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Abimbola Gbemi Alao

Raising Awareness of Frontotemporal Dementia among Nigerian Immigrant Communities, in the UK, through Storytelling

An Autoethnography Thesis, Using an Art-based Research Approach

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Supervised by

Professor Satu Uusiautti, University of Lapland

Professor Mirja Hiltunen, University of Lapland

Adjunct Professor Erika Sarivaara, University of Lapland

Reviewed by

Professor Anne Basting, University of Wisconsin-Milwaukee

Dr Isabella Gatt, University of Malta

Opponent

Dr Isabella Gatt, University of Malta

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ABSTRACT

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Even though medical research on dementia is wide and has long roots internationally, the awareness of the condition varies among different populations. People in ethnic minority communities, for example, may view dementia issues through a traditional or cultural lens. In these communities, diagnosis is more likely to occur at an advanced stage of the disease, and there is a low take-up of mainstream dementia services.

This study explores new ways of raising awareness of dementia in such groups, in this case, among Nigerian immigrants in the UK. This group is understudied, even though they represent the largest number of people of African origin in the UK.

The research questions set for the research are:

(1) How can the awareness of frontotemporal dementia (FTD) be raised using an art-based approach?

(2) What autoethnographic process preceded the development of the play '*My Name is Beatrice*'?

My research approach is art-based, and the tool I used for my data interpretation is ethnodrama, which is a written transformation and adaptation of research data into a dramatic play script. I aim to present an aesthetically sound, intellectually rich, and emotionally evocative play that can capture my audience's attention and leave them with enduring memories.

The analysis focused on both the process that preceded the writing of a play about someone with dementia in a Nigerian immigrant community and the play itself. The data comprised two sets: my previous works and desktop research. These were analysed for their contribution to the process preceding the playwriting. The art-based part of this thesis included the play '*My Name is Beatrice*' and its critical commentary.

This research explores and discusses the efficacy of using drama as an educational tool to raise awareness of a disease. Art has an instantaneous effect on an audience because it can capture their attention and leave enduring memories. In addition, my research shows evidence of the complex needs of people living with dementia in Black Minority Ethnic (BME) communities that can be highlighted through art-based research and methods in a meaningful way.

This art-based research has shown how ethnodrama can facilitate engagement and action from the researcher, participant, and audience. The aim is that this research would enlighten BME communities about FTD, the importance of early diagnosis and holistic approaches to care. The research will be a microcosm for further work that will enable educators and healthcare workers to share similar information within larger BME communities in the United Kingdom, other developed countries, and Africa. It will also enable educators and medical practitioners to understand the needs of BME communities and other similar groups worldwide.

Keywords: frontotemporal dementia, autoethnography, art-based research, ethnodrama, Black Minority Ethnic (BME), Nigerian immigrants.

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LIST OF ABBREVIATIONS

ABR	Art-Based Research
BME	Black Minority Ethnic
BPSD	Behavioural and Psychological Symptoms of Dementia
FTD	Frontotemporal dementia
PBR	Practice-Based Research
PWD	People with Dementia
QoL	Quality of Life
SWB	Subjective Well-being

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PROLOGUE

I grew up in Nigeria, where the oral tradition is alive and part of family and community life. My storytelling journey began about four decades ago when three women laid a firm foundation for my storytelling career. The first woman was my maternal grandmother, who told real-life stories, some of which were about her experiences as a woman raising her children in a polygamous home. The second person was my mother, who told us Bible narratives every night before we went to bed. She built the first bookshelf we had in our living room and filled it with books of all kinds, many of which she got from charity organisations in Ibadan, the city of my birth.

The third woman who was instrumental in stirring my passion for storytelling was a nanny that we had when I was eight years old. Every night, when she returned from her evening classes, she told my siblings and me fictional tales in nearly every genre of the oral tradition, performing them with songs and chants. Her storytelling style was very different from what I have witnessed in my community; she performed her stories as opposed to straightforward telling. She never sat in one place to tell tales; she was constantly moving, gesticulating, singing and asking us to join in on the chants.

When the nanny left our house, I stepped into her shoes as the family storyteller. Every evening after school and during the holidays, I told stories to my siblings and the children who lived in our neighbourhood. I told tales I had heard, plus the ones I had read in books. I also made up sagas, which I relayed over a long period of time, encouraging my exuberant audience to participate in the songs and movement. We had so much fun. There were other griots and storytellers whose contagious enthusiasm for the oral tradition helped me to build on this foundation. These people generously shared their repertoire of stories. They were my heroes.

Today, I live in the UK, and I am privileged to perform as a storyteller in schools and various communities. I also provide training sessions and workshops for teachers, outdoor educators and fellow storytellers. I always ask my audience what they hope to learn from my workshops. All good storytellers want to engage effectively with their audience because that is what creates a memorable experience. One of the ways in which I engage with my audience and keep them immersed in my stories is by using the call-and-response method. This involves the storyteller starting a song (this is the call) and the audience singing the chorus, thereby ‘responding’ to the tale they are hearing.

Why do I engage my audience with a call-and-response narrative style? In today's 'fast-paced' society, an audience is exposed to first-rate entertainment through films, theatre or television; it may take more than straightforward narration to hold their attention. A call-and-response narrative reinforces the absence of the 'fourth wall' in storytelling, and it builds rapport between tellers and listeners. Another way by which I engage my audience is through music. As a Djembe drummer and percussionist, I provide an environment for my audience to be encapsulated by the music that we create together. Repetition of chants and songs in the stories helps my audience remember and retell the stories.

After twelve years of working as a performance storyteller, something happened that changed my career trajectory. In 2010, I visited Nigeria, and I was told that my paternal uncle had been diagnosed with Alzheimer's. Prior to that time, I did not think about the issue of dementia. Though I live in the UK and have heard accounts in the media, I did not have any reason to focus on it. However, when I heard about my uncle's condition, I was devastated; it was a strange form of bereavement. Uncle was alive, but I was discouraged from visiting him because 'he wouldn't recognise me'. That was the beginning of my journey into dementia research.

My initial response to my uncle's diagnosis was to research medical interventions. However, to my dismay, I discovered there was no cure for the disease. My uncle later died of Alzheimer's. As I dealt with my loss, my passion for working with people who live with dementia intensified, and I sought and found scientific papers on psychosocial interventions for people who have dementia. My question then was, 'If there is no cure for dementia, could there be alternative ways of helping people with dementia (PWD) have a good quality of life?'

I continued my research and found that some memory cafés, where PWD and their families go for daily activities, provided creative programs for PWD. However, many of these activities focused on doing things for participants instead of allowing PWD to be creative themselves. What I was looking for was a person-centred program that would empower participants, reduce stress levels, get them to engage and communicate with other people and, most importantly, give them a feeling of well-being.

In many memory cafés where I facilitated storytelling workshops, PWD responded to the activities because the programs were engaging. I introduced them to musical instruments from various countries worldwide and encouraged them to participate in gentle exercises involving dance movements and songs. The storytelling aspect of the program also helped participants use their imagination to create brilliant narratives.

As I continued visiting these cafés and care homes, I became aware of the low representation of the Black Minority Ethnic (BME) community in the programs I facilitated. I will expatiate the term BME in the following chapter. Initially, I thought perhaps dementia was not prevalent in BME communities. However, I embarked on searching for answers and found that an estimated 25,000 people of BME origin live with dementia in the UK. Also, while the number of white British people with dementia is expected to double by 2051, the number of people from BME communities is expected to increase sevenfold in the same time.

During my investigation on how to promote inclusiveness and encourage more people from BME communities to access care, I discovered a type of dementia that I did not know much about hitherto. It is called frontotemporal dementia. The devastating effect of it on younger people made me curious about its prevalence, causes and care protocols. As I intensified my research, I found out that many people from BME communities are ignorant of this type of dementia and do not know how best to support people living with it. This is the foundation of my thesis.

I aim to explore how to raise awareness of frontotemporal dementia within the Nigerian immigrant community in the UK. This group is grossly understudied, and research about the prevalence of frontotemporal dementia within this group or any other BME community within the UK is almost non-existent. This research also has a pedagogical purpose. It aims to contribute to the body of literature that explores effective care access for PWD in BME communities.

I know the various cultural and religious beliefs surrounding mental health issues in my community. Some of these are rooted in superstition and animist beliefs. However, as an immigrant, I have experienced first-hand some of the challenges and limitations of access to culturally relevant healthcare provisions for BME communities. I will explore some of these, firstly in the session titled 'The researcher's position' and in subsequent chapters in this thesis.

1. INTRODUCTION

1.1 Context and the Importance of This Study

Researchers opine that one out of 88 people in the UK lives with one type of dementia or another. It is also estimated that about 25 thousand people from BME communities in the UK have dementia. By 2051, the number is expected to increase sevenfold (Bristol BME People and Dementia research group, 2017). In the UK, dementia care costs the economy about 23 million pounds a year, which means the cost of dementia is greater than a combination of the cost of cancer and heart disease (Luengo-Fernandez et al., 2010). In 2015, the global costs of dementia were estimated at US $818 billion, an increase of 35% since 2010 (Wimo et al., 201).

In the case of Alzheimer's disease, no single therapy exerts anything beyond a marginal symptomatic effect, with little or no effect on disease progression (Bresden & John, 2013). Nevertheless, a broader-based therapeutic approach may be more effective in caring for people with Alzheimer's. In most healthcare systems, cognitive issues are the focus for dementia, and pharmacological approaches are used as the first-line treatment. However, there is now more interest in non-cognitive problems, such as mood disorders, agitation, aggression and eating problems, grouped under Behavioural and Psychological Symptoms of Dementia (BPSD).

Presently, there is still no known cure for dementia, but more than 40% of people with dementia are placed on neuroleptic drugs, even though there is increasing evidence of side effects, such as falls, sedation and other negative effects in patients (Wei et al., 2016). Research shows that neuroleptic treatment of dementia reduces well-being and quality of life and accelerates cognitive decline in PWD (Dutcher et al., 2014). Scholars have put antipsychotics in the spotlight for many years. Antipsychotic drugs and benzodiazepines have been known to cause fractures, cardiovascular problems and falls; however, some researchers argue that these risks could be minimised if usage is not prolonged (Lapeyre-Mestre, 2016).

In this research, I aim to explore art-based approaches to raising awareness of dementia among Nigerian immigrants in the UK. Nigerians living in the UK are categorised as Black Minority Ethnic people (BME). The term BME or BAME (Black, Asian and Minority Ethnic) refers to "people of non-White ethnicities who are minoritised in the UK" (The Law Society, 2022, p. 3). There are controversies surrounding the use of the term BAME or BME, as critics suggest it means diverse ethnicities are being grouped together as having a homogenous ethnic identity. Nevertheless, these terms are how some immigrants are identified in the UK.

Research conducted in the UK in 2021 asked people what they preferred to be called. Most ethnic minority Britons slightly prefer 'ethnic minority' as an umbrella term, with two-thirds (68%) saying they either support or accept the term and 13% opposed it (British Future, 2021). Some say the term should only be used in research or data collection, not outside that boundary. In this thesis, I will use the term BME as an umbrella term, but my main focus is raising awareness of FTD among Nigerian immigrants living in the UK.

The urgent need for data on the prevalence of FTD among minority groups in the UK and the importance of raising awareness cannot be overemphasised. For people in BME communities, diagnosis is more likely to occur at an advanced stage of the disease, and there is lower take-up of mainstream dementia services (Bristol BME People and Dementia research group, 2017). One of the ways to create awareness is through education, not only for community members but also for healthcare practitioners (Mkhonto & Hanssen, 2017).

In many developed countries, there is a huge disparity in access to mental health services for BME groups. Researchers have identified some of the reasons for this disparity. People are reluctant to discuss psychological distress or seek help. There is also the issue of an "imbalance of power and authority between service users and providers, cultural naivety, insensitivity and discrimination towards the needs of BME service users" (Memon et al., 2016, p. 1). Scholars have suggested that people from BME communities would benefit from knowing more about mental health issues, which will combat stigma. Some scholars also advocate for more training for healthcare workers and providers to help them provide culturally sensitive care (Memon et al., 2016).

My focus in this study is on frontotemporal dementia, a type of dementia affecting the frontal and temporal lobes of the brain. Compared to Alzheimer's disease, which has a four-fold risk, the mortality risk associated with frontotemporal dementia is six-fold (Bott et al., 2014). Progression of FTD is slow, and symptoms include personality and behavioural changes, social deterioration, and impairment of language functions and intellect. The neuropathology of FTD is more of selective atrophy of the frontal and temporal lobes, without the occurrence of plaques and neurofibrillary tangles seen in normal ageing; however, as the disease progresses, memory loss occurs (WHO 1992 and Alzheimer's Society, 2016).

In the last twenty years, there has been an accumulation of data about FTD from population studies in the United Kingdom (Harvey et al., 2003), Canada (Feldman et al., 2003), Spain (Garre-Olmo et al., 2010) and the United States (Knopman & Roberts, 2011). However, in these surveys, more than 95% of subjects were Caucasian, which means non-white populations were underrepresented. Despite the increase in knowledge about FTD, which is helping scientists understand the neurobiology of the disease, there is still a huge gap in the estimation of frontotemporal distribution within BME communities in developed countries and

Africa as a whole. Researchers have suggested that there is a need for collaborative studies to plug these gaps (Onyike & Diehl-Schmid, 2013).

Epidemiologic studies on the prevalence of frontotemporal dementia are rare, even though it is the second most common type of dementia after Alzheimer's (Rosso et al., 2003). Although FTD is not as commonly spoken about as other types of dementia, studies have shown that it is more prevalent than researchers recognised. Bernadi et al. (2012) conducted door-to-door research to estimate FTD prevalence in a group of people in Southern Italy, and they reported an unusually high FTD prevalence in the investigated population but a low prevalence of Alzheimer's disease.

This research is crucial because it will contribute to the body of work on frontotemporal dementia for scholars researching BME groups. The importance of this thesis is two-fold: firstly, it will raise awareness of frontotemporal dementia, which would allow Nigerian immigrants in the UK to know about FTD, thereby encouraging early diagnosis and access to necessary care. Secondly, it will provide the much-needed culturally sensitive education for healthcare professionals and providers who need to understand how best to serve BME communities deemed 'hard to reach'.

When I started my PhD, I reviewed the existing literature on frontotemporal dementia to find studies on its prevalence among BME groups. However, such information is almost non-existent. Also, in many European countries, African immigrants were often seen as part of a larger homogeneous community (Wamwayi, 2019). They are frequently placed in the same immigrant population as Asians (Diaz et al., 2015). Researchers have acknowledged the need for more studies in this area (Onyike & Diehl-Schmid, 2013); however, a creative approach is needed in order to reach this group because PWD still experience stigmatisation due to prevalent cultural and religious beliefs (Brooke & Ojo, 2020; Spittel et, al., 2019). In order to understand and access vital information about the cultural beliefs surrounding dementia, I decided to work within my ethnic group. Nevertheless, the research will be a microcosm for further work that will enable educators and healthcare workers to share similar information within a larger BME community in the United Kingdom, other developed countries, and Africa.

Memon et al. (2016) conducted extensive research to find out why people in BME communities do not access healthcare services, even when these services are placed within their communities. A major factor in their findings was the inability of care providers to understand cultural barriers. The people who were interviewed talked about the stigma surrounding mental health issues; people in the community felt they just had to be strong and get on with it.

As a member of this community, I understand this sentiment; people rarely talk about depression, anxiety or other mental health problems, even when it is obvious that the person who is having the issues needs help. People try to manage their problems in many ways, independent of healthcare services. For example, seeking 'spiritual' help or simply ignoring the issue. These responses are a result of the stigma associated with mental health issues, which can lead to discrimination and isolation (Arthur et al., 2010).

Another major barrier is the inadequate care system that does not understand the needs of BME people, especially in the area of prescription drugs for mental health issues. Research shows that some participants do not want drugs but would rather have access to people who will listen to them and allow them to talk (Memon et al., 2016). People who originate from African countries know the benefits of storytelling, social interactions and creative approaches to care; unfortunately, these therapies are rarely offered.

In Caribbean communities, many people are concerned about the risk of being 'locked up' if they visit their doctor to talk about mental health issues (Baghirathan et al., 2018). This fear is not irrational; there is evidence that high numbers of black people are detained under the Mental Health Act 2007, spending longer periods of time in hospitals than other ethnic groups (Care Quality Commission, 2011). This calls for education for healthcare professionals to include alternative therapies that can offer support for BME communities. Rather than label BME groups as 'hard to reach', perhaps care providers could be given more training to understand the diverse needs of marginalised people.

1.2 Aim of Research

Through a full-length play and accompanying critical commentary, this research aims to explore how to raise awareness of frontotemporal dementia among the Nigerian Immigrant community in the UK. Since this research theme is based on a personal journey as a storyteller and my work with people with dementia and their carers, my approach is autoethnographic. That means I will examine what autoethnographic process preceded the development of the play '*My Name is Beatrice*'.

I decided to focus my thesis on how to raise awareness of FTD among Nigerian immigrants in the UK because they are understudied (Bruton et al., 2020; Harrison, 2017), even though Nigerian immigrants represent the largest number of people of African origin in the UK. Statista (2021) records that there were approximately 178,000 Nigerian nationals residing in the United Kingdom in 2021. According to Imoagene (2017), one in five black Africans in the UK is a Nigerian, a large increase from the previous figure of 2008, which was 90,0000 people. Statistics also show that when it comes to annual growth in the UK, Black Africans have the highest growth rate, with an average of 6.2%, compared to the Caribbean, having 0.9%, while other Africans are 3.3% (ONS, 2012).

The term migration is used to describe a group of people who are leaving their countries and settling in another. This process has various motivations, such as seeking economic prosperity or avoiding instability (Stalker, 2001; Enegho, 2005). There are numerous historical examples of migration to Britain from various parts of the world, for example, the Jews and French people escaping terrors of religious persecution. Push factors for modern migration in the 21st century include people fleeing conflict and poverty (Phillimore, 2011).

Nigeria is a country that has witnessed a massive emigration of its people, beginning in the 1950s and continuing today. Nigeria is a former British colony located in the Western part of Africa. Before the British arrived, the region comprised various flourishing empires and kingdoms, such as Benin, Oyo and the Hausa Caliphate. Nigeria has three major tribes: Igbo, Hausa and Yoruba, but there are hundreds of other ethnic groups in the country. The British, upon arrival, made laws in 1914 that forcefully amalgamated the distinct tribes into one major state (Crowder, 1966).

Subsequently, the British introduced their way of life to the people through education, culture and religion, and Nigerians were encouraged to forego their indigenous practices and embrace the British culture. At some point, there was a need for more people to access tertiary education abroad, as the universities built by the British were few and could not meet the demand. Therefore, the migration of students from Nigeria seeking higher education in the UK, which the British encouraged by giving scholarships, commenced (Anouyuo-Nwaenyi, 2009).

Another phenomenon that preceded a large influx of migrants from Nigeria to Britain was the Nigerian Civil War of 1967-1970, a secessionist movement that sought to make the Biafran region autonomous from Nigeria. It was the first modern civil war in sub-Saharan Africa after independence and one of the bloodiest (Akresh et al., 2017). From the early Eighties to the present day, Nigerian migration to the UK has been predominantly economic in nature, comprising mostly educated Nigerians who are frustrated by the decline in education, health and security systems – the result of incompetent and corrupt political leadership.

One of the challenges of immigration in host countries is the lack of integration among the various cultures. The migrant, on their own part, may find it difficult to adjust to their new environment (Lazarus & Folkman, 1984). The pressure of adapting to and trying to become part of a different culture could put a strain on the relationship between the migrant and their host. As a result, this could impact how migrants access support systems, such as healthcare. This could be one of the reasons for health inequality in many host countries.

Some scholars argue that in many cases, the health conditions of migrants are impaired before leaving their home countries; for example, the trauma of fleeing a war-torn nation can create mental health issues, which, in turn, can contribute to the demand for health care in host countries. Examples are studies about health inequalities between Eastern European immigrants and German citizens and health inequalities in the UK (Burnett & Pell, 2001; Ronellenfitsch & Razum, 2004).

As previously noted, various factors influence how migrants seek or access medical care in the UK. Research shows that many people from BME communities depend on their cultural and religious beliefs when faced with health challenges (Aldwin, 1994). In their home countries, it is common for people of African descent to seek 'spiritual' help from healers or spiritualists; these are acceptable healthcare support systems (James & Gashinki, 2006). It is, therefore, not surprising that Nigerian immigrants, even in their Western host countries, continue with such practices.

It is important to cater for the cultural and religious beliefs of a group because such beliefs are ingrained; they are what make a people unique. Nevertheless, in the case of dementia, particularly frontotemporal dementia, where early diagnosis is key, such practices may be a deterrent to adequate care for PWD. Recently, there has been a breakthrough in early diagnosis of frontotemporal dementia in the UK; it was grossly misdiagnosed in the past because FTD symptoms are known to mimic other conditions such as depression, schizophrenia, bipolar affective disorder or chronic stress (Valekoulis et al., 2009).

In many Nigerian immigrants and other BME communities, many people with dementia do not access adequate care systems. Research shows that this is influenced by traditional health practices and cultural values (Sackett et al., 2014). Scholars have shown that in many immigrant communities, people use a combination of both traditional and Western medicine (Kraut, 1990). Symptoms such as psychosis are still seen as a 'spiritual or demonic attack', and people tend to seek the services of healers instead of conventional medicine (Redbridge CVS, 2008). Research also shows that many health facilities are not well utilised (Olujimi, 2006), despite the efforts made by the government through the NHS and community programs. As a Nigerian immigrant, I am only too familiar with these issues.

This thesis aims not to criticise a particular religious or cultural belief. I am a Christian who believes in 'divine' intervention through prayer, though not to the exclusion of modern medicine. I aim to seek ways by which an awareness of FTD could be raised among the Nigerian immigrant community; this could help to address the dangers of late diagnosis. Although this thesis will focus on a particular BME community in the UK, the aim is that it will be a microcosm in the area of access to healthcare services for a wider community of minority ethnic people in the UK, US and other European countries.

The findings of this research could be used, for example, in some indigenous contexts. As I am conducting this research at the University of Lapland in Finland, I also found it natural to familiarise myself with the local population. According to former studies, there are similarities between the BME communities in the UK and indigenous Saami people. The groups of indigenous people living in Finland, Norway, Sweden, Russia and Kola are called Sami. The population is estimated to be between 50,000 – 80,000, and Norway has the majority of Sami – approximately 40,000 people (Norway, 2010; Instituhtta, 2008). Studies show the prevalence of dementia among the Saami people is understudied; hence there are no estimates (Blix & Hamran, 2017). Scholars opine that among the Saami, dementia is largely underdiagnosed because they access health care at a much later stage. They are known to present more severe symptoms than other populations (Cooper et al., 2010); this could be because of late diagnosis of the illness.

Some scholars argue that Saami people use healthcare systems as much as other population groups (Gaski et al., 2011); however, research shows that compared with other Norwegian populations, Saami people are less satisfied with the quality of care they receive. Their reluctance to seek and accept help is based on socio-historical processes and cultural norms, interpersonal factors including healthcare professionals' cultural backgrounds and language competence (Blix & Hamran, 2017). For many service users, it is not just about what help is available to them but to whom they tell their stories.

Similar to the research about the reluctance of BME communities in the UK to access health care for dementia because of a long history of discrimination and style or approach to care, Saami people also have a long history of discrimination and colonialism in the region (Sarivaara et al., 2013), which sometimes creates a negative atmosphere that breeds lack of trust in the care system (Dyregrov et al., 2014). Nevertheless, rather than provide an exclusive care system for the Saami, the Norwegian government aims to integrate the Saami into the system (Utredninger, 1995). However, the Saami do not only rely on conventional medicine to care for their own people. They consult healers; it is important for them as a community (Nymo, 2015).

This thesis is not a comparative study of Nigerian immigrants and the Saami; however, I am highlighting the similarities in the reluctance of these two groups to access the dementia care system due to social, religious and cultural practices prevalent among the people. This could hinder appropriate care, which is important for early diagnosis of dementia. Amongst the Saami, traditional healers are considered important personalities in health care for the sick. Complementary and Alternative Medicine (CAM) is commonly used in Norway (Bakken et al., 2006), though some scholars may view it as traditional medicine.

Saami people are natural storytellers who communicate their strong beliefs in traditional healing or the power of the healers through oral tradition. Some scholars opine that the stories themselves have the power to heal (Negard, 2005). Research shows that many Saami people combine traditional healing with conventional healing, but they are reluctant to share this with their doctors, perhaps because of the fear that their condition may be seen as worse than it is (Kiil & Salamonsen, 2013). Similarly, a report shows that a group of BME patients in London refused to share details of their religious beliefs to avoid being sectioned (Copsey, 1997).

The efficacy of storytelling as a non-confrontational approach to raising awareness of health-related issues cannot be overemphasised. I aim to use autoethnography as a research methodology, focusing on art-based research through ethnodrama to communicate my findings. This will be in the form of a full-length play, and it will explore, in a creative way, the devastating effect of frontotemporal dementia, the importance of early diagnosis and the limitations of some religious or cultural practices that may hinder adequate care for people living with the condition.

The use of arts and humanities in dementia care is a recent development (Philips & Conn, 2009), but there are established research on the benefits of non-pharmacological interventions, such as art therapy, storytelling, music, diet and physical exercise. Some studies show the efficacy of non-pharmacological therapies, such as Cognitive Stimulation Therapy, as an intervention for dementia care (Olakehinde et al., 2019). Some of these interventions have been shown to reduce the behavioural and psychological symptoms of dementia (BPSD) (de Oliveira et al., 2015), improve mood and confidence (Young & Dinan, 1994), and help reduce daytime agitation and restlessness (Alessi et al., 1999). However, little research has been carried out on the effectiveness of these programs as an intervention in disease progression.

According to Dunbar et al. (2012), music performance, which includes dancing and singing, helps to release endorphins, whereas just listening to music does not have the same effect. Some scholars opine that engaging in percussion music, such as drumming, may result in cognitive enhancement. A 2014 study was published in the Journal of Huntington's Disease after two months of drumming intervention in Huntington's patients. The study provided preliminary evidence that drumming may enhance cognitive enhancement and improve callosum white matter microstructure (Metzler-Baddeley et al., 2014).

Research on the use of music therapy for people with Alzheimer's shows that it reduces their neuropsychiatric symptoms, with singing improving psychomotor speed (Satoh et al., 2015). However, a 42-week music therapy intervention program showed that the frequency and severity of agitation did not reduce (Ledger & Baker, 2007). There is evidence that lifestyle changes could positively affect cognitive decline; however, this evidence is mixed. Nevertheless, there are incidences reported in various countries that led researchers to believe that it is possible to reduce rates of dementia through lifestyle changes (Livingston et al., 2017, p. 4).

My thesis will creatively explore the devastating effect of frontotemporal dementia, the importance of early diagnosis and the limitations of some religious or cultural practices that may hinder adequate care for people living with FTD. The play will also explore non-pharmacological approaches to how PWD can be cared for in community settings. These approaches will be culturally relevant to BME communities. Art enables us as researchers to empathise with the experience of others through forms that are evocative and compelling. An art-based research approach utilises the expressive form to show qualities of life that impact the knowledge we create and how we live (Barone & Eisner, 2012).

FTD is still shrouded in mystery in many BME communities. Therefore, my thesis is important as it will inform these communities and provide information concerning the symptoms and services available for care. When people know more about the disease, early diagnosis, which is crucial, will be possible. This is not traditional ethnography research in which a scholar situates herself in a community and observes the group. This is autoethnography research in which I reflect on my work as a storyteller and writer and use the knowledge that I have gained to explore how to raise awareness about a critical health issue within my ethnic group.

Since the 1960s, the boundaries of what constitutes art or science research have been blurry; however, an important aspect of what makes a piece of work research can be found in the very definition of research. It is a process of perceiving phenomena and scrutinising the world in a way that allows it to be reexperienced (Barone & Eisner, 2012). Some critics say scientific research adheres to the word 'scrutinising', while art-based research is viewed as 'subjective' or lacking depth of scrutiny. Other critics argue that scrutinising happens when art-based researchers actively prepare for their creative pieces or production. For example, writers read historical documents and have conversations with subjects. Such attendance to and observation of the physical and social world is research (Barone & Eisner, 2012).

As an art-based researcher, my initial approach to this work was to be more observant of the beliefs about mental health issues within my community. I knew about the taboos and animist beliefs, but I needed to gain a deeper understanding of the root of some of these superstitions. As an insider, who is also an immigrant, I have experienced first-hand some of the challenges and limitations of access to culturally relevant healthcare provision for BME communities. I will explore some of these in this thesis.

I have also witnessed a diverse approach to the issue of dementia within my community. Some of these approaches are based on ignorance, religious beliefs and superstition. There is also a lack of awareness about FTD amongst many Nigerian immigrants; hence, when a person manifests symptoms, there is the likelihood that their family may put it down to a non-medical issue such as 'demonic oppression' and take steps to exorcise rather than seek medical help.

1.3 The researcher's position

In all the phases of a research process, including research question design, data collection and analysis, findings and conclusion, reflexivity is important (Bradbury-Jones, 2007; Guillemin & Gillam, 2004). Reflexivity is the process by which researchers create an internal dialogue with themselves and critically self-evaluate their own position within the research. It is also a process that allows them to acknowledge that such a position may affect the process and outcome of their research (Bradbury-Jones, 2007; Guillemin & Gillam, 2004; Pillow, 2003; Stronach et al., 2007). The subject of reflexivity is a critical component of qualitative research, especially as research methods continue to evolve and expand in methodologies such as autoethnography, reflexive ethnography, and autobiography (Wint, 2011).

Scholars opine that knowledge construction is not achieved in a singular way (Eisner, 2008). Knowledge creation is influenced by a researcher's position, and such positionality is also influenced by some personal characteristics, such as age, gender, race, immigration status, beliefs, biases and emotional responses to participants (Finlay, 2000; Hamzeh & Oliver, 2010; Horsburgh, 2003; Kosygina, 2005; Padgett, 2008). One cannot overemphasise the impact of these characteristics on research. For example, a researcher's race can impact the work because respondents may be more willing to share their experiences with a scholar they view as sympathetic to their plight (De Tona, 2006).

Beyond the obvious characteristics such as race or age, "the positionality of the researcher in relation to the data is based upon philosophical beliefs and assumptions accumulated throughout a lifetime which inhabit the unknowing mind of the researcher" (Pitard, 2017, pp.1-2). As a Nigerian immigrant living in the UK, I am qualified to create my play from an insider point of view because I understand the challenges and experiences of the people in my community and can provide culturally appropriate education through my findings. Research shows that people in BME communities wish to see more scholars and healthcare providers from similar ethnic backgrounds at the forefront of care because they can make better judgements about their needs (Malat et al., 2010). Having said that, the notion of being an 'insider' has been questioned in terms of the authenticity and objectivity of the researcher (Chammas, 2020; Labaree, 2002).

Scholars argue that being an outsider might be more advantageous because an outsider could view things overlooked or taken for granted by the insider. However, being an insider or an outsider is seen by some scholars as complex; hence, the importance of seeing positionality as ever-shifting and permeable (Naples, 1996). My positionality in this research is that of an insider because I focus on Nigerian immigrants. Perhaps, if I were to travel back to Nigeria to work with people in their own country, in West Africa, that positionality might be blurred, and I may be an in-between researcher, who is an immigrant, living in Western culture and investigating a phenomenon in African culture. That blurred positionality would give me the benefits of being both an insider and an outsider (Ergun & Erdemir, 2010).

In this study, firstly, I am an art-based researcher who understands the role of art in creating meaning. Secondly, I am an autoethnographer who aims to deconstruct dominant narratives while simultaneously exploring unique outcomes. I continue to self-monitor the impact of my beliefs and personal experiences on my research, to maintain the balance between the personal and the universal (Berger, 2013). One way by which I have been able to maintain this balance is through reflective practice.

As a storyteller, I understand the power of narratives in bringing communities together to reflect on their values and beliefs. I have told stories professionally in the UK for twenty years. I perform stories on stage and encourage my audience to join me in chants and music as we explore various stories. I have witnessed the power of storytelling in creating awareness, educating people, challenging negative belief systems and celebrating diversity. Storytelling provides a rich source of insight into a society's present cultural and social issues (Janet, 2005).

As a researcher, I watched documentaries on dementia and listened to stories of people living with various forms of dementia. This informed my practice and created more compassion for PWD. It also helped me to understand how empathy embodies everything I did as a practitioner. It is a process that enables me to better understand myself and how I connect with others in my working environment (Hunt, 1998). Scholars have reviewed strategies for maintaining reflectivity. These include triangulation, peer review, journaling or keeping a diary and conducting repeated interviews with the same participants (Frisina, 2006; Padgett, 2008; Smith, 1999; Ahern, 1999).

My personal journey through health challenges and finding pathways to healing creates an empathic insight into how I approach the writing of my thesis. Researchers suggest that art-based research is a cyclical process whereby research leads to development. It involves reflective observation, planning, theoretical background work and artistic work, after which the results are documented as research material (Jokela & Huhmarniemi, 2018).

I choose to present my findings in a creative art form because 'academic' forms of writing that are deemed acceptable do not always represent the complexity of the human experience. Having said that, one of the critiques of creative art forms such as storytelling in research is that it runs the risk of being subjective. This is because of the dichotomy created in research concerning 'theory versus story'. This dichotomy should not necessarily exist because they are not mutually exclusive. Pollock (2006) describes it as doing theory and thinking stories.

In this work, I do not use theory as a mere add-on. Firstly, I engage with the theory behind storytelling and dementia and interpret my data using a dramatic storytelling form. I then critically evaluate the play by using theory to ask questions about the validity of my story and the experiences presented. Borrowing from Pollock's idea, this is the way I *do* theory and *think* stories. Throughout my thesis, I engage with both by citing pertinent theoretical texts. This gives credibility to my work and shows the relationship between theory and story.

Furthermore, my aim for this work is transformative; those who engage with my play will better understand what FTD is and see its devastating effect on families. In our research stories, when we show our audience how ordinary people cope with difficult experiences, they can also consider important aspects of their own lives (Bochner, 2012). This is one of the reasons I chose to explore ethnodrama to show my audience the stumbling blocks to early diagnosis of FTD. When the audience engages with the play, the aim is for them to empathise by putting themselves in the place of others (Jackson, 1995). They would experience, through storytelling, what life living with FTD is like and how important it is to seek help.

My journey as an autoethnography researcher did not start as a scientific quest. Eight years ago, I started journaling my experience of battling perimenopause symptoms. The issues started as hot flushes but soon intensified into multiple symptoms that began to impact my life. I started having insomnia, brain fog, heart palpitations and numerous other issues. I went to my General Practitioner (GP) regularly, especially when anaemia became a compounding problem due to a heavy monthly period. However, the offers I received from my GP, which included Endometrial Ablation surgery and HRT (Hormone Replacement Therapy), were not the options I was willing to consider. I had heard about HRT and its negative effects, so my response was, "No, I do not want HRT. Are there natural ways by which I can overcome these issues?"

What I initially found frustrating was the lack of adequate information about perimenopause. There were numerous books and articles about menopause, but as for perimenopause, information was sparse. Through independent research, I found out that my symptoms were because of that season of my life. I just thought I was very unwell and had no clue why the symptoms were occurring simultaneously. Another interesting thing I discovered was that these symptoms had roots; they were not just there for the entire perimenopause journey. I found that I could heal my body and be well again.

At that time, I discovered many women were not ready to discuss perimenopause issues. I joined several online groups to get a glimpse of how other women were dealing with the symptoms; however, the majority of sites I found were 'pity-party' communities. I did not need that. I wanted to find a way out of being unwell. However, perimenopause issues were not the only problems I was battling with. In 2016, I was diagnosed with osteoarthritis. After requesting a second opinion and x-rays, I was told to use Ibuprofen, which had no effect on my condition. I was told osteoarthritis had no cure, and it was degenerative.

I embarked on ploughing through websites, books and YouTube videos in search of answers. I sought a natural cure or anything that could give me relief but could not find what really worked. I began to sink deeper into despondency and hopelessness. At that moment, I decided to revisit my cultural roots. Unfortunately, when my symptoms were really bad, my mother had passed away, and I was not close to some of my aunts who were still alive. However, memory is a powerful thing. I recalled my mother's voice during our conversations and evening prayers when she was alive. Her message was always laced with hope and faith. Day and night, as I prayed, my late mother's voice mingled with my thoughts, and I started having faith that I would be okay soon.

The first ray of hope for me came one day after I had left my job as a lecturer to spend some time healing. I left because my insomnia was so bad I sometimes dozed off in class, and it was impacting my work. However, that day, I managed to convince myself that I would be well again. At that time, I did not understand how or why my mind got into that mode, but what I knew was that for the first time in many months, I got up from my meditation smiling, and I put some uplifting music on and danced. I had not done that in ages because I was always fearful that things would only get worse.

