, they found that carers made autonomous decisions about treatment for their relative with dementia, and

only informed members of the family who may be expected to financially contribute to the care after the treatment decision was made.

This current study builds on this by highlighting that, in some cases, there was no communication at all regarding the desired support. This reveals how cultural norms relating to open discussion about care responsibilities may hinder open conversations, leading to emotional stress and heightened the need for support. Lindeza et al.'s (2020:44) observation that managing dementia illness had a 'huge negative impact' on carers' daily lives echoes here. However, these current findings indicate that it is not solely the financial burden itself, but the lack of explicit discussion regarding expectations for financial support that can exacerbate that strain.

Furthermore, the negative perception participants had of other carers influenced how they perceived the carer's lack of support. These negative perceptions were often related to the participants making claims about the other carer's lack of money to support caregiving. This communicates a deep level of disappointment due to the imbalanced distribution of caregiving. It also reveals that where families have not explicitly negotiated care responsibilities, the main caregiver by default can feel abandoned, while other passive carers may perceive their role as trivial, fostering a one-sided expectation.

Based on the findings, shared caregiving responsibilities that are promoted in the Ubuntu philosophy are not always applicable to some instances of caregiving in Africa. There were a lot of imbalances amongst the majority of participants because care was reportedly provided with inadequate support from other carers. Thus, the gap between collective ideas of care and the lived experiences of individuals providing care is highlighted here. Therefore, it becomes clearer that the Ubuntu philosophy could be extended to incorporate the modern caregiving context in Africa, as discussed earlier in this chapter.

## 8.4 What the findings say about negotiating dementia care in the context of Nigeria

In this thesis, informal caregiving is characterised by judgements, cultural scripts, unspoken expectations (both familial and societal expectations), and financial constraints. Informal carers in Nigeria were often negotiating dementia care amidst diverse complications and pressures. Participants' need to seek validation is their way of confirming the importance of the role they play in their care network, which reinforces their identity as 'good carers.' Furthermore, in reflecting on my role as a PhD student researching carers' lived experiences negotiating and providing dementia care in Nigeria, I may have been perceived as someone who knows more

about dementia and how a person with dementia should be cared for. This could explain a unique finding in this thesis, which is the participants' use of the interview as a tool to manage their reputation.

Additionally, there are patterns of expectations amongst the informal carers in this thesis; these expectations were often of themselves, or expectations they thought other carers have of them. These expectations often went unspoken amongst carers for a variety of reasons, such as cultural scripts, family dynamics, fear of conflict, and the assumptions that the expectation is obvious to the other carer. Although unspoken expectations have a variety of implications, for carers in this thesis, it was often associated with judgements, misinterpretations, conflicts, unmet needs, and pressures. These unspoken expectations had a large impact on participants' caregiving experience, especially how participants experienced and evaluated their caregiving and that of others.

Furthermore, the analysis reveals a growing tension between the ideas of the EoC and Ubuntu, and the realities of current-day caregiving in Nigeria. While these theories are crucial in the conceptualisation of care, the necessity for extensions to these theories is increasingly apparent. Extending these theories will allow the development of familial responsibility of care to go beyond the traditional caregiving role. That is, extensions can be made to include the modern realities of providing care for a person with dementia. With the shifting trends of the families being the sole providers of LTC in Nigeria, it is very important that theories which conceptualise our understanding of what care evolves with changing times.

Therefore, in conceptualising care within the context of the EoC and Ubuntu philosophies, I argue that the moral obligation to care, and the interconnectedness of relationships amongst other tenets the theories postulate, does not end just because the carer no longer provides hands-on care at home for the person with dementia. As Brear et al. (2024a) in their recent study has found that good care can be provided by people who are not family members of the person with dementia. This is in line with other studies that have found that care conceptualisations also encompass arranging and paying for care (Kadi et al., 2022, Kokorelias et al., 2021, Midgette and Ferreira, 2024, Peacock et al., 2020).