A few days later, I found some articles on the power of the imagination and how each person can use it for their well-being. I also found some articles on how to use herbs and vitamins such as B12, C, D and K. I found more information and learned how to prepare simple vegetable and fruit juices and healthy smoothies and do regular gentle exercises. I learned about good sleep hygiene, eating healthily and being positive. As I created in my mind the picture of a healthy, energetic and healed me, most of the symptoms gradually disappeared.

In my journal, I wrote freely about each day, what I learned and how I am using my new knowledge. The art of journaling is self-narrative; this helps people create meaning from life events (Gergen & Gergen, 1988). Scholars argue that when we put emotional experiences into words, we can improve our mental health significantly, even for just 15 minutes a day (Gergen & Gergen, 1988; Pennebaker et al., 1999). The journal became very useful when I wrote my book 'Dear Toriola: Let's Talk About Perimenopause'.

Initially, I found the lack of information on how a woman can heal her body holistically very frustrating. Although I was a regular patient at my GP surgery, none of the medical advice was helpful for me personally. I was not interested in HRT or the continuous use of painkillers, which did nothing to alleviate the arthritic pain I suffered in addition to a mirage of symptoms. That was why I embarked on a personal journey that led me to a breakthrough. About six months after I felt much better, I went for a blood test, and my GP was shocked to see that I no longer had anaemia and some of the other symptoms. I tried to explain what I had been doing holistically and spiritually, but he dismissed me rather rudely. In fact, I left the GP surgery embarrassed that I had even opened my mouth to discuss my 'unconventional' pathway to wholeness.

However, I decided to share my experience with other women, not only in my immigrant community but around the world. For the book, the style I used is called epistolary. I created two fictional characters – friends – who lived on different continents and communicated by writing letters to each other. Through the narrative of the two women, my readers are able to learn about holistic approaches to overcoming perimenopausal symptoms.

One of the challenges I had to overcome when writing 'Dear Toriola' was the ethical issue of writing a narrative involving others, such as family members or friends. Several times during my writing, I stopped to evaluate these ethical issues and critique my work in that light. Reflexivity helps researchers to explore ways in which the influence of a study acts upon and informs the research (Nightingale & Cromby, 1999). This reflection led me to create fictionalised accounts, altering dates, times and identities of people. Autoethnography is a form of self-narrative that “critiques the situatedness of self with others in social contexts” (Spry, 2001, p. 710).

The book was published in 2019, and judging by the reviews, it seemed I achieved my aim of writing a book that women going through mid-life challenges find useful. The book is a fictional autobiography, which some scholars refer to as autofiction. I wrote the book about my experiences of battling with perimenopause issues retroactively and selectively. When I wrote the journals, it was not with the view of publishing them; hence when I consulted my journals to aid recall, I did it using hindsight (Bruner, 1993). More importantly, writing the story of my journey of how I brought my body back to homoeostasis deconstructs the dominant allopathy narrative that perimenopause issues are mainly about a woman’s hormones, and there are treatments just for such. My healing journey started when I began to deeply acknowledge that I am not just physical, but I have a spirit and a soul.

When I started my PhD, I revisited the process of writing my book ‘Dear Toriola’ because the aim of my thesis is similar. My quest is to find the most effective way to create awareness for frontotemporal dementia among Nigerian immigrants living in the UK while deconstructing the dominant narrative that BME communities are hard to reach. Statistics show that ethnicity can be a significant factor in the extent to which dementia is understood (Department of Health, National Dementia Strategy, 2009).

There is an urgent need to develop public information campaigns to support the current UK National Dementia Strategy. There is also a need to reanalyse current services for PWD and their carers to determine if these services take cultural differences into account (Department of Health, National Dementia Strategy, 2009). Researchers have acknowledged that there are gaps in our knowledge about minority groups and developing regions, and there is a need for descriptive population studies to fill these gaps (Onyike & Diehl-Schmid, 2013).

When I started searching for information about the prevalence of FTD among Nigerians and other BME communities, I could not find any information. However, a further search resulted in a UK report about dementia in general, focusing on PWD in BME communities instead of frontotemporal dementia. Nevertheless, it is one of the very few reports conducted in England by the Bristol BME Dementia Research Group investigating why the needs of PWD from Caribbean, South Asian and Chinese communities in Bristol are not adequately met. There was no one from Nigerian or African communities represented in this report.

The researchers addressed issues such as late diagnosis and inadequate service provision. The group found that contrary to the belief that BME communities are ‘unreachable’, the people were more likely to use services that were BME-led because they felt they could better meet their needs. The study highlights the need for more researchers from BME communities to be present in dementia research. It also addressed the issue of dementia being a stigmatised condition among BME communities, and this could hinder PWD in these communities from utilising mainstream care services (Bristol BME People and Dementia research group, 2017).

The UK 2011 Census indicates that the number of PWD in the BME community is increasing, but the understanding of dementia is limited. Also, BME communities have historically been marginalised from strategic health initiatives (Truswell, 2011). Nigerian immigrants are part of the BME communities in the UK, but statistics about the number of Nigerian immigrants living with dementia in the UK are non-existent; hence I will rely on data from other BME groups in the UK and the United States. Dementia has no respect for age, ethnicity or race. It affects people from all ethnic groups. In England, it is estimated that about 25,000 people from BME groups are affected by one form of dementia or another. That is huge when compared with the total number of ethnic minority groups in England, which is 9% of the population (NHS UK, 2011 Census).

Even though illness is a complex issue, BME groups have poorer health than the majority of white British because of direct and indirect discrimination, differential access to health-promoting resources, migration, genetic factors and cultural practices (Turner et al., 2012). Additionally, within the Nigerian diaspora community, many people are in denial of frontotemporal dementia for many reasons: cultural, religious and personal beliefs, to name a few. I wrote a full-length play, ‘*My Name is Beatrice*’, to address these issues, and I will explore them further in this thesis.

2. OVERVIEW OF DEFINITIONS AND ART BASED APPROACH TO DEMENTIA

In this chapter, I will provide a review of dementia and frontotemporal dementia. In addition to the definition, my focus will be on types of dementia, how the condition is diagnosed, the quality of life for people living with dementia and the efficacy of storytelling and drama in raising awareness of dementia.

2.1 Definition of Dementia

The term dementia is used to describe progressive impairment of thinking and memory that interferes with daily function. It is a complex disease that causes shrinkage in the hippocampus (McKeith et al., 2001) and carries a set of symptoms that include loss of memory and other intellectual abilities. Although it tends to affect older people, it is not a part of normal ageing. Dementia is not a specific disorder. It is a condition with many causes, and Alzheimer's disease is the most common cause of dementia. There are other causes which include frontotemporal dementia – a behavioural variant, vascular dementia, dementia with Lewy bodies and a few others that I will examine in this chapter.

According to the World Health Organisation, dementia is a syndrome caused by brain disease, usually of a chronic and progressive nature, in which there is the disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning, capacity, language and judgement (WHO, 1992). At the onset, some of the symptoms may be insignificant; however, as the disease progresses, the symptoms worsen and become severe enough to interfere with daily life or personal activities, such as cooking, eating, washing and personal hygiene.

There are historical references that reveal the complexity of dementia, which is not only limited to cognitive decline. Alois Alzheimer described the behaviour of one of his patients, a 51-year-old woman, in his writing. According to him, the woman had memory and behavioural problems; she was delusional and was hallucinating (Alzheimer, 1907). The emphasis on cognitive decline as a main focus for dementia came about during the eighteenth and nineteenth centuries. Berrios called this the cognitive paradigm – the view that an impairment of cognition is sufficient to define dementia (Berrios, 1987).

Dementia could start when the brain is damaged by diseases such as Alzheimer's or a series of strokes. Dementia is a collection of symptoms and other features that co-exist to form a recognised pattern. The term dementia is used to describe certain clinical symptoms that occur when the brain is affected by specific diseases and conditions. Symptoms depend on which part of the brain is damaged and which disease is causing dementia (Alzheimer's Society, 2017, p. 2).

People are diagnosed when the development of multiple cognitive deficits is severe enough to interfere with daily functioning. Some cognitive deficits that PWD experience include memory impairment and at least one of the other cognitive domains, including agnosia, apraxia, aphasia or executive functioning disturbances (American Psychiatric Association, 1987). Often, people with dementia experience mood changes; they could be apprehensive, irritable or withdrawn. Visual hallucination is also a common symptom of some types of dementia. Dementia is a progressive and degenerative condition, though the speed of degeneration depends on the individual. As the condition worsens, some people behave in a way that carers may see as 'out of character', such as repetitive questions, agitation or restlessness (Alzheimer's Society, 2017, p. 3).

Worldwide, researchers are interested in the prevalence of dementia because of the phenomenon of ageing populations. One of the reasons why dementia is a topical issue for various governments is because they want to commit to actions, such as prevention and reduction of risk factors, early intervention, care plans and cost. Close to 50 million people worldwide live with dementia. This is projected to double every 20 years (Alzheimer's Disease International (ADI), 2017). In the UK, the Alzheimer's Society reported that dementia currently affects about 850,000 people, and it is estimated that by 2025 the number will rise to over 1 million.

In both developed and developing countries, the challenges of coping with chronic conditions such as dementia are likely to dramatically affect public health delivery, care and funding (Bennett, 2007). These conditions do not only have financial implications, but they also impact the social, psychological and physical well-being of the sufferers and their carers.

Researchers have opined that the prevalence of dementia in the population might be subject to change. Some factors that might increase prevalence include obesity, inactivity, diabetes and people living longer. However, this has been challenged by researchers who suggest that in higher-income countries, there might be a decrease in the prevalence of dementia and severe cognitive impairment (Matthews et al., 2013). Some researchers have associated this decrease with a major reduction in risk factors, such as diabetes, stroke and vascular diseases, factors modified by societal changes and improvements in education and prevention strategies in recent years (Capewell & O'Flaherty, 2011).

2.2 Types of Dementia

Frontotemporal Dementia and how it affects quality of life

Frontotemporal dementia, also known as Picks' disease, is a progressive type of dementia that occurs in mid-life, usually between 50 and 65, but there are also cases found in people as young as 45. Frontotemporal dementia occurs when the nerve cells in the frontal and or temporal lobes of the brain die and the pathways that connect the lobes change (Alzheimer's Society, 2016). The frontal lobe is found behind the forehead, and it is associated with behaviour, control of emotions, problem-solving and planning, while the temporal lobes are found on either side of the brain. The left side is associated with word meanings and names of objects, while the right side is associated with face and familiar object recognition.

The variants of FTD are behavioural and language. The behavioural variant accounts for nearly 60% of cases, with the language variants less common (Onyike & Diehl-Schmid, 2013). The progression of this type of dementia is slow, and symptoms include personality and behavioural changes, social deterioration, and impairment of language functions and intellect. The symptoms of FTD vary. Memory loss is often associated with other forms of dementia, such as Alzheimer's. The neuropathology of FTD is more of selective atrophy of the frontal and temporal lobes without the occurrence of plaques and neurofibrillary tangles seen in normal ageing. However, as the disease progresses, memory loss occurs (WHO, 1992; Alzheimer's Society, 2016).

The exact prevalence of frontotemporal dementia is still unknown, although some studies estimate that FTD accounts for about 8% of people with dementia (Journal of Neurology, Neurosurgery and Psychiatry, 1994). There has been an accumulation of data about FTD from population studies in the United Kingdom (Harvey et al., 2003; Barker & Brayne, 2008; Dawson & Hodges, 2002), Canada (Feldman et al., 2003), Spain (Garre-Olmo et al., 2010) and the United States (Knopman et al., 2004). However, in these surveys, more than 95% of subjects were Caucasian, which means non-white populations were underrepresented (Onyike & Diehl-Schmid, 2013). Worldwide, among people of African descent, there have been few descriptions of frontotemporal syndromes (Onyike et al., 2021).

Unfortunately, there are still no disease-modifying treatments for frontotemporal dementia. There are continuous efforts in drug trials, but these have yielded disappointing results (Ahmed et al., 2021). Frontotemporal dementia is also categorised as 'Young Onset Dementia'; this category of dementia is defined as beginning before age 65, and it is rarer than late-onset dementia (Harvey, 1998). Some researchers suggest it is the second most common cause of Young Onset Dementia (Ratnavalli et al., 2002). That is not to say that FTD does not occur in the over-60s and the elderly. Studies reveal that FTD is also frequent among elderly people in countries in Latin America (Herrera et al., 2002). However, in the young-onset group, the number of people with FTD is higher than among the older people who develop dementia.

This could also mean that the social and psychological needs of people with FTD differ from those of older people with dementia (Cox & Keady, 1999). Many people with FTD have children living at home with them, unlike older people whose children may have left home. Many children, who are also carers for their parents, who have FTD, suffer emotional trauma because of some of the symptoms associated with the disease. In a study, Luscombe et al. (1998) revealed that many of these children experience stigma, shame and bewilderment because of their parent's condition. Some adolescents whose parents suffer from FTD can also be at risk of social and emotional difficulties, which may be unnerving because of their fear of the disease (Allen et al., 2009).

Allen et al. (2009) discussed their findings about the various aspects of dementia that impacted the well-being of their subjects, who were the children of people with young-onset dementia. Five areas were identified: changes in behaviour, delay in diagnosis, difficult behaviour, parent's safety and understanding of the illness. Many young people notice their parents' changes in behaviour, but in cases of FTD, these behaviours can easily be dismissed by the parent, which could cause the young person to also overlook them. However, if these changes are rapid and unbecoming of the person with the disease, the family is affected.

Another challenge that FTD poses is a delay in diagnosis. FTD symptoms are known to mimic other conditions such as depression, schizophrenia, bipolar affective disorder or chronic stress (Valekoulis et al., 2009); hence, in many cases, the illness can be misdiagnosed. In many clinical settings, Frontal Behavioural Inventory (FBI), a neurobehavioral tool, is used to distinguish FTD from other forms of dementia (Milan et al., 2008). There are now centres for FTD where a diagnosis is more effectively attempted. However, many BME families do not avail themselves of these services because issues like FTD can be dismissed as other conditions, such as acute stress. Also, many are not aware that the disease even exists, so they do not know what to look for or how best to seek help.

One of the symptoms that families find most distressing is difficult behaviour. It is common for people with FTD to have disinhibition, aggression and incontinence. What makes these more distressing is that the parent experiencing these symptoms was often never like that before their illness. It is common for many families to source their information from the Internet and professionals (Allen et al., 2009).

Progression of FTD is slow, and symptoms include personality and behavioural changes, social deterioration and impairment of language functions. This makes the disease more devastating for families, especially those who have young children. My aim in undertaking this research is to investigate how to raise awareness of FTD, alleviate the trauma of people with the disease, and highlight the importance of seeking professional help. Presently, FTD, like all other dementias, has no cure; nevertheless, the quality of life of PWD can be enhanced with the help of their families and care team.

Alzheimer's disease

Alzheimer's is the most common type of dementia in elderly people, and it is responsible for 60-70% of cases (Fratiglioni et al., 2007). Mixed dementia is also very common with PWD. This happens when there is a combination of Alzheimer's and other forms of pathology; a common one is vascular dementia. The diagnosis of Alzheimer's is neuropathological, and it is determined by the presence of neurofibrillary tangles and senile plaques in the brains of PWD (Xu et al., 2013). The onset of Alzheimer's can be early (before the age of 65-70) or late. With the former, there is the likelihood of a family history of similar dementia, and with the latter, the disease is slower and characterised by a more general impairment of higher cortical functions (WHO, 1992).

People diagnosed with Alzheimer's present with brain changes, including a reduction in neuron population in the hippocampus, substantia innominata, locus ceruleus and temporoparietal and frontal cortex. There is also the appearance of neurofibrillary tangles made of amyloid plaques, although plaques without amyloid also exist (WHO, 1992). Alzheimer's was discovered over 100 years ago by Alois Alzheimer's, a German psychiatrist (Maurer et al., 1997). While many of the causes of the disease are still unknown, there are hereditary forms of the condition.

The symptoms of Alzheimer's vary from person to person, but the most common is the gradual decline in sufferers' ability to remember new information. As the disease progresses, cognitive and functional abilities decline in PWD. Other challenges such as planning activities, confusion about time and date, mood swings and poor judgment make the individual more vulnerable and dependent on carers for daily care such as feeding and hygiene. People in the final stages require round-the-clock care; they lose the ability to communicate and fail to recognise loved ones (Xu et al., 2013).

Vascular dementia

Vascular dementia is the second most common form of dementia, caused by the reduced blood supply to the brain due to diseased blood vessels, which leads to reduced neuronal function, resulting in the death of brain cells (Dening & Babu Sandilyan, 2015). The neural network that delivers blood to the brain is called the vascular system; hence damage to this system within the brain, leading to leakage or blockage, means the blood cannot reach the brain cells, and they eventually die. This causes problems with cognition, that is, thinking, reasoning and memory. Vascular dementia occurs when these cognitive problems are bad enough to impact daily life significantly (Alzheimer's Society, 2014).

There are various types of vascular dementia: acute stroke-related, multiple-infarct and subcortical vascular dementia. Acute stroke-related vascular dementia develops rapidly after a succession of strokes, although not everyone that has a stroke develops vascular dementia (WHO, 1992). Multiple-infarct dementia is more gradual than the acute type. It happens after transient ischaemic attacks (TIA). The symptoms of these mini-strokes last for less than 24 hours. Subcortical vascular dementia is a common form of dementia caused by small vessel diseases. This happens when blood flows through the small vessels and is reduced, causing them to develop thick walls and become twisted (Alzheimer's Society, 2014).

Rarer types of dementia

There are also rarer types of dementia worth mentioning in this chapter. In the UK, rarer types of dementia account for around 5% of all cases of dementia (Alzheimer's Society, 2015). One such type is corticobasal degeneration (CBD). This disorder is challenging to diagnose before death because of the way it presents with multiple phenotypes. Presently, there is genetic evidence supporting the microtubule-associated protein tau (Grijalvo-Perez & Litvan, 2014). CBD causes brain shrinkage, which affects the cortex and basal ganglia. The typical age of sufferers is between 60 and 80. Initial symptoms include movement issues such as stiffness and jerkiness in the limbs and 'alien hand syndrome' whereby the person affected cannot control hand movement on one side. In the advanced stages of CBD, sufferers develop memory, balance, speaking and swallowing problems (Alzheimer's Society, 2015).

Another rare type of dementia is Creutzfeldt-Jacob Dementia (CJD). This form of dementia was discovered by Hans Gerhard Creutzfeldt, a German neurologist, in 1920 and later by Alfons Maria Jakob. CJD is a rapidly progressive neurodegenerative disorder that can lead to death within 6 months to 2 years of diagnosis. It is estimated that the disease affects one in 1 million people. It is caused by a prion, an abnormally shaped protein infecting the brain (Alzheimer's Society, 2015; WHO, 1992). At the onset of the disease, people may experience minor memory lapses and clumsiness. The disease rapidly progresses to limb stiffness, shakiness, loss of speech and inability to connect with their environment.

Human immunodeficiency virus (HIV) can also cause some problems in the brain, known as HIV-Associated Neurocognitive Disorder (HAND). These include problems with thinking and reasoning, although these symptoms do not always lead to dementia. Before people with HIV started using antiretroviral drugs, about 20-30% of people in advanced stages developed dementia. Today, the figure is around 2%. This is because modern treatment can reverse cognitive damage caused by HIV or prevent the impairment from getting worse (Alzheimer's Society, 2015). Some researchers have a different opinion, in that despite these antiretroviral drugs, the neurocognitive disorder is still prevalent and remains a major challenge for people living with HIV (Sacktor & Robertson, 2014).

Dementia and other cognitive difficulties also occur in about 50% of people with Huntington's disease (Zarowitz et al., 2014). Huntington's is a degenerative disease transmitted by a single autosomal dominant gene. Progression is slow, but death may occur within 10-15 years of diagnosis (WHO, 1992). It is characterised by jerky and rigid movements, cognitive degeneration and personality change. The condition occurs most frequently between 30 and 50 years of age, with the juvenile onset seen in about 4-10% of cases (Quarrell et al., 2012), while 20% have onset at over 50 years of age (Bloch, 2014).

2.3 Diagnosis of dementia

Dementia diagnosis in the UK is based on a combination of tests and assessments carried out in a GP surgery or by specialists in a hospital. PWD are usually advised to attend such meetings with their carers or family. Doctors obtain key information such as when symptoms started, how they are affecting daily life and any existing conditions or comorbidity, for example, diabetes, cardiovascular disease, depression or stroke. They also want to know if these are managed properly and what medication the patient is taking.

There are several factors that inhibit early diagnosis of dementia. As aforementioned, the symptoms of dementia may present as other diseases. For example, changes in mood and personality may lead the physician to diagnose the patient as having depression instead of dementia (Vernooij-Dassen et al., 2005). Social aspects of dementia are also a factor that can impede early diagnosis. This is prevalent in many developing countries, such as West Africa, where people still view dementia as a part of 'normal ageing' rather than a disease.

In many developed countries, similar issues are prevalent, as carers and family doctors are hesitant to diagnose a person with dementia because of the stigma and complexity of the disease (Downs & Bowers, 2008). An example of such is found in an Italian study carried out by Antonelli et al. (1992). In a rural community, dementia diagnosis in older people is left until the time when the family economy is disrupted because of the cognitive losses of PWD. Such was the respect given to elderly people in the community that families continue to support the elderly until they can take time off their own work to care for them.

Also, the varying development of dementia can make it difficult for healthcare practitioners to recognise the syndrome (Iliffe et al., 2009). In many healthcare settings, finding the delicate balance between mild cognitive issues and dementia could be a challenge. The difficulties associated with early diagnosis create the need for the provision of more educational programs for healthcare providers on skills needed for diagnosis.

There are some prevalent brief screening tests for assessing cognitive function. These include the General Practitioner Assessment of Cognition (GP-COG), Mini-Cog Assessment Instrument, Memory Impairment Screen (MIS), Six item Cognitive Impairments Test (6CIT), Mini-mental State Examination (MMSE), Memory Alteration Test (MAT) – this is a test for verbal, episodic and semantic memory and it helps to distinguish early Alzheimer's disease from mild cognitive impairment (MCI) Assessment Instrument, Memory Impairment Screen (MIS), 6-item Cognitive Impairment Test (6CIT), Mini-mental State Examination (MMSE), Memory Alteration Test (MAT) – this is a test for verbal, episodic and semantic memory and helps to distinguish early Alzheimer's disease from mild cognitive impairment (MCI) (Ilife et al., 2009).

Diagnostic tests include:

Blood Tests

GPs usually arrange for blood tests in order to exclude other diseases that can be confused with dementia. These blood tests usually check kidney, liver and thyroid function, haemoglobin A1c (to check for diabetes) and vitamin B12 and folate levels.

Brain Scans

These are often used after simpler tests have eliminated other issues. However, brain scans on their own are not used to diagnose dementia but as part of the wider assessment. Sometimes these scans may not show obvious changes, but it does not mean that a person does not have dementia. Some of the scans used are: MRI Scan – helpful in showing the disease causing dementia; CT Scan – used to check for signs of brain tumour or stroke; SPECT and PET Scans – these can show abnormalities in the blood flow in the brain and can also show how the brain functions.

Cognitive Assessment

Doctors conduct these tests to assess mental abilities, such as thinking or memory. These do not diagnose dementia, but they can indicate whether a person has memory problems that need further investigation. A person's level of education may influence the scores. For example, a person who is not numerate or literate may have a lower score but may not have dementia. In contrast, a person with a higher education level may achieve a higher score but may have dementia. Specialists use a number of cognitive tests to assess different mental abilities, such as short or long-term memory, attention span and concentration, communication skills, language skills and orientation.

The aforementioned tools are good, but they indicate a linear diagnosis process, whereby testing is done for an individual, and treatment commences once tests indicate the person has dementia. However, due to the complexity of the disease, a more robust and holistic method of diagnosing is needed because other symptoms may be in full swing before the person and their carers notice a cognitive decline. An approach whereby doctors consult with carers and examine patients' stories of emerging symptoms using 'illness scripts' are a better non-linear structure for diagnosing long-term chronic diseases such as dementia. That means the diagnosis journey does not start with testing but an analysis of a patient's narrative of illness, and this is not done in one consultation but over several (Iliffe et al., 2009).

2.4 Quality of life and dementia

The term Quality of Life (QoL) is subjective and cannot be defined in simple terms because it differs from person to person. For one individual, quality of life may be taking an evening stroll by a beach; for another, it is simply having a quiet meal with a loved one. For some, it is listening to their favourite music, while another person may view QoL as sitting on a front porch to enjoy the sunset. Nevertheless, there have been theories about positive psychological interventions and the creation of well-being (Rusk & Waters, 2015).

There are many competing theories about what constitutes well-being, and there is no resolution to these debates presently or in the nearest future. Scholars opine that although pluralism in the definition of well-being is inevitable, the notion of well-being is still similar across some theories, but it depends on the context in which the notion is assessed (Alexandrova, 2017). Some scholars make a distinction between different well-being theories. Parfit (1985) postulates three distinctions: Objective list theories that suggest some things are bad for people while certain things are good; Desire-fulfilment theories suggest that what fulfils a person's desires throughout his life are those things that are best for him; Hedonistic theories suggest that what makes someone's life happiest are those things that are best for him (Parfit, 1985).

For many years, societies have viewed well-being as crucial to the health and productivity of people. Hence, indicators such as life expectancy, income, environment, etc., are considered objective well-being. Policymakers consider GDP an indicator of their societies' well-being (Reinhart & Reinhart, 2010); however, scholars have denounced this as invalid because well-being is too complex to only be about material things. To this end, another theory emerged called subjective well-being. This theory suggests well-being is about how individuals perceive and experience their lives (Durand, 2015).

The field of subjective well-being (SWB) is wide and varied. One school of thought posits a eudemonic view that places importance on a person's potential (Vanhoutte & Nazroo, 2014), while another presents a hedonic view that emphasises an individual's sense of well-being, as indicated by feeling and thinking. Subjective well-being, according to the hedonic view, is based on the feeling that one's life is desirable irrespective of how other people see it (Diener, 2009).

In many countries, healthcare practitioners and researchers have focused on how best to support PWD to live well. However, the words 'Well-being' and 'Quality of Life' are used interchangeably in dementia research. Some researchers have challenged this usage, saying subjective well-being is not equivalent to QoL. Measuring well-being and or QoL has always been challenging when it comes to dementia because of the various school of thought. Nevertheless, some scientists say PWD are able to experience positive lived experiences (Woverson et al., 2016). There have been differing opinions on the items used for measuring QoL in dementia. Some authors argue that including cognition and physical functions that decline as the disease progresses automatically indicate that QoL declines (Rabins et al., 1999). This, however, prompts the question: is QoL only defined by cognitive and functional abilities? Can people who live with advanced dementia have a quality of life despite the decline in these domains?

World Health Organisation has defined QoL as the perception of an individual about their position in life in the context of their culture and value system in which they live, in relation to their goals, standards and concern (WHO, 1995). Researchers and specialists have debated the importance of measuring QoL in PWD for over a decade. In the process, they came up with various measures that were developed specifically for PWD. Some researchers say that measuring the quality of life of people with dementia will result in better-targeted care for those living with the condition (Comans et al., (2020). Some scholars are of the view that there are not many differences between QoL domains in people with Alzheimer's and those with FTD. Results show that people with Alzheimer's scored lower memory and higher on the friend's subscale. Aside from this, they found no difference in other items (Millenaar et al., 2017).

The model that has influenced many QoL researchers is Lawton's model of QoL. Lawton posited that when doing a QoL assessment, researchers should consider both subjective and objective factors in the following: psychological well-being, behavioural competence that included cognitive and functional abilities, objective environment and perceived QoL (Lawton, 1994). Since the emergence of Lawton's measurement, several researchers have attempted to translate and modify it, but many still rely on its structure. Some argued that it is too narrow, especially the inclusion of domains such as cognitive abilities that tend to decline as the condition worsens, which means QoL automatically nose dives with such decline. However, the topic of QoL in dementia continued to be of interest to researchers, and several scales and measures emerged over the years. An in-depth study of QoL measures was done by researchers (Ready & Ott, 2003), who reviewed nine dementia QoL scales in literature from 1966-2002. They excluded measures for

Parkinson's disease but included Alzheimer's and mixed dementia. I will examine these below:

Albert et al. – Affect and Activity Ratings (Albert et al., 1996). This incorporates activities and effects – domains that are observable and quantifiable. They are effective in the sense that they can be used for people with mild to advanced stages of dementia. The drawback, however, is that it is a rather narrow measuring scale focusing on two dimensions: activity and affect (Ready & Ott, 2003).

Alzheimer Disease Related Quality of Life (ADRQL) (Rabins et al., 1999). The development of this scale was guided by focus groups comprising PWD, carers and caregivers. It measures positive and negative behaviours across some important measurable domains, namely social interaction, self-awareness, feelings and mood, enjoyment of activities and response to surroundings. The downside to ADRQL is that there are hardly any published data regarding its psychometric characteristics, and there's no clarity as to where it can be used – in the home or institutional settings (Ready & Ott, 2003).

Cornell-Brown Scale for Quality of Life (CBS). This is a popular and widely used scale based on research that positive affect, physical and psychological satisfaction and an absence of negative affect can create high quality of life. Clinicians interview both carers and PWD jointly at various times over one month and incorporate their perspectives into one rating. According to (Ready & Ott, 2003), the scale ranges from -2 (negative pole anchor) to +2 (positive pole anchor), and total CBS scores can range from -38 to +38. The more negative the score, the poorer the QoL rating. Positive scores are obtained when positive ratings outweigh negative ratings and indicate higher QoL.

Dementia Care Mapping (DCM) (Fossey et al., 2002; Brooker et al., 1998; Beavis et al., 2002). The focus of DCM is people in care homes who cannot provide reliable responses about their situations, and it can be used with moderate to severely impaired patients. One of its strengths is that it is intensive, and specialists can rate patients' QoL indicators very regularly; for example, every 5 minutes over a 6-hour period (Beavis et al., 2002). The downside is that this may not be feasible for practitioners who are limited in time and resources.

Dementia Quality of Life (DQoL) (Brod et al., 1999; Burgener & Twigg, 2002; Burgener et al., 2002). This is a unique 29-item scale developed solely for patients without the input of carers or caregivers; hence it can only be for people with mild to moderate dementia. It measures five domains of quality of life: Positive Affect, Negative Affect, Feelings of Belonging, Self-esteem and Sense of Aesthetics (Ready & Ott, 2003).

Psychological Well-Being in Cognitively Impaired Persons (PWB-CIP) (Burgener & Twigg, 2002; Burgener et al., 2002). This is almost the opposite of DQoL in that it is observer-rated, measuring positive and negative affective states. The positive aspect of it is that because it is observer-rated, it can be used for people with severe dementia; however, on the negative side, its focus is narrow as it only takes into consideration affect and behaviour.

Quality of Life in Late-Stage Dementia (QUALID) Scale (Weiner et al., 2000). This is similar to Albert et al.'s rating scale, and it is used with patients with advanced dementia, rating activities and emotional states. Its positive aspect is that it is not as intensive as the others, and it is used in care home settings, where patients are observed for a week, and items are rated on a 5-point Likert scale. A technician can administer it within 5 minutes (Albert et al., 1996).

Quality of Life-Alzheimer's Disease (QoL-AD) (Logsdon et al., 1999; Logsdon et al., 2002). Researchers use a qualitative and quantitative approach in administering QoL-AD, in that both patients and carers are involved in the process; patients are interviewed while carers fill out questionnaires. The domains that the scale measures are quite broad: memory, mood, physical conditions, functional abilities, interpersonal relationships, ability to participate in meaningful activities, financial situation and global assessment of self and QoL as a whole (Ready & Ott, 2003).

*Quality of Life Assessment Schedule (QoLAS) (Selai et al., 200*1). Similar to QoL-AD, QoLAS employs both qualitative and quantitative methods; however, the difference that makes it unique is that it is only for patients, and carers do not get involved. It explores the domains of cognitive functions, physical, psychological and social functions and usual activities. Patients get to identify what is important for their quality of life, and they pick two issues from each of the aforementioned domains and rate on a 6-point scale how many problems they are experiencing with the issues they have identified. A higher score signals a poor QoL.

An important point to consider is the reliability of the measures, especially those that depend solely on patients' input. Many patients have moderate to advanced dementia; how reliable are their views about the domains explored in these measures? On the other hand, can we also rely on carers' views without questioning bias, especially when dealing with a disease such as dementia? Carers could be overprotective of patients and be in denial about their QoL, or they could be overtly negative and feel they don't have any quality of life because of the disease.

How can researchers address these issues? A prominent theory is PERMA, which explores five elements of well-being: Positive emotion, Engagement, Relationships, Meaning and Accomplishment (Seligman, 2012). Researchers have been using this model for many years, and they opine that there are positive associations between the model and health and life satisfaction (Kern et al., 2014). Some critics say that deciding what constitutes well-being is not an easy question, and PERMA does not really offer something unique above other widely used models of well-being, such as the one created by Dr Ed Diener in 1984 (Kashdan, 2017).

Nevertheless, PERMA remains a model that many health practitioners, who view it as important for understanding well-being, use in their practice. For long, dementia researchers have focused on health decline, loss and the inability of the person, as opposed to looking for the experiences that enhance their life. I will hereby explore the PERMA model and PERMA + below. The latter is an extension of the former, whereby the + includes other areas such as optimism, nutrition, physical activity and sleep.

Positive emotion: This transcends being joyful; it is an indicator of a flourishing life, and a person can learn how to have positive emotions to enhance well-being (Fredrickson, 2001). For PWD, thinking positively may be a challenge because of cognitive impairment. Nevertheless, in a dementia café or care home, positive emotion can be encouraged by creating an engaging and friendly environment. Setting the scene for a productive day of activity can invite PWD to engage with others.

Engagement: This is when a person is completely absorbed in an activity. It includes the disappearance of self-awareness, described by Csikszentmihalyi as 'flow' (Csikszentmihalyi & LeFevre, 1989). People can experience 'flow' when they pursue a clear goal with full concentration. It is more gratifying if their skill is sufficient for the activity despite its challenges. Examples of flow include playing board games, playing a musical instrument, dancing, gardening, etc.; the list is endless. Having a meaningful or interesting conversation is another example.

In a memory café, organisers can offer activities in groups, and PWD can decide which one they are happy to engage with. We see examples of 'flow' when service users get absorbed in the activities. An example is the percussion music sessions of the program StoryWeavers for dementia that I offer in memory cafés in Plymouth, UK. Many participants have never seen or used these hand percussions, but they get so absorbed in making music that they don't want to return the instruments at the end of the sessions. Perhaps, connecting with music helps them connect with their past and other group participants. This means they are able to become social participants again (Matthews, 2015).

Relationship: As people age, connecting with others – be it family or friends – becomes more important. Human beings are social people, and a positive social environment is known to be crucial in cognitive decline prevention. Researchers view social connections as pivotal to improved well-being in older people (Siedlecki et al., 2014). For PWD, especially older adults, social connections may become more challenging due to isolation, not only because of the disease but because as people get older and retire from work, social connections are not as strong and active as before. Memory cafés provide PWD and their carers opportunities to engage with other people with similar interests in games, music, storytelling or other activities.

Meaning: According to Seligman (2012), belonging to and serving something bigger than the self gives a person a sense of purpose. In our world today, many societies rarely provide roles for the elderly that allow them to have a meaningful existence. For people who live with dementia, outwardly, it may seem that the disease has deprived them of this sense of purpose, as many people find their purpose in their career, a worthy cause or some achievement. However, care providers can enable a sense of purpose through the provision of creative engagement and by allowing PWD the freedom to choose and participate in activities they are passionate about.

Accomplishment: In the PERMA model, accomplishment is linked with well-being because it enables people to reflect on their lives and be proud of their achievements (Seligman, 2012). When working with PWD, it is important to encourage them to focus on their process instead of being fixated on what the product will be. This enables people to be motivated to keep working on their projects and finish them. Celebrating success is also crucial to accomplishment.

A professional example I witnessed was in 2015. Alzheimer's Society Plymouth sponsored a Story-Weavers for Dementia project in the memory cafés in Plymouth. The 12-week program included gentle exercises, storytelling and music. The original stories told by PWD were recorded and proofread but not edited; we wanted the stories to be in their original forms. All the participants knew that we were compiling the stories and that they would be published, but they were focused on each week's program. At the end of the project, we published the stories in an anthology titled '*Narrative Adventures from Plymouth Memory Cafés*'. We celebrated our achievement with a party, where each participant got a copy of the book.

PERMA +

There are other areas, apart from the five mentioned in PERMA above, that are important to mental health and well-being. This includes optimism, nutrition, physical activity and sleep. These areas are particularly important for PWD because as some people age, they do not give priority to physical activities, good sleep, being optimistic and good nutrition. PERMA + advocates for the importance of optimism as critical to well-being. Scholars opine that people who are optimistic are able to manage stressful events better and have lower levels of depression (Carver et al., 2010). PERMA + also explores the importance of good sleep as one of the ways of decreasing depression and negative thinking, which in turn could lead to numerous mental illnesses. Sleep deprivation affects people's psychological state and mental health (Harvard Medical School, 2019).

Scholars opine that physical activity and good nutrition are key to well-being. People who have negative emotions are likely to have poor health habits, such as being sedentary or inactive. These increase the risks of diseases, whereas being physically active could decrease symptoms of depression and improve mental focus (Hyde et al., 2013). Good nutrition is also important for well-being, not only for the elderly. O'Neil et al. (2004) show through their research on children and adolescents that a poor diet containing refined carbohydrates, processed food and high levels of saturated fat caused poorer mental health. A balanced diet rich in vegetables, nutrients and berries, fruits, legumes, fish and unsaturated fats could provide many health benefits (Parletta et al., 2017).

2.5 Storytelling as non-pharmacological approach in dementia care

Despite the complexity of narratives, there is a sequence that researchers have identified in stories. The first one is that a story has a dual nature: a sequence of events and an evaluation of the recounted events. Here, the narrator or storyteller is placed in the extra-diegetic position, almost like an omniscient narrator who sees all and decides how the narrative arc is structured.

As communicators, human beings are prolific story producers. The structure of our narratives is distinct and story-like; that's how we communicate with others (Mar, 2004; Miller, 1995). Unfortunately, for many people with dementia, linguistic and cognitive issues are big challenges. Perhaps, the question we should explore is: what is the stumbling block? Is it the disease or the way society interprets what storytelling is and how a story should be told?

While synthesising the literature on this topic, I found a common trend in the works of authors exploring narrative neuropsychology. The notion of how humans comprehend and produce stories comes up in some of these works. Storytelling is a complex activity; hence it is difficult to operationalise. However, linguists agree on three key components or networks relating to narrative processes: the Default Mode Network, the Limbic Network and the Salience and Stable Control Network. Research shows that the dysfunction of these networks may lead to failure to attend to social cues; it also indirectly leads to deficits in spontaneous narrative organisation and production (Gola et al., 2015).

The researchers found that these deficits are not typically the same for every type of dementia; for example, people with Alzheimer's disease have memory dysfunction of the Default Mode Network; hence they will have difficulty remembering and organising past events, while patients with frontotemporal dementia show emotional deficits such as apathy and social withdrawal and are not likely to respond to social cues; hence they tell fewer spontaneous stories in a casual conversation (Gola et al., 2015).

Cognitive processing and its associative problems

Narrative researchers tend to focus on the cognitive processing involved in storytelling. They suggest that this processing is dependent on a well-functioning semantic memory and executive functions. Unfortunately for PWD, both semantic and working memories are affected by dementia, so their abilities to tell or comprehend stories are limited (Hydén, 2013). This theory has fundamental problems that tend to pose a stumbling block to PWD, as shown below:

The brain as a memory place: In his work on the embodied theory of narrative and storytelling, Hydén observed the problems associated with the framework of the cognitive processing theories, which states that storytelling and listening could be described in terms of cognitive processes. Critiquing the works of Brockmeier

(2010) that suggest that memory is archived somewhere in the brain and then retrieved when necessary, Hydén argued that there is no distinct part of the brain that could be called the memory place; instead, experiences are embodied and situated in the actual ways the body moves and the voice or artefacts used (Hydén, 2013).

In my storytelling workshops with PWD, I challenge the narrative of Brockmeier in the way I present storytelling to participants. Rather than be the teller who expects the participants to remember and retell, I encourage my audience to create spontaneous stories, which I help them record and celebrate. Participants are given musical instruments, and they are allowed to inject song/music into emerging stories (Holm et al., 2004).

One such occasion was at a care home, where a participant who had advanced-stage dementia could not join in the activities because she had aphasia. We gave her an African cowbell, and she began to beat it with a gong. Everyone quietly listened to the shrill sound of the bell, which was her contribution to the emerging narrative. When it was time to tell stories, the group decided that the protagonist was walking down a beach; the music from the cowbell was quickly incorporated into the story, and after much laughter, the storytelling continued.

Storytelling as a solo activity: The cognitive processing theory suggests that the production of stories is an activity that the teller performs and doesn't involve other people. The theory was debunked by researchers who propose that storytelling is a social activity that involves both tellers and listeners in a setting where stories are expected to be told. The most basic elements of a story include a setting and a storyteller who has a goal, whose progress towards that goal may be impeded by certain events (Mar, 2004; Oately, 1992). Storytelling engages both the teller and the listener. Researchers have suggested that storytelling may be a way of accomplishing interpersonal activities, both for tellers and recipients; the latter (listeners) are active participants in the narrative event to the extent that they can even redirect the account of the story (Mandelbaum, 1989). In the memory cafes, the participants that I work with are active. I present them with pictures to prompt a spontaneous narrative, and the participants begin to create their 'once upon a time' stories. There is never a dull moment as hilarious narratives emerge that redirect the account of the stories.

Linear Relationship – disease versus performance: When a narrative is disembodied, researchers see a linear relationship between disease and performance. However, it is evident from research that people with dementia have a way of compensating for their disability when they tell stories. Gestures, body movement, use of the voice, connection with the audience and a host of many other ways of compensating come to play. Hydén (2013) argues that when we approach storytelling as an embodied activity, we see the connection between disease and narratives because changes in the brain make way for other semiotic resources other than spoken language.

Therefore, the performance of stories is emphasised. Selfhood persists even with severe dementia because it is an embodied dimension of human existence (Kontos, 2004).

Storytelling is logged in the text: Researchers focusing on cognitive processing took more interest in how discourse is affected in PWD. Some describe it as abilities that deteriorate, marked by a digression from a topic and empty speech in discourse (Ehrlich, 1994). Other researchers focus on the structuralist model in which a story is constructed into macro-proposition and transformed into complex surface text through the generation of abstract rules. However, Hydén argues that storytelling involves multiple perceptual channels, such as vision, rhythm, hearing and touch, and motor activities. She also argues that people with some types of dementia, like Alzheimer's, are aware of what is expected of them as storytellers in conversation (Hydén, 2013).

In spite of the perceived challenges that storytelling poses for PWD, researchers continue to explore the non-verbal aspects of storytelling and see it as a resource for communicating and negotiating identities in everyday encounters. They call for a shift in the way the temporal and referential focus is given prominence in the storytelling for PWD. They suggest that more emphasis should be placed on the performative aspects of their narratives, which is an aspect ignored by researchers of the neuropsychology of narratives (Hydén & Örulv, 2009).

2.6 The role of storytelling and drama in raising awareness of dementia

In most healthcare systems, cognitive issues are the main focus for dementia, and pharmacological approaches are used as the first-line treatment; however, there is now more interest in non-cognitive problems, such as mood disorders, agitation, aggression and eating problems, grouped under BPSD (Behavioural and Psychological Symptoms of Dementia). Although there are a number of works of literature on non-pharmacological approaches to dementia care, such as music and exercise, there is hardly any literature on the use of ethnodrama in raising awareness of frontotemporal dementia in BME communities.

However, there is literature on the use of theatre in raising awareness of health issues in rural communities. One example is Dwight Conquergood's article titled '*Health Theatre in a Hmong Refugee Camp: Performance, Communication, and Culture*'. The researcher worked with refugees and helped them design a health education campaign using theatre based on the native beliefs of the people. They started a performance company, using storytelling, skits and scenarios to communicate the importance of good hygiene to the refugees. "Instead of didactic health messages instructing the Hmong to change their behaviour, we developed performances that would stimulate critical awareness about the camp environment…" (Conquergood, 1988, p. 190).

O'Neil et al. (2011), in their work 'A Systematic Evidence Review of Non-pharmacological Interventions for Behavioural Symptoms of Dementia', analysed some non-pharmacological interventions for BPSD through a systematic evidence review. It identified twenty-one reviews on cognitive/emotion-oriented sensory stimulation interventions and behaviour management techniques. However, none of the reviews explored storytelling or drama; they focused on examining a comparison of the effectiveness, safety and cost of non-pharmacological treatments of behavioural symptoms with pharmacological approaches.

As discussed earlier in this thesis, there are numerous reasons why people in BME communities do not access available services that support the care of people living with FTD. Firstly, the nature of the disease is shrouded in taboo and superstition, in addition to ignorance and religious and cultural beliefs. Also, the lack of trust in a system that the people feel does not have their interest at heart or fails to meet their unique needs makes it difficult to raise awareness and provide crucial information, such as the importance of early diagnosis. This has resulted in some researchers concluding that this group is 'unreachable'. This is the main reason I turned to drama as a method of reaching a group that is rarely represented in research on frontotemporal dementia.

Some researchers have explored the place of drama therapy in dementia care; however, these papers focus on how to improve the quality of life of PWD rather than creating awareness of dementia. The research of Jaaniste et al. (2014) aims to evaluate the effect of drama therapy on the quality of life (QoL) of elderly people with mild to moderate dementia using a mixed method (quantitative and qualitative) approach. They found that although not statistically significantly different, the average QoL-AD score for the drama group increased while it decreased for the movie group. Also, the former was able to express ideas and feelings through drama therapy. In their play, 'Cracked: New Light on Dementia', scholars Sherry Dupuis, Gail Mitchel, Pia Kontos and Christine Jonas-Simpson, shed light on how society views dementia in a one-dimensional way (Jonas-Simpson et al., 2012). The play critiques the notion of loss and understanding of dementia (Gray et al., 2015).

Storytelling is a powerful medium through which information can be shared in a non-confrontational way. The human being thinks and lives in a story framework (Young & Saver, 2001); because of the way people immerse themselves in the narrative, they are drawn to stories. I chose the narrative form to convey information about FTD, hoping that in a cyclical process, The Story of Beatrice, the woman who has FTD and Ireti, her daughter, will enhance the knowledge of my audience. They, in turn, will take in the story and tell it back to themselves and others (Lewis, 2011).

Some researchers have examined the resilience of storytelling in the face of progressive cognitive loss. Fels & Astell (2011) created 'Storytelling as a Model of Conversation for People with Dementia and Caregivers'. They looked at how storytelling could continue to fulfil a social function for people with dementia. However, their investigation was based on the comparison between the stories told by PWD and those who do not have the disease. Their aim was to find out if the stories of these two groups retain the same conventional form. This is very different from my storytelling focus, which is to create awareness of FTD using drama.

One may ask the question, why storytelling or why use drama? Could we not just organise lectures or print out leaflets and target the audience that needs awareness of FTD? Research has shown that when we listen to lectures with data and facts, the language portion of the brain works alone to decipher the words; however, if the same information is presented in story form, the brain decodes the language and stimulates other parts of the brain that are relevant to the theme (Simpleshow, 2021). For example, when we watch a character who is distressed and crying on stage, this could cause the audience's motor cortexes to light up and mirror the same emotion that the character is going through.

We live and think in a story framework that is brain-based and deeply human (Young & Saver, 2011). The human experience is highly influenced by the act of comprehending, producing and executing stories (Mar, 2004). Stories can influence or even change our beliefs about the world around us. Fiction readers have been found to change their attitudes and worldviews just by being exposed to stories (Green & Brock, 2000). Storytelling is the only medium where one witnesses the creation of an imagined world that mirrors our own realm of experience (Mar, 2004). When people are absorbed in stories, they drop their guard, unlike how they put their shields up when engaging with non-fictional narratives that encourage people to be critical and sceptical (Gottschall, 2012).

In West Africa, griots or storytellers tell tales not just for the fun of it; they are custodians of culture and heritage, medicine men or women, horticulturists, community leaders, politicians, artists, teachers and historians. A griot is the conveyer of the collective wisdom of the tribal peoples of Africa, and their stories are presented in stylistic ways and associated with great enjoyment (Henrich, 2001). As a storyteller, I always have a purpose for each story I tell, and my narrative goes beyond the stage. Though I never offer a moral at the end of my telling because I want my audience to create their own moral from what they've heard; nevertheless, I mount every stage with the excitement of a griot, a custodian of culture and a teacher.

There are numerous forms and genres of the oral tradition of storytelling: fables, folktales, fairy tales, myths and legends, parables and autobiographical narratives. Usually, storytellers decide on the form they will share with an audience before commencing performance; however, there are stories that are told spontaneously to a ready audience, and there are some that a group create and tell together without prior preparation. Storytelling helps human beings to present their identities. They do so by sharing stories about things they have done. These stories help the audience to know more about the teller and their worldview (Hydén & Örulv, 2009).

Human beings tell stories every day – whether in conversation with others, which include narration of personal experiences, gossip and the retelling of stories or performance of stories. Citing the works of Hirsh et al. (2013) and Bluck (2003), Gola describes everyday storytelling as a complex social practice integrating diverse cognitive and socio-emotional processes. It also functions to foster rapport and intimacy with others (Gola et al., 2015).

From childhood, we begin to master the skill of forming a story goal and putting the events in a comprehensible order. There are several studies that have examined storytelling in everyday family life, suggesting that children's home environment is densely populated with stories (Miller, 1995); hence it is not surprising that by the age of two, some children would have stepped into the narrative culture of their families (Brunner, 1990).

The ability to put emotional experiences into words improves people's mental health significantly. Gergen & Gergen (1988) talk about self-narrative as the ability to create meaning from the events that have taken place in our lives. Pennebaker et al. (1999) conducted extensive research on narrative psychology, focusing on writing rather than oral storytelling. They found that writing about important personal experiences in an emotional way for as little as 15 minutes over the course of three days brings about improvements in mental and physical health (Pennebaker et al., 1999).

Human beings' addiction to stories is one of the great unsolved mysteries; however, these mysteries are being examined by researchers whose works show us that stories help us to present or create identities and make meaning of life's events. Fiction seems more effective at changing beliefs than nonfiction, designed to persuade through argument and evidence (Gottschall, 2012). Through my play, people will be aware of FTD. The aim is that with relevant knowledge, people will begin to challenge their preconceived beliefs about the disease and how to care for people manifesting the symptoms of FTD.

3. RESEARCH QUESTIONS

This research aims to raise awareness of frontotemporal dementia among the Nigerian Immigrant community in the UK. I intend to explore autoethnography as my research methodology, and I will communicate my findings through an art-based method by producing a full-length play titled '*My Name is Beatrice*'.

Researchers estimate an increase of sevenfold in the number of people with various types of dementia in BME communities by 2051. In comparison, the increase in the number of white British people with dementia is estimated to double in the same year (Tuerk & Sauer, 2015). However, when it comes to accessing services and health care services for PWD, people in BME communities are less likely to use the facilities.

My main research questions are:

(1) How can the awareness of frontotemporal dementia be raised using an art-based approach?

(2) What autoethnographic process precedes the development of the play '*My Name is Beatrice*'?

FTD is still shrouded in mystery in many BME communities because of issues such as misinformation and cultural and religious belief systems. My thesis is important as it will help the community to know about the disease, its symptoms and the health care services available. When people know more about it, early diagnosis, which is crucial, will be possible. This is autoethnography research in which I will reflect on my work as a storyteller and writer and use the knowledge I have gained to explore how to raise awareness about a critical health issue – frontotemporal dementia.

My research questions are as valid as why I am telling the story and how I intend to tell it. Human experiences are not merely linear but multi-layered and complex; therefore, in other to successfully express these experiences through storytelling, researchers need to be aware of the consequences of their choices pertaining to the decision on how and why they tell their stories (Aaltonen & Bruun, 2014).

In the play, '*My Name is Beatrice*', I intend to explore some obstacles likely to prevent BME people from accessing medical services for dementia. In these communities, early-onset dementia, such as frontotemporal dementia, is prevalent (Healthcare for London, 2009); however, historically, it is a community that has been marginalised from strategic health initiatives (Truswell, 2011). The play will create a platform where people can learn about frontotemporal dementia and the need for early diagnosis in a creative environment such as a theatre. The play will be culturally relevant to the people, and it is non-confrontational. It will appeal to audiences' emotions and encourage a change of perspective in how PWD are seen and supported. Drama is a powerful catalyst for empathetic connection and person-centred care (Kontos et al., 2010).

Dissemination of my research findings will be instrumental in educating care practitioners and healthcare workers on how best to engage with BME communities, especially people living with frontotemporal dementia. Drama is an effective pedagogical tool in educating healthcare practitioners and medical trainees to reflect on their practice (Kontos et al., 2010).

It is pertinent to note that my autoethnography research is not a study of Nigerian immigrants. My focus is on my practice as a writer and storyteller and how that influences the creation of a play that will create awareness of frontotemporal dementia within the Nigerian community in the UK. Also, I didn't have to apply for ethical approval for my research because I am staging qualitative research as fiction with the intention of protecting the identity of those studied (Richardson, 2000).

4. METHODOLOGICAL APPROACHES

My study process is a qualitative research process of inquiry that explores and gives deeper insight into real-world problems (Moser & Korstiens, 2017) while also seeking an in-depth understanding of social phenomena. Qualitative researchers do not rely on logical and statistical procedures; they use multiple methods to study human phenomena. This includes ethnography, autoethnography, and grounded theory, to name just a few. Qualitative research seeks to ask open-ended questions which provide answers that are not linear like quantitative research (Cleland, 2017).

I have chosen autoethnography as my research methodology. In this chapter, I will explore what autoethnography is and how I will use it in this work. I will also analyse my research approach, which is art-based, and ethnodrama, the tool that I intend to use within my art-based research.

4.1 Autoethnography as the foundation for this research

The term autoethnography was coined by David Hayano, an anthropologist, who was interested in the role of a researcher's own identity in their research. Hayano's belief was that when a researcher conducts and writes ethnographies of their own people, such writing has great value (Hayano, 1979). The early use of the term is also credited to a few other scholars, such as Karl Heider and Walter Goldschmidt, in the 1970s.

These researchers described autoethnography as a study in which cultural members give an account of their culture. It also describes anthropologists who study their own people as full-fledged natives. Such research reveals personal investments, interpretations and analyses (Godschmidt, 1977; Hayano, 1979; Hieider, 1975;). Since then, autoethnography has incorporated many other meanings and applications, which makes it difficult to give a single definition to the term.

Autoethnography is an autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the cultural (Ellis & Brochner, 2000). In the 1980s, researchers in the field of sociology, performing arts, gender and women's studies began to advocate for the use of storytelling, personal narrative and reflexivity in research. Their efforts to include themselves and their personal experiences as part of their research were met with disapproval from scholars who focused on traditional methods. Nevertheless, these researchers were non-relenting in their rejection of the traditional ’objectivity’ narrative (Adams et al., 2015).

By the 1990s – 2000s, researchers started using the term ’autoethnography’ more liberally, and they continued to place more emphasis on works that engage personal narratives in reflective ways. In the last twenty years, autoethnography has gradually become a legitimate method of doing research, and it now flourishes in academic conferences and professional journals (Adams et al., 2015). Researchers create work by initially focusing outward on the social and cultural aspects of their personal experience. They look inward, exposing a vulnerable self that is moved by and may move through, refract and resist cultural interpretations (Ellis & Bochner, 2000; Reed-Danahay, 1997; Deck, 1990). This motion of moving backwards and forwards creates a distinctive blur between the cultural and the personal.

At the onset of my PhD, I asked questions about how my positionality would influence my research questions, data collection and how I analyse my data (Coemans et al., 2019; Kara, 2017). I also began to ask questions about how I construct knowledge. Since civilisation began, people have used various ways to understand the world and create knowledge. One such is empiricism. This philosophy states that human knowledge is derived from senses or experience. Scientific research uses empirical knowledge through rigorous scientific studies. “Such knowledge can be transmitted to others through testimony, preserved by memory, and amplified via inference” (Gorodeisky & Marcus, 2022, pp. 2507-2508).

Another way of knowing is through aesthetic knowledge. This knowledge is “embodied. It comes from practitioners understanding the look, feel, smell, taste and sound of things in organisational life” (Ewenstein & Whyte, 2007, p. 689). Some practitioners that embrace aesthetic knowledge are architects, dancers, painters, storytellers and other artists who might feel constrained by the narrow focus of empirical knowledge.

I embrace both aesthetic knowledge and storytelling as ways of knowing. These are almost interchangeable because, in my work as a storyteller and writer, aesthetic knowledge is symbolic and includes visual and musical languages (Gagliardi, 1996). Practitioners know aesthetic work to be experiential and expressed through feeling. For example, one may ask how a dancer, performing storyteller, actor, or architect creates knowledge or how a painter knows that a piece of work is satisfactory enough to be placed in a gallery to communicate his thoughts or the knowledge he has formulated during the making of the art.

Such information may not conform to hard-core empirical knowledge making; however, knowledge could be made through reflectivity, feedback during the process of making the art, and through “sensing, symbol-processing, interpreting, intuiting and ‘thinking’ with aesthetic knowledge” (Ewenstein & Whyte, 2007, p. 699). As an artist, who performs stories, creates plays and writes books, I create knowledge by reflecting on my work, which goes through rigorous processes of drafts, feedback from peers and audiences and continuous improvement on my work.

Also, storytelling is a way of knowing me as a person of African origin. In the culture that I grew up in, it is the way by which we interpret the world around us. More of this is written in various chapters in this thesis. I "conceptualise stories as a form of cultural brokerage…while creating culturally grounded health messages" about FTD (Szkupinski, 2015, p. 6; Alexander et al., 2008). Telling the story of a Nigerian immigrant battling FTD and showing the nuances and cultural beliefs of the people about mental health issues draw on a socially shared symbol system. This also gives the community confidence that I am a member of the group and understand the values and norms of the culture. Therefore, the message I share is consistent with the group's cultural practices (Hecht & Miller-Day, 2009; Szkupinski, 2015).

Some scholars suggest that autoethnographers should explore deconstructive autoethnography, whereby they engage with the discursive construction of experience and confront it as questionable and incomplete. In that light, I critically examine what constitutes knowledge or experience. In my narrative of how I overcame the symptoms of perimenopause, my experience is valid, but I do not present it as universal. I am exploiting the limit of my experience by "presenting an 'I' that is 'becoming' through the telling" (Jackson & Mazzei, 2008, p. 309). The telling did not start with the writing of 'Dear Toriola'; it started with writing a journal about my daily experiences while recovering. Reflecting on and analysing the journals was another process of 'becoming'.

There is criticism about the validity of autoethnography as a research method. Some traditional researchers see it as subjective, while others criticise it as self-indulgent and narcissistic (Coffey, 1999). In spite of the negative views, there are advantages to the writing of personal narratives; one of such is that it provides rich data, as it gives people access to the private world of the writer (Pavlenko, 2002, 2007). The critique about subjective autoethnography provoked some scholars to postulate a critical and analytical writing style, as this creates a more objective analysis of their subjects and allows researchers to develop a theoretical understanding of the phenomena they are examining (Anderson, 2006).

Some scholars opine that autoethnography can be limited in its conclusion because of its reliance on personal stories. However, this notion cannot be held as 'gospel truth' because autoethnography also provides the researcher with the tool for reflexivity, critical awareness of knowledge formation and aesthetic distancing in storytelling devices (Aaltonen & Bruun, 2014). Some critics view autoethnography as a methodology that is weak and lacks analytical rigour (Delamont, 2007), while others say that rejecting autoethnography outrightly stems from positions situated in a traditional understanding of research (Chang et al., 2013).

My research aims to create meaningful knowledge that can raise awareness of FTD among Nigerian immigrants and create a better understanding of the disease.

For many autoethnographers, creating knowledge that can change the world for the better is more important than notions of accuracy and rigour (Ellis et al., 2011). Initially, I struggled to wade through the swamp of the different types of autoethnography writing and the decision about what would be the best theoretical framework for my thesis. There are a few categories of autoethnography: confessional or self-critical, descriptive or self-affirmative and analytical or interpretive autoethnography (Chang, 2016). There is a blur between autoethnography, memoir, native ethnography, self-ethnography, and autobiography; the list is endless (Ellis & Brochner, 2000).

As I examined the literature on this, I found out that when a writer shows how the aspects of the experience illuminate more general cultural phenomena, the writing goes beyond autobiography; it takes the form of autoethnography (Jones et al., 2016). Autoethnography is not just the narration of self. It should have profound cultural analysis and interpretation; if it is only about self-exposure, writing becomes a memoir or descriptive autobiography (Chang, 2016). In this thesis, I am not writing an autobiography; it is not a story about myself and how I overcame health issues. It is a story that examines the cultural beliefs of a group of people and how they could impact their access to adequate healthcare. It also examines my work as a writer and storyteller and my experience of overcoming chronic health issues. Autoethnography varies in methodological strategies; nevertheless, a good autoethnography "should be ethnographical in its methodological orientation, cultural in its interpretive orientation, and autobiographical in its content orientation" (Chang, 2008, p. 1).

Autoethnographies differ in style, purpose and presentation. Despite the critiques, it is a valuable method that helps to break silences by addressing understudied, hidden and/or sensitive topics (Jones et al., 2016). My topic is understudied and hidden because, presently, in the Nigerian immigrant community and other BME communities in the UK, information about the epidemiology of frontotemporal dementia is almost non-existent (Healthcare for London, 2009). The issue I am addressing in this thesis is present even though it is not spoken about widely in academic or immigrant communities.

The data collection for this research is non-traditional. Autoethnography enables me to use data from my own life stories in the way it is situated in sociocultural contexts. This helps me to gain an understanding of society through the unique lens of self (Chang et al., 2013). Part of my data is the analysis of some of my published books, for example, *Dear Toriola, Let's Talk About Perimenopause,* which examines my journey through perimenopause. Overcoming the mirage of symptoms through holistic ways inspired me to share my story with a wider audience, albeit in an epistolary form.

By producing a text that is accessible, I have made my personal experience meaningful, and I've also been able to reach a more diverse audience that traditional researchers usually disregard (Ellis, 1995). In this thesis, through my observation of how people in my culture view issues of mental health and through studying stories of people with FTD, I have created a play that has the potential to raise awareness of the condition. Autoethnography seeks to describe and analyse (graphy) personal experience (auto) in order to understand cultural experience (ethno) (Ellis et al., 2011). It enables researchers to also deliberate on their past experiences introspectively.

4.2 Art-based Research Approach

In this thesis, using an art-based research approach gives my audience the opportunity to engage with the topic I am investigating in an accessible way. This promotes discernment, empathy and learning. This is also termed empathetic engagement (Leavy, 2018). As an artist and researcher, art-based research allows me to explore multi-sensory and multi-perspective methods, enabling me to progress beyond what I can share by using only the written word (Gray et al., 2015; Leavy, 2009).

ABR enables me to challenge the dominant paradigm of 'expository essay', which many academics regard as the only valid way of writing about research (Eliastam, 2019). This challenges the polarity of fact versus fiction that exists in traditional research. Fictionalisation in my research helps me focus on the academic journey rather than the finished product. This means the knowledge I am gaining does not only emerge from the final product but from the process of discovery and creation (Eliastam, 2019).

Raising awareness about Frontotemporal dementia among Nigerian immigrants in the UK is a topic that has not been explored previously; hence ABR being a heuristic method, will give the audience access to valuable information about the disease. Most times, in our scientific deductive system, people see art as paradigmatically different from theory or science (Rasmussen, 2010); however, theory is not just housed in university or books, but it is an activity that occurs each time a possibility is imagined (Butler, 2004). As a researcher, ABR helps me to gain more knowledge on the aesthetic interpretation of my work. Such interpretation can occur in how the play – '*My Name is Beatrice*' – unfolds and how the characters manifest their roles (Gray et al., 2015).

Over the last 30 years, art-based research (ABR) has been used by researchers to investigate the human experience because it gives us insight into complex issues pertaining to social interaction; it also allows the researcher to have a better understanding of the inquiry or investigation (Barone & Eisner, 2012). Some artistic forms and methods through which we can gain more knowledge about our world include autoethnography, music, photography, poetry or theatre (Coemans et al., 2015; Foster, 2012).

The possibilities of ABR are ever-expanding, and its methodologies are equally diverse, such as a/r/tography – representing the intersection of artist, researcher and teacher, and scholARTistry – a merging of artist and scholar practices and identities (Harris et al., 2015). Many ABR researchers are now moving away from trying to defend its relevance to research; many are confidently producing new forms of knowledge. This creates, in research, more understanding of how we live and how relevant ABR is to creating such understanding.

As a qualitative researcher, I invent my findings through the process of writing rather than merely representing the findings (Clifford, 1986; Denzin, 1997; Goldstein, 2012). Art-based research is an inventive process that allows researchers to explore multi-sensory and multi-perspective methods (Harris et al., 2015; Denzin, 2003). One of the ways this is done is through theatre, which allows scholars to create work that transcends the limitations of written words in the way it engages audiences in ethical, political and social debates (Harris et al., 2015; Jackson, 2007). My play allows me to use a multi-sensory approach to the dissemination of knowledge gained through this research. It will engage with a wider audience and aims to invite people to discuss some of the issues concerning FTD and healthcare access.

Life experiences are complex and multifaceted. Many researchers now view traditional methodologies as predominantly privileging cerebral, verbal and linearly temporal approaches to knowledge and experience. If forms of art-based research are to be taken seriously as emerging fields within educational research, then perhaps they need to be understood as methodologies in their own right, not as extensions of qualitative research (Springgay et al., 2005). The structure of my thesis does not conform to the design of experiments because the complexity of the human experience is unscripted and cannot be neatly tucked into a survey report. Nevertheless, an innovative performative aspect of art-based research can be demonstrated in storytelling, dance, painting, poetry, dialogue, script and many more artistic expressions (Mullen, 2003).

Art is often understood to be diametrically opposed to the scientific and evidence-based approaches that have traditionally dominated research. However, ABR exists at the intersection of art and science in its ability to provide an understanding of key issues through exploration and analysis. This alternative form of inquiry is particularly useful for investigations into nuanced and less tangible experiences that the rigidity of fact-based methods might struggle to evaluate. This makes art-based research a useful phenomenological tool. Using art in research presents an expansive arena through which personal experience can be communicated sensitively and creatively, generating holistic answers to increasingly complex research questions (Leavy, 2018).

The complexity of the human being shows that communication is deeper than the intellect. Dramatic arts mirror this complexity by showing that we communicate through our bodies as well as with words. My aim with this work is to invoke multidimensional responses from my audience. My approach in this thesis is to use the play as a tool to create an awareness of frontotemporal dementia. Therefore, the play represents my data collection, analysis and presentation of my findings. Another dominant approach in ABR is the use of research as an investigation into the art itself (Greenwood, 2012). However, this is not the aim of my research.

One of the trademarks of arts-based research is interaction with aesthetic understandings as well as discursive explanations. The definition of aesthetic is disputed (Greenwood, 2011; Hamera, 2011); however, it is used here to describe the interaction of senses and emotions. It also mirrors the importance of being culturally aware. This enables artists and their audiences to respond to art in various ways. As a result, an emotional and intellectual response to art is produced. It may be at peace with ambiguity and refrain from expressing itself verbally.

Art-based research is inclusive and allows various forms of narratives (Riessman, 2008). It also allows scholars to explore indigenous knowledge and ways of sharing and using knowledge (Smith, 2014; Tomkins, 1994), for example, the use of autoethnography as a methodology (Ellis, 2004). I found ABR advantageous because, through my play, I can explore marginalised and controversial issues that could be difficult to analyse using a more traditional methodology. Whilst working as a storyteller and creative arts facilitator in memory cafés for people with dementia, I was amazed at how responsive the participants were – even those with advanced dementia. I saw how the arts created rapport amongst participants, carers and organisers. It was more delightful but surprising to hear that these participants looked forward to the sessions.

Art-based research creates an embodied encounter through visual and textual interactions, although it is not a new area of qualitative research (Springgay et al., 2005). Art in research may be used in a variety of ways to create useful and meaningful approaches. As a writer, I am passionate about immortalising the stories that participants in memory cafés tell because the stories are spontaneous and different from traditional storytelling. The participants are the storytellers, not me. I only facilitate the program and give them prompts, such as pictures which lure them into becoming storytellers.

Creative arts provide opportunities for researchers and research participants to reflect on their lived experiences and better understand themselves (Foster, 2007). According to Daykin (2009), music elicits rich information and gives us insight into complicated, diverse topics. The arts can capture the attention of people. I decided to explore ethnodrama as a method of interpreting my data because art has an instantaneous effect on an audience because it is able to capture their attention and leave enduring memories. Many researchers who use arts-based approaches do so to raise critical awareness, encourage contemplation, develop empathy, forge coalitions, challenge stereotypes, and encourage social action. Research that is done or presented using arts-based techniques has the capacity to transform (Leavy, 2009).

I have not used a focus group to see if the play will raise awareness of FTD. This will be the next stage after my PhD. One of the goals of the play, '*My Name is Beatrice*', is to challenge the disparity in access to mental health services for people in BME communities. One such is that some people are reluctant to discuss psychological distress or seek help. Another one is the "imbalance of power and authority between service users and providers, cultural naivety, insensitivity and discrimination towards the needs of BME service users" (Memon et al., 2016, p. 1).

In order to address these issues successfully, an art-based method is suitable because the play is non-confrontational. People go to the theatre and enjoy watching an emotional play that has the potential to be a conversation starter. The play, though a tear-jerker, makes a delicate subject less frightening. One of the advantages of art-based research is that it helps bring writing closer to people, as opposed to academic writing, which could be sterile and lack feelings or experiences (Colucci, 2013).

Hayden opines that storytelling is embodied and situated because it is not just dependent on cognitive processes but on the coordination between bodily, cognitive and semiotic processes (Hydén, 2013). Some scholars have argued that people with advanced dementia, especially Alzheimer's, can still recall past events. The major problem is using verbal language to present these memories. However, these memories exist in an embodied state. Some scholars claim that "selfhood is embodied and characterised by an observable coherence and capacity for improvisation that is sustained at a pre-reflective level by the primordial as well as the socio-cultural significance of the body" (Kontos, 2004, p. 831).

I will hereby give an example of how I use storytelling in my work with PWD in dementia memory cafés. This is a narrative used to buttress my point about the efficacy of storytelling for PWD. In these memory cafés, I use the craft of story-making to engage the participants. I share picture prompts and ask open-ended questions to stimulate storytelling ideas. Participants engage enthusiastically as we watch each story unfold. Participants' imaginations are profound irrespective of their diseases. Some participants have advanced dementia; for some, aphasia has set in, and they can hardly talk. However, they still engage with us actively through dance, gestures, use of hand percussion, smiles, nods and a host of other body languages. For the majority, the joy on their faces cannot be described in words. Research shows that people's physical and mental health can be significantly improved when they engage with the arts (Howarth, 2015).

For example, when I started visiting memory cafés and care homes as a storyteller, my programs drew polite applause from my audience, but when I reflected on the activities, I felt there was something missing. My aim was to bring joy to the community of PWD and encourage them to be creative storytellers, but I discovered that PWD do not fit neatly into my storytelling 'paradigm'. Many of the elderly patients had advanced dementia. In addition to memory loss, some were confused, irritable and had trouble with language. I was 'another' entertainer, despite my lofty ideas of engaging them to be creative.

At that point, my initial excitement gave way to despair, and I concluded that perhaps storytelling was not the way forward. What then? A few months after my initial visits to memory cafés, I came across a storytelling program called 'Time Slips', a program that encourages participants to improvise with storytelling rather than rely on reminiscing. The method uses pictures as prompts to stimulate creativity and opens storytelling to everyone by replacing the pressure to remember with encouragement to imagine. According to the founder of the program, Anne Basting, Time Slips creates the role of a storyteller for people living with dementia. It is a role that offers opportunities for meaningful self-expression and growth (Basting, 2011).

After my TimeSlips training, I decided to create a program called StoryWeavers for Dementia. I wanted participants to engage in more creative activities. I started working on this program in 2013 and volunteered in some care homes and community events. The storytelling was awesome, but in addition, I also created a music and gentle exercise program using the Octaband – a colourful, flexible material.

Studies show the efficacy of music as a therapeutic way of engaging with people with dementia. Music arouses participants "...out of a state of malaise, anxiety, confusion or depression, and into a state where they connect" (Matthews, 2015, p. 578). Research also shows that physical exercise improves mood and confidence. It can also help to reduce daytime agitation and restlessness; it reduces the number of falls and improves mental health and sleep (Alessi et al., 1999; King et al., 1997; Young & Dinan, 1994).

Some scholars opine that in prehistoric times, people believed movement, music, and word rhythms contributed to the balance of the human body systems. This, in turn, creates good health (The RSPH Working Group on Arts, Health and Wellbeing 2013). King Solomon, the writer of the Book of Proverbs, gives a similar description when he said, "A heart at peace gives life to the body; a cheerful heart is good medicine..." (Proverbs 14:30; Proverbs 17:22, Biblica 2011).