However, with the economic difficulties and state of formal LTC (particularly care homes) in Nigeria, formal LTC is currently not a feasible option for the majority of families living with dementia, especially due to affordability and availability issues. Although family care is often described as the norm in SSA, from the findings, it is evident that family members are often not equipped to provide dementia care. This shows that for informal carers to be sustained for as long as possible to provide care for people with dementia (until alternatives to this form of LTC are established in Nigeria), there needs to be more support for informal carers. Free education

and training to enhance carers' skills and ability to provide dementia care is an essential part of supporting families living with dementia. This finding and the importance of psychoeducation and training early in dementia are echoed in several studies in SSA (Adedeji et al., 2022, Gurayah, 2015, Mahomed and Pretorius, 2022, Mushi et al., 2014).

# Chapter 9 Conclusion

This thesis aimed to investigate how informal carers of older people with dementia negotiate everyday caregiving in Nigeria. To achieve this aim, this thesis sought to understand how informal carers experience and evaluate their caregiving and that of others, how they divide and arrange care responsibilities, and how they perceive the support they receive (or not) from within and outside their family network. From the analysis, there were strong themes of judgements, validation-seeking, which could highlight carers' overwhelm, and a desire to be seen as a 'good carer.' In this thesis, informal caregiving in Nigeria is characterised by unspoken expectations (both that the carer has of themselves and others have of them) and cultural scripts, which influence how carers arrange and share their care responsibilities. Therefore, making care expectations more openly discussed could help improve relationships within care networks.

Due to the financial constraints and the current economic state in Nigeria, it is not surprising that financial support was the most mentioned form of support carers desired. When this support was not received, it negatively impacted the carer's caregiving experience. Furthermore, an original contribution of this thesis is the concept of reputation management, which is the informal carers using the interview as a tool to manage their reputation as the main/sole providers of care. Their need to do this was driven by their desire to portray themselves in the best light possible. These findings contribute key knowledge to the existing literature and expand what is known about dementia caregiving in Nigeria and SSA at large.

The insights of this thesis raise implications for what is known about the EoC, Ubuntu philosophy and Finch and Mason's negotiation of family responsibilities. While these theories are important in our understanding of care and negotiating care responsibilities, the necessity for extensions to these theories has become clearer. This is to allow the development of familial responsibility of care beyond the traditional caregiving role, and account for the influence of cultural scripts on how care is negotiated within families. That is, extensions can be made to include the modern realities of providing care for a person with dementia within the socio-cultural context of Nigeria, which may be transferable to other contexts within SSA.

In the next sections of this conclusion chapter, I discuss the practice and policy recommendations, limitations, and suggestions for future research.

## 9.1 Practice and policy recommendations

In light of the findings from this thesis, two overarching recommendations can be made for practice and policy to support informal carers in Nigeria more effectively. First, post-diagnostic support for families living with dementia in Nigeria needs to improve. Healthcare providers should encourage families living with dementia to plan care, including having discussions on what is expected from each member of the care network. Furthermore, the education and training for informal carers needs to extend beyond enhancing their care provision skills and ability to manage caregiving burden, to include other practical realities of caregiving, such as relationship management (with other carers in the care network).

Considering the financial constraints that characterise caregiving in Nigeria, the government and NGOs could form partnerships to provide trainings for free and make it accessible at the community level. Moreover, organisations in Nigeria could include mechanisms of financial support for carers, particularly those facing economic hardship. The trust that exists between community and religious leaders could also improve the success of these practical recommendations. Therefore, healthcare organisations can work in partnership with these faith-based organisations, which could facilitate the dissemination of accurate information on dementia care as well as support available for informal carers.

Second, the 2021 national policy on ageing for older people needs to include guidelines on dementia. While the implementation of policies in Nigeria poses significant challenges, older people with dementia and their carers should be part of the conversation on how the policy can best capture their needs. Nonetheless, the local and state governments could initiate guidelines on dementia caregiving on a small scale; if successful, it could increase the chances of scalability at a national level. While a national strategy on dementia may seem far-fetched, especially with the policy-making landscape in Nigeria, from the findings of this thesis, it is clear that the Nigerian government needs to go beyond deliberation to drafting and implementing this strategy.