In 2014, I felt the program was ready, so I started meeting with gatekeepers in dementia memory cafés and educators in Plymouth, Devon and Cornwall to introduce it. Initially, many of the meetings were not successful; however, I continued to take this program to memory cafés in Plymouth; the participants and their carers were excited about it. They wanted more! When delivering StoryWeavers for Dementia program, I encouraged PWD to play the percussion instruments that I took to the cafés. I did not teach them rhythms; we asked someone to just tap or play a rhythm on their instrument, and the other people in the group joined in.

I also asked them to tell spontaneous stories using visual prompts. I encouraged participants to choose prompts with bold pictures that are not too 'busy' with extra images. I then asked open-ended questions such as: 'Who is in this picture?' 'What is their name?' 'Where are they?' 'What are they about to do?' Participants were always eager to answer these questions, which eventually developed into spontaneous stories I recorded for them to enjoy after the sessions. As a non-pharmacological approach to dementia care, storytelling helps people with dementia to "participate as equals in a social situation, feel positive about themselves, and be successful" (Ranasinha, 2021, p. 4).

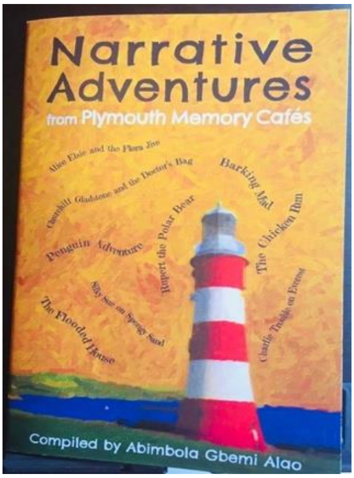
The program was a great method of communication and education not only for the PWD but for me as a healthcare professional (Bergman, 1999). I was able to see the themes that unfold in the stories, even though the storytellers have dementia. I was able to recognise each participant's ability to engage meaningfully (Basting, 2013). Their imaginations were profound, irrespective of their diseases. Storytelling evokes cognitive aspects in participants Fels & Astell, 2011). I observed that a prominent issue with dementia is isolation; people with dementia could become withdrawn. However, for me as a storyteller, I became very keen to keep storytelling alive.

As a writer, I was passionate about immortalising the stories the participants told because what we did in the cafés was spontaneous and different from traditional storytelling. The participants were the storytellers; I only facilitated the program and gave them prompts, such as pictures which lured them into becoming storytellers. The group chose a picture, and we started a spontaneous narrative, with me asking open-ended questions, such as: 'What name do you want to give the person in this picture?' 'Where is this place?' 'What day is it?' 'What is happening here?' The atmosphere was usually exhilarating, and people roared with laughter at some of the suggestions that emerged as we told the stories. Part of my work, however, was to modulate and gently weed out rude suggestions.

In 2015, after some practical sessions and after participants had told their carers how much they enjoyed the activities, I got a call from the Alzheimer's Society to design a three-month program for the memory cafés in Plymouth. With the people's permission, we began to record the tales by writing them down and eventually printed the stories. The book is titled '*Narrative Adventures from Plymouth Memory Cafés*'.

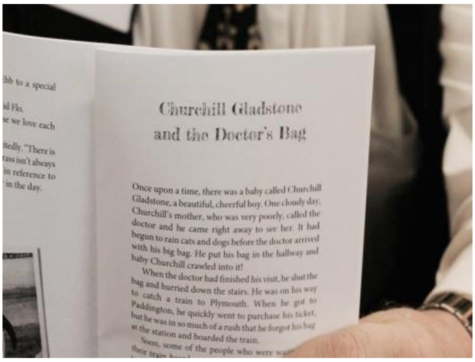
Picture 1

Book: *'Narrative Adventures from Plymouth Memory Cafés'* (Compiled by A. Alao, 2015)



One of the stories that I found intriguing is the one titled: 'Churchill Gladstone and the Doctor's Bag'.

Storytelling Prompt Picture by TimeSlips (2015)



Churchill Gladstone
and the Doctor's Bag

Once upon a time, there was a baby called Churchill Gladstone, a beautiful, cheerful boy. One cloudy day, Churchill's mother, who was very poorly, called the doctor and he came right away to see her. It had begun to rain cats and dogs before the doctor arrived with his big bag. He put his bag in the hallway and baby Churchill crawled into it!

When the doctor had finished his visit, he shut the bag and hurried down the stairs. He was on his way to catch a train to Plymouth. When he got to Paddington, he quickly went to purchase his ticket, but he was in so much of a rush that he forgot his bag at the station and boarded the train.

Soon, some of the people who were

Churchill Gladstone and the Doctor's Bag (A story from the book 'Narrative Adventures from Plymouth Memory Cafes', 2015)

This story was chosen for publication because of the passion accompanying the telling and the storyline itself. On the day of the telling, after the group had finished with their gentle exercise, I gave them three picture prompts to choose from, and the majority chose the picture of a baby in a bag. I asked my volunteers to take the other pictures from the group and hand out the chosen picture to everyone. Then the storytelling started with me asking open-ended questions like, 'Who is this baby?' 'Why is he in a bag?' 'Where is he?' The group did not disappoint! They were coming up with possible answers, which our volunteers recorded in writing.

As an artist who uses the craft of storytelling to explore human experiences, I have witnessed the transformative power of creative art. Creativity has various definitions; some say it is thinking outside the box or taking a new approach to an old problem. Gene Cohen states that creativity means we are adding something new that has value to the world (Cohen, 2001). Many programs I found use creative title engagement for people with dementia. However, creativity is not simply entertaining someone; creative engagement can involve collaborating to express themselves through music, movement, painting or storytelling.

In a research study, participants with dementia were given drama therapy and another group of PWD were asked to watch movies over a 4-month period. The researchers found that the group that had drama therapy could express ideas and feelings and unveil conscious awareness of their own well-being and quality of life (Jaaniste et al., 2014). They used the Quality of Life Alzheimer's disease tool (QoL-AD), Independent sample t-test – which compares two means, and Fisher's exact test – a statistical significance test used in the analysis of contingency tables.

Usita et al. (1998) also outlined the narrative components of PWD in their research titled, 'Narrative Intentions: Listening to Life Stories in Alzheimer's disease'. They looked at the influence of these narrative forms on their private and social lives. The authors found that the stories of this group were less chronologically organised and had a lot of repetition. This paper looks at a comparison of storytelling between people who do not have cognitive impairment and PWD. The research does not examine theatre or drama, and it is not robust. There were only six participants.

Although the aforementioned papers do not focus on raising awareness of frontotemporal dementia, they are crucial to the narrative about the efficacy of the arts in improving the quality of life for PWD. I explored this theme in my play in the scene where Beatrice, the woman who has FTD, is given the opportunity to attend creative workshops where she could share her poems. Research shows that patients who have difficulty communicating can benefit from stories, poetry and music (Breslin, 1996). Beatrice discovered Haiku Poetry during her crisis, and she was able to express her sentiments (Reisberg et al., 1999).

Art-based research has many advantages, but there are also disadvantages to using it as a research method. One of the disadvantages is that knowledge of how to analyse data obtained using art-based approaches could be scarce. This could be a drawback (Colucci, 2013), as it could be time-consuming, and it may necessitate the acquisition of new skills. Having explored what ABR is, I will hereby explain the tool I intend to use practically.

4.3 Ethnodrama as an Art-based Research Method

The field of ethnodrama can be described as "the aesthetic assumptions of performance and the methodological and theoretical ambitions of research" (Mienczakowski, 2001, p. 468). According to Mienczakowski, ethnodrama enables the researcher to present their findings in a language accessible to a wider audience, for example, in a performance or dramatic script. There are countless examples of researchers who use the method in their ethnography works. For example, in reflective practices (Rogers et al., 2002; Vanover & Saldana, 2002), healthcare issues (Mienczakowski et al., 2002), a connection between clients and professionals in care homes (Baur et al., 2014), homeless youths in New Orleans (Saldana, 2005), and a couple's story of their child's abortion (Ellis & Bochner, 1992).

I decided to create a play script to interpret my findings because this art form is an effective modality for communicating my observations of the cultural and social issues I am highlighting in my thesis (Saldana, 2016). Many people go to watch plays in the theatre to suspend disbelief; however, a large proportion of people come out of a theatre after a live performance and comment that the piece of theatre 'made things seem more real'. That is the power of theatre; it heightens the representation and presentation of social life (Saldana, 2016).

As a playwright, I am only too familiar with the challenges of creating a dramatic script from the data collected. One such challenge is the question: how do I entertain my audience? Many scholars may argue with this notion, but the main goal of theatre is to entertain; hence the researcher using ethnodrama for her findings must still focus on this goal, and they have the responsibility of creating an experience that is richly informative as well as evocative and entertaining, for the audience (Saldaña, 2003).

In spite of the challenges, there are benefits of using ethnodrama to interpret my findings; I intend to present an aesthetically sound, intellectually rich, and emotionally evocative play that can capture my audiences' attention and leave them with enduring memories. Ethnodrama can facilitate engagement and action from the researcher, participant, and audience (Cannon, 2012). On the whole, I do not want my audience or readers to be passive spectators; I want them to care for and desire change (Bochner & Ellis, 1996).

Evocative writing is part of new writing practices; it allows us to study how we make meaning of the world around us (Richardson, 2000). This style will embrace my introspection of the topic I am examining, thereby luring the reader or audience into connecting with my feelings and experiences (Anderson, 2006). My aim in this thesis is not only to evocatively self-examine; though I will explore how I reflectively create meaning from my work, I aim to analyse, through my play, how to raise awareness of frontotemporal dementia and critique the cultural beliefs that hinder effective access to care, in BME communities. Ethnographers immerse themselves in the culture they study to understand the culture's core beliefs and values, with the purpose of helping the cultural members and outsiders understand the culture.

Unlike researchers who create real-life vignettes from their interviews or focus view data, I did not conduct formal interviews. As an autoethnographer and a Nigerian immigrant, I actively engage with my community, especially in the diaspora. There were times when I chatted informally with people in my community either to find out what they knew about frontotemporal dementia or how some religious groups view or react to mental health issues; this informed the spectacles I created in the play. I have access to members of my culture (Berry, 2005); hence, gaining a better understanding of their beliefs about frontotemporal dementia and how they relate to people with the disease was not difficult.

Furthermore, a large part of my research into understanding FTD was through the study of real-life individuals with the disease and the stories their carers tell. It would have been difficult to access such information by interviewing people in my community. Firstly, because of the ignorance of what FTD is and how it manifests; secondly, because of the taboo surrounding mental health issues. Also, my aim was to raise awareness of the disease by using my experience as a storyteller and playwright to create an engaging narrative that people can relate to.

Ethnodrama is a theatrical performance where characters engage one another and the audience through monologues and dialogues. Dramatic tension also creates spectacular and memorable scenes. Many researchers use arts-based approaches to raise critical awareness, encourage contemplation, develop empathy, forge coalitions, challenge stereotypes, and encourage social action. When art is used in research, "stakeholders and members of the organisation or community can be included in the research, and tacit knowledge and experiences can be obtained from them, which are not conveyed through traditional qualitative research methods based on verbal or written language" (Jokela & Huhmarniemi, 2018, p. 1).

Drama can also help healthcare providers to better understand and therefore cope with issues in practice that are complex, interpersonal, emotional, and embodied. My research-based ethnodrama, '*My Name is Beatrice*', aims to fictionalise my data, using information that emerges directly from my literature review as I researched frontotemporal dementia. Although there is no literature that has explored the use of ethnodrama to raise awareness of frontotemporal dementia in BME communities, some researchers have explored the form in medical education and research. For example, Kontos and Naglie (2006) used ethnodrama to interpret their findings on how selfhood is expressed through bodily habits and actions in spite of severe cognitive decline.

In many BME communities in the UK, some people with frontotemporal dementia and their families live in denial, mainly due to cultural, religious and social reasons. PWD are sometimes referred to as mad, depressed, or demon-possessed. This carries a stigma, which means that early diagnosis is near impossible; hence, most people with the disease are usually in the advanced stages before seeking help. Only a third of people with dementia receive a formal diagnosis at any time in their illness. Diagnoses are often made at times of crises, some of which could be avoided if a diagnosis had been made earlier (Department of Health UK, 2009).

I embarked on this research to create awareness of the disease in the Nigerian diaspora community and share my findings with the academic community, where I work as a trainer and course developer in medical humanities. I chose autoethnography as a methodology because it gives me the opportunity to reflect on my practice as a writer and storyteller in dementia memory cafés.

5. THE ETHNOGRAPHY DATA COLLECTION AND ANALYSIS

5.1 Data Collection Process

5.1.1 An Overview to the Research Process

Data collection for autoethnography research can include life experiences, letters, interviews, documents, personal journals, and family artefacts, to mention a few. It is important that autoethnographers find what works for them. Researchers talk about the blur and enlargement of the ethnography genre. Other forms, such as drama, poetry, conversations and readers' theatre, are included (Richardson, 2000). Autoethnography data collection is wide and varied; it includes self-observation, self-reflective and self-narrative reading responses and interviews (Chang, 2008).

My theoretical framework is based on the notion of writing as a research process, postulated by Laurel Richardson (2002), who proposes that writing is a method of inquiry. According to her, "...who we are and what we can be, what we can study, and how we can write about what we study are all tied to how a knowledge system disciplines..." (Richardson, 2002, p. 887). As I focused on creating awareness of frontotemporal dementia, I realised I needed to do a few investigations. The first was to know about the nature of the disease; the second was to find out how to communicate my findings to the community. The former is analysed in the literature review section of this thesis, and the latter is reviewed in the methodology, data analysis and findings of this work. My understanding of frontotemporal dementia widened through certain processes during data collection.

The set of data collected is divided into two phases; however, there was a pre-data collection stage which was informal chats and observation. The rest of the data collection includes desktop research on FTD and analysis of my previous published works. I used the cyclical process described by Jokela and Huhmarniemi (2018). At the beginning of my data collection, I did not have a definite plan for interpreting my findings. Throughout my desktop research on FTD, I kept thinking about how I could raise awareness among Nigerian immigrants in the UK. There were times when my work process was confusing, and my methods were not clear at the beginning. Nevertheless, through trial and error, I proceeded intuitively, and my topic and questions became clearer as the research progressed (Borgdorf, 2009, 2011; Jokela & Huhmarniemi, 2018).

Firstly, I will start with what informed my research question. In ethnography research, scholars talk about 'entering the field' as a process by which they could familiarise themselves with their chosen field of research. This process includes mapping the setting, becoming acquainted with the beliefs and language of the people they're researching, and locating and building relationships (Schensl et al., 1999).

As an autoethnographic researcher, I am aware of this process, though, I aim to raise awareness of FTD within a group to which I belong; hence I don't need to immerse myself into the culture. I am already immersed in it. Before I started my PhD, I was interested in knowing what people in the Nigerian diaspora community in the UK knew about FTD. I began to have informal conversations with the people; this enabled me to be more conscious of prevalent beliefs that people have about dementia and accessing health care services for people with mental health issues.

5.1.2 The Pre-Data Phase: Informal Chats and Observation

As I narrated in the prologue section of this thesis, before I started my PhD, I worked as a storyteller and workshop leader in various memory cafés in Plymouth, UK, where I led storytelling, exercise and music workshops for people in various stages of dementia. It was during this period that I found out about frontotemporal dementia. However, what led to the title of this thesis was that during the years I worked with PWD, I did not meet anyone from any BME community in the workshops or programs that we held for PWD.

My first thought was perhaps it was because all my workshops were based in Plymouth, which is known not to have a large number of BME communities. That notwithstanding, I decided to find out what my community knows about FTD. My inquiry was in the form of informal chats (Berry, 2005). Scholars opine that sometimes, informal conversations are the only way to generate data (Swain & King, 2022), and in some cases, informal, unrecorded interviews may be the best way (Rutakumwa et al., 2020). The people I chatted with were not in the medical profession; I wanted to know what people, who were not doctors or nurses, knew about the disease. Everyone I spoke with knew nothing about FTD. Some have heard of dementia, but they thought it only affects older people. They did not know about the different types of dementia.

I spoke to friends, acquaintances, people in community clubs and church members; our conversation always yielded the same result. Many people did not know about frontotemporal dementia. However, whenever I explained the symptoms, people were shocked to know there is a type of dementia that affects younger people and that the symptoms mimic psychiatric disorders such as schizophrenia, bipolar affective disorder and major depression (Velakoulis et al., 2009). Interestingly, some went on to describe relatives that presented such symptoms, and they felt it could be FTD; hence, education is necessary for more awareness. However, they were not interested in investigating further.

The settings of these chats were not formal; they were casual meetings in town centres, at family events or on the phone. Some scholars talk about the flexibility of informal conversations during research. These conversations take place almost anywhere, for example, in a school corridor, on the street or on an army parade ground (Swain & King, 2022). I did not have a recorder or a notepad to jot down things. In this community, conversation about mental health issues and dementia comes up from time to time. However, it is nearly impossible to dig deep into these issues due to cultural beliefs.

I met with a handful of people who had elderly parents living with Alzheimer's. However, none of them utilised memory cafés or programs available for PWD. They hired private care. Some of these people were professionals in full-time jobs, and they were happy with the arrangements they made for their parents. Also, accessing community services for PWD was not something that they were interested in exploring. Studying the relational practices and common beliefs in this culture helped me create a meaningful art-based informative artefact that will benefit the people both within and outside the culture (Maso, 2001).

Sometimes, after chatting with people, who described some of the symptoms that their friend or family member presented, I tried to encourage them to get a diagnosis, but there were always negative reactions from such individuals. Many people I chatted with explained that the symptoms they described were some form of psychosis; however, from my research, FTD could mimic psychotic symptoms; the best way forward is to get diagnosed.

Initially, I thought it would be good to provide community workshops or talks on FTD and its devastating effects; however, I didn't have the boldness to go through that pathway because the few times I tried to talk to people about FTD, I was seen as a bearer of bad tidings. Some dismissed me with phrases such as, "Are you a doctor?" Some were not so aggressive, but their subtle "all will be well" was a polite way of ending the conversation.

How could I change the culture of 'silence' about FTD? How could I raise awareness about the importance of early diagnosis? These were the questions that plagued my mind as I wrote my PhD proposal. I knew the arts stood a better chance of influencing a culture with such powerful beliefs in occultism, demonic oppression and the like. I am a Christian, and I believe in the power of prayer; however, I am also a researcher who understands the role of medical sciences in the well-being of a community.

As I wrote my PhD proposal and questions, it became clearer that the pathway of art-based practice would be positive. When I started writing my play, there were times when I had to seek help from friends who knew about my research, and they gave me detailed information. One such was when I needed to know more about exorcism, and what goes on in certain religious sects I was unfamiliar with. As a child living in Nigeria, I had witnessed countless exorcisms in my neighbourhood; however, I saw these events as an 'outsider' who did not belong to the religious group; hence, I needed 'insiders' who knew the details.

Autoethnography also enables researchers to deliberate on their past experiences introspectively. I remember vividly an incident that happened to a woman in my neighbourhood when I was 10 years old. The woman was a friend of one of our neighbours. She was a kind woman; each time she visited our neighbourhood, she brought my siblings and me delicious *puff-puff* (Nigerian doughnut). I noticed that she had a peculiar way of walking and speaking. Sometimes, she seemed okay, but many other times, she stared in a strange way and talked to herself.

The woman was a teacher and owned a beautiful car, which her sister never allowed her to drive. They always got someone to drive her. One of the women in the neighbourhood once described her as an intelligent woman well respected in the Ministry of Education. There were times when we did not see her for a long time, and her friends said she was unwell. The way they talked about her was strange; there was always an eeriness to their gossip.

One day, I heard a strange noise coming from my neighbour's house, and I crept to their door to peep. The woman lay in the middle of the room, surrounded by her friends and some strangers. I watched as she muttered unintelligibly, occasionally writhing as if in pain, but the noise of the people around her drowned her voice. They raised their hands as if praying and matched around her, chanting in loud voices.

Later that day, I heard the woman's friend talking to one of the neighbours. "Oh, she is under a demonic attack again, and she's actually getting worse." Apparently, the woman had woken up in the middle of the night, dancing and yelling profanities. Her mood swings were becoming more frequent, and her speech had started slurring, which made it difficult for people to hear her. To make matters worse, the frustration of being asked to repeat herself made her more aggressive. "It is good that you brought her here so she can be delivered," the other woman concluded as they parted ways. I could hardly believe that this same woman, whom I respected and thought of as kind and generous, was "aggressive and demon-oppressed." I chose not to believe it. Sadly, I never saw her again.

When I started this research, I thought about her a great deal and wondered if she had been battling frontotemporal dementia. At that time, in the late 1970s, dementia was hardly known in Nigeria, let alone its variant, frontotemporal dementia. One of the things I observed during my research was that many Nigerian immigrants still held on to cultural and religious beliefs about people with mental health challenges. These deep-seated beliefs are not easy to shake off, even amongst people who are expatriates living in Western culture.

In order to proceed with my enquiry, I designed my research questions as follows:

(1) How can the awareness of frontotemporal dementia be raised using an art-based approach?

(2) What autoethnographic process preceded the development of the play '*My Name is Beatrice*'?

To answer the first question, I decided to use the form of ethnodrama, which I analysed in previous chapters. I chose ethnodrama because it enables me, as a researcher, to present my findings in a language accessible to a wider audience (Mienczakowski, 2001). Having established my methodology, which is autoethnography, and having decided on the form of my presentation, which is ethnodrama, I began to explore the autoethnography processes that preceded the development of my play.

Firstly, my position as an autoethnographer is more than being a researcher who wishes to raise awareness of a disease. I am a Nigerian immigrant; I understand the issues that my community faces daily in regard to accessing useful information about healthcare. Therefore, I could not proceed without examining my personal stories of health challenges and the struggle to overcome them. In chapter one of the thesis, I narrated my predicament of battling with perimenopause issues and the difficulty I encountered trying to find relief or alternative to HRT drugs, which is the standard answer modern medicine in Western countries has for women of my age going through these issues.

I had heard of the numerous side effects of HRT; hence I was not keen on trying it. The question for me at the time was, what can I do? I was suffering unimaginably, and my life and work were being impacted. Going back to my root as a person brought up to believe in God and the power of prayer helped me tremendously, as this encouraged me not to give up. With hope comes clarity of mind, and I eventually achieved my aim of bringing my body back to homeostasis.

As a writer and storyteller, I could not keep this information to myself; I set about writing a book that would help women, not only in my immigrant community in the UK but in various communities around the world. The sub-culture of people who believe in the power of prayers is not encouraged to share their experiences, especially when it comes to health issues. Some of the reasons could be some religious sects have diabolical practices. Nevertheless, there are still people who wish to express their faith in prayer.

Exploring my journey of recovery from multiple symptoms associated with perimenopause was the first autoethnography process that preceded the development of my play. Although one of the earlier criticisms of autoethnography is that the method is self-indulgent, narcissistic, introspective, and individualised (Wall, 2016), and some critics see the method as subjective, some researchers argue that even though autoethnographies are highly personalised accounts, they draw on the researcher's experience to extend sociological understanding (Sparkes, 2000).

In qualitative research, the researcher is the data collection instrument, and they cannot separate themselves from the research (Jackson, 1990). No matter how much we try to suppress ourselves, it is always present in our writing. Having said that, autoethnographers should not rely entirely on their personal memory as the only data source; the validity of such can be questioned. The researcher can selectively shape memory, and the story can be retold as it is shaped by one's experience, even though it does not mean the person is lying (Muncey, 2005). Muncey made a valid point about memory being selective; hence I did not just rely on my memory, but I revisited my previously published book on how I raised awareness of perimenopause. In addition, I explored my practice as a writer and storyteller and how my experience became valuable for creating an engaging drama.

5.1.3 Data 1: Previous Published Works

Part of my data collection process for this thesis was revisiting the process of writing my five books and one play. These are:

- Alao A. (2019) *Dear Toriola, Let's Talk About Perimenopause*
- Alao A. (2016) *Trickster Tales for Telling*
- Alao A. (2016) *How to Enhance Your Storytelling with Music'*
- Alao A. (2011 & 2003) *The Legendary Weaver: New Edition*
- Alao A. (2010) *The Goshen Principle: A Shelter in the Time of Storm*
- Alao A. (2008) *Legal Stuff Play*

It is important that I critically examine my research process and how my data gathering developed; hence, I am asking pertinent questions about how my data is constructed by this process (Willig, 2001). Artists have a way of "constantly researching both previous solutions of form (from the canons and their own previous work) and the specific elusive relationship between form and meaning that suits their present purpose" (Greenwood, 2012, p. 4).

In this section, I will briefly introduce the books and examine how I have used them for this research. This will enable me to show how revisiting the writing process of my books informs the data gathering and analysis that led to the creation of the play – '*My Name is Beatrice*'. I have not presented these books in the chronological order of their publication. I chose to start with 'Dear Toriola' because it was the book I found most useful as an autoethnographical piece and relevant to the theme of my thesis.

Alao A. (2019) *Dear Toriola, Let's Talk About Perimenopause*

This book is an epistolary narrative of my battle with perimenopause symptoms, but it challenges the predominant allopathic narrative that a woman is a victim of her hormones, thereby encouraging interventions that range from surgery to hormone replacement therapies. Many of the books on perimenopause and menopause, at the time I was writing, were full of medical jargon, while some others were condescending. I decided to use the form of storytelling to share my message that women are not at the mercy of their ovaries – active or retired. There is a pathway that leads to these symptoms, and there is a way out. I chose the epistolary style and created rapport between two women living on different continents; I then used my diaries and journals as correspondence for their communication – one learning from the other on how to overcome the symptoms. Autoethnography is a qualitative research method that uses a researcher's personal experience to describe and critique cultural beliefs, practices, and experiences (Adams et al., 2015).

Writing this book opened my eyes to certain facts about autoethnography. One of them is the importance of reflective journaling and desktop research. My data collection for the book was in two phases. Firstly, I read numerous books, peer-reviewed journals and papers on the issue of perimenopause. While researching, I found some information on menopause; however, perimenopause was a rare subject. Many health professionals see perimenopause as a natural transition of a woman into middle age.

Though the word disease is not attributed to perimenopause, for some women, their predicament is worse than a disease because perimenopause has the potential to render a woman's body weak and susceptible to other illnesses. Some conditions, such as heart disease, affect an area of the body, so doctors focus on treating it. However, for some women who are going through perimenopause, multiple body systems are affected. They experience palpitations (cardiovascular), acid reflux (digestive), erratic menstrual cycles (endocrine), lethargy (immune), osteoporosis (musculoskeletal), panic attacks and depression (nervous) and certain allergies (respiratory). These symptoms can affect their daily routines and social lives.

In order to immerse myself into the sub-culture of women going through perimenopause, I joined several online groups, and I discovered that in spite of the numerous health challenges associated with perimenopause, many women are not interested in Hormone Replacement Therapy that they were being offered, neither do they want to be guinea pigs for new 'mood enhancement' drugs. They just want their lives back and enjoy their work and families. Atkins describes the art of writing personal stories as a way by which authors purge their burdens (Atkinson, 2007). My book, '*Dear Toriola*,' allows me to question conventional and authoritative narratives (Toloyan, 1987) about perimenopause, which is not empowering for women.

The next phase of my data collection for the book was consulting and analysing my personal journals. Throughout my ordeal, I kept a daily journal of battles with insomnia, brain fog, hot flushes, dizziness and a host of maladies. Writing personal stories is therapeutic for me; it helps me to make sense of myself and my experiences (Kiesinger, 2002).

I aimed to write an accessible book that any woman between the ages of 35 and 55 could pick up and enjoy. I was keen on reaching women in third-world countries, many of whom may not have access to good medical care. I, therefore, created two women, one in Devon and the other in Nigeria. They exchanged letters through which we got a glimpse of non-pharmacological approaches to having symptom-free perimenopause. The autoethnographer not only tries to make personal experience meaningful and cultural experience engaging but also, by producing accessible texts, she may be able to reach wider and more diverse mass audiences that traditional research usually disregards (Ellis et al., 2010).

The next phase of my book project was the interpretation of data. I soon realised that the collection of data was one thing, but the choice of how to interpret the data was another. I decided to make the book aesthetic and evocative by using conventions of storytelling such as character, scene, and plot development so that it would engage readers (Ellis & Ellignson, 2000).

It seems the world is warming up to the idea of autoethnography as a valid form of inquiry; nevertheless, one must be aware of the power of narrative to mesmerise. It is possible for autoethnographers to be carried away by storytelling; however, it is not enough to just tell stories or create journal entries (Coia & Taylor, 2006); one must be faithful to the calling of autoethnography, which is to create robust cultural analysis.

In my book, Dear Toriola, after collecting data from my memoirs and diaries about my journey through perimenopause, I began to analyse and critique my stories from the point of view of established literature on perimenopause. I looked back at the mirage of symptoms I had battled with and asked questions about their root causes. I enrolled on naturopathy courses that enhanced my knowledge of how the body can be brought back to homeostasis. Some of the knowledge I gained from the programs challenged my preconceived notions about perimenopause symptoms being a natural pathway for middle-aged women.

My stories were beginning to change from that of a victim to one of curiosity about how to achieve well-being. I began to write my message of hope. It is also a message to challenge the established allopathy narrative of drug-based interventions for women experiencing debilitating symptoms of perimenopause. What autoethnography does well is to challenge the notion of 'silent authorship', whereby the writer or researcher is seen and not heard. Such a notion is hailed as a mature scholarship when a researcher's actual voice is no voice at all (Charmaz & Mitchell, 1997).

After analysing my data, I decided to share my findings in an accessible format. I wanted my audience to be immersed in the narrative, even though the book is non-fiction. Therefore, I chose the epistolary form and used elements of fiction, such as characterisation and an engaging setting. I created interesting characters, whom my readers can sympathise with, and also created interesting family issues and other relatable narratives to make the book engaging. Most often, through the use of conversation, 'showing' allows writers to make events engaging and emotionally rich (Ellis et al., 2010).

Each chapter starts with a salutation that draws the reader to the day-to-day life experiences of people, irrespective of culture or creed.

> "Dear Toriola,
> I am happy to hear that the bank is no longer threatening to lay you off.
> That news was like a great birthday present for me this month...!"
> (Alao, 2019, p. 24).

The chapters start with a letter in which one of the women replies to an initial letter the other woman sent to ask questions about her health problems. In the body of each letter, the writer uses stories and personal narratives to explain what perimenopause is and why some women experience terrible symptoms. The most enchanting part of the letters is the encouragement not to give up. This is depicted using fables, metaphors, folk tales and various other forms of storytelling. As an autoethnographer, I am, first and foremost, a communicator and a storyteller. It is a way to describe or portray people struggling to overcome adversity and also shows the meaning of their struggles (Bochner & Ellis, 2006).

I wrote the book to help me make meaning of a terrible experience, but more importantly, to give other women going through perimenopause the opportunity to seek non-drug pathways to bring their bodies back to homeostasis. However, the story of how I ploughed through the labyrinth of perimenopause symptoms does not end in the confines of reflection, as seen in the way I wrote this book. As a narrator, I chose what event I intended to narrate and ordered them in a way that interpreted my reality. It is a meaning-making process rather than a chronology of events (Barthes, 1977).

One thing I aimed to communicate in this book was the understanding of the root of health challenges. Many health problems have a root that needs to be examined; this helps people to understand where or how to start their healing journey. In the chapter titled '*April 2013*', there is a subheading titled '*Digging Deeper into the Root*'. The narrator (me) explains how the sudden death of her father led to her food allergies and intolerance.

> "In 2004... my father, who had only been ill for a few months,
> died at the age of 66. I didn't see it coming at all;
> he had been so healthy and agile...I had to bury my grief and
> be there for my siblings. A few months after my father died,
> I ... developed an egg allergy..." (Alao, 2019, p. 31).

In the same chapter, the narrator explains the reason for injecting these personal stories.

> "I am sharing these personal stories with you to make a point: that
> there is a pathway to ill health...you need to dig deeper, get to the
> root of the issues that are plaguing you and turn
> things around for yourself." (Alao, 2019, p. 32).

I still remember my GP telling me to avoid 'trigger' foods while battling food allergies. I was never satisfied with his response because my food allergies were increasing. Moreso because I did not suffer from many of the allergies, such as egg intolerance, before the age of 37. Why did I suddenly become intolerant to these foods? My quest led me to research various natural pathways to healing, but what gave me a total breakthrough was digging deep to get to the root of the issues. Then I began my uphill journey to healing.

I felt my story was worth sharing, especially with people who are despondent about their health conditions. I aimed to give them hope. However, when I started writing the book, my dilemma was how to present my message in an accessible and interesting way. Story-making enables us to acknowledge the surprises that the human condition throws at us, and it allows us to accept the imperfection of our grasp of the condition (Bruner, 2002).

How did my experience of writing 'Dear Toriola' become an autoethnographical tool for my PhD thesis? When I started my PhD, I was faced with a similar dilemma after researching and learning about frontotemporal dementia. The questions I had to answer were: how do I communicate the information I had gathered about FTD with a group of immigrants, many of whom are still ignorant about its existence? How do I convince people sceptical about care services that they feel are not culturally relevant to them about the importance of early diagnosis? In a community that has cultural and religious opinions about mental health issues, one has to find an accessible way of getting the message across to the people.

One of the challenges I had to overcome when writing '*Dear Toriola*' was the ethical issue of writing a narrative involving others, such as family members or friends. Several times during my writing, I stopped to evaluate these ethical issues and critique my work in that light. Reflexivity helps researchers to explore ways in which the influence of a study acts upon and informs such research (Nightingale & Cromby, 1999). This reflection led me to create fictionalised accounts, altering dates, times and identities of people. Autoethnography is a form of self-narrative that "critiques the situatedness of self with others in social contexts (Spry, 2001, p. 710).

Using my experience of writing 'Dear Toriola' as data for my thesis poses a few challenges. Firstly, I am aware of the lack of interest in narratives of personal experience in the body of research on institutional discourse (Keller-Cohen & Dyer, 1997); however, researchers have argued that we cannot separate narrative and self (Ochs & Capps, 1996). Human beings make meaning of life experiences through the telling of what is known (Polkinghorne, 1988). The question – of what constitutes 'validity' in research – is an age-long debate that tends to put researchers that explore traditional quantitative research against those who use qualitative research methods. Some argue that self-reflection can validate a study, while others talk about the irrelevance of self-reflexivity because there are limits to how one can self-reflect (Lenzo, 1995).

Alao A. (2016) *Trickster Tales for Telling*

This book is a collection of stories about the sly trickster, the tortoise. These tales give storytellers the opportunity to engage creatively with their audiences. The call-and-response style used in this book is great for audience participation. The trickster, the tortoise, captivates storytellers around the world; his eloquence and resourcefulness are subjects of discussion in many storytelling circles, especially in West Africa. He moves at a slow pace and carries a huge shell on his back; nevertheless, he is able to bring mighty animals, like the hippopotamus and the elephant, to their knees.

I heard these stories when I was growing up in Nigeria, and I thoroughly enjoyed them. Unfortunately, many of them are only available as oral narratives in the Yoruba language, my mother tongue; they were not recorded in books, so I had to rely on my imagination each time I tried to retell them in schools or communities. A few years ago, I decided to write and publish some of them so that the next generation of storytellers could access them.

The first part of the journey was to translate the original stories from Yoruba to English in order to share them with a wider, non-Yoruba-speaking audience. A few years before embarking on this project, I had translated seven books for a major publisher; therefore, I thought this project would be easy, but I soon realised it was no mean feat. Nevertheless, after many months, I finished the first part and moved on to adaptation. This also had its own challenges; one of them was how to write the tales to suit a modern audience. To overcome this challenge, I decided to modify the stories, and I also wrote brand new scenes, characters and plots. I enjoyed recreating each of these stories and giving them a contemporary twist.

When I was young, I was bullied, and I dreaded going to school because the bullies took my lunch money and sometimes beat me up. The other students saw what was happening but did nothing, and I was too frightened to tell my parents. I knew they would come to the school, and I thought that would make matters worse. I was shy and didn’t engage with my classmates, but I noticed that our class teacher loved clever and quiet students. My quietness was the only thing I had going for me at that time.

Before long, in Year 2, the teacher noticed I was responsible enough to be given the job of writing down the names of ‘noise-makers’ any time she went out of the class. Well, that was my breakthrough; I had the pen and paper. Suddenly, boys and girls who wouldn’t say a word to me in the class started coming to my desk to give their advice on whose names should or shouldn’t be on my paper. That was the first time a teacher in school gave me the opportunity to do anything, even if it was as insignificant as writing down names.

As a little girl, I used to imagine the bullies as powerful, and I saw myself as a tiny cockroach that could be snuffed out at any moment; however, the situation changed when I got the teacher’s attention and subsequently made more friends. I gradually became bolder, and I even raised my hand to answer questions in class. I love trickster tales because the protagonists are usually small and weak, yet they are able to overcome terrible situations. Also, these anthropomorphised animals don't recoil into their shells. They use their imagination to 'plot' their way out of negative situations.

In Nigerian, where I grew up, storytelling was not just for entertainment; that's why the chant "Itan yi ko wa wipe..." "*The moral of this story is...*" that griots and their audience chant at the end of a narrative is usually the icing on the cake of any storytelling session. Immediately after a story, the narrator starts the chant, and the audience sings along and finds a moral for that story. The aim of storytelling is to teach a moral. Today, I inject short stories – be it a fable, folk tale or parable into my writing and teaching for the same purpose – to buttress a point, to teach a moral. This reveals my individuality and style as well as reveals the society that has shaped my worldview. It shows how I am also becoming a shaping agent (Keller-Cohen and Dyer, 1997).

I translated and adapted the stories in this book for publication because of my fascination with how tricksters negotiate the bends and curves of life, I am sometimes amused at their quick wit, but I also see how their actions mirror the natural world. It is rare to find a creature that sits by and allows itself to be destroyed by another without putting up a fight. Illnesses or diseases can be a metaphor for life's bully.

I used this theme in the play that I created in this thesis. The two main characters, Beatrice and Ireti, tell a story in this book. Beatrice later uses the story as a 'prophetic' metaphor. Though there is no cure for her FTD condition, she sees herself overcoming some of her challenges, just as the trickster overcame the problem that would have totally destroyed him and the other animals.

As a storyteller, telling these tales to my audience is my way of assuring them that they can learn survival skills from tricksters, whether they are battling a disease or any other life challenge. They teach us how to challenge the negative chatter and mini-narratives that occupy our subconscious mind and render us helpless and immobile. Tricksters are never immobile; they are too busy planning and plotting to give in to despondency.

Mar (2004) opined that storytelling is the only medium where one witnesses the creation of an imagined world, which mirrors our own realm of experience. Studies show that when we read non-fiction, we read with our shields up; we are critical and sceptical, but when we are absorbed in a story, we drop our intellectual guard. We are moved emotionally, making us rubbery and easy to shape (Gottschall, 2012).

Our experiences in life are not linear; they are full of twists and turns. Trickster tales mirror this complexity, and they can be likened to instruction manuals on the essence of life and wisdom. The trickster and his antagonists play many roles; these produce layers of social meanings that are complex. We see this manifest in how the trickster can disrupt and reorganise (Sekoni, 1994).

In my personal life, I have witnessed how trickster tales can influence thoughts and actions. As a little girl, I couldn't get enough of the tales of Ijapa. Perhaps I sought refuge in them when the fear of bullies was overwhelming. We live and think in a story framework that is brain-based and deeply human (Young & Saver, 2001). The human experience is highly influenced by the act of comprehending, producing and executing stories (Mar, 2004).

Stories can influence or even change our beliefs about the world around us. Readers of fiction have been found to change their attitudes and worldviews just by being exposed to stories (Green & Brock, 2000). When I started the first draft of the play, '*My Name is Beatrice*', I used this book as a resource to inspire my creation of the bond between the protagonist and her mother, who was battling with illness. These two main characters shared storytelling moments, using the style I created in the book '*Trickster Tales for Telling*'.

Alao A. (2016) *How to Enhance Your Storytelling with Music*

This book is a resource for storytellers, teachers, community workers and parents who wish to create an engaging storytelling experience and connect more effectively with their audience. Music is a universal language that everyone connects with, irrespective of age, culture or race. Songs can be used to stir the emotion of an audience, thereby creating a high level of rapport between the teller and the listener. Music can be used to synchronise groups of people as they engage in a common activity (NIH News in Health, 2010).

The book offers practical call-and-response storytelling examples that could take peoples' performances to a new level. I have been telling stories professionally in various settings for almost two decades. However, my best experiences have always coincided with the times I have used music in my storytelling. Music creates an unforgettable experience that helps me connect to my audience.

The theme of call-and-response storytelling features in the play '*My Name is Beatrice*', albeit briefly. There is research that explores the efficacy of music as a person-centred approach to dementia care; music performance, which includes drumming, dancing and singing, helps to release endorphins (Dunbar et al., 2012). Music gives a sense of satisfaction. The audience feels that they have been part of the whole narrative experience. A sense of 'community' is built as the emphasis shifts from the storyteller to the group having a storytelling experience.

Alao A. (2011 & 2003) *The Legendary Weaver: New Edition*

This is my first young adult novel. The story is set in Nigeria, where Kike, the protagonist, lives with her mother, Aduni, in a remote village. A serious bout of fever leaves Kike weakened. She recovers slowly but gradually loses her hearing until, in her early teens, she is totally deaf. After a period of deep depression, she turns her disability into a challenge and this challenge into a wondrous capability as she advances from her lowly station to a symbolic house on the hill. The theme in this novel is overcoming adversity, a theme that is prevalent in all my creative work.

The structure of The Legendary Weaver as a frame narrative was deliberate. I wanted it as a storytelling novel with a narrator, hence the use of a prologue and epilogue. A grandmother was telling the story of the origin of a hair design known as Cornrow that enables young African girls to use their hair as a canvas to create intricate designs that tell artistic stories.

During my data collection for this thesis, I revisited my notes and drafts for this novel; I wanted to see how the protagonist emerged and transformed; the novel must have gone through more than twenty drafts. However, each draft showed me the process of creating memorable characters, settings and plots. This experience was valuable in creating the protagonist for the play – '*My Name is Beatrice*'. In the play, Ireti, Beatrice's daughter, is the protagonist, though Beatrice is the woman who has frontotemporal dementia. I want to show the plight of a young carer to buttress the fact that families of people with dementia suffer a great deal, especially young carers. I aimed to create an emotional piece.

Alao A. (2010) *The Goshen Principle: A Shelter in the Time of Storm*

This book is a typological allegory that explores the narrative of the Israelites' deliverance from slavery in Egypt. According to the narrative in the book of Exodus in the Bible, certain supernatural events occurred in Goshen that cast a metaphoric spotlight on the name.

The biblical account talks about a man named Moses, who was called by God to lead the Israelites out of slavery; however, the Pharaoh, at that time, would not let them go. Therefore, following the instruction that God gave to Moses, he performed some wonders in the presence of Pharaoh to convince him, but he could not convince the king to let the people go. Subsequently, the country suffered from plagues, twelve in total, and the last plague was the death of all the firstborn Egyptians. After this, Pharaoh released the people. The miraculous event, however, was that none of these plagues was seen in Goshen, where the Israelites lived, because God had promised that no plague would appear in their dwelling places.

Using this story as a typology, I wrote an inspiring exegesis of the narrative. The main purpose was to explore the symbolism of Goshen and draw significant parallels about how to experience God's deliverance even when people appear to be in the 'darkest places' as they journey through life.

What did I learn from the data-gathering process of writing The Goshen Principle? Firstly, I researched publications that gave an account of the ancient and current location of Goshen. Many of these were travellers' narratives of the lusciousness of the land. The Bible was my main resource on the story of how the Israelites came to live there and how they became slaves. Secondly, the challenge of not finding publication on my theme for the book was frustrating, but I persevered and found other books that talked about spiritual growth. This experience came in handy when I was struggling with finding data on my current research question. I learnt how to look further afield for similar materials.

My Award-Winning Stage Play – *Legal Stuff*

In 2008, I wrote a play titled '*Legal Stuff*', and it won the BBC Royal Court '24 Degrees' Writing Competition in England. The play is about immigration issues relating to legal documents and their associated problems. When I was doing my initial research for this play, I found that many people did not want to discuss their immigration status, let alone how they plan to overcome these challenges. Some people ventured into arranged marriages with people who have European passports to obtain their legal papers. After a few months, they get a divorce, but they become European citizens by marriage. I was intrigued by these acts and thought about my sheltered life, being oblivious to these matters. However, I also knew of the dangers that lawbreakers face; hence I decided to write a play to create awareness of other options aside from breaking the law.

My data gathering process for '*Legal Stuff* was through desktop research and observation. I heard about a case of an arranged marriage gone wrong. That was the first time I became aware of the problems that illegal immigrants face. I knew about some of the issues, but I was not aware of the extent some people would go not to be deported to their country of origin. I began seeking more information and asking questions from people I knew. I did not conduct formal or semi-formal interviews. Our conversations were friendly chats; a few people were forthcoming with information. I told them about the play I was writing and assured them that the characters in my play would be totally anonymised.

How did the experience of writing this play inform my thesis? I had similar challenges when I began my research. Dementia is still a taboo subject in many Nigerian immigrant communities; families do not talk about their relatives' mental health issues. One of the ways I overcame the challenge of finding people to speak with was to revisit the research process of my play '*Legal Stuff*'. I had informal chats with people and asked questions about their knowledge of frontotemporal dementia. Many people that I spoke with had never heard of frontotemporal dementia. However, when I explained the symptoms, some felt they had relatives presenting with the symptoms but did not know how to help them.

Also, my skill as a playwright lent itself to the development and creation of the play, '*My Name is Beatrice*', where I explored the elements of dramatic writing.

5.1.4 Data 2: Desktop research and review of articles on frontotemporal dementia

Researchers have acknowledged the need for descriptive population studies to fill gaps in our knowledge about minority groups and developing regions (Onyike & Diehl-

Schmid, 2013). My search on the prevalence of FTD among BME communities only yielded reports about dementia in general, as opposed to frontotemporal dementia. A report that was useful for my investigation was conducted in England by the Bristol BME Dementia Research Group to investigate why the needs of PWD from Caribbean, South Asian and Chinese communities in Bristol are not adequately met. There was no one from Nigerian or African BME community represented in this report; the subjects were from Caribbean, South Asian and Chinese communities.

The researchers addressed issues such as late diagnosis and inadequate service provision. The group found that contrary to the belief that BME communities are 'unreachable', the people were more likely to use services that were BME-led because they felt they could meet their needs. The study highlights the need for more researchers from BME communities to be present within dementia research. It also addressed the issue of dementia being a stigmatized condition among BME communities, and this could hinder PWD in the community from utilising mainstream care services (Bristol BME People and Dementia research group, 2017).

During my work with PWD and their carers, I learnt about the different types of dementia; however, I was drawn to research more about Frontotemporal dementia (FTD). I found that research into the prevalence of frontotemporal dementia amongst immigrant communities in the UK was almost non-existent. I started to research what studies has been done on FTD among immigrant groups. I was looking for research on the prevalence of FTD among Nigerian immigrants in the UK.

I did not find any such research, so I narrowed my search to finding out about FTD in general. I then analysed many peer-reviewed articles and research from leading scientific journals and websites such as, Sage Journals, Google Scholar, ResearchGate, The Lancet, Alzheimer's Research UK, Journal of Neurophysiology, The British Medical Journal (BMJ) and other published materials. These papers gave me information about FTD, even though the subjects were not people from BME communities. Nevertheless, I had information about the symptoms, neuropathology, co-morbidity and prevalence of FTD. This formed the foundation for creating the play '*My Name is Beatrice*', which is the art-based finding of my research. Furthermore, I didn't need to look for human participants; hence there was no need for ethical review. The mandatory consideration for using published materials was acknowledging the texts (Berger, 2012).

Through my research, I discovered key information about the disease. Firstly, diagnosis is usually challenging. Researchers have revealed that there is an overlap between frontotemporal dementia (FTD) and a variety of primary psychiatric disorders, challenging the artificial divisions between psychiatry and neurology (Miller & Llibre, 2019). The similarity of the prominent behavioural features of FTD and some psychiatric disorders allows for misdiagnosis; however, there is currently advanced clinical imaging and molecular characterisation; this has helped to improve the accuracy of FTD diagnosis (Park & Sun Jun, 2016).

There are numerous challenges that hinder the search for accurate information on the prevalence of FTD amongst the people of African ancestry in general and Nigerians in diaspora in particular. A diligent and thorough research on FTD was important because it is important that the play is believable and that it addresses the issues I intend to raise. I created a file for all the information that I had gathered and used them to create believable scenarios in my play. For example, a typical symptom is insomnia and other sleep disorders. Insomnia was reported in about 48% of FTD cases, while sleep-disordered breathing is reported in 68% of cases (McCarter et al., 2016). Hypersexuality, risk of falls (Burrell & Hodges, 2018) and eating disorders such as, binge eating, lack of appetite and particular food preference (Aiello et al., 2016) are other symptoms of FTD. In my play, I showed the main character manifesting these symptoms.

Research is ongoing as to why a person develops FTD; however, many of these are inconclusive. I used this information in a poignant way when the main characters tried to look for answers. They wanted to know why or how FTD became an unwanted part of their lives. From my research, around 40% of people with the disease have a family member who also has it (Khan & De Jesus, 2021). The issue of genetic predisposition to FTD still remains unclear, especially amongst people of African ancestry. Some scholars opined that only a fraction of the genetic diversity among Africans has been surveyed with less than 2% of genome-wide association studies (GWAS) comprising African data (Akinyemi et al., 2022).

5.2 Data Analysis

5.2.1 Analysis of the autoethnography process

In qualitative research, data collection and data analysis work simultaneously (Merriam 2002, p. 14). According to Josselson (2006), narrative research is interpretative at every stage, starting from when the research is conceptualised to the collection of data and the writing process. "Autoethnographic data analysis and interpretation involves moving back and forth between self and others… The interweaving of data collection, analysis, and interpretation ultimately leads to the production of autoethnography" (Chang, 2008, p. 9).

In this chapter, I will analyse the two data sets I collected to help me answer my research questions. The data includes:

1) Analysis of previous works

2) Desktop research and review of articles on frontotemporal dementia

Although the main analytical method is narrative, I will examine multiple models I used for each data.

5.2.2 Analysis of Data 1: Previous Published Works

The first data that I will examine is my previous published works. For this, I used Labov's model as a framework (see Appendix 1: Analysis of the Autoethnography Process). This method is a major framework of narrative analysis used by researchers (McCormack, 2004; Mishler, 1995; Patterson, 2013; Riessman, 2008) to identify the meaning of stories that are told. Labov (1972) focused on oral narratives rather than dwelling on written text; nevertheless, my narrative of using my previous works to navigate how to best present my findings about FTD could be analysed using his theory.

Labov postulates six main parts of a narrative; researchers can use each of these to analyse narrative patterns, thereby recognising themes and ideas as they occur. The six parts are abstract, orientation, complicating action, evaluation, resolution and coda. This model is advantageous because it helps me, the researcher, and my readers explore the story being told here.

The abstract section is a brief summary of the story. Labov sees this as the point where the audience's interest is piqued, and they want to hear the rest of the story. The orientation stage allows the speaker or writer to share more information about the setting of the story and the characters who will influence the narrative. Complicating action is where the actual events that move the narrative forward feature. This could be physical action or words. Evaluation is a crucial part of the model because it refers to why the story is being told. I have endeavoured to reveal this in a way that the reader would understand the purpose of the story.

The resolution section shows the end of the story or how it has come to a close. Coda gives the author the opportunity to share the relevance of the story by connecting it with everyday life or with other events or actions that fall outside the story frame (UKEssays, 2018). The Coda section for each of the books shows the relevance of my data collection experience to my thesis. This experience has enabled me to create an engaging drama that interprets the data I collected for this research.

5.2.3 Analysis of Data 2 – Desktop Research on and review of articles on Frontotemporal Dementia

The second data that I will explore is desktop research on frontotemporal dementia. When I started my research into frontotemporal dementia, I analysed many peer-reviewed articles and research from leading scientific journals and websites such as Sage Journals, Google Scholar, ResearchGate, The Lancet, Alzheimer's Research UK, Journal of Neurophysiology, The British Medical Journal (BMJ) and other published materials. I examined the symptoms, neuropathology, co-morbidity and prevalence of FTD. This formed the foundation for creating the play '*My Name is Beatrice*', which is the art-based finding of my research.

I used ethnodrama as a method of analysis because art has an instantaneous effect on an audience in the way it captures their attention and leaves enduring memories.

Research that is presented using arts-based techniques has the capacity to transform (Leavy, 2009).

Desktop research was a major part of my journey through this PhD. The information I gathered from scientific and peer-reviewed papers, outlined in the literature review section, gave me information about the prevalence of dementia and frontotemporal dementia in particular.

I analysed the information by first examining the themes that are emerging. These themes include the role of storytelling and the narrative of personal experiences in academic work and how it influences data interpretation in autoethnography research; the importance of music in the way it elicits rich information and gives insight into complicated, diverse topics; the need for more studies on the prevalence of FTD in BME communities and the importance of narrative medicine.

The next step was to examine the contributions of my findings to this research. The first topic that emerged was the efficacy of using drama as an educational tool to raise awareness of a disease. I found that using ethnodrama to interpret data reveals how art has an instantaneous effect on an audience because it can capture their attention and leave enduring memories. Furthermore, through my research, I was able to explore the complex needs of people in BME communities. There is evidence that a system with physicians who can acknowledge the stories and difficulties of their diverse patients can gain the trust of the people who use it. Overall, my research helped me to create a dramatic piece that would enlighten the community about FTD, the importance of early diagnosis and holistic approaches to care.

A large part of the data for my play came from my desktop research about frontotemporal dementia. This was woven together with professional experience of working with PWD and personal reflection on my practice. I read real-life stories of families who are carers and fictional plays about real-life people who have the disease. Some scholars work collaboratively with playwrights and theatre directors to create engaging productions directly from their research data, group discussions, reflection and personal experience. An example is the play, 'I'm Still Here' by Mitchell et al (2006). The aim of these scholars was to explore what relationship, loss and hope mean for PWD.

Jokela and Huhmarniemi (2018) describe the art-based research process as cyclical. The first part is planning, followed by an investigation of the socio-cultural situations or community. The next step is to look at what has been done before, and lastly, intervention. I started my research journey by observing my cultural group and asking questions informally. I am a Nigerian immigrant living in the UK; I did not have to go as a researcher to observe this group; I am immersed in it. I began formulating my research questions as I continued observing how people around me respond to mental health issues, especially dementia.

After analysing my previous works and the data from the desktop research, I began to write the play '*My Name is Beatrice*'. Scholars opine that essential research materials can include artistic work, production, and participatory observation of activities (Jokela & Huhmarniemi 2018). My first draft was created with the knowledge I gained about FTD and how it impacts families. The creative work involved creating characters who are Nigerian immigrants and finding names that are culturally relevant and believable for the characters.

I had a few challenges when I presented the first draft for critique. I could not find BME artists where I lived, so I gave the draft to one of my colleagues who taught drama. However, there were no BME students in his class to do a performed reading. Initially, I did not think it mattered, as I wanted to hear the play. However, during the reading, I felt it would have been great to hear the opinion of the readers on some cultural issues going on in the drama. I did not get such reviews, but I got feedback on the dramatic elements.

The first critique was that I did not allow the audience to have a feel of the mother-daughter relationship between Beatrice and her daughter Ireti. They said the play would prosper if I could add an opening scene. Initially, I was apprehensive of this because I aimed to start the play In Medias Res. This is a Latin phrase for 'into the midst of things.' It is a device whereby a writer puts their readers into the middle of the plotline without beating about the bush. The readers said they would like to know more about the characters before seeing their affliction. I debated this and wondered if I should introduce a scene that shows a backstory of how Ireti's family lived before her mother's illness.

Eventually, I rewrote the play and created an opening scene without compromising starting the story In Medias Res so as to grab the audience's attention. I rewrote the first scene to accommodate the suggestions and introduced the two main characters enjoying an evening of storytelling and hair braiding. I did not create a new scene that was too long. I wanted to make the play engaging; hence it should have a good narrative hook, and it should move at a steady speed. Writers should be careful not to overdo things during the process of revision. They should allow good judgement to guide them on what to keep or discard (Smiley, 2005).

There are a few ethical issues surrounding practice-based research; one of such is: how do we know that the work presented by an artist has made a real addition to knowledge? One way is to make artistic work comprehendible without ambiguity. In order words, a context explanation should always accompany a creative piece. This may be debatable in visual arts, as one could ask why we need a linguistic explanation for a painting. One could argue that a painting is open to multiple interpretations by various people. However, in order to know the function of an art piece in research and knowledge production, it is important to communicate the expression of knowledge in a widely agreed-upon meaning (Candy & Edmonds, 2018).

Forcing creative art research into the mould of traditional or established methodologies may distort the entire research; nevertheless, creative art research needs a methodology that is appropriate and sympathetic to the nature of the discipline, though it should not be less rigorous or accountable than science and social science methodologies (Gray & Malins, 1993).

Questions about the devastating nature of dementia, how PWD experience the complex issues and care provision, or lack of care can be explored through fiction. One of the fictional works that I studied while writing my play was '*Still Alice*' (Westmoreland & Glatzer, 2014). It is the story of a 50-year-old woman named Alice, who has early-onset Alzheimer's. The story aims to challenge the predominant narrative of loss and tragedy in Alzheimer's while allowing the reader to navigate the world of the protagonist.

In 'Still Alice, readers are given an inside story, through the protagonist's viewpoint, instead of the viewpoint of her family or friends. There lies one of the ways in which the novel challenges the narrative of the loss of selfhood that dominates information and stories about dementia. Furthermore, the protagonist's initial experience of dementia was at the age of 49. She was a professional in the prime of life, as opposed to a sick old woman stereotypically presented with Alzheimer's. The play challenges preconceived ideas about ageing and disease.

Some scholars use ethnodrama to find out the opinion of the general public about topical issues, and they create fictional stories from their research. An example is the play 'Sarah's Daughters written by Jeffrey Nisker. The focus of Nisker's play was genetic testing for cancer genes, and the aim was not the creation of awareness but to seek people's opinions and encourage people to explore the ethical implications of screen testing. My play, '*My Name is Beatrice*', will be presented in BME communities, where issues and barriers impeding the prevention of FTD and care access can be identified.

5.3 Summary of the Analysis of the Autoethnography Process

In order to understand the process of creating awareness for FTD through my thesis, I needed to revisit my work as a writer and storyteller. Analysing the process of writing my books allowed me to reflect on the purpose of my writing. A few themes emerged as I revisited these books. The first is how I confronted conventional and authoritative narratives about perimenopause which is not empowering for women. Another one is how I used autoethnography and epistolary style as art-based method of interpreting data, which also enabled me to navigate the ethical issue of writing a narrative that involves others, by fictionalizing my data. A prominent theme is the role of storytelling and the narrative of personal experiences in academic work and how it influences data interpretation in an autoethnography research.

The next question I asked after analysing this data was, how does this contribute to the writing of my thesis? Firstly, I was able to gain more understanding of how to use autoethnography as a methodology and ethnodrama as art-based method of interpreting data. In addition, I was able to confront the predominant narrative in healthcare about BME communities being 'inaccessible', similar to how I confronted authoritative narratives about perimenopause in my book 'Dear Toriola'. Another major contribution was the influence of my books on creating engaging plot and memorable characters for my play. This aspect is crucial to every type or genre of writing; believable characters and good plots aid the success of every story.

My desktop research data enabled me to understand the role of storytelling and the narrative of personal experiences in academic work and how it influences data interpretation in an autoethnography research. I gained knowledge on the efficacy of storytelling and music as non-pharmacological approaches to dementia care. I also understood why there is a need for more studies on the prevalence of FTD in BME communities, and the efficacy of using drama as an educational tool to raise awareness of a disease. This research enabled me to create a dramatic piece that would enlighten the community about FTD and the importance of early diagnosis and holistic approaches to care.

Analysing autoethnography data is complex and time consuming because the focus is not on hard numbers to measure differences between variables, but on creating meaning through exploration and description. Initially, I visited existing methods of qualitative analysis. Polkinghorne's insight into what constitutes narrative meaning gives researchers the opportunity to explore narrative analysis as a method of analysing data. Polkinghorne (1988), creates a distinction between an analysis of narratives and narrative analysis. In the former, researchers endeavour to make sense of the stories that they collect thematically. In the latter, literary principles, such as plots and motifs are used to make sense of data which may not in its raw form read like stories (Mihas & Institute, 2019).

Based on my analyses, five main themes emerged from my data interpretation. The first is how reflecting on and analysing previous works and writings can influence a new autoethnography research. The second theme is the role of storytelling and the narrative of personal experiences in academic work and how it influences data interpretation in an autoethnography research. The third one is how data can be fictionalised in autoethnography because of issues pertaining to ethics. The fourth theme is the need for more studies on the prevalence of FTD in BME communities, and the fifth is the importance of narrative medicine.

Firstly, autoethnography has enabled me to connect the personal to the cultural by examining multiple layers of consciousness (Ellis, 2001). Analysing the process of writing my book, 'Dear Toriola', enabled me to explore my personal experience as a storyteller and writer, and to understand my position as a researcher and a member of the Nigerian immigrant community. The book, a narrative of raising awareness about medical issues and how to navigate a labyrinth is similar to the aim of this thesis – raising awareness of FTD. Autoethnography is a form of self-narrative that critiques the situatedness of self with others in social contexts (Spry, 2001). The story I am telling is not just mine; it situates me with others within the social context of dementia care.

The second theme that emerged is the role of storytelling and the narrative of personal experiences in academic work and how it influences data interpretation in an autoethnography research. Autoethnography allows me to reflect upon my practice as a storyteller and writer; it gives me the opportunity to critique how I have used storytelling not only in entertainment, but also as an educational tool. In my books, storytelling offers interpretation of how humans make meaning of life's challenges. Could I do the same here through writing an engaging play? In autoethnographies, writers construct and disclose selves. Writers may also interpret the past, translating and transforming contexts, and envisioning a future (Jones, 2008).

The third theme is how data can be fictionalised in autoethnography. In my book, 'Dear Toriola', I made the decision to interpret my data through an epistolary style and I fictionalised the narrative, as explained in the previous chapter. Similarly, the interpretation of my data for this thesis is in form of a stage play. This will enable me to reach a wider audience and create lasting changes, because of the power and efficacy of storytelling. Stories influence or even change our beliefs about the world around us. Readers of fiction have been found to change their attitudes and worldviews just by being exposed to stories (Green & Brock, 2000).

Research has shown the efficacy of using drama as an educational tool to raise awareness of a disease because creative arts provide opportunities for both researchers and research participants to reflect on their lived experiences and understand themselves better (Foster, 2007). According to Daykin (2009), music elicits rich information and gives us insight into complicated diverse topics. The arts have the ability to capture the attention of people; hence,

I decided to explore ethnodrama as a method of interpreting my data because of the way art leaves long-term memories.

As I wrote the play, '*My Name is Beatrice*', I constantly asked myself how useful the story is and how might it be used (Bochner, 2002). One of the ways an autoethnography work is judged is in the area of its effectiveness in improving the lives of the reader (Ellis, 2004). Therefore, it was important to me that I create a piece that would enlighten the community about the disease, the importance of early diagnosis and holistic approaches to care. The play is also a deliberate attempt to provide a platform for public debate, strategic analysis and provocation for change (Greenwood, 2012).

The fourth theme that emerged from my data interpretation was the need for more studies on the prevalence of FTD in BME communities. Literature on this is almost non-existent. It is well documented that in many European countries, African immigrants were often seen as part of a larger homogeneous community (Wamwayi, 2019) and they are usually placed in the same immigrant population with Asians

(Diaz et al., 2015). This research will enable educators and medical practitioners understand the needs of this group.

The fifth theme is closely linked to the fourth. It is about the importance of narrative medicine. The field of narrative medicine emerged in response to a healthcare system that focuses more on bureaucratic issues than the needs of patients. In many healthcare systems the needs of people in BME communities are complex. They go beyond the physical ailments that they present to doctors. These needs are multifaceted; however, a system that has physicians who are able to acknowledge the stories and difficulties of their diverse patients can gain the trust of the people who use it.

6. FINDINGS

This chapter includes the art-based findings created with the ethnodrama method in my research. Firstly, I will briefly introduce the play, followed by the play itself – the main result of this research process. The last part of this chapter focuses on the critical commentary of the play; this explains how the dramatic elements respond to the second research question of this thesis.

6.1 A Short Description of the Play – 'My Name is Beatrice'

The play, '*My Name is Beatrice*' is situated in the 'Appendix' section of this thesis. It is important that the play is read before examining the critical analysis in the next section. I chose to fictionalise my findings not only for ethical reasons but also because it is the best way to create awareness about FTD in my community. This is a play in three acts. It is a full-length drama that explores frontotemporal dementia from the point of view of a young carer, Ireti, who is caring for her mum, a 43-year-old immigrant nurse from Nigeria. Beatrice is also known as Bee in the play.

This play tells the story of Bee, who exhibits symptoms of FTD and has been misdiagnosed a couple of times. There are two main characters: Bee and her daughter Ireti and five minor characters. The play is as much the story of Bee as it is of her daughter Ireti, who is the heroine on a journey to find a cure or simply a diagnosis for her mother. However, she has a dark secret; she would go to any length to get her mother diagnosed. She is also self-medicating in an attempt to prevent the disease that is plaguing her mother and which may have been the cause of her grandmother's death.

At the start of the play, we get to know the two main characters, Bee and Ireti, as they bond. We are also introduced to Eileen, Bee's friend. As Bee's condition degenerates, her daughter, Ireti, is plunged into a hellish abyss, especially as her aunty, the only extended family she has, thinks her mother is demonically oppressed and is doing everything to exorcise the demons. Bee is misdiagnosed, and we see the horror of FTD as her personality changes. Ireti does not give up but forges on in her quest to help her mother until Professor Omole comes on the scene. She is a like a lifesaver for the family. Later in the play, Bee is diagnosed with FTD after an initial misdiagnosis. She is placed on some medication, though there is no cure for her FTD.

6.2 Critical Analysis of the play – 'My Name is Beatrice'

Dementia is complex, as is any form of discourse about the disease. However, the reason why fiction is crucial to writing or understanding dementia is that it is able to analyse the experience of PWD better than any other form of representation. The inspiration for this play came through direct experience, as analysed in previous chapters, where I explored my work with PWD. My epiphany about the struggle that people in BME communities face in accessing care, the lack of scholarly work on the prevalence of FTD among BME communities and my experience witnessing ignorant practices about mental health issues in my community are catalysts for this narrative. It begs the question, what can I do about it?

My play also has a pedagogical purpose because care givers, dementia researchers and healthcare workers will be able to engage in discussions regarding effective care access for PWD in BME communities. Making data theatrical is a notion that many researchers have critically evaluated. Some scholars note that a performance text could give a broader perspective, interpretation and cultural critique than an academic text (Denzin, 1997).

In this section, I will examine a few key components I have used to create an engaging drama. The essentials of drama are the same, and they are valid now as they were thousands of years ago. They include character, diction, plot, story, thought, melody and spectacle (Smiley, 2005). In this analysis, I will use Smiley's ideas on the principles of drama to explore my style and how the principles have enabled me to create memorable characters and plots.

6.2.1 Characterisation

In a play, characters are imitations of real human beings, and each has a function or need. Characters are figures that represent a social milieu problematically; the rhetorical purposes that they serve must be relevant to the real world (Wood, 2011). Exploring the importance of characters is important because they help to further the plot, express an idea and contribute to the spectacle (Vidhya & Arjunan, 2015).

My first challenge when I started writing this play was answering the question, who is the main character? There was an obvious protagonist – Beatrice (also known as Bee) – she is the one experiencing FTD. However, is the story only about her? I paused several times to answer this question, but it didn't get any easier. I chose Ireti as the protagonist because I needed her to fight for her mother to get the correct diagnosis. I also intend to explore the plight of a young carer; hence, a strong teenager on a quest to see her mother getting the right care and treatment was crucial to the story.

Characters are created to struggle with the big questions; hence, they mirror real life. Being true to the big feelings and questions within us will affect a play on all levels (Harper, 2008). In the play, Ireti's big question is how she can get her mother the right diagnosis. Her big feeling is her frustration and loss as she continues this epic journey. Ireti's role as the protagonist allows me to create an engaging narrative, even when her mother starts to show signs of aphasia. Her disillusionment and tragic experience of FTD did not diminish the plot and spectacle; we rely on Ireti and the other characters to advance the plot.

Though challenging, creating a unique and believable character makes a play memorable. I did not want to use stereotypes in my character development so as not to create oversimplified and formulaic character traits. According to Smiley (2005), there are six character traits that playwrights can ascribe to their characters: biological, physical, dispositional, motivational, deliberative and decisive. Playwrights can use any or all of the six traits in their drama; however, they should consider using only essential traits and only as many as needed for a specific action (Smiley, 2005).

Ireti, though a teenage carer, is a strong character with unique deliberative and decisive traits. These appear in how she plans to achieve her goal of getting her mother diagnosed and some of the unethical ways she did it. The love and bond between mother and daughter are revealed in her determination to fight any obstacle on her way – be it the medical system or extended family. In Act 1: Scene 3, we see her standing up to her aunt and the prayer warrior group who were trying to exorcize her mother of 'evil spirits'. Also, in Act 3: Scene 2, we see Ireti lying about her mother's condition because of her desperation to get her properly checked for the right diagnosis. In each of these incidents, she was rebuked by the adults in her life, but she was non-relenting.

Ireti: Leave me alone. I'm staying with my mum!

Ladun drags her off the stage.

Ireti: I keep asking who that man is, but you're/
Ladun: /Is this the first time anyone has come to your house to pray?
Ireti: No, but it's the first time some weird people in flowing white garments have come here, holding candles over my mum's head.

…

Ireti: /She hasn't got an evil spirit! What she needs is a doctor, not a freaking Wolii and some smelly water…
Ladun: (Arms akimbo) Ehen? From your mouth, Ireti? 'Freaking Wolii'?
Ireti: I'm not going to sit here with you while that weirdo hurts Maami! She's ill, and you're freaking her out.
Ladun: (Stands in front of her) Where do you think you're going?
Ireti: To save my mother from you horrible lot!

…

Bee is on a bed with drips inserted into her forearm at Wellington Hospital. Ireti is sitting on a chair beside her, holding her hand. Eileen comes on stage; she's wearing her nurse's uniform.

Ireti: But you said she needed to see a neurologist. That was why I lied three days ago when she fell and hurt herself.
Eileen: What do you mean you lied? She fell, didn't she?
Ireti: Of course. She fell, but she didn't hit her head. I only said that so that they'd do a brain scan for her.
Eileen: Now listen to me, child. You can't go around lying to doctors because you want them to do a scan for your mother. It's not right.
PAUSE
So, what happened this time? Did you lie again? Did she really hit her head on the bathroom sink?
SILENCE

On a closer look, Ireti may appear angry and rude sometimes, but considering the crisis of her mother's health, her decisive trait endears the audience to her. They know her needs and inner nature, and they might even forgive the unethical ways by which she goes about achieving her goals. For this character, I aim to 'show' rather than 'tell'. Rather than name her traits in my stage directions, I allow the audience to witness them in action, which permits character and plot to fuse properly (Smiley, 2005).

Some of Ireti's decisions create linear character development in the play. At each stage, a decision creates a change in the character and alters her relationship with other characters. For example, in earlier scenes, Eileen, Bee's friend, sees Ireti as a young girl, perhaps that needs guidance on the issues pertaining to her mother's health. However, Ireti keeps pushing boundaries, which Eileen does not approve of. Nevertheless, we see Ireti's relationship with Eileen change as the latter begins to understand that nothing can stop Ireti from achieving her goals. Eileen also sees a mature girl whom she would need to support in order to gain her confidence. In Act 3: Scene 2, after Professor Omole tells both of them about Bee's suicide attempts, she wants Ireti to leave the room, but Eileen stands by Ireti's decision to be there.

Professor Omole: Ireti, come with me. I'll take you to my other office where you can have a drink and wait while I speak with…with…
Eileen: Eileen.
Ireti: No! I'm okay. I want to be here.
Eileen: She'll be okay, Prof. She's with her mum most of the time. She may be able to answer more questions than I can.

In another instance, in Act 3: Scene 1, Ireti's relationship with her aunt takes a nosedive after she stops her from taking her mother to a meeting where they would 'pray' for her. Ladun gets the message that Ireti is not someone to be messed around with, and she vows never to step into their house again. She also takes Ireti's threat to call the police very seriously. Although she sees Ireti as a rude girl, she also sees a girl who is determined to do anything to protect her mother.

Ladun is about to go to Bee's bedroom.

Ireti: (Stands in her way) Don't even try or I'll/
Ladun: /Or you'll what?
Bee: (OS) Ireti, who was it?
Ireti: (To Ladun) Sh...sh... If you even say a word, I swear I'll call the police. Ladun raises her hand at Ireti, who quickly steps back and takes a photo of Ladun with her mobile phone.

...

Ireti: Just imagine the headline: "A Nigerian woman goes to her nieces' house with a live cockerel to conduct ritual killing. She was about to kill the little girl, who quickly dialled 999 on her mobile."

Ladun swallows hard, holds on to the flapping cockerel and heads for the door.

Ladun: Evil child. You're now raving mad, but you don't know it yet.
Ireti: Old news, Aunty. Have you forgotten that madness runs in the family?
Ladun: (Sucks her teeth loudly as she exits stage) If I ever set my feet here again, cut both off. But mark my words, one day, you and your mother will come, begging me to bring my prayer warriors to your house, and then we'll see who will have the last laugh!
Ireti: And when that time comes, slam the door on our faces. But for now, leave my mum alone!