## 9.2 Limitations

One of the limitations of this thesis is that the majority of the findings rely on self-reports of care (which can be influenced by personal interpretation and social desirability) rather than direct observation. Nonetheless, this kind of data is still incredibly valuable in dementia care research. Self-reports of care can provide valuable insights into how individuals experience and perceive their roles as carers (and the role of other carers), and the socio-cultural and emotional principles that influence how they make meaning of their experiences.

This is particularly crucial in cultural settings such as Nigeria, where caregiving is influenced by complex cultural and social norms and unspoken expectations. Through these self-reports of care, we can understand not just what happens but how informal carers negotiate daily care within the socio-cultural context of their environment. These insights may not easily be understood through observation alone, particularly considering the ethical and practical difficulties of observing intimate care and care arrangements within Nigerian households.

Although a commonly stated limitation of the qualitative research methods is the generalisability of its findings, I did not intend to generalise the findings to the population of informal carers in Nigeria. Rather, I aimed to provide rich, in-depth context-specific insights into some informal carers' negotiation of dementia care in Nigeria, which may resonate within the wider socio-cultural context of Nigeria. Furthermore, as the research was conducted in what are considered urban-rural settings in south-south Nigeria, the experiences of carers described in this thesis may be considerably different from those in rural areas.

Despite efforts to involve a variety of participants, most of the carers interviewed were females, potentially affecting the range of carers' perspectives reflected in the findings. Nevertheless, the analytical focus of this thesis is not on distinctive characteristics of the individual participants, such as gender; rather, the focus is on finding patterns across the dataset and how the participants' subjective experiences can be situated within the larger socio-cultural setting of Nigeria.

## 9.3 Suggestions for future research

The focus of this thesis was to investigate how informal carers of older people with dementia negotiate everyday caregiving in Nigeria. The findings aided an understanding of how informal carers experience and evaluate caregiving, how they share and divide care responsibilities, and how they perceive the support they receive (or do not receive). However, there are three key areas where further exploration could broaden our understanding of how informal carers in Nigeria negotiate dementia care. First, future research could explore the extent to which the evaluations informal carers make of themselves, and others impact their everyday caregiving.

Second, further exploration is required to understand the existing cultural scripts within the Nigerian caregiving contexts, and how these scripts evolve across diverse socio-economic contexts (especially rural areas where access to support may differ). Finally, longitudinal research could be key in understanding how carers' experiences, evaluations, and care arrangements change over time. This is particularly important as dementia is a progressive condition, that is, deterioration occurs over time. Therefore, a longitudinal study could capture

changes in family structure, expectations, use of the cultural scripts, and family dynamics as dementia progresses.

## 9.4 Summary

This research adds to the existing body of literature on what is known about informal caregiving in Nigeria and the EoC, Ubuntu philosophy, and Finch and Mason's concept of negotiating family responsibilities as discussed earlier. Based on this, I make recommendations such as the apparent need for a national strategy for dementia in Nigeria. However, the complex nature of dementia care in Nigeria is exacerbated by the lack of dementia knowledge, financial constraints, and a comprehensive guideline on managing the condition. Therefore, given the challenges associated with drafting and implementing policies in Nigeria, practice recommendations such as improvements in post-diagnostic support for carers may be more achievable. Especially when the trust between individuals and community healthcare workers/leaders, as well as religious leaders, are leveraged. Nonetheless, future research can build on the findings of this current study. For example, longitudinal qualitative research studies could investigate how carers experience, evaluate their caregiving (and that of other carers), and how care arrangements change over time. This longitudinal research could also capture how informal carers use or challenge the cultural scripts in their everyday caregiving, especially as dementia progresses over time.