In this play, Ireti is shown as formidable and determined. However, she is also a believable character, and we see certain traits that reveals her love, humanity and moments of weaknesses, especially when she buckles under the strain of her family's tragedy.

6.2.2 Dialogue

In ethnodrama, dialogue serves several purposes in its aim to move a narrative forward. In this play, I have used dialogue creatively to reveal characters and show their purpose. Saldana (2011) posits that sometimes, dialogues are mundane;

however, it also shows the audience the cultural world of the characters. I use dialogue to show the theme of friendship and camaraderie among the characters. An example is where we get to know that Ireti had worked very hard to have made the shortlist for the private school where she hopes to do her A-levels, and her mother and Eileen are really proud of her.

Eileen: …C'mon girl, go break a leg in Bath and do us proud. First girl in the family to go private ed., innit?
Bee: "In the family" did you say? In my entire generation. Hehehe…

Everyone falls about laughing.

I couldn't believe my ears the day she came back from school and told me she got a letter from Mastai…Matai… I mean, Matilda Girls School saying she was shortlisted. How did that even happen?
Eileen: I've always told you she's a prodigy. Just look at her... See. my girl? See how/
Ireti: /Yikes! Can you guys just stop already?

In the opening scene, the conversation between mother and daughter may seem mundane; nevertheless, it was intentional so that the audience could see the rapport and love between the two main characters before I introduce the symptoms of frontotemporal dementia, which became a burden for the family. Here we also see the camaraderie between mother and daughter, typical in the Nigerian community.

Ireti: Maami, it's getting a little embarrassing now, you singing that song to me every time you make my hair. I'm going to be 16 soon.
Bee: My darling, a child is never too old to be pampered by her mother…

Bee continues singing and swaying.

Ireti: Phew!

Bee pinches Ireti's cheeks playfully.

Bee: There you go, my princess. You look smashing!
Ireti: (Hugs Bee) Aww, thanks. Love you.
Bee: I love you too, my darling… Very much.
Ireti: (Looks at her hair in the mirror above the fireplace) That'll last for another month.

This camaraderie was not long-lasting because of Bee's disease. Dialogue subsequently becomes more impacting as the play moves towards the climax, where tension and conflict arise as a result of the behavioural variant of frontotemporal dementia. Bee is experiencing aphasia, aggression and gluttony. She starts using profanity, which is not characteristic of her. Ireti, though a strong character, is beginning to buckle under the strain.

Eileen: Sorry to barge in on you. If it's not a good time, I'll/
Bee: /You're right, not a good thai...time.

Eileen makes to leave.

Ireti: Why are you leaving? Are you afraid she'll bite you?
Eileen: What's come over you, Ireti?
Ireti: (Dramatically) What's come over you, Ireti? Ha ha ha. I've been drinking holy water and...

Bee draws close to her and slaps her.

Bee: Get out! Bastard!
Eileen (Drops her bag) Bee!

Ireti exits stage, crying.

When creating dialogues, playwrights sometimes use slang in an attempt to create a sense of place and time. However, my aim is that this play will have a broad audience, and I don't want its shelf life to be lessened. For that reason, I created a balance in the dialogue of my characters. For example, we hear Ireti's teenage voice, but it is not an overtly 'Cockney' accent, even though she lives in London. We hear Eileen's Irish voice through her cultural overview rather than through regional slang or accent.

A notable feature of the dialogues in my play is the use of forward slash to create overlapping speech. This feature is attributed to Caryl Churchill's post-1979 play scripts. Scholars have various interpretations of this feature; some opine it marks interpersonal opposition, lack of interest, self-centeredness – or enthusiasm and support (Ivanchenko, 2007). However, my interpretation is based on the dramatic situation in my play. I often use the feature in my dialogues to show the essence of a realistic conversation, where interruptions occur naturally, and to mirror real-life dialogues. 'Neat' conversations are not realistic. In a real-life conversation, people interrupt one another; it is rare to hear people talking uninterrupted throughout a conversation.

Dialogues show an audience what the characters are going through, heightened emotions and feelings. Therefore, there are moments of heated debates, emotional upheavals or situations. In my play, I use overlapping speeches to show such moments. In Act 1: Scene 6, Ireti announces that she isn't going for the interview for her new school. When her mother's condition worsened, she decided to stay with her instead of going for the interview.

Eileen: Ireti, I'm not going to talk to social services. Just hear me out. Firstly, tomorrow is your assessment and interview at Bath and/
Ireti: /Not going!
Eileen: Over my dead body. You and I will go to Bath, even if I have to drag you!
Ireti: You had better get ready to do the dragging then. I ain't leaving London. I am not going for any damn assessment or interview. Don't/
Eileen: /Ha! Really?
Ireti: /you get it?
Eileen: And that decision to throw away all you've worked for is the right one?
Ireti: Do I look like I care?
Eileen: (Moves closer to Ireti) My darling, please, let's talk this through. I know your mum is ill, but what do you think she'll want you to do if she was in the right frame of mind?
Ireti: Watch my lips, I DON'T CARE! I'm staying with Mum, and I'm looking after her. And that's all there is to it!

Dialogue shows the complex situation of characters; it also moves the plot forward dramatically.

6.2.3 Plot

In drama, the plot is the organisation of the sequence of events and actions. The responsibility of a playwright is to create unity within the series of events or activities to bring about a well-structured plot. For example, in the '*Heidi Chronicles*', the author, Wasserstein, creates a catalogue of actions that shows the main character's quest for self-fulfilment. My play adheres to the classic structure of beginning, middle and end because drama is a time art (Smiley, 2005). The play follows a three-act structure, whereby the play is divided into three parts: setup, confrontation and resolution (Field, 2005).

The plot includes the actions of the characters, their interaction with other characters, conflict and the series of incidents that move from beginning to end. In scene one of the first Act of my play, we meet the two main characters and their family friend, Eileen. The purpose of this is to establish the main characters and their relationship. We see a lively camaraderie and friendly banter among the trio, and we have a feel of their world.

Eileen: Hey, you, what's up?
Bee: Nothing much, we just had dine…diner… Oh, bother, dinner!
Ireti: You missed Mum's cooking tonight. Jollof rice and fried plantain.
Eileen: No need to rub it in. I can smell it a mile away.

Everyone laughs.

Look at you, all curled up. You guys make me want to rethink my decision not to have a child.
Bee: Too late now, my love.
Eileen: There's something called adoption, sweetie.
Bee: Ah well.

Later in the same Act, I introduce the inciting incident, a catalyst that confronts Bee, and we see the beginning of her battle with frontotemporal dementia. Before this incident, we hear Bee's occasional aphasia in scene one, as she shows signs of speech impediment. This is a gentle hint on what is to come.

Bee: I couldn't believe my ears the day she came back from school and told me she got a letter from Mastai…Matai… I mean, Matilda Girls School saying she was shortlisted. How did that even happen?
…
Eileen: (To Bee) On a more serious note, have you even thought of how amazing it would be if Ireti gets that scholarship?
Bee: Are you telling me? Hmm… I'll forever be grateful to her biology teacher, Mrs Adedeji. She pulled me aside one day after Ponto and said/
Eileen: /Ponto?
Bee: I mean Pont…Pit…
Ireti: PTA?
Bee: Yeah, PTA.

Throughout Act 1, we see Bee's ordeal, and we see Ireti's character established as the 'warrior' who will defy all odds to get her mother the right diagnosis. There are several dramatic situations and dramatic questions framed in the main character's call to action. Ireti would stop at nothing when she realises no one was going to help her; she took some unethical steps, including lying to paramedics and doctors, just to make sure her mother saw a neurologist. We have a turning point that signals the end of the first act; her mother is taken to the hospital. This leads us to the second act.

The opening of Act 2 shows the rising action; Dr Baines consults with Bee but gives her a wrong diagnosis. He says she is battling depression and gives her some drugs based on his diagnosis. That means our protagonists' problems are still unresolved. One of the reasons it seems protagonists cannot resolve their problems is because they lack the skills to deal with the forces of antagonism that confront them (Three-act structure, 2022). Although Ireti is not satisfied with the diagnosis, and she even questions the doctor's opinion, nevertheless, she does not have enough experience or knowledge about her mother's condition, and she will set about to find out more.

Dr Baines: After our chat earlier, I think I'll put you on Prozac.
Bee: What?
Eileen: Um... Prozac?
Dr Baines: Mood swings, suicidal thoughts, bad judgement, especially the errors that/
...
Ireti: You sure it's depression?
Dr Baines: Beg your pardon?
Ireti: I said... Oh, never mind.
Dr Baines: Shouldn't you be on your way?

Ireti is not budging.
...
Dr Baines: My next patient is waiting.
Ireti: It's always about the next one and the next one. Why aren't you interested in knowing more about her condition?
Dr Baines: We're doing our best.
Ireti: Yeah?
Dr Baines: Okay, I'll speak with Eileen.
Ireti: Eileen isn't even her carer. I am!

In this scene, I reveal a typical burden of FTD on the family, especially young carers. One of the burdens of FTD is the threat of an impediment to normal development in children and young people who care for their parents (Barker & Parker, 1998). This usually happens when a young person responds to the perceived threat of the loss of a vulnerable parent by trying to take responsibility for that parent's physical care and emotional well-being (Allen et al., 2009). From this point, we see Ireti's development as she decides to research her mother's condition. A fundamental point in character development is that they learn new skills and become aware of who they are and their capability to deal with their problems. This can also change who they are (Three-act structure, 2022).

Professor Omole: Talk to me, Ireti. How do you know that your mother doesn't have depression?
Ireti: From online.
Professor Omole: Online?
Ireti: I've been looking up her symptoms.

Professor Omole Nods.

Another burden of FTD that many families find distressing is difficult behaviour. Disinhibition and aggression are quite common for people with FTD. Bee is from a religious background; in her culture, swearing and inappropriate behaviour are not encouraged. However, she begins to use profane words and, at some point, even tries to seduce her doctor by touching her breasts inappropriately.

In an attempt to make these conditions more vivid, I have tried to show Bee in her motherly element at the start of the play. I have juxtaposed her degenerative state in the scene below, where her character is almost unrecognisable. This makes young Ireti all the more determined to get her mother diagnosed and put on the right medication.

Ireti: My friend is coming today.
Bee: What friend?
Ireti: Anna from school. We're just gonna hang out.
Bee: NO ONE is come…coming into this house. Understand?
Ireti: But you like Anna. You braided her hair once, remember? Anyway, she's already on her way.
Bee: Your mobile phone still working then?
Ireti: Yeah, why?
Bee: Then phone her, DUMB ASS! Tell her your mother said NO VISITORS!
Ireti: No! I won't call her. YOU will have to explain why YOU don't want her here!
Bee: You bet I will.
…
Ireti: (Screaming) Did you have to do that? I'm talking to you! I said, did you have to do that?
You know what, suit yourself. Live in your squalor and drown in your wee and holy water. I've had enough. Now everybody at school will know my mother is a lunatic. You've gone right ahead and exposed yourself to the world.

In the final act, the audience experiences two main factors. The first is the climax, where Bee's condition is getting worse, and the medication given by Dr Baines, who had given a wrong diagnosis, is having a negative effect on Bee. She is admitted to the hospital, and it seems Ireti does not see the breakthrough she wants. However, there is a turn of events as I introduce 'denouement', which is part of a play where strands of the plot are pulled together, and we have some resolution. Professor Omole comes to the rescue, and she does a thorough investigation that leads to the diagnosis of frontotemporal dementia.

Ireti is greatly relieved; she is glad that her mother is given the correct diagnosis, and she lets the people around her know that she has been reading up on the symptoms; she is happy that her mother will find help, even though the disease cannot be reversed. We see a state of calm in the midst of a storm. Frontotemporal dementia is degenerative, and there is no cure for it, but there are ways to help people living with the condition have a good quality of life with help from the medical community. This is the main message of this thesis – that early diagnosis is crucial, and people need to know where and how they can find help.

Post diagnosis, Professor Omole introduced Bee to a social activity where she could engage with a community of people who have similar challenges but are exploring creative arts.

Professor Omole picks a leaflet from her table and gives it to Ireti.

My research unit is looking at cognitive stimulation and a few non-pharmacological approaches. There's a centre here in the hospital that I think your mum may like since she's not responding positively to the community groups.

Ireti: Isn't that just another group?

Professor Omole: Well, it's a beautiful space where people can come and chill. Having said that, there are mini courses. Here, check out the leaflet for more information. They have an open mic once a month. I've only been once. One of my clients invited me the day he shared his collection of short stories.

My research into non-pharmacological care approaches for dementia informed the writing of this scene and the subsequent ones where Bee writes and shares her Haiku poems. In the PERMA model of enhancing the quality of life I explored in previous chapters, the A represents accomplishment, which is linked with well-being because it enables people to reflect on their lives and be proud of their achievements (Seligman, 2012). Bee is motivated to work on her poems. Celebrating success is also crucial to accomplishment, hence the scene where her friend and daughter read her poems.

Similarly, the E in PERMA focuses on engagement and the importance of a person being completely absorbed in an activity. This enables them to experience 'flow' when they pursue a clear goal with full concentration. Examples of flow include playing board games, playing a musical instrument, dancing, gardening and other activities. For Bee, she experiences flow as she writes Haiku poems.

6.2.4 Setting

This is the time and place of the story being told. The setting is usually introduced at the beginning of the story, along with the characters. For example, William Shakespeare reveals the setting for Romeo and Juliet at the very beginning of the play. "In fair Verona, where we lay our scene." He also foreshadows the tragedy that will unfold there: "where Civil blood makes civil hands unclean" (Romeo and Juliet 1.1. 2-4). The setting may include the environment of the story, that is, physical location, climate or social and cultural surroundings (Literary Terms, 2015).

My research into how FTD manifests helped me to create a believable setting. It also helped me to accurately depict plot events. In the play, I created settings that complement my plot. One of the settings is the home of the main characters. In Act 1: Scene 3, Bee, who has FTD, is shown in her bedroom, where we see a manifestation of her disease progression.

> "...we are in Bee's dimly lit bedroom.
> There are cartons and boxes under the bed,
> on the table and in every available space.
> Other items include an old sewing machine,
> an exercise bike and boxes of old shoes.
> There are clothes everywhere. Beside the
> double bed are a dressing table and chair.
> A nurse's uniform is on the chair. Bee is sitting
> on the bed, staring absentmindedly at her
> right palm and holding her nurse's badge in the other."

Another prominent setting is the hospital; this is significant to the development of conflict and rising action. My intention is to create settings that will enable my audience to engage with the characters' experiences. These settings provide a vivid illustration of the traumatic events in the characters' lives. The hospital setting is pivotal to the turning point in the story. Though it is the place where Bee is misdiagnosed, it is also the place where Professor Omole painstakingly goes through the history of Bee's ailment and diagnoses her with FTD.

ACT 3: Scene 2

Professor Omole: There is evidence of frontotemporal lobar degeneration, so I sent for Bee's hospital record. When it arrived, I saw that she had presented with some of the symptoms, but they hadn't been diagnosed.

It is important that time and place are clearly depicted in the setting to avoid confusion in the plot. In each of my settings, I provided information about the time of the day and place. Sometimes, this is woven into the play as subtext; however, I achieved this mainly through stage direction.

6.2.5 Intertextuality

To create an engaging plot, I introduced a rhetorical element known as intertextuality. In its simplest meaning, this device is the concept of texts borrowing words and concepts from each other. Intertextuality is attributed to Julia Kristeva, who coined the usage in the 1960s (Martin, 2011). James Joyce's Ulysses said to be a retelling of The Odyssey, is an example of intertextuality in literature. Some scholars also consider the bible as intertextual, especially in instances where quotes from the Old Testament are used in the New Testament.

Intertextuality 1: The use of fable

Intertextuality helps us to think about how meaning is constructed. The aim here is not to critically analyse intertextuality but to emphasise how I used it to enhance my writing. It helps me to 'show' character rather than merely 'tell' a story. In Act 1: Scene 1, Bee is telling her daughter the story of 'The Tortoise and the One-Eyed Lion. I used this to reveal the relationship between mother and daughter and the cultural values of sharing stories.

Secondly, I use this story metaphorically in the play to create a three-part narrative of loss. Bee is telling the story at the beginning of the play, but she doesn't finish it. In the middle of the play, as the action rises, the duo does not revisit the story because there's a narrative of loss due to frontotemporal dementia. The play opens with Bee telling her daughter the story of the one-eyed lion and the tortoise. The lion, too old to hunt, threatened the animals with loud roars. He demanded that they come to him one by one to be eaten, or else he'll hunt them down. The tortoise volunteered to be his first victim, but rather than get eaten, he led the lion to the river, where he tricked him into thinking there was another lion in the river. The old lion saw his reflection and jumped in to fight the fake lion but drowned.

When Bee started telling the story, she was already showing early signs of aphasia, but she was still trying to be strong. At the end of the play, after Bee has been diagnosed and given some medication to stabilise her and help her sleep better, both mother and daughter revisit the story, and Bee tries her best to finish it, albeit with much difficulty due to aphasia. Her daughter helps her to finish telling the story.

The story itself is a narrative arc – Beginning, middle and end. The beginning shows the animals' struggle, the middle shows the tortoise devising a plan to help the animals, and at the end, they defeat their enemy, the lion. In Bee's case, we see a clear beginning and a call to action for Ireti, her daughter. Bee did not continue the story during the rising action in the play when she was going through trauma, but we have a conclusion to the story at the end of the play. Bee offers the audience an interesting 'prophetic' metaphor. She describes FTD as a bully. Even though there is no cure for her condition, she sees herself overcoming some of her challenges, just as the trickster overcame the problem that would have totally destroyed him and the other animals.

Bee: I love tricksters… They teach me how to deal with bullies.
Ireti: Bullies? Who'd bully you, Mum? You're a ninja!
Bee: (Smiles) Bullies come in various shapes and forms, child.
Ireti: Hey? Such as?
Bee: Don't worry, my darling. You won't understand.

Intertextuality 2: The use of Haiku poetry

Haiku is a Japanese poetry that only became an established poetic form towards the end of the 19th century (Higginson, 1985). However, it soon gained popularity in Western societies, where it has evolved from the traditional five-seven-five three-line structure to free-form styles. Although the rules of Haiku are often conflicting, there is an agreement that the poem must be compact, depict a season or nature, but shouldn't just be a catalogue of words about nature. Haiku needs to have depth and suggest something more profound than they often depict (Blasko & Merski, 1998). Some critics say the best Haiku should leave the readers wondering (Higginson, 1985).

In the Haiku poem Bee wrote, which her daughter and friend later performed for an audience, I chose to adhere to the traditional five-seven-five structure, as it gives me the discipline to create a good narrative. I created a three-part Haiku that mimics the narrative arc of the beginning, middle and end of a story. I included the 'Kigo', which is a Japanese word for a seasonal referent; however, I did not use 'Kireji' – that is, 'cutting word' because I didn't want it to be too prescriptive, as that would lessen the believability of my character, being able to create such a specific piece.

Research shows that some patients with FTD experience paradoxical functional facilitation, in which a loss of activity in one part of the brain leads to a release of activity in another (Kapur, 1996). There are records of heightened artistic expression in patients who have damage in their left frontal and temporal lobes. In my play, Bee starts to present with primary progressive aphasia due to left temporal lobe damage. However, we see her displaying altered aesthetic preferences with a rise in her passion for poetry (Erkkinen et al., 2018). It is almost as if her brain is compensating for the damage by encouraging an expression for art. This is a new development for Bee, who did not write poems before her brain degeneration.

Ireti: /Prof, I was about to tell you earlier that my mum has started writing poems?

Professor Omole: Really? That's brilliant!
Ireti: She's never written a line of poem until recently, and now she can't stop.
Professor Omole: What do you write about?
Bee: Oh, this and that, nothing special.
Ireti: She's just being modest. She's written funny ballads, and now it's Haiku.
Professor Omole: Haiku! That's another level Bee!

Later in the play, we hear about the success of Bee's poetry during the event where it was presented.

Professor Omole: How did it go at your event? So sorry I couldn't make it eventually. I had a last-minute emergency. Did many people come?
Eileen: Fifteen in total. People were very generous with their feedback. Ireti created a feedback sheet, and we gave them out.
Bee: I was very proud of my daughter…and…Eileen, too.
Eileen: Don't be silly. You wrote the poems. Someone said in their feedback that they cried all the way through.

Haiku allows me to give Bee a voice through which we hear her turmoil. Researchers postulate that artistic expression does not require linguistic eloquence, memory, conceptual knowledge, or abstract reasoning; nevertheless, it gives researchers the opportunity to view the inner world of patients who otherwise may struggle to communicate in more conventional ways (Erkkinen et al., 2018).

In the three-part Haiku, I started by mimicking the artistic expression of the brain. Some artists depict the brain as looking like a tree with branches. FTD is commonly found in people who are in the prime of their lives. They are blossoming, but the disease threatens the very essence of their being. The first three stanzas show us Bee's struggle at the beginning of the play. We see a picture of her bed wetting and confusion. The last stanza of part 1 ends with a spectacle. It illustrates the 'spiritual', white-garment churches and their attempt to exorcise Bee of her 'demons'. Some readers may read this stanza and think that Bee is having images of heaven or out-of-body experience because of the "Cherubim and Seraphim" reference; however, this refers to a denomination of white-garment churches in Nigeria and the diaspora.

The tree has blossomed
But alas a big bad hole
Threatens the branches

Waves crash around me
Just a brand-new experience
On a flooded bed

As the night crawls in
Cherubim and Seraphim
Ring their bells and dance

The second part of the poem depicts the middle and climactic part of the play, where Bee's situation gets worse, but her daughter fights to get her mother diagnosed. In the first stanza, we hear Bee lamenting her plight. Again, we see the reference to seasons; nevertheless, there is a question. Bee is saying she is not enjoying her mid-life; rather, she was plunged to the end of her life because of dementia. In the last stanza, we move on to her hospital experience and the climax, where she eventually gets a diagnosis and support.

Oh, crazy seasons
What, No summer? No autumn?
Winter! You're early

Machines' ceaseless beeps
Mirror my old restless soul
That needs to be calmed

What magic, what joy
A tree surgeon's breath of life
Health for the branches

The last part of the poem depicts the end of the play. In the first two stanzas, even though Bee is not healed, she has been diagnosed and given some medication to help her navigate the labyrinth of the chronic disease. The last stanza is a celebration of her daughter, friend and physicians who are helping her.

The grey skyscrapers are gone
And now we have luscious green
Here on London streets

Beautiful cadmium
So colourful in the sky
I have just seen you

Daughters, friends, healers
Agates, Rubies, Kyanites
Love keeps me alive

One of the points I focused on in this work is the use of art therapy in dementia care. In the play, Bee objected to many of the programs that are available to PWD, mainly because they are for older people with Alzheimer's; they did not interest her. Nevertheless, Professor Omole listens to her and suggests alternative programs, including creative art workshops. Bee begins to blossom and creates Haiku poems. Some scholars opine that more research is needed on the topic of using art therapy in dementia care. Beard (2011), in his paper titled, '*Art therapies and dementia care: A systematic review*', critiques the evidence base of the use of art therapies for PWD (which at the time of publication was scarce) and suggests how it can be strengthened.

6.2.6 Spectacle

In theatre, a spectacle is an unusual, entertaining or dramatic public display. Some notable examples include scenes in Phantom of the Opera, where the main character rows a boat through floating candles. The scene in Miss Saigon, where a helicopter lands on stage, is another example of the effect that a great spectacle could have on stage plays. Aristotle describes six elements of drama: plot, character, theme, diction, thought and spectacle. A spectacle is a device that helps a playwright create memorable moments in a dramatic piece.

In my play, I created a spectacle during the exorcism scene and the scene where Ireti stands up to her aunt, who came to their house, holding a live cockerel. Language, costume, and special effects grab the audience's attention and force them to deeply reflect on the complexity of the day-to-day lives of PWD and their family, albeit from the point of view of a culture which may be alien to many people in the Western world. Bee's sister-in-law was adamant that she was 'suffering from demonic oppression', and she brought a group of 'prayer warriors' to Bee's house.

This scene, apart from being spectacular, is a message to a community that seeks diabolic healers who prey on innocent people. As a Nigerian, I have witnessed a few of these events, though it is difficult to speak against them because of how ingrained the practice is in the community. As a Christian, I believe in the power of prayer but believe each individual can seek God for themselves and be part of a prayer group. However, there are also people who prey on people who are vulnerable.

In the play, we witness a spectacular scene of exorcism, as the 'prayer warriors' attempt to heal Bee of her 'strange condition'.

Wolii takes a jug from the table and pours some water into a bowl. He then begins to chant into the water.

Wolii: Ya si mimo, ya si mimo, ya si mimo, holy Michael. (Sanctify it, sanctify it, sanctify it, holy Michael)
Ladun: Ya si mimo, ya si mimo, ya si mimo, holy Michael.

Wolii sprinkles water round the room as the chant intensifies.

Wolii: Ladun, show us around Beatrice's house so we can sprinkle the holy water.
...
Wolii: (To Bee) Arabirin, kneel and let's pray.

Bee kneels.

Wolii: Mimo, mimo, mimo... (Holy, holy, holy...)
Ladun: Holy Michael...

Ladun begins to shake vigorously, chanting louder than Wolii.

Wolii sprinkles Bee with water.
Bee is shivering because of the cold water.

6.2.7 Theme

The theme refers to the central idea. It is the message that the reader or audience receives from the play. In this drama, I explored multiple themes. The obvious one is the debilitating symptoms of FTD and young carers' burden. However, the play also has a pedagogical purpose. It aims to contribute to the body of literature that explores effective care access for PWD in BME communities. Scholars have critically evaluated the notion of making data theatrical. They opine that a performance text could give a broader perspective, interpretation and cultural critique than an academic text (Paget, 1993; Denzin, 1997).

The theme of narrative medicine is carefully woven into the play. In this review, it may seem that I am contradicting myself, but I am not. Initially, through the character Ireti, we see a critique of animism, traditional healing practices and superstition; however, in this play, I am also examining the importance of narrative medicine as a practice crucial to modern medicine. Narrative medicine was made popular by Rita Charon, a medical doctor and literary scholar who debunked the idea that it is impossible for doctors to engage with a patient's narrative within the given 15 minutes of consultation.

Research shows that, on average, doctors listen to patients for about eleven seconds before interrupting them (Ospina et al., 2019). Some patients have a deep understanding of their bodies and can tell informative stories about their symptoms if they are listened to. I have had personal experiences of sitting with my GP and trying to communicate what I felt could be the root of my problems, but I only got condescending nods after being dismissed and told to keep up with my 'Ibuprofen' painkiller. Eventually, I took courses on naturopathy medicine to get a better understanding of my body and was able to get rid of my health challenges.

I wove this theme into my play by giving Ireti a strong voice. Though a teenager, she challenged the diagnosis of depression given by Dr Baines, the first clinician that attended to her mother, but the doctor did not listen to her. After all, she was 'only a child'. I juxtaposed this experience with their later consultation with Professor Omole, the second doctor who investigated the issues through scans and deliberate history-taking. She was patient and diligent and provided alternative community programs when her patient declined the ones on offer.

Narrative medicine allows medical practitioners to have empathy (Charon, 2001). I have been teaching a module on non-pharmacological approaches to dementia care at Plymouth University for the past six years; some of the iconic moments were the practical sessions we had with PWD in memory cafés. Medical students interacted with participants through music, gentle exercises and storytelling. For their theoretical work, they close read literature and wrote reflective essays. This could enhance students' ability to illuminate four of medicine's central narrative situations: physician and patient, physician and self, physician and colleagues, and physicians and society (Charon, 2001).

Many of these students later described how the experience they had on the module I taught them challenged their ideas on how to interact with patients. They talk of how they have developed empathy, better listening skills and more understanding of narrative medicine. Another aspect of narrative medicine is how it engages with the 'narrative of healing', told by patients who are from different cultures. In many immigrant communities, some people use a combination of traditional and Western medicine (Kraut, 1990), and mental health issues are sometimes seen as spiritual problems, which means some people feel safer seeking the help of 'healers' (Redbridge, 2008).

There are similar stories among the indigenous Sami in Finland and Norway, where people consult healers (Nymo, 2015). The views or beliefs of these people can easily be dismissed by doctors practising Western medicine; however, these narratives should not be ignored. It doesn't mean that the doctor is endorsing these beliefs; it only means the storytellers are assured of being heard. Physicians need scientific ability; they also need to be able to listen to their patients' narratives (Charon, 2001).

In conclusion, my play is a creative artefact that acts as a bedrock for the contribution that this thesis makes to knowledge. The critical overview that accompanies the play shows its relevance. Music, poetry and plays are creative artefacts that can be used to establish claims of originality; however, they are accompanied by critical examination that shows the relevance and context of the claims (Skains, 2018).

7. DISCUSSION

7.1 Ethical Questions and Reliability

At first glance, autoethnography research seems easy when it comes to ethical issues because it is autobiographical by definition. However, researchers do not exist in isolation (Ellis et al., 2011). We have a web of family, friends, colleagues and associates surrounding us, and we could implicate them in our research. However, I did not have to apply for ethical approval for my research because I am staging qualitative research as fiction. This can protect the author from criminal charges and may protect the identity of the people who are studied (Richardson, 2000).

In autoethnography research, the methods of data collection are different compared to other methodologies; however, validity should not be compromised (Feldman, 2003). There should be an explicit description of the data collection method and how data is interpreted, and the researcher should show evidence of how the work has changed them and what value it is bringing to the profession; this will show other educators the validity of the research (Feldman, 2003). Having said that, for many autoethnographers, validity is measured by how they are able to evoke in their reader the feeling that the experience they described is believable and true. Autoethnographers ask questions such as: how useful is my story or how can my audience or readers use my story (Bochner, 2002)?

In response to positivists' critique of the validity and reliability of qualitative research, some scholars decide to use a different term to describe a researcher's naturalistic work. They postulated four ways by which a qualitative researcher can ensure that their work is trustworthy: is the work credible, dependable, confirmable and transferable? A researcher must aim to be trustworthy for the work to be seen as credible (Lincoln & Guba, 1985).

One of the ways to ensure credibility is by making sure that data collection and analysis adhere to methods that have been successfully used by similar studies (Yin, 1994). I adopted this principle in my thesis by adhering to a well-established method in my data gathering and analysis. Part of my data collection involved searches for peer-reviewed articles from leading scientific journals and websites such as, Sage Journals, Google Scholar, ResearchGate, The Lancet, Alzheimer's Research UK, Journal of Neurophysiology, The British Medical Journal (BMJ) and other published materials. I then used autoethnography as a methodology and ethnodrama to interpret my data. I explored narrative analysis for data analysis.

Scholars suggest that qualitative researchers should have prolonged engagement with the people they are studying (Erlandson, 1993). As initially communicated, the group for which I intend to raise awareness of FTD is the immigrant group I am a part of; hence, the issues of prolonged engagement and establishing trust are settled.

I am aware of the ethical issues surrounding the use of informal chats or interviews as data. Some scholars argue that such chats should be categorised as interviews, even if they are informal; others describe the researcher or interviewer who is prodding or asking questions as someone with the agenda of data collection; hence they are deceptive because the interviewee divulges information, thinking they are just having an informal chat (Hammersley & Atkinson, 2007). To avoid these ethical issues, during the informal chats I had with people, I told them of my interest and current research and what I was doing to promote awareness of FTD in the community.

A major ethical dilemma that I had was about 'relational ethics. Scholars opine that relational ethics is heightened for autoethnographers (Ellis, 2007). The community I am writing about is identifiable, especially the sub-culture of 'white garment' churches. This raises questions such as: how have they been represented in my story? What would readers think about this group? Although I did not record any chats apart from the information I needed on exorcism, and no one is implicated in that information because it is general, relational concerns were still uppermost in my mind throughout my research and writing process (Ellis et al., 2011). One way I have navigated ethical issues is to create a fictional interpretation of my data; hence, I did not have to apply for ethical approval because I am staging qualitative research as fiction.

Another way of ensuring credibility is continuous debriefing sessions between the researcher and her superiors (Shenton, 2004). Throughout this PhD process, I had regular meetings with my supervisors, who critiqued my work and made valuable recommendations for my research. On the issue of reliability, I am aware that there is a possibility of a change in narrative, depending on who is telling a story, even if it is the same event (Tullis et al., 2009). Memory can be unreliable, and what I see as 'truth' could change depending on how others view it or how it is presented. Despite this, I put my work through strict scrutiny and, at various times, presented it for peer review.

Guba and Lincoln (1989) raised a critical point about progressive subjectivity, whereby researchers reflect on patterns that emerge from their data. In my thesis, I analysed patterns and themes that emerged from my data collection. Having reflected on how they align with my research question, I wrote a critical commentary about the play I used to interpret my data. This commentary helps the reader to see the effectiveness of my study and its use.

Some scholars stress the importance of the credibility of a qualitative researcher and therefore suggest that the researcher is as important as the suitability of their methods (Patton, 1990; Alkin et al., 1979). In the opening chapter of this thesis, I included a section titled Prologue. There, I told the story of my relevant professional work and personal experiences that led to this study. Some scholars suggest that qualitative researchers should include relevant personal and professional details in their study (Maykut & Morehouse, 1994).

Dependability

The issue of dependability is closely related to credibility. Quantitative research scholars use methods that aim to show how research repeated in the same context can show results that are homogeneous to the original study. However, this could be difficult in qualitative research, especially ethnography or autoethnography, because even if groups are similar in another study that aims to repeat the findings, human beings are complex, and situations are different. Furthermore, phenomena changes; they are not static (Fidel, 1993). In spite of these challenges, the results of qualitative research can still be repeated if the researcher can give a detailed report of the process within the study (Shenton, 2004).

In this thesis, my process is detailed in a way that Shenton (2004) describes as a prototype model. This will enable other researchers or readers to understand the design and process, allowing them to repeat the work. I have explained how I used autoethnography in my data-gathering and reflective practice processes and how I used ethnodrama to interpret the data I gathered in my literature review. There is clarity of purpose in how I analysed my process from data collection to analysis and the critique of the play that represents my findings.

Confirmability

Researchers' bias in qualitative research is unavoidable, though there are ways to make sure research is objective rather than subjective. Acknowledging one's bias, intrusion or preferences, such as choice of methodology, is crucial to the reliability and confirmability of research. In my literature review, I analysed some researchers that have successfully used art and storytelling in dementia care and how this is a catalyst for my enquiry. I also discussed why the methods that these scholars used are inadequate for my own scholarly work and the reason for my choice of ethnodrama.

This acknowledgement and continuous reflective commentary in my work show my readers the objectivity of my work. Shenton (2004) describes this as an audit trail, which allows my readers to track how my research questions gave rise to my data collection, analysis and findings. Throughout the process of this thesis, I presented the development of my work to my supervisors and peers for critique. This enabled me to identify gaps that I may have missed and to mitigate bias.

Transferability

Positivists advocate that the results of research work should be transferable to a wider community. This view is not demonstrable for much qualitative research because the findings and conclusions may not be applicable to other situations and populations; hence, it may be difficult to demonstrate this (Shenton, 2004). Scholars have differing views on the issue of transferability. Some (Erlandson, 1993; Firestone, 1993; Lincoln & Guba, 1998) reject generalisation because in order to make meaning of observation, one must consider the contexts. Each practitioner can apply the information of a finding to their individual situation if they find it relevant. Some scholars (Denscombe, 1998; Stake, 1994) opine that transferability is crucial in research but should be pursued in a realistic manner.

Every research should impact the community within which it is done, and the findings should be transferable; nevertheless, it should not be done in a mechanistic way. One of the aims of my research is for it to be transferable. The findings could be used, for example, in some indigenous contexts. Studies have shown that there are some similarities between the BME communities in the UK and indigenous Saami people. Some scholars (Blix & Hamran, 2017; Cooper et al., 2010) opine that the prevalence of dementia among the Saami people is understudied; hence there are no estimates. They also reveal that this group present more severe symptom than other population. This is similar to what we have in the BME communities in the UK.

My aim is that the findings of my study can be used in Finland, where the play can be presented on stage. Sami people are natural storytellers, and they communicate their strong beliefs in traditional healing through storytelling, which has the power to heal (Negard, 2005). The Sami people of Finland are just an example of a community that can benefit from the transferability of my research. There are numerous BME communities in Europe and America that could benefit from the awareness of FTD and the importance of early diagnosis and care.

What is most important in my autoethnography research findings is that it seeks verisimilitude and recalls a feeling in the readers that the experience that I am describing is believable and possible (Ellis et al., 2011). My preoccupation with this research is not accuracy; rather, I aim to inspire change by creating a text that is accessible and analytical.

7.2 Conclusion

My research journey started with a quest: how can I raise awareness of FTD among Nigerian immigrants living in the UK? As I examined the literature on this topic, it became obvious that there was hardly any scientific paper or work done on this topic. I continued to seek information on the issue of dementia and the prevalence of FTD in a wider group. My literature review section shows the work that scholars have done on how dementia manifests, how it is diagnosed and what creative interventions are available for people living with dementia. My work is unique in the sense that there are no scholarly works on how to engage in art-based research to create awareness of FTD among Nigerians or any other BME groups in the UK.

Some of the literature I found about dementia care include PERMA and PERMA + and Quality of Life (QoL) in dementia. PERMA postulates five elements of well-being: Positive emotion, Engagement, Relationships, Meaning and Accomplishment (Seligman, 2012), though some scholars say that deciding what constitutes well-being is not an easy question. Scholars opine that measuring the quality of life for people with dementia will result in better-targeted care (Coman et al., 2020). However, some researchers say there are not many differences between QoL domains in people with Alzheimer's and those with FTD (Millenaar et al., 2017). Nevertheless, Lawton's model of QoL remains an influence on many QoL researchers. Lawton posited that researchers should consider both subjective and objective factors in the following: psychological well-being, behavioural competence that included cognitive and functional abilities, objective environment and perceived QoL (Lawton, 1994).

Having examined studies on FTD and other forms of dementia, I engaged in research on a non-pharmacological approach to dementia care. There are numerous studies that show the importance of art therapy, storytelling, drama and other forms of art, such as music, in enhancing the quality of life of people with dementia. However, my research focus is to find ways of raising awareness of a type of dementia within the Nigerian community, one of the BME communities in the UK. To answer this question, I decided to examine, through autoethnography, my own story of struggle through chronic conditions and how I was able to overcome them.

This story started in the form of journaling but was eventually published, not as a scientific journal but as an epistolary narrative, which gave access to other women who might be going through a similar situation. I examined my journey through writing the book '*Dear Toriola*' and noted how I used art to create meaning. I created awareness of perimenopause issues and how a woman can overcome these even if they do not want to go the pathway of taking HRT or ablation surgeries. I placed this work as a backdrop against my thesis. I also examined other books I wrote; the knowledge I gained as I reflected on my practice as a storyteller and writer enabled me to create a dramatic piece that would engage the audience and encourage them to ask meaningful questions about the topic explored in this thesis.

As a writer and storyteller, my training and career focus for nearly three decades have been on creating and interpreting narratives. In this thesis, I explored realism, using ethnodrama as my mode of representation. Realist ethnographies focus on the researchers' and participants' perspectives to create a sense of verisimilitude, the feeling of reality. Realist ethnographers are storytellers who move from story to interpretation. Text may take the form of ethnodrama, layered accounts, analytic autoethnography or research reports (Adams et al., 2015).

I decided to explore ethnodrama, which is a written transformation and adaptation of ethnographic research data into a dramatic play script staged as a live, public theatrical performance (Given, 2008). It is important to note that ethnodrama is different from ethnotheatre. The former is a play script, while the latter is a theatrical production of the former. My work focuses on ethnodrama, not the production of the play. Having said that, my aim for the future relevance of this thesis is to create a theatre production of my play, which I will direct for stage. This will be made available in theatres, religious centres and other BME communities. It will also be presented to medical practitioners and medical students; this will enable people to engage with the findings of my thesis in a more accessible way.

This thesis is significant and would contribute to the body of knowledge on how to reach people in BME communities and encourage them to access available healthcare provisions for early diagnosis of FTD or other forms of dementia. People in BME communities do not access available services that support the care of people living with FTD for various reasons; some include taboos and superstitions, ignorance, and religious and cultural beliefs. Also, many people do not trust the healthcare system to meet their unique needs; this makes it difficult to raise awareness and provide crucial information, such as the importance of early diagnosis. Educating healthcare professionals on how to meet the unique needs of PWD in ethnic minority communities is crucial; it enables healthcare staff to have more empathy (Cowdell, 2010).

A group of scholars, Sherry Dupuis, Gail Mitchel, Pia Kontos and Christine Jonas-Simpson, use drama to shed light on how society views dementia in a one-dimensional way (Jonas-Simpson et al., 2012). Their play, '*Cracked: New Light on Dementia*', critiques the notion of loss and the understanding of dementia (Gray et al., 2015). However, this work is not precedent to my research; I have been able to create new knowledge on how to raise awareness of FTD in immigrant communities. Storytelling is a powerful medium through which information can be shared in a non-confrontational way. My aim is that the story of Beatrice (Bee) will enhance the knowledge of my audience, and after leaving the theatre, they will tell the story back to themselves and others (Lewis, 2011) in a cyclical process.

In various chapters in this thesis, I explored in detail the importance and influence of storytelling in communities and how it can shape identity, enable us to make meaning of our world and create awareness about topical issues. In the story of Beatrice, I take on the mantle of the African griot, a custodian of culture and heritage whose aim is not only to entertain but to convey wisdom while presenting my narrative in stylistic ways (Henrich, 2001). I aim to invite the people who will watch my play to suspend disbelief and change their attitudes and worldviews through their exposure to the story (Green & Brock, 2000).

Beyond this research, I aim to explore the richness of research-informed theatre methodology (Julia et al., 2015) to also share my work among communities in various countries in Europe, the USA and the continent of Africa. The play will be staged in various communities, followed by conversations that will highlight the issues raised. For example, the Sami people of Finland are a community that can benefit from the transferability of my research. Using storytelling as a way of communicating relevant information is readily accepted in Nigerian communities; this is also prevalent among the Saami, who are natural storytellers, and they communicate their strong beliefs in traditional healing through storytelling (Negard, 2005).

My play is a slight polemic about 'healers' who prey on innocent people, though it is not a condemnation of faith or belief in healing. Nigerians and the Saami are known for not relying on conventional medicine alone to care for their own people. The Saami, for example, consult healers; it is important for them as a community (Nymo, 2015). However, there is a need for a conversation about balance and the importance of seeking medical help for early diagnosis of conditions.

Writing a script can be useful for ethnographers because it often allows them to be deeply reflexive in how they portray participants (Goldstein, 2008). When well-written, ethnodrama can facilitate engagement, more nuanced representation, reflexivity, and even action from the researcher, participant, and audience (Cannon, 2012). I chose to interpret my data, using the narrative form to make it widely accessible, especially within the culture that I am focusing on.

Autoethnographical representational forms are diverse. The decision about which form to use usually comes after a writer has thematised their writing, and it is beginning to take shape. One might choose a more traditional route, such as a monograph or a creative form, such as narrative, poetry, performance or other art forms (Adams et al., 2015). Some forms of representation that autoethnographers use include realism, impressionism, expressionism, and conceptualism. Some researchers use a combination of these rather than focus on one. Using the art-based method in autoethnography research has been advantageous for me because narrative and arts-based approaches allowed me to explore marginalised, controversial, and disruptive perspectives frequently overlooked in more traditional research methodologies (Estrella & Forinash, 2007).

As an autoethnographer, I mirror the conventions of ethnography; however, there is a major difference between the two. Ellis & Bochner (2000) opine that with autoethnography, the researcher also participates in the social world she is studying; therefore, emphasis is placed on the researcher's personal experiences as she seeks to understand the dimensions of her community. I aim to create knowledge that can challenge long-held beliefs about mental health issues, improving our world. Data accuracy and rigour were not foremost in my plan (Ellis et al., 2011); changing the culture was more important to me.

Lastly, I hope this work will create a more ethical relationship, not only between me and the BME community audiences, but also between me, the researcher, and the medical community, who will benefit from the conversations on how best to provide culturally relevant healthcare information for people from BME communities. There is documented evidence of how drama (Jonas-Simpson et al., 2012) can be used successfully to educate healthcare professionals about dementia care. Baillie et al. (2016) examined how a healthcare system used ethnodrama to educate staff about dementia patients' experiences. It was a successful project that reportedly made a lasting impression on the staff. The project showed a 12-minute film titled '*Barbara's Story*' between September 2012 and April 2013. This film was watched by 11,054 staff, and there were group discussions after each session. After my research, I intend to do something similar to the '*Barbara's Story*' project by encouraging participation through discussion, and I intend to document the responses of those who engage with the play.

REFERENCES

Aaltonen, H., & Bruun, E. (2014). Practice as research in drama and theatre: Introducing narrative supervision methodology. *Information - Nordic Journal of Art and Research, 3*(1), 52–68. https://doi.org/10.7577/IF.V3I1.939.

Adams, T., Holman Jones, S., & Ellis, C. (2015). *Autoethnography: Understanding qualitative research.* Oxford University Press

Ahern, K. (1999). Ten tips for reflexive bracketing. *Qualitative Health Research, 9,* 407–411.

Ahmed, R.M., Hodges, J.R., Piguet, O. (2021). Behavioural Variant Frontotemporal Dementia: Recent Advances in the Diagnosis and Understanding of the Disorder. In: Ghetti, B., Buratti, E., Boeve, B., Rademakers, R. (eds) Frontotemporal Dementias. Advances in Experimental Medicine and Biology, vol 1281. Springer, Cham. https://doi.org/10.1007/978-3-030-51140-1_1

Aiello, M. Silani, V. & Rumiati, R. (2016). You stole my food! Eating alterations in frontotemporal dementia. *Neurocase, 22*(4):400-409. https://doi.org/10.1080/13554794.2016.1197952

Akinyemi, R., Yaria, J., Ojagbemi, A., Guerchet, M., Okubadejo, N., Njamnshi, A., Sarfo, F., Akpalu, A., Ogbole, G., Ayantayo, T., Adokonou, T., Paddick, S., Ndetei, D., Bosche, J., Ayele, B., Damas, A., Coker, M., Mbakile-Mahlanza, L., Ranchod, K., … Ogunniyi, A. (2022). Dementia in Africa: Current evidence, knowledge gaps, and future directions. *Alzheimer's Dement*; 18: 790– 809. https://doi.org/10.1002/alz.12432

Akresh, R., Bhalotra, S., Leone, M., & Osili, U. (2017). *First and second generation impacts of the Biafran war*. Discussion paper series. IZA Institute of Labour Economics, Deutsche Post Foundation. https://ftp.iza.org/dp10938.pdf

Albert, S.M., Del Castillo-Castaneda, C., Sano, M., Jacobs, D.M., Marder, K., Bell, K., Bylsma, F., Lafleche, G., Brandt, J., Albert, M. and Stern, Y. (1996). Quality of Life in Patients with Alzheimer's Disease as Reported by Patient Proxies. Journal of the American Geriatrics Society, 44: 1342-1347. https://doi.org/10.1111/j.1532-5415.1996.tb01405.x

Allen, J., Oyebode, J., & Allen, J. (2009). Having a father with young onset dementia. The impact on well-being of young people. Dementia. 8. 455-480. 10.1177/1471301209349106.

Alzheimer, A. (1907). Über eine eigenartige Erkrankung der Himrinde. Allgemeine Zeitschriftfür Psychiatrie und Psychisch-Gerichtliche Medizin 64,146-148. Translated in R. H. Wilkins and 1. A. Brody (1969). Alzheimer's disease. *Archives of Neurology 21*, 109-110.

Alzheimer's Research UK. (2019). *Urvashi's story: living with frontotemporal dementia.* https://www.youtube.com/watch?v=nPg6xyeIoU012TH

Alzheimer's Speaks. (2019). *David talks openly about his ftd journey*. https://www.youtube.com/watch?v=O6MIySp4vL0

Alzheimer's Society. (2017). *What is Dementia?* https://www.alzheimers.org.uk/download/downloads/id/3416/what_is_dementia.pdf

Alzheimer's Society. (2014). *What is Vascular Dementia?* https://www.alzheimers.org.uk/download/downloads/id/2427/factsheet_what_is_vascular_dementia.pdf

Alzheimer's Society. (2016). *What is Frontotemporal Dementia (FTD)?* https://www.alzheimers.org.uk/download/downloads/id/1758/factsheet_what_is_frontotemporal_dementia.pdf

Alzheimer's Society. (2015). *Rarer causes of dementia.* https://www.alzheimers.org.uk/download/downloads/id/1767/factsheet_rarer_causes_of_dementia.pdf

American Psychiatric Association. (1987). *Diagnostic and statistical manual of mental disorders, Third Edition-Revised (DSM-III-R).* American Psychiatric Association.

Anderson, L. (2006). Analytic autoethnography. *Journal of Contemporary Ethnography, 35*, 373-395.

Antonelli Incalzi, R., Marra, C., Gemma, A., Capparella, O. & Carbonin, P. (1992). Unrecognized dementia: sociodemographic correlates. *Aging Clin Exp Res* **4**, 327–332 (1992). https://doi.org/10.1007/BF03324114

Atkinson, R. (2007). The life story interview as a bridge in narrative inquiry. In D. J. Clandinin (Ed.), *Handbook of narrative inquiry* (pp. 224–245). Sage.

Arthur, C., Hickling, F., Robertson-Hickling, H., Haynes-Robinson, T., Abel, W. & Whitley, R. (2010). "Mad, sick, head nuh good": mental illness stigma in Jamaican communities. *Transcult Psychiatry*, 47, 252–275. https://doi.org/10.1177/1363461510368912

Baghirathan, S., Cheston, R., Hui, R., Chacon, A., Shears, P. & Currie K. (2018). A grounded theory analysis of the experiences of carers for people living with dementia from three BAME communities: Balancing the need for support against fears of being diminished. *Dementia.* 19(5):1672-1691. doi:10.1177/1471301218804714

Baillie, L., Sills, E. & Thomas, N. (2016). Educating a health service workforce about dementia: A qualitative study. *Quality in Ageing and Older Adults, 17,* 119–130. https://doi.org/10.1108/QAOA-11-2015-0051

Bakken, K., Melhus, M. & Lund, E. (2006). Use of hypnotics in Sámi and non-Sámi populations in northern Norway, International Journal of Circumpolar Health, 65:3, 261-270, DOI: 10.3402/ijch.v65i3.18098

Ballard, C., Gauthier, S., Corbett, A., Brayne, C., Aarsland, D., & Jones, E. (2011). Alzheimer's disease. *Lancet*, 377, 1019-1031.

Ballard, C., & O'Brien, J. (1999) Pharmacological treatment of behavioural and psychological signs in Alzheimer's disease: how good is the evidence for current pharmacological treatments? *BMJ, 319*, 138–139.

Barone, T., & Eisner, E. W. (2012). *Arts based research.* Sage.

Barthes, R. (1977). Introduction to the structural analysis of narratives. New Literary History, 6(2), 237–272.

Basting, A. (2003). Reading the story behind the story: context and content in stories by people with dementia. *Generations*, 27(3). 25–28.

Basting, A. (2011). *Time Slips training manual.* University of Wisconsin-Milwaukee.

Basting, A. (2013). Time Slips: creativity for people with Dementia. *Age in Action, 28*(4), 1–5.

Batson, P., Thorne, K., & Peak, J. (2002). Life story work sees the person beyond the dementia. *Journal of Dementia Care*, *3*(10), 15–17.

Baur, V., Abma, T. & Baart, I. (2014). "I stand alone." An ethnodrama about the (dis)connections between a client and professionals in a residential care home. *Health Care Analysis: Journal of Health Philosophy and Policy*, *22*(3), 272–291. https://doi.org/10.1007/s10728-012-0203-6

Beard, R. (2011). Art therapies and dementia care: A systematic review. Dementia. 11(5):633-656. doi:10.1177/1471301211421090

Beavis D., Simpson, S. & Graham, 1. (2002). A literature review of dementia care mapping: methodological considerations and efficacy. *Journal of Psychiatric and Mental Health Nursing, 9*(6), 725–736. https://doi.org/10.1046/j.1365-2850.2002.00508.x

Bennett, D. (2007). Editorial comment on 'Prevalence of dementia in the United States: the aging, demographics, and memory study' by Plassman et al. *Neuroepidemiology; 29*(1-2), 133-135.

Berger, I. (2012). YouTube as a source of data. *PsyPag Quaterly*, 9-12.

Berger, R. (2013). Now I see it, now I don't: researcher's position and reflexivity in qualitative Research. *Qualitative Research, 15*(2). https://doi.org/10.1177/1468794112468475

Bergman, P. (1999). Storytelling as a teaching tool. *Clinical Excellence for Nurse Practitioners*, *3*(3), 154–157.

Bernardi, L., Frangipane, F., Smirne, N., Colao, R., Pucio, G., Curcio, S., Mirabelli, M., Maletaa, R., Anfossi, M., Gallo, M., Geracitano, S., Conidi, M., Lorenzo, R., Clodomiro, A., Chiarra, C., Marzano, S., Comiso, F., Valenti, V., Zirilli, M., … Bruni, A. (2012). Epidemiology and genetics of frontotemporal dementia: a door-to-door survey in southern Italy. *Neurobiology of Aging, 33*(12), 2948.e1-2948.e10. https://doi.org/10.1016/j.neurobiolaging.2012.06.017

Berrios, G. (1987). Dementia during the seventeenth and eighteenth centuries: a conceptual history. *Psychological Medicine, 17*, 829–837.

Berry, K. (2005). To the "speeches" themselves: An ethnographic and phenomenological account of emergent identity formation. *International Journal of Communication, 15*(1–2), 21–50.

Blasko, D., & Merski, D. (1998). Haiku poetry and metaphorical thought: An invitation to interdisciplinary study. *Creativity Research Journal*, 11(1), 39– 46. https://doi.org/10.1207/s15326934crj1101_5

Blix, B., & Hamran, T. (2017). "They take care of their own": healthcare professionals' constructions of Sami persons with dementia and their families' reluctance to seek and accept help through attributions to multiple contexts. *International Journal of Circumpolar Health, 76*(1), art. 1328962. https://doi.org/10.1080/22423982.2017.1328962

Bochner, A. (2002). Perspectives on inquiry III: The moral of stories. In M. L. Knapp & J. A. Daly (Eds.), *Handbook of interpersonal communication* (pp.73–101). Sage.

Bochner, A. (2012). On first-person narrative scholarship. *Narrative Inquiry, 22*(1), 155–164. https://doi.org/10.1075/NI.22.1.10BOC

Bochner, A., & Ellis, C. (2006). Communication as Autoethnography. In Shepherd, G., St John, J. & Striphas, T. (Eds.), *Communication as…: Perspectives on theory (pp. 110–122).* Sage.

Bochner, A., & Ellis, C. (1996). Talking over ethnography. In A. Bochner & C. Ellis (Eds.), *Composing ethnography: alternative forms of qualitative writing* (pp. 13–45). Alta Mira Press.

Bott, N., Radke, A., Stephens, M. & Kramer, J. (2014). Frontotemporal dementia: diagnosis, deficits and management. *Neurodegenerative Disease Management, 4*(6), 439–454. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4824317/

Boustani, M., Peterson, B. & Hanson, L. (2003). Screening for dementia in primary care: a summary of the evidence for the US preventive services task force. *Annals of Internal Medicine, 138*(11), 927–937. https://doi.org/10.7326/0003-4819-138-11-200306030-00015

Bradbury-Jones, C. (2007). Enhancing rigor in qualitative health research: exploring subjectivity through Peshkin's I's. *Journal of Advanced Nursing, 59,* 290–298.

Bredesen, D. (2014). Reversal of cognitive decline: A novel therapeutic program. *Aging, 6*(9), 707–717.

Bredesen, D., & John, V. (2013). Next generation therapeutics for Alzheimer's disease. *EMBO Molecular Medicine, 5*(6), 795–798. https://doi.org/10.1002/emmm.201202307

Breslin, E. (1996). Metaphorical communication as aesthetic method for nursing practice. *Issues in Mental Health Nursing, 17*(6), 507–516.

Bristol BME People and Dementia Research Group. (2017). *The Dementia experiences of people from Caribbean, Chinese and South Asian Communities in Bristol.* https://www.bristolhealthpartners.org.uk/uploads/documents/2017-02-23/1487859789-dementia-needs-of-people-from-bme-communities-in-bristol.pdf

British Future. (2021). Beyond 'BAME': What does the public think? https://www.britishfuture.org/beyond-bame-what-does-the-public-think/

Brockmeier, J. (2010). After the archive: Remapping memory. *Culture and Psychology, 16,* 5–35.

Brooke, J., & Ojo, O. (2020) Contemporary views on dementia as witchcraft in sub-Saharan Africa: a systematic literature review. *Journal of Clinical Nursing, 29*, 20-30. https://doi.org/10.1111/jocn.15066

Brod, M., Stewart, A., Sands, L. & Walton, P. (1999). Conceptualization and measurement of quality of life in dementia: The dementia quality of life instrument (DQoL). *The Gerontologist, 39,* 25–35. DOI: 10.1093/geront/39.1.25

Brooker, D., Foster, N., Banner, A., Payne, M. & Jachson, L. (1998). The efficacy of Dementia Care Mapping as an audit tool: Report of a 3-year British NHS evaluation. *Aging & Mental Health, 2: 1,* 60–70. DOI: 10.1080/13607869856957

Bruner, J. (1993). The autobiographical process. In R. Folkenflik (Ed.), *The culture of autobiography: constructions of self-representation*. Stanford University Press.

Bruton, J., Jones, K., Jenkins, R., Davies, B., Ward, H. & Tolendo, M. (2020). Enabling participation of Black and Minority Ethnic (BME) and seldom-heard communities in health research: A case study from the SCAMP adolescent cohort study. *Research for All, 4*(2), 207–219. https://doi.org/10.14324/RFA.04.2.06

Burgener, S., & Twigg, P. (2002). Relationships among caregiver factors and quality of life in care recipients with irreversible dementia. *Alzheimer Disease and Associated Disorders, 16,* 88–102.

Burgener, S., Twigg, P., & Popovich, A. (2002). Measuring psychological well-being in cognitively impaired persons. *Dementia,* 4(4). https://doi.org/10.1177/1471301205058303

Burnett, A., & Peel, M. (2001). Asylum seekers and refugees in Britain: Health needs of asylum seekers and refugees. *BMJ: British Medical Journal, 322*, 544-547. https://doi.org/10.1136/bmj.322.7285.544

Burrell, J. R., & Hodges, J. R. (2018). Falls in frontotemporal dementia and related syndromes. *Handbook of Clinical Neurology, 159,* 195-203.

Candy, L., & Edmonds, E. (2018) Practice-based research in the creative arts: foundations and futures from the front line. *Leonardo, 51*(1), 63–69. https://doi.org/10.1162/LEON_a_01471

Cannon, A. (2012). Making the data perform an ethnodramatic analysis. *Qualitative Inquiry, 18*(7), 583–594. https://doi.org/10.1177/1077800412450153

Care Quality Commission. (2011). *Count me in*. Care Quality Commission.

Carver, C., Scheier, M. & Segerstrom, S. (2010). Optimism. *Clinical Psychology Review, 30*, 879–889.

Capewell, S., & O'Flaherty, M. (2011) Rapid mortality falls after risk-factor changes in populations. *Lancet, 378,* 752–753.

Centres for Disease Control and Prevention. (2015) Creutzfeldt-Jakob Disease, Classic (CJD). https://www.cdc.gov/prions/cjd/index.html

Chaitin, J. (2003). Narratives and storytelling. www.beyondintractability.org

Chammas, G. (2020). The insider-researcher status: a challenge for social work practice research. *The Qualitative Report, 25*(2), 537–552.

Chang, H. (2016). *Autoethnography as method (Developing Qualitative Inquiry).* Routledge.

Chang, H. (2008). Autoethnography as method: Raising cultural consciousness of self and others. https://www.academia.edu/1244871/Autoethnography_as_method pp. 1-25.

Charmaz, K., & Mitchell, R. (1997). The myth of silent authorship: Self, substance and style in ethnographic writing. In R. Hertz (Ed.), *Reflexivity and voice* (pp. 193–215). Sage.

Charon, R. (2001). Narrative medicine: a model for empathy, reflection, profession, and trust. *JAMA, 286*(15), 1897–1902. https://doi.org/10.1001/jama.286.15.1897

Christine, H. (2020). *CBC.* https://www.cbc.ca/news/canada/newfoundland-labrador/storytelling-is-human-1.5511027

Clarke, C., Woods, B., Moniz-Cook, E., Mountain, G., Oksnebierg, L., Chattat, R., Diaz, A., Grove, D., Vernooij-Dassen, M. & Wolverson, E. (2020). Measuring the well-being of people with dementia: a conceptual scoping review. *Health and Quality Life Outcomes, 18,* art no. 249. https://doi.org/10.1186/s12955-020-01440-x

Cleland, J. (2017). The qualitative orientation in medical education research. *Korean Journal of Medical Education, 29*(2), 61-71. https://doi.org/10.3946/kjme.2017.53. 61-71

Coemans, S., Wang, Q., Leysen, J. & Hannes, K. (2015). The use of arts-based methods in community-based research with vulnerable populations: Protocol for a scoping review. *International Journal of Educational Research, 71,* 33-39.

Coemans, S., Raymakers, AL., Vandenabeel, J. & Hannes, K. (2019). Evaluating the extent to which social researchers apply feminist and empowerment frameworks in photovoice studies with female participants: a literature review. *Qualitative Social Work, 18*(1), 37–59.

Coffey, P. (1999). *The ethnographic self.* Sage.

Cohen Miller, A. (2018) Visual arts as a tool for phenomenology. *Forum Qualitative Social Research Volume, 19*(1), Art. 15.

Cohen, G. (2001). *The creative age: awakening human potential in the second half of life*. William Morrow Paperbacks.

Coia, L., & Taylor, M. (2006). From the inside out and the outside in: co/autoethnography as a means of professional renewal. In Kosnik, C., Beck, C., Freese, A. & Samaras, A. (Eds.), Making a difference in teacher education through self-study: Studies of Personal, Professional and Program Renewal. pp. 19–33: 10.1007/1-4020-3528-4.

Colucci, E. (2013). Arts-based research in cultural mental health. In Y. Kashima, E. S. Kashima, & R. Beatson (Eds.), *Steering the cultural dynamics: Selected papers from the 2010 Congress of the International Association for Cross-Cultural Psychology.* https://scholarworks.gvsu.edu/iaccp_papers/108/

Comans, T., Nguyen, KH., Ratcliffe, J., Rowen, D. & Mulhern, B. (2020). **Valuing the AD-5D Dementia Utility Instrument: An Estimation of a General Population Tariff**. *PharmacoEconomics*, *38*, 871–881. https://doi.org/10.1007/s40273-020-00913-7

Conquergood, D. (1988). Health Theatre in a Hmong Refugee Camp: Performance, Communication, and Culture. *TDR (1988-)*, *32*(3), 174–208. https://doi.org/10.2307/1145914

Cooper, C., Tandy, A., Balamurali, T. & Livingston, G. (2010). A systematic review and meta-analysis of ethnic differences in use of dementia treatment, care, and research. *The American Journal of Geriatric Psychiatry*, *18*(3), 193–203. https://pubmed.ncbi.nlm.nih.gov/20224516/

Copsey, N. (1997). *Keeping faith: The provision of community mental health services within a multi-faith context.* The Sainsbury Centre for Mental Health. http://www.scmh.org.uk/pdfs/keeping+faith.pdf

Cowdell, F. (2010). Care of older people with dementia in an acute hospital setting. *Nursing Standard, 23*, 42–48.

Cox, S., & Keady, J. (Eds.) (1999). *Younger people with dementia: Planning practice and development.* Jessica Kingsley.

Csikszentmihalyi, M., & LeFevre, J. (1989). Optimal experience in work and leisure. *Journal of Personality and Social Psychology, 56*(5), 815–822.

Daykin, N. (2009). Knowing through music. Implications for Research, 229-243.

de Oliveira A., Radanovic, M., de Mello, P., Buchain, P., Vizzotto, A., Celestino, D., Stella, F., Piersol, C. & Forlenza, O. (2015). Nonpharmacological interventions to reduce behavioral and psychological symptoms of dementia: a systematic review. *Biomed Research International, 2015*, art. 218980. https://doi.org/10.1155/2015/218980

Dening, T., & Babu Sandilyan, M. (2015). Dementia: definitions and types. *Nursing Standard, 29,* 37–42.

Department of Health UK. (2009). Living well with dementia. Equality Impact Assessment for the National Dementia Strategy. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/168222/dh_094054.pdf

De Tona, C. (2006). But what is interesting is the story of why and how migration happened. *Forum: Qualitative Social Research, 7,* art. 13.

Diaz, E., Calderón-Larrañaga, A., Prado-Torres, A., Poblador-Plou, B. & Gimeno-Feliu, LA. (2015). How do immigrants use primary health care services? A register-based study in Norway. *European Journal of Public Health, 25*(1), 72-78 DOI: 10.1093/eurpub/cku123

Diener, E. (2009). *The science of well-being: The collected works of Ed Diener*. Springer.

Downs, M., & Bowers, B. (2008). Caring for people with dementia. *British Medical Journal, 336*, 225–226.

Dunbar, R., Kaskatis, K., MacDonald, I. & Barra, V. (2012). Performance of music elevates pain threshold and positive affect: implications for the evolutionary function of music. *Evolutionary Psychology, 10*(4), 688-702.

Durand, M. (2015). The OECD better life initiative: How's life? and the measurement of well-being. *Review of Income and Wealth, 61P.,*(1), 4–17. https://doi.org/10.1111/roiw.12156

Dutcher, S., Rattinger, G., Langenberg, P., Chhabra, P., Liu, X., Rosenberg, P., Leoutsakos, JM., Simoni-Wastila, L., Walker, L. Franey, C. & Zuckerman, I. (2014). Effect of medications on physical function and cognition in nursing home residents with dementia. *Journal of the American Geriatrics Society, 62*(6), 1046–1055. https://doi.org/10.1111/jgs.12838

Dyregrov, K., Berntsen, G. & Silviken, A. (2014) The need for and barriers to professional help: a qualitative study of the bereaved in Sámi areas. Suicidology Online Open access journal, (5), s. 47-58. https://fhi.brage.unit.no/fhi-xmlui/bitstream/handle/11250/286330/SOL-ISSUE-5-1.pdf?sequence=3.

Eisner, E. (2008). Art and knowledge. In J. G. Knowles & A. L. Cole (Eds.), *Handbook of the arts in qualitative research: perspectives, methodologies, examples and issues* (pp. 3–12). Sage.

Eliastam, J. (2019). *Fictionalisation in research. Unfolding narratives of Ubuntu in Southern Africa.* https://www.academia.edu/39238418/Fictionalisation_in_Research.

Ellis, C. (1995). *Final negotiations: A story of love, loss, and chronic illness*. Temple University Press.

Ellis, C. (2004). *The ethnographic I: A methodological novel about autoethnography*. AltaMira Press.

Ellis, C., & Bochner, A. (1992). Telling and performing personal stories: The constraints of choice in abortion. In C. Ellis & M. G. Flaherty (Eds.), *Investigating subjectivity: Research on lived experience* (pp. 79–101). Sage.

Ellis, C., & Bochner, A. (2000). Autoethnography, personal narrative, reflexivity. Researcher as subject. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 733–768). Sage.

Ellis, C., Adams, T. & Bochner, A. (2011). Autoethnography: An overview. *Forum: Qualitative Social Research, 12*(1), Art. 10. http://www.qualitative-research.net/index.php/fqs/article/view/1589/3095.

Ellis, C., & Ellingson, L. (2000). Qualitative methods. In E. F. Borgatta & R.J. V. Montgomery (Eds.), Encyclopedia of sociology (2nd ed., Vol. 4, pp. 2287- 2296). New York: Macmillan.

Enegho, F. (2005). Migration: A historical and ethical assessment. In Iroegbu, O. & Echekwube A. (Eds.), *Kpim of morality: ethics – general, special and professional* (pp. 190-199). Heinemann Educational Books PLC.

Ergun, A. & Erdemir, A. (2010). Negotiating insider and outsider identities in the field: "insider" in a foreign land; "outsider" in one's own land. *Field Methods, 22*(1), 16–38. https://doi.org/10.1177/1525822X09349919

Erkkinen, M., Zúñiga, R., Pardo, C., Miller, B. & Miller, Z. (2018). Artistic Renaissance in Frontotemporal Dementia. *JAMA,* ;319(13):1304–1306. https://doi.org/10.1001/jama.2017.19501

Estrella, K., & Forinash, M. (2007). Narrative inquiry and arts-based inquiry: multinarrative perspectives. *Journal of Humanistic Psychology*, *47*(3), 376–383.

Ewenstein, B., & Whyte, J. (2007). Beyond words: aesthetic knowledge and knowing in organizations. *Organization Studies, 28*, 689–708. https://doi.org/10.1177/0170840607078080

Feldman, A. (2003). Validity and quality in self-study. *Educational Researcher, 32*, 26–28.

Feldman, H., Levy, A., Hsiung, G., Peters, K., Donald, A., Black, S., Bouchard, R., Gauthier, S., Guzman, D., Hogan, D., Kertesz, A. & Rockwood, K. (2003). ACCORD Study Group. A Canadian cohort study of cognitive impairment and related dementias (ACCORD): study methods and baseline results. *Neuroepidemiology*: 265-74. doi: 10.1159/000071189. PMID: 12902621.

Fels, D., & Astell, A. (2011). Storytelling as a model of conversation for people with dementia and caregivers. *American Journal of Alzheimer's Disease and Other Dementias, 26*(7), 535–541.

Field, S. (2005). *Screenplay: The foundations of screenwriting revised edition*. Delta.

Finlay, L. (2000). 'Outing' the researcher: the provenance, process, and practice of reflexivity. *Qualitative Health Research, 12*, 531–545.

Fossey, J., Lee, L. & Ballard, C. (2002). Dementia Care Mapping as a research tool for measuring quality of life in care setting: Psychometric properties. *International Journal of Geriatric Psychiatry, 17,*1064–1070.

Foster, V. (2007). 'Ways of knowing and showing': imagination and representation in feminist participatory social research. *Journal of Social Work Practice*, *21*(3), 361–376.

Foster, V. (2012) The pleasure principle: employing arts-based methods in social work research. *European Journal of Social Work, 15*(4), 532–545. https://doi.org/10.1080/13691457.2012.702311

Fratiglioni, L., Winblad, B. & Strauss, E. (2007). Prevention of Alzheimer's disease and dementia. Major findings from the Kungsholmen Project. *Physiology &Behavior, 92*(1–2), 98–104. https://doi.org/10.1016/j.physbeh.2007.05.059

Fredrickson, B. L. (2001). The role of positive emotions in positive psychology: The broaden-and-build theory of positive emotions. *American Psychologist*, *56*(3), 218–226.

Frisina, A. (2006). Back-talk focus groups as a follow-up tool in qualitative migration research: the missing link? *Forum: Qualitative Social Research, 7,* 1–8.

Garre-Olmo, J., Genís Batlle, D., del Mar Fernández, M., Marquez Daniel, F., de Eugenio Huélamo, R., Casadevall, T., Turbau Recio, J., Turon Estrada, A. & López-Pousa, S. (2010). Registry of Dementia of Girona Study Group (ReDeGi Study Group). Incidence and subtypes of early-onset dementia in a geographically defined general population. Neurology. 5;75(14):1249-55. doi: 10.1212/WNL.0b013e3181f5d4c4. Epub 2010 Sep 1. PMID: 20810999.

Gaski, M., Melhus, M., Deraas, T., & Førde, O. H. (2011). Use of health care in the main area of Sami habitation in Norway - catching up with national expenditure rates. *Rural Remote Health, 11*(2), art. 1655. https://munin.uit.no/bitstream/handle/10037/4146/article.pdf?sequence=1&isAllowed=y.

George, D. R. (2014). *How a creative storytelling intervention can improve medical student attitude towards persons with dementia: A mixed methods study.* Sage.

Gola, K. Thorne, A., Veldhuisen, L., Felix, C., Hankinson, S., Pham, J., Shany-Ur, T., Schauer, G., Stanley, C., Glen, S., Miller, B. & Rankin, K. (2015). Neural substrates of spontaneous narrative production in focal neurodegenerative disease. *Neuropsychologia, 179*(A), 158–171. https://doi.org/10.1016/j.neuropsychologia.2015.10.022

Gorodeisky, K., & Marcus, E. (2022). Aesthetic knowledge. *Philosophical Studies, 179*, 2507–2535. https://doi.org/10.1007/s11098-021-01775-1

Gottschall, J. (2012). *The storytelling animal: how stories make us human.* Houghton Mifflin Harcourt.

Gray, C., & Marlins, J. (1993). *Research procedures. Methodology for artists & designers.* http://carolegray.net/Papers%20PDFs/epgad.pdf

Gray, J., Baer, P. & Goldstein, T. (2015). Shaping research-informed theatre: working beyond an 'aesthetic of objectivity'. *UNESCO Observatory Multi-disciplinary Journal in the Arts, 5,* 1-29. https://tspace.library.utoronto.ca/bitstream/1807/87263/1/ShapingResearchInformed.pdf

Green, M., & Brock, T. (2000). The role of transportation in the persuasiveness of public narratives. *Journal of Personality and Social Psychology, 79*(5), 701–721. https://doi.org/10.1037/0022-3514.79.5.701

Greenwood, J. (2012). Arts-based research: weaving magic and meaning. *International Journal of Education & the Arts, 13*(Interlude 1), pp. 1-21. http://www.ijea.org/v13i1/

Greenwood, J. (2019) Arts-based research. In *Oxford Research Encyclopaedia of Education.* https://oxfordre.com/education/view/10.1093/acrefore/9780190264093.001.0001/acrefore-9780190264093-e-29 pp. 1-21.