# Appendix A Ethical Approval

Approved by Research Integrity and Governance team - ERGO II 80048

University of Southampton

ERGO II – Ethics and Research Governance Online https://www.ergo2.soton.ac.uk

Submission ID: 80048
Submission Title: Care practices of informal caregivers of older people with dementia in Nigeria
Submitter Name: Lilian Odaro

The Research Integrity and Governance team have reviewed and approved your submission.

You can begin your research unless you are still awaiting specific Health and Safety approval (e.g. for a Genetic or Biological Materials Risk Assessment) or external review.

# Appendix B Interview Guide (Informal Carers)

## Interview guide (Informal carers)

**Introductory Questions**

- Please tell me about yourself
- Can you please tell me about the composition of your household?
- Please tell me how you are related to the person with dementia?

**Questions on organising care**

- Can you please tell me what kinds of care your [person with dementia] currently needs?
- Can you please tell me how the care needs of your [person with dementia] have changed over time?
- How long have you provided care for [person with dementia]?
- Can you please describe a typical day with your [person with dementia]?
- Are there any difficult aspects of organizing care for [person with dementia]?

**Questions on sharing care responsibilities**

- Can you please tell me if you share your care responsibilities with anyone? If yes, please can you tell me who?
- Can you please tell me how the decision on who is responsible for each caregiving task is made?
- Are there any challenges that you encounter during the process of sharing the care responsibilities?
- How has the decision to share the caregiving responsibilities for your [person with dementia] been so far?

**Back up questions for where care responsibilities are not shared**

- Can you please tell me why you are providing care alone for [person with dementia]?
- Can you please tell me what it is like caring alone for [person with dementia]?
- Are there any particular challenges you have encountered caring alone for [person with dementia]?

**Questions about support with caregiving**

- Do you receive any form of help with caregiving such as using paid care for your [person with dementia]?
- Can you please tell what type of support you receive for caring [person with dementia]?
- Would you say you are satisfied with the help and support you have received so far?
- Is there anything else you want from the sources of support available to you?
- Is there anything else you would like to say about your daily care practices.
- Do you have any questions for me.

# Appendix C Interview Guide (Paid Helpers)

## Interview guide (Paid helpers)

**Introductory Questions**

- Please tell me about yourself
- Can you please tell me how long you have been providing care for an ill person?
- Can you please tell me who hired you to assist with caring for [the person with dementia]?

**Questions on types of assistance rendered**

- How long have you provided paid help for [person with dementia]?
- Can you please describe your daily duties?
- Can you please describe a typical day with [person with dementia]?
- Are there any difficult aspects of being paid to help with daily care for [person with dementia]?
- Are there any positive aspects of being paid to help with daily care for person with dementia]?

**Concluding questions**

- Do you receive any form of help on how to care for someone with the condition?
- Would you say you are paid a fair amount for the type of help you provide?
- Is there anything else you would like to say about your experiences assisting in caring for [person with dementia]?
- Do you have any questions for me?

# Appendix D Observation Guide

## OBSERVATION GUIDE

Adapted from Ritchie *et al.* (2014)

### 1. Background

Location: .....

Date: .....

Time (start-end): .....

Participant being observed: .....

### 2. Information to note prior to observation

| | |
|---|---|
| Nature of caregiving tasks to observe | |
| Other context notes (weather, what happened before the interview/observation) | |
| Notes on physical environment (specific details, layout or changes observed) | |

**3. Notes on care tasks that occurred during the visit, how it was organized and who performed it**

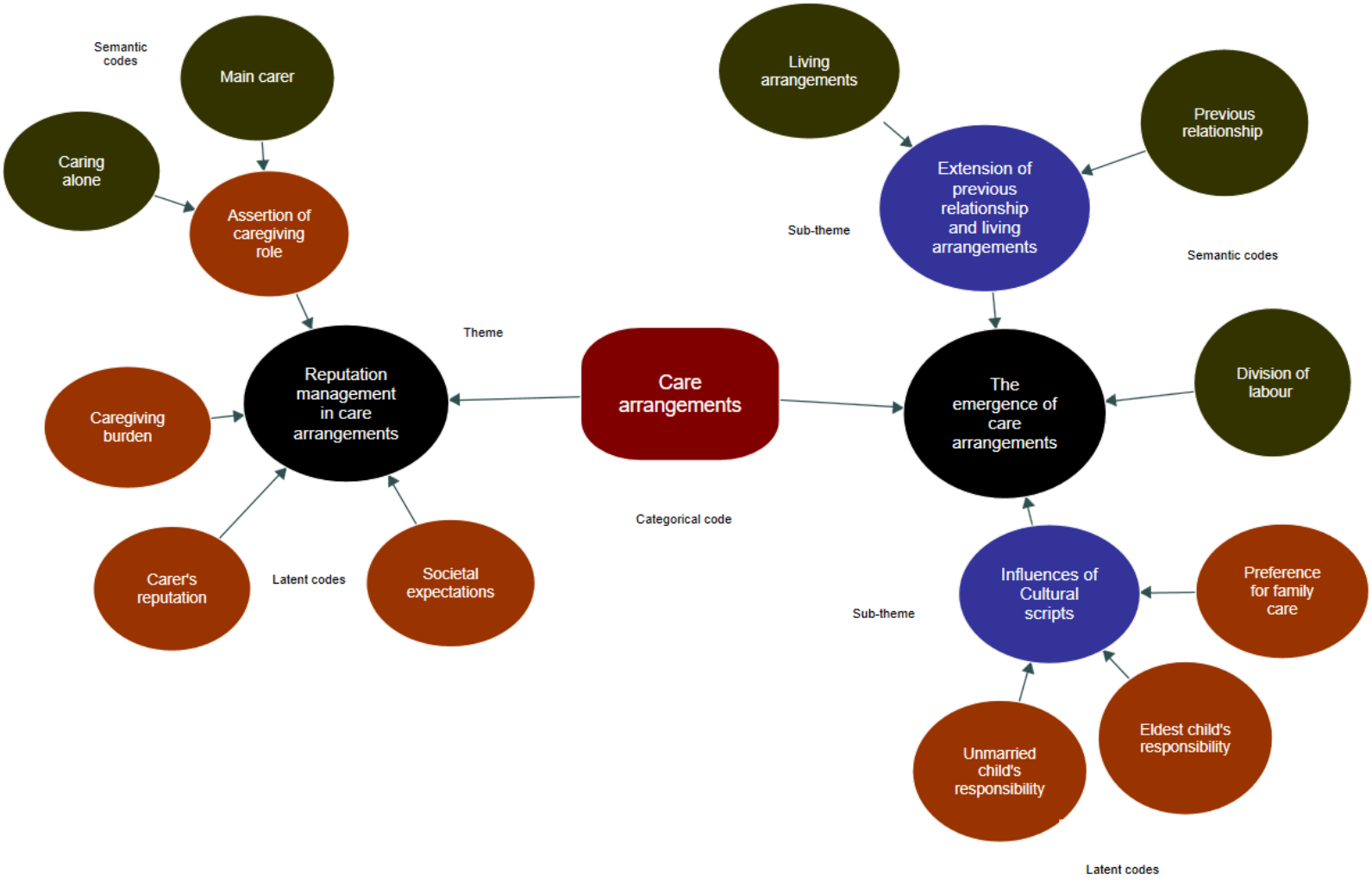
| |
|---|
| |

**4. Notes on interactions (verbal and nonverbal) and emotions that occurred as a result of caregiving**

| | |
|---|---|
| Between informal caregiver and person with dementia | |
| Between informal caregiver and paid help | |
| Between paid help and person with dementia | |

**5. My reflections after the interview/observation**

# Appendix E Concept Map of Codes and Themes



# Appendix F Literature Search Strategy

**Search database**: PsycINFO and Web of Science.

**Search topic**: Care practices of informal caregivers of older people with dementia

**Search terms**:

***Note:*** *started by having the below terms in the title, then widened to abstract/full text search*.

(Dementia OR "memory loss" OR "cognitive deficit*" OR "cognitive* impair*" OR "memory impairment*" OR "Alzheimer* OR ADRD")

**AND**

(Informal care pratic* OR "informal care practis*" OR "care practice*" OR "care practis*")

***Note****: started by using the above terms with explicit reference to care PRACTICE, when that did not return enough results, I also searched for 'care' OR 'caring' without reference to practice*.

**AND**

(Famil* OR "care$giver*" OR "family care*" OR "Carer*" OR "informal care*" OR "unpaid care*")

***Comment: I used the snowballing technique to examine the reference lists of articles that are relevant to my research to search for other potentially relevant literature*.**

# Appendix G Informal Carers' Consent Form

UNIVERSITY OF Southampton

## CONSENT FORM

**Study title**: Care practices of informal caregivers of older people with dementia in Nigeria

**Researcher name**: Lilian Iluobe Odaro
**ERGO number**: 80048

***Please initial the box(es) if you agree with the statement(s):***

| | |
|---|---|
| I have read and understood the information sheet (17/05/2023/version 3 of participant information sheet) and have had the opportunity to ask questions about the study. | |
| I agree to take part in this research project and agree for my anonymised data to be used for the purpose of this study and stored in the University of Southampton repository for future research. | |
| I agree to be contacted for repeat interviews. | |
| I understand my participation is voluntary and If I want to withdraw from the study I will let the researcher know within the week and the researcher is free to contact me to confirm I want my data retained. | |
| I understand that health information will be collected to achieve the objectives of the study. | |
| I understand that I will not be directly identified in any reports of the research or future research. | |
| I understand that taking part in the interviews involves audio recording which will be transcribed and anonymized after data collection. | |
| I understand that I am free to stop or pause the interviews at any time during the process without any penalties. | |

***Please initial the box(es) if you agree with the statement(s):***

| | |
|---|---|
| I agree for the researcher to carry out observations on how I carry out daily care and interactions that take place in my home. | |
| I understand that the observation involves note taking which will be typed and anonymized after data collection. | |
| I understand that I am free to stop or pause the observation at any time during the process without any penalties. | |
| I understand that I can request for a summary of the findings of the research in hard-copy or by email as preferred. | |

[16/06/2023] [3] [Ethics Number: 80048]

# Appendix H Paid Helpers Consent Form

UNIVERSITY OF Southampton

## CONSENT FORM

**Study title**: Care practices of informal caregivers of older people with dementia in Nigeria

**Researcher name**: Lilian Iluobe Odaro
**ERGO number**: 80048

***Please initial the box(es) if you agree with the statement(s):***

| | |
|---|---|
| I have read and understood the information sheet (17/05/2023 /version 3 of participant information sheet) and have had the opportunity to ask questions about the study. | |
| I agree to take part in this research project and agree for my anonymised data to be used for the purpose of this study and stored in the University of Southampton repository for future research. | |
| I agree to be contacted for repeat interviews. | |
| I understand my participation is voluntary and If I want to withdraw from the study I will let the researcher know within the week and the researcher is free to contact me to confirm I want my data retained. | |
| I understand that health information will be collected to achieve the objectives of the study. | |
| I understand that I will not be directly identified in any reports of the research or future research. | |
| I understand that taking part in the interviews involves audio recording which will be transcribed and anonymized after data collection. | |
| I understand that I am free to stop or pause the interviews at any time during the process without any penalties. | |

***Please initial the box(es) if you agree with the statement(s):***

| | |
|---|---|
| I agree for the researcher to carry out observations on how I assist with daily care and interactions that take place while I am working. | |
| I understand that the observation involves note taking which will be typed and anonymized after data collection. | |
| I understand that I am free to stop or pause the observation at any time during the process without any penalties. | |
| I understand that I can request for a summary of the findings of the research in hard-copy or by email as preferred. | |

[16/06/2023] [3] [Ethics Number: 80048]

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