Grijalvo-Perez, A., & Litvan, I. (2014). Corticobasal degeneration. *Seminars in Neurology, 34,* 160-173. https://doi.org/10.1055/s-0034-1381734

Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity and 'ethically important moments' in research. *Qualitative Inquiry, 10*, 261–280.

Hamera, J. (2011). *Performance ethnography.* Sage.

Hamzeh, M., & Oliver, K. (2010). Gaining research access into the lives of Muslim girls: researchers negotiating muslimness, modesty, inshallah, and haram. *International Journal of Qualitative Studies in Education, 23*(2), 165–180.

Harper, G. (2008). *Creative writing guidebook.* Continuum International Publishing Group.

Harvard Medical School. (2019). Sleep and mental health. *Harvard Mental Health Letter,* https://www.health.harvard.edu/newsletter_article/sleep-and-mental-health.

Harvey, R. J. (1998). *Young onset dementia: Epidemiology, clinical symptoms, family Burden, support and outcome*. London Imperial College.

Harvey, R., Skelton-Robinson, M. & Rossor, M. (2003). The prevalence and causes of dementia in people under the age of 65 years. *Journal of Neurology, Neurosurgery, and Psychiatry, 74*(9), 1206–1209.

Hayano, D. (1979). Auto-ethnography: Paradigms, problems, and prospects. *Human Organization, 38*(1), 99–104, 113–120.

Healthcare for London. (2009). *Dementia services guide appendix 9: equality impact assessment (EqIA).* http://www.londonhp.nhs.uk/wp-content/uploads/2011/03/09-Dementia-EqIA.pdf

Herrera, E., Paulo, C., Barreiros, S. & Ricardo, N. (2002). Epidemiologic survey of dementia in a community-dwelling Brazilian population. *Alzheimer Disease and Associated Disorders, 16*(2), 103-108. https://doi.org/10.1097/00002093-200204000-00007

Harris, A., Hunter, M. & Hall, C. (2015). Critically evolving: critical approaches to arts-based research. *UNESCO Observatory Multidisciplinary Journal in the Arts*, *5*(1). https://www.academia.edu/16675651/Critically_Evolving_Critical_Approaches_to_Arts_Based_Research_editorial_UNESCO_Observatory_Multidisciplinary_Journal_in_the_Arts_open_source_e_journal

Higginson, W. (1985). *The haiku handbook: How to write, share, and teach haiku*. Kodansha.

Holm, A., Lepp, M., & Ringsberg, K. (2004). Dementia: involving patients in storytelling – a caring intervention. *Journal of Clinical Nursing*, *14*(2), 256-263. doi: 10.1111/j.1365-2702.2004.01042.x. PMID: 15669935.

Horsburgh, D. (2003) Evaluation of qualitative research. *Journal of Clinical Nursing, 12,* 307–312.

Howarth, L. (2015) Creative health: the arts for health and wellbeing. *Perspectives in Public Health, 138*(1), 26–27. https://doi.org/10.1177/1757913917736680

Hunte, B. L., & Golembiewski, J. A. (2014). Stories have the power to save us: a neurological framework for the imperative to tell stories. *Arts and Social Sciences Journal, 5*(2), Art. 73.

Hyde, A., Maher, J. & Elavsky, S. (2013). Enhancing our understanding of physical activity and wellbeing with a lifespan perspective. *International Journal of Wellbeing*, *3*(1), 98–115.

Hydén, L., & Örulv, L. (2009). Narrative and identity in Alzheimer's disease: A case study. *Journal of Aging Studies*, *23*(4), 205–214. https://doi.org/10.1016/j.jaging.2008.01.001

Hydén, L. (2013). Towards an embodied theory of narrative and storytelling. In M. Hatavara, L.-C. Hydén, & M. Hyvärinen (Eds.), *The travelling concepts of narrative* (pp. 227–244). https://doi.org/10.1075/sin.18.15hyd_

Iliffe, S., Jain, P., Wong, G., Lefford, F., Warner, A., Gupta, S., Kingston, A. & Kennedy, H. (2009). Dementia diagnosis in primary care: Thinking outside the educational box. *Aging Health, 5,* 51-59. https://doi.org/10.2217/1745509X.5.1.51

Imoagene, O. (2017). *Beyond expectation: Second-generation Nigerians in the United States and Britain*. University of California Press.

Instituhtta, S. (2008). *Hvor mange samer er det egentlig. How many Sami are there really?* http://www.sami-statistics.info/default.asp?nc=6809&id=110

Ivanchenko, A. (2007). An 'interactive' approach to interpreting overlapping dialogue in Caryl Churchill's Top Girls (Act 1). *Language and Literature*, *16*(1), 74–89. https://doi.org/10.1177/0963947007072846

Jackson, A., & Mazzei, L. (2008). Experience and "I" in Autoethnography: A Deconstruction. *International Review of Qualitative Research, 1,* 299–318. https://doi.org/10.1525/irqr.2008.1.3.299

Jackson, J. (1990). I am a fieldnote: Fieldnotes as a symbol of professional identity. In R. Sanjek (Ed.), *Fieldnotes: The making of anthropology* (pp. 3–33). Cornell University Press.

James, C. W., & Gashinki, L. K. (2006). The Challenges of Religious Pluralism in Kinston, Ontario. In: *Canadian Journal of Urban Research. Special Issue – Our Diverse Cities: Challenges and Opportunities.* Metropolis: CJUR, Vol. 15, Issue 2 Supplement. pp. 50-66.

Janet, H. (2005). Why tell stories? Constrasting themes and identities in the narratives of Maori and Pakeha woman and men. In F. Scott & B. Christina (Eds.), *Intercultural discourse and communication* (pp. 110–134). Blackwell.

Jokela, T., & Huhmarniemi, M. (2018). *Art-based action research in the development work of arts and art education.* https://lauda.ulapland.fi/bitstream/handle/10024/63653/Sivut%209-25_Jokela.Timo?sequence=1

Jonas-Simpson, C., Mitchell, G., Carson, J., Whyte, C., Dupuis, S. & Giles, J. (2012). Phenomenological shifts for healthcare professionals after experiencing a research-based drama on living with dementia. Journal of Advanced Nursing, 68: 1944-1955. https://doi.org/10.1111/j.1365-2648.2011.05877.x

Jones, S., Adams, T. & Ellis, C. (2016). *Handbook of autoethnography*. Routledge.

Jones, K. (2008). Narrative matters: The power of the personal essay in health policy. *Journal of Health Care for the Poor and Underserved, 19*(3), 1010–1011.

Journal of Neurology, Neurosurgery and Psychiatry (1994). Clinical and neuropathological criteria for frontotemporal dementia. *Journal of Neurology, Neurosurgery and Psychiatry, 57*(4), 416-418. https://doi.org/10.1136/jnnp.57.4.416

Julia, G., Baer, P. & Goldstein, T. (2015). Shaping research-informed theatre: Working beyond an 'Aesthetic of Objectivity'. *UNESCO Observatory Multi-disciplinary Journal in the Arts, 5,* 1-29. https://tspace.library.utoronto.ca/bitstream/1807/87263/1/ShapingResearchInformed.pdf

Kapur, N. (1996). Paradoxical functional facilitation in brain-behaviour research. A critical review. *Brain, 119*(Pt 5), 1775–1790.

Kara, H. (2017). Identity and power in co-produced activist research. *Qualitative Research 17*(3), 289–301.

Kashdan, T. (2017). How many ways can we measure well-being? *Psychology Today.* https://www.psychologytoday.com/gb/blog/curious/201710/how-many-ways-can-we-measure-well-being

Keller-Cohen, D., & Dyer, J. (1997). Intertextuality and the narrative of personal experience. *Journal of Narrative and Life History, 7*(1–4), 147–153.

Kern, M. , Waters, L. , Adler, A. & White, M. (2014). Assessing Employee Wellbeing in Schools Using a Multifaceted Approach: Associations with Physical Health, Life Satisfaction, and Professional Thriving. *Psychology, 5,* 500-513. doi: 10.4236/psych.2014.56060.

Khan, I., & De Jesus, O. (2021). *Frontotemporal lobe dementia*. StatPearls. https://www.ncbi.nlm.nih.gov/books/NBK559286/

Kiesinger, C. (2002). My father's shoes: The therapeutic value of narrative reframing. In A. P. Bochner & C. Ellis (Eds.), *Ethnographically speaking: Autoethnography, literature, and aesthetics* (pp. 95–114). AltaMira.

Kiil, M., & Salamonsen, A. (2013). Embodied health practices: The use of traditional healing and conventional medicine in a North Norwegian community. *Academic Journal of Interdisciplinary Studies, 2,* 483–488.

Knopman, D., & Roberts, R. (2011). Estimating the number of persons with frontotemporal lobar degeneration in the US Population. *Journal of Molecular Neuroscience, 45*(3), 330–335. https://doi.org/10.1007/s12031-011-9538-y

Kontos, P., & Naglie, G. (2006). Expressions of personhood in Alzheimer's: Moving from ethnographic text to performing ethnography. *Qualitative Research, 6*(3), 301–317.

Kontos, P. et al. (2010). Using drama to improve person-centred dementia care. *International Journal of Older People Nursing, 5,* 159–168. https://doi.org/10.1111/j.1748-3743.2010.00221.x

Kontos, P. (2004). Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. *Ageing and Society, 24*(6), 829–849. https://doi.org/10.1017/S0144686X04002375

Kosygina, L. (2005) Doing gender in research: reflection on experience in field. *Qualitative Report, 10*(1), 87–95.

Kraut, A. (1990). Healers and strangers: Immigrant attitudes toward the physician in America—A relationship in historical perspective. *JAMA, 263*(13), 1807–1811.

Labaree, R. (2002). The risk of 'going observationalist': negotiating the hidden dilemmas of being an insider participant observer. *Qualitative Research, 2*(1), 97–122.

Labov, W. (1972). *Socioloinguistic patterns.* University of Pennsylvania Press.

Lapeyre-Mestre, M. (2016). A review of adverse outcomes associated with psychoactive drug use in nursing home residents with dementia. *Drugs & aging, 33*(12), 865–888. https://doi.org/10.1007/s40266-016-0414-x

Ledger, A., & Baker, F. (2007). An investigation of long-term effects of group music therapy on agitation levels of people with Alzheimer's Disease. *Aging & Mental Health, 11,* 330–338.

Lawton M. (1994). Quality of life in Alzheimer disease. *Alzheimer Disease and Associated Disorders, 8*(Suppl.6), 138–150.

Lazarus, R., & Folkman, S. (1984). *Stress, appraisal and coping.* Springer.

Leavy, P. (2017). *Handbook of arts-based research.* Guilford Press.

Leavy, P. (2009). *Method meets art: arts-based research practice.* Guildford Press.

Lenzo, K. (1995). Validity and self-reflexivity meet poststructuralism: Scientific ethos and the transgressive self. *Educational Researcher, 24*(4), 17-23.

Lewis, P. J. (2011). *Storytelling as research/research as storytelling.* Sage.

Literary Terms. (2015). What is Setting? https://literaryterms.net/setting/.

Logsdon, R., Gibbons, L., McCurry, S. & Teri, L. (1999). Quality of life in Alzheimer's disease: Patient and caregiver reports. *Journal of Mental Health and Aging, 5,* 21–32.

Logsdon, R., Gibbons, L., McCurry, S. & Teri, L. (2002) Assessing quality of life in older adults with cognitive impairment. *Psychosomatic Medicine, 64,* 510–519. doi: 10.1097/00006842-200205000-00016. PMID: 12021425.

Luengo-Fernandez, R., Leal, J. & Gray, A. (2010). *Dementia 2010: the prevalence, economic cost and research funding compared with other major diseases.* University of Oxford for the Alzheimer's Research Trust.

Luscombe, G., Brodaty, H. & Freeth S. (1998). Younger people with dementia: Diagnostic issues, effects on carers and use of services. *International Journal of Geriatric Psychiatry, 13*, 323–330. https://pubmed.ncbi.nlm.nih.gov/9658265/

Malat, J., Purcell, D. & van Ryn, M. (2010). Factors affecting whites' and blacks' attitudes toward race concordance with doctors. *J Natl Med Assoc* 2010;102:787–93. 10.1016/S0027-9684(15)30675-1.

Mandelbaum, J. (1989). Interpersonal activities in conversational storytelling. Western Journal of Speech Communication. https://doi.org/10.1080/10570318909374295

Mar, R. A. (2004). The neuropsychology of narrative: Story comprehension, story production and their interrelation. *Neuropsychologia, 42*(10), 1414-1434.

Martin, E. (2011). Intertextuality: An Introduction. *The Comparatist, 35*, 148-151. https://doi.org/10.1353/com.2011.0001

Maso, I. (2001). Phenomenology and ethnography. In Atkinson, Paul., Coffey, A., Delamont, S., Lofland, J. & Lofland, L. (Eds.), *Handbook of ethnography* (pp.136–144). Sage.

Matthews, F., Arthur, A., Barnes, L., Bond, J., Jagger, C., Robinson, L. & Brayne, C. (2013). A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II. *Lancet, 382*(9902), 1405–1412. https://doi.org/10.1016/S0140-6736(13)61570-6

Matthews, S. (2015). Dementia and the power of music therapy. *Bioethics, 29*(8), 573–579. https://doi.org/10.1111/bioe.12148

Maurer, K., Volk, S. & Gerbaldo, H. (1997). Auguse D and Alzheimer's disease. *Lancet, 349*, 1546–1549.

McCarter, S., St Louis, E. & Boeve, B. (2016). Sleep disturbances in frontotemporal dementia. *Current Neurology and Neuroscience Reports, 16*(9), art. 85. https://doi.org/10.1007/s11910-016-0680-3

McKeith, I., & Fairbairn, A. (2001). Biomedical and clinical perspectives. In C. Cantley (Ed.), *A handbook of dementia care* (pp. 7-25). Open University Press.

Méndez, M. (2013). Autoethnography as a research method: Advantages, limitations and criticisms. *Colombian Applied Linguistics Journal, 15*(2), 279–287.

Memon, A., Taylor, K., Mohebati, L., Sundin, J., Cooper, M., Scanon, T. & de Visser, R. (2016). Perceived barriers to accessing mental health services among black and minority ethnic (BME) communities: a qualitative study in Southeast England. *BMJ Open*, *6*(11), art. e012337. https://doi.org/10.1136/bmjopen-2016-012337

Merriam, S. (2002). *Qualitative research in practice: examples for discussion and analysis.* Jossey-Bass Publishers.

Metzler-Baddeley, C., Cantera, J., Coulthard, E., Rosser, A., Jones, D. & Baddeley, R. (2014). Improved executive function and callosal white matter microstructure after rhythm exercise in Huntington's disease. *Journal of Huntingtons Disease, 3*(3), 273-283. DOI: 10.3233/JHD-140113

Milan, G., Lamena, F., Lavorone, A., Galeone, F., Lore, E., De Falco, C. Sorrentino, P. & Postiglione, A. (2008). Frontal Behavioural Inventory in the differential diagnosis of dementia. *Acta Neurologica Scandinavia, 117*(4), 260-265. https://doi.org/10.1111/j.1600-0404.2007.00934.x

Millenaar, J., Hvidsten, L., de Vugt, E., Engedal, K., Selbæk, G., Bruun Wyller, T., Johannessen, A., Haugen, P., Bakker, C., van Vliet, D., Koopmans, R. Verhey F. & Kersten, H. (2017). Determinants of quality of life in young onset dementia - results from a European multicenter assessment. *Aging and Mental Health, 21*(1), 24-30. https://doi.org/10.1080/13607863.2016.1232369

Miller, P. J. (1995). Personal storytelling in everyday life: Social and cultural perspectives. In R. S. Wyer Jr. (Ed.), *Advances in social cognition. Knowledge and memory: The real story* (pp. 177–184). LEA.

Miller, B., & Llibre, J. (2019). Frontotemporal Dementia. *Handbook of Clinical Neurology Volume, 165*, 33-45.

Mienczakowski, J. (2001). Ethnodrama: Performed research – limitations and potential. In P. Atkinson, A. Coffey, S. Delamont, J. Lofland, & L. Lofland (Eds.), *Handbook of ethnography* (pp. 468-476). Sage.

Mienczakowski, J., Smith, L. & Morgan, S. (2002). Seeing words—Hearing feelings: Ethnodrama and the performance of data. In C. Bagley & B. Cancienne (Eds.), *Dancing the data* (pp. 34-52). Peter Lang.

Mihas, P., & Institute, O. (2019). Learn to use narrative analysis to analyze written narratives. Sage. https://methods.sagepub.com/base/download/DatasetStudentGuide/narrative-analysis-written-narratives-united-states.

Mkhonto, F., & Hanssen, I. (2017). When people with dementia are perceived as witches. Consequences for patients and nurse education in South Africa. *Journal of Clinical Nursing, 27*(1-2), e169–e176. https://doi.org/10.1111/jocn.13909

Montero, A. L. (2016). *Serious storytelling – a first definition and review.* Springer Science+Business Media.

Moos, I., & Björn, A. (2006). Use of the life story in the institutional care of people with dementia: a review of intervention studies. *Ageing Society, 26*, 431–454.

Morse, J. (2003). Principles of mixed methods and multimethod research design, In A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social and behavioral research* (pp. 189–208). Sage.

Moser, A., & Korstjens, I. (2017). Series: Practical guidance to qualitative research. Part 1: Introduction. *European Journal of General Practice, 23*(1), 271–273. https://doi.org/10.1080/13814788.2017.1375093

Mullen, C. (2003). Guest editor's introduction: A self-fashioned gallery of aesthetic practice. *Qualitative Inquiry, 9*(2), 165–181.

Muncey, T. (2005). Doing autoethnography. *International Journal of Qualitative Methods*, *4*(1), 69–86. https://doi.org/10.1177/160940690500400105

Naples, N. (1996). A feminist revisiting of the insider/outsider debate: the "outsider phenomenon" in rural IA. *Qualitative Sociology, 19*(1), 83–106.

Negard, J. (2005). *The secret Northern Norway*. Cappelen Akademisk Forlag.

New International Version Biblica. (2011). *Bible gateway.* https://www.biblegateway.com/passage/?search=Prov.+17%3A22&version=NIV

Ngujiri, F. (2011) Studying spirituality and leadership: A personal journey. In W. Chang & D. Boyd (Eds.), *Spirituality in higher education: Autoethnographies* (pp. 183–198). Left Coast Press.

Nightingale, D., & Cromby, J. (Eds.) (1999). *Social constructionist psychology: A critical analysis of theory and practice.* Open University Press.

NIH News in Health. (2010). *Strike a chord for health: Music matters for body and mind.* http://newsinhealth.nih.gov/2010/January/feature1.htm

Norberg, A., Bergsten, M., & Lundman, B. (2001). A model of consolation. *Nursing Ethics*, *8(6*), 544–553. https://doi.org/10.1177/096973300100800608

Norway, S. (2010). *Sámi statistics 2010.* SSB.

Nurse Next Door. (2020, January 28). https://www.nursenextdoor.com/blog/benefits-of-storytelling-for-dementia/

Nusbaum, E. (1988). Finding spirituality: Mark Rothko at the national gallery. *Traditional Home, July 1988*, 90-92.

Nymo, R. (2015). Everyday life between knowledge systems in the Markebygd areas. In B. Miller (Ed.), *Idioms of Sami health and healing* (pp. 157–182). Polynya Press.

Oatley, K. (1992). *Best laid plans: The psychology of emotions*. Cambridge University Press.

Ochs, E., & Capps, L. (1996). Narrating the self. *Annual Review of Anthropology, 25*, 19–43.

Olakehinde, O., Adebiyi, A., Siwoku, A., Mkenda, S., Paddick, S., Gray, W., Walker, R., Dotchin, C., Mushi, D. & Ogunniyi, A. (2019). Managing dementia in rural Nigeria: feasibility of cognitive stimulation therapy and exploration of clinical improvements. *Aging and Mental Health, 23*, 1377–1381. https://doi.org/10.1080/13607863.2018.1484883

O'Neil, A., Quirk, S., Housden, S., Brennan, S., Williams, L., Pasco, J., Berk, M. & Jacka, F. (2014). Relationship between diet and mental health in children and adolescents: A systematic review. *American Journal of Public Health*, *104*(10), 31–42. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4167107/

O'Neil, M., Freeman, M., Christensen, V., Telerant, R., Addleman, A. & Kansagrara, D. (2011). *A systematic evidence review of non-pharmacological interventions for behavioral symptoms of dementia*. Department of Veterans Affairs (US). https://www.ncbi.nlm.nih.gov/books/NBK54971/

Onyike, C., & Diehl-Schmid, J. (2013). The epidemiology of frontotemporal dementia. *International Review of Psychiatry*, *25*(2), 130–137.

Onyike, C. U., Shinagawa, S., & Ellajosyula, R. (2021). Frontotemporal Dementia: A Cross-Cultural Perspective. *Advances in experimental medicine and biology*, *1281*, 141–150. https://doi.org/10.1007/978-3-030-51140-1_10

Ospina, S., Phillips, K., Rodriguez-Gutierrez, R., Guarderas, A., Gionfriddo, M., Branda, M. & Montori, V. (2019). Eliciting the patient's agenda- secondary analysis of recorded clinical encounters. *Journal of General Internal Medicine, 34*, 36–40. https://doi.org/10.1007/s11606-018-4540-5

Padgett, D. (2008). *Qualitative methods in social work research*. Sage.

Park, J., & Sun Jun, B. (2016). Frontotemporal dementia. https://www.researchgate.net/publication/315643454_Frontotemporal_Dementia

Parsons, C. (2017). Polypharmacy and inappropriate medication use in patients with dementia: an underresearched problem. *Therapeutic Advances in Drug Safety*, *8*(1), 31–46. http://doi.org/10.1177/2042098616670798

Parletta, N., Zarnowiecki, D., Cho, J., Wilson, A., Bogomolova, S., Villani, A., Itsiopoulos, C., Niyonsenga, T., Blunden, S., Meyer, B., Segal, L., Baune, B. T., & O'Dea, K. (2019). A Mediterranean-style dietary intervention supplemented with fish oil improves diet quality and mental health in people with depression: A randomized controlled trial (HELFIMED). *Nutritional neuroscience*, *22*(7), 474–487.

Patton, M. (2002). *Qualitative research and evaluation methods* (3rd ed.). Sage.

Pavlenko, A. (2007). Autobiographic narratives as data in applied linguistics. *Applied Linguistics, 28*, 63–188.

Pennebaker, J., & Seagal, J. (1999). Forming a story: 'The Health Benefits of Narrative', *Journal of Clinical Psychology, 55(*10), 1243–1254.

Phillimore, J. (2011). Refugees, acculturation strategies, stress and integration. *Journal of Social Policy, 40*, 575-593. https://doi.org/10.1017/S0047279410000929

Phillips, L., & Conn, V. (2009). The relevance of creative expression interventions to person-centered care. *Research in Gerontological Nursing, 2*(3), 151–152.

Pillow, W. (2003). Confession, catharsis, or cure? Rethinking the uses of reflexivity as methodological power in qualitative research. *International Journal of Qualitative Studies in Education, 16*, 175–196.

Pillow, W. (2010). Dangerous reflexivity: rigour, responsibility and reflexivity in qualitative research. In P. Thomson & M. Walker (Eds.), *The Routledge doctoral student's companion* (pp. 270–282). Routledge.

Pitard, J. (2017). A journey to the centre of self: positioning the researcher in autoethnography. *Forum: Qualitative Social Research*, *18*(3), art. 10. https://doi.org/10.17169/fqs-18.3.2764

Polkinghorne, D. (1988). *Narrative knowing and the human sciences*. State University of New York Press.

Pollock, D. (2006). Part I introduction: Performance trouble. In D. S. Madison & J. Hamera (Eds.), *The SAGE handbook of performance studies* (pp. 1-8). Sage.

Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W. and Ferri, C. (2013). The global prevalence of dementia: A systematic review and metaanalysis. Alzheimer's & Dementia, 9: 63-75.e2. https://doi.org/10.1016/j.jalz.2012.11.007

Prince, M., Guerchet, M. & Prina, M. (2013). *Policy brief for heads of government: the global impact of dementia 2013 – 2050.* Alzheimer Disease International.

Quarrell, O., O'Donovan, K., Bandmann, O. & Strong, M. et al. (2012). The prevalence of juvenile Huntington disease: a review of the literature and meta-analysis. *PLoS Currents, 20*(4), e4f8606b742ef3. http://currents.plos.org/hd/article/the-prevalence-of-juvenile-huntingtons-disease-a-review-of-the-literature-and-meta-analysis/

Rabins P., Kasper, J., Kleinman, L., Black, B. & Patrick, D. (1999). Concepts and methods in the development of the ADRQL: An instrument for assessing health-related quality of life in persons with Alzheimer's disease. *Journal of Mental Health and Aging, 5,* 33–48.

Ranasinha, R. (2021). Use of arts for dementia patients: A literature review. *Academia Letters,* https://doi.org/10.20935/AL3047

Rasmussen, B. (2010). *Art-based research and drama as a way of knowing. Drama in three movements.* A Ulyssian Encounter.

Ratnavalli, E., Brayne, C., Dawson, K., & Hodges, J. R. (2002). The prevalence of frontotemporal dementia. *Neurology*, *58*(11), 1615–1621. https://doi.org/10.1212/wnl.58.11.1615

Ready, R. (2002). Quality of life in dementia. *Medicine and Health, 85*(7), 216–218.

Ready, R., & Ott, B. (2003). Quality of Life measures for dementia. *Health and Quality of Life Outcomes*, *1*, 11. http://doi.org/10.1186/1477-7525-1-11

Ready, R., & Ott, B. (2002) The Cornell-Brown Scale for quality of life in dementia. *Alzheimer Disease and Associated Disorders, 16,* 109–115.

Redbridge, C. V. S. (2008). Barriers to seeking help report. https://www.redbridgecvs.net/sites/redbridgecvs.net/files/annualreport0809.pdf.

Reed-Danahay, D. (1997). *Auto/ethnography: rewriting the self and the social (Explorations in Anthropology).* Berg.

Reinhart, C. & Reinhart, V. (2010). *After the fall.* Technical report. National Bureau of Economic Research.

Reisberg, B., Kenowsky, S., Franssen, E. H., Auer, S. R., & Souren, L. E. (1999). Towards a science of Alzheimer's disease management: a model based upon current knowledge of retrogenesis. *International psychogeriatrics*, *11*(1), 7–23. https://doi.org/10.1017/s1041610299005554

Richardson, L. (2000). New writing practices in qualitative research. *Sociology of Sport Journal*, *17*(1), 5-20. https://doi.org/10.1123/ssj.17.1.5

Richardson, L. (2002). Poetic representation of interviews. In J. Gubrium & J. A. Holstein (Eds.), *Handbook of interview research: Context and method* (pp. 877-892). Sage.

Riessman, C. (1993). *Narrative analysis*. Sage.

Riessman, C. (2008). *Narrative methods for the human sciences*. Sage.

Rittel, H., & Webber, M. (1973). Dilemmas in a general theory of planning. *Policy Sciences*, *4*(2), 155–169.

Robson, C. (1993). *Real world research. A resource for social scientists and practitioner–researchers.* Blackwell Publishers.

Ronellenfitsch, U., & Razum, O. (2004). Deteriorating health satisfaction among immigrants from Eastern Europe to Germany. *International Journal for Equity in Health, 3,* art. 4. https://doi.org/10.1186/1475-9276-3-4

Rosso, S., Kaat, L., Baks, T., Joosee, M., Koning, I., Pignenburg, Y., Jong, D., Dooijes, D., Kamphorst, W., Ravid, R., Niermeijer, M., Verheij, F., Kremer H., Scheltens, P., van Duijn, C., Heutink, P. & van Swieten, J. (2003). Frontotemporal dementia in The Netherlands: patient characteristics and prevalence estimates from a population-based study. *Brain, 126*(Pt 9), 2016-2022. https://doi.org/10.1093/brain/awg204

Rusk, R., & Waters, D. (2015). A psycho-social system approach to well-being: Empirically deriving the five domains of positive functioning. *The Journal of Positive Psychology*, *10*(2), 141–152.

Sabat, S., & Harre, R. (1992). The construction and deconstruction of self in Alzheimer's Disease. *Ageing and Society, 12,* art. 44346 1.

Sackett, K., Carter, M., & Stanton, M. (2014). Elders' use of folk medicine and complementary and alternative therapies: an integrative review with implications for case managers. *Professional case management*, *19*(3), 113–125. https://doi.org/10.1097/NCM.0000000000000025

Sacktor, N., & Robertson, K. (2014). Evolving clinical phenotypes in HIV-associated neurocognitive disorders. *Current opinion in HIV and AIDS, 9*(6), 517–520.

Saldaña, J. (2003). Dramatizing data: a primer. *Qualitative Inquiry, 9,* 218-236. https://doi.org/10.1177/1077800402250932

Saldaña, J. (2011). *Ethnotheatre: Research from page to stage* (1st ed.). Routledge.

Saldaña, J. (2016). *Ethnotheatre: Research from page to stage* (Qualitative Inquiry and Social Justice). Routledge.

Saldaña, J. (Ed.) (2005). *Ethnodrama: An anthology of reality theatre*. Altamira Press.

Sarantakos, S. (2005). *Social research* (3rd ed.). Palgrave Macmillan.

Sarivaara, E., Uusiautti, S. & *Määttä, K.* (2013). Critical Sámi research as the means of finding ways of seeing. *International Journal of Social Science Research, 2*(1), 1-18. https://doi.org/10.5296/ijssr.v2i1.4521

Sarivaara, E., & Uusiautti, S. (2014). Audiovisual frame story as a method of critical consciousness sharing in indigenous research. *International Journal of Research Studies in Psychology, 3*(3), 113-123.

Satoh, M., Yuba, T., Tabei, K., Okubo, Y., Kida, H., Sakuma, H., Tomimoto, H. (2015). Music therapy using singing training improves psychomotor speed in patients with Alzheimer's disease: a neuropsychological and fMRI Study. *Dementia and Geriatric Cognitive Disorders Extra, 5*(3), 296-308. https://doi.org/10.1159/000436960

Schank, R. C., & Abelson, R. P. (1995). *Knowledge and memory: the real story*. Lawrence Erlbaum Associates.

Schensl, S., Schensl, J. & LeCompte, M. (1999). *Essential ethnographic methods: Observations, interviews, and questionnaires.* Altamira Press.

Scott, J. (1991). The evidence of experience. *Critical Inquiry, 17*(4), 773–797.

Sekoni, R. (1994). *Folk poetics: a socio-semiotic study of Yoruba trickster tales*. Greenwood Press.

Selai, C., Trimble, M., Rossor, M. & Harvey, R. (2001). Assessing quality of life in dementia: Preliminary psychometric testing of the Quality of Life Assessment Schedule (QOLAS). *Neuropsychological Rehabilitation, 11,* 219–243

Seligman, M. E. P. (2002). *Authentic happiness: Using the new positive psychology to realize your potential for lasting fulfillment*. Free Press.

Seligman, M. E. P. (2012). *Flourish: A visionary new understanding of happiness and well-being*. Atria Paperback.

Seligman, M. E. P. (2011). *Flourish.* Free Press.

Shakespeare, W. (2018). *Oxford School Shakespeare: Romeo and Juliet.* Oxford University Press.

Shenton, A. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information, 22,* 63–75.

Siedlecki, K., Salthouse, T., Oishi, S., & Jeswani, S. (2014). The Relationship Between Social Support and Subjective Well-Being Across Age. *Social indicators research*, *117*(2), 561–576. https://doi.org/10.1007/s11205-013-0361-4

Simpleshow. (2021). What happens in your brain when you hear a good story? https://videomaker.simpleshow.com/what-happens-brain-when-good-story

Sikes, P. (2015). *Ethical considerations in autoethnographic research.* https://www.sheffield.ac.uk/polopoly_fs/1.586562!/file/SREGP-Autoethnography-2015.pdf

Skains, L. (2018) Creative practice as research. *Discourse on Methodology, Media Practice and Education, 19*(1), 82–97. https://doi.org/10.1080/14682753.2017.1362175

Smiley, S. (2005). *Playwriting: The structure of action, revised and expanded edition*. Yale University Press.

Sparkes, A. (2000). Autoethnography and narratives of self: reflections on criteria in action. *Sociology of Sport Journal, 17,* 21–43. https://doi.org/10.1123/ssj.17.1.21

Spittel, S., Maier, A., & Kraus, E. (2019). Awareness challenges of mental health disorder and dementia facing stigmatisation and discrimination: a systematic literature review from Sub-Sahara Africa. *Journal of global health*, *9*(2), 020419. https://doi.org/10.7189/jogh.09.020419

Springgay, S., Irwin, R. & Kind, S. (2005). A/r/tography as living inquiry through art and text. *Qualitative Inquiry, 11,* 897–912. https://doi.org/10.1177/1077800405280696

Spry, T. (2001). Performing autoethnography: an embodied methodological praxis. Qualitative *Qualitative Inquiry, 7,* 706-732. https://doi.org/10.1177/107780040100700605

Smart, A., & Harrison, E. (2016). The under-representation of minority ethnic groups in UK medical research. *Ethnic Health, 22*(1), 65–82. https://doi.org/10.1080/13557858.2016.1182126

Smith, B. (1999). Ethical and methodological benefits of using a reflexive journal in hermeneuticphenomenological research. *Journal of Nursing Scholarship, 31,* 359–363.

Stalker, P. (2001). *International migration*. Verso.

Statista INC. (2021). *Nigerian nationals population of the UK 2008-2021*. Statista. https://www.statista.com/statistics/1241672/nigerian-population-in-united-kingdom/#statisticContainer

Stronach, I., Garratt, D., Pearce, C. & Piper, H. (2007). Reflexivity, the picturing of selves, the forging of method. *Qualitative Inquiry, 13,* 179–203.

Swain, J., & King, B. (2022). Using informal conversations in qualitative research. *International Journal of Qualitative Methods,* First published online March 24, 2022. https://doi.org/10.1177/16094069221085056

Szkupinski, S. (2015). Performative storytelling as knowledge creation. Paper given at *Exploring Collaborative Contestations and Diversifying Philosophy*, Villanova University, PA, May 28, 2015.

Takashi, T., & Zhang, R. (2014). Cerebral hemodynamics of the aging brain: risk of Alzheimer disease and benefit of aerobic exercise. *Frontiers in Physiology,* https://doi.org/10.3389/fphys.2014.00006

Taylor, R. (2010). Humanizing Dementia Care: A call to action. http://www.eldercaretalk.blogspot.co.uk

The Law Society. (2022). *A guide to race and ethnicity terminology and language.* https://www.lawsociety.org.uk/topics/ethnic-minority-lawyers/a-guide-to-race-and-ethnicity-terminology-and-language.

Thompson, R. (2011). Using life story work to enhance care. *Nursing Older People*, *23*(8), 16–21.

Tololyan, K. (1987). Cultural narrative and the motivation of the terrorist. *The Journal of Strategic Studies*, *10*(4), 217–233.

Tompkins, J. (1994). Theatre and the world: performance and the politics of culture. *Theatre Journal*, *46*(2), 296.

Truswell, D. (2011). Black, minority ethnic and refugee (BMER) communities and the National Dementia Strategy: the London experience. *Diversity in Health and Care 8*(2), 113–119.

Tuerk, R., & Sauer, J. (2015). *Dementia in a Black and minority ethnic population: characteristics of presentation to an inner London memory service. BJ Psychology Bulletin, 39*(4), 162–166. https://doi.org/10.1192/pb.bp.114.047753

Tullis Owen, J., McRae, C., Adams, T. E., & Vitale, A. (2009). Truth troubles. *Qualitative Inquiry*, *15*(1), 178–200.

Tullo, E. S. (2010). Systematic review: Helping the young to understand the old. Teaching interventions in geriatrics to improve the knowledge, skills, and attitudes of undergraduate medical students. *Journal of the American Geriatrics Society*, *58*, 1987–1993.

Turner, D., Salway, S., Chowbey, P. & Mir, G. (2012). Mini case study book. Real world examples of using evidence to improve health services for minority ethnic people. https://shura.shu.ac.uk/26584/1/EEiC_mini_case_study_book.pdf

UKEssays. (2018). *Labov's model of narrative analysis.* https://www.ukessays.com/essays/english-language/labovs-model-narrative-analysis-2563.php?vref=1

Utredninger, N. N. O. (1995). *Plan for helseog sosialtjenester til den Sámiske befolkning i Norge* [Norwegian Governmental Document. Plan for health and social services to the Sami population of Norway]. Statens forvaltnngstjeneste.

Usita, M., Hyman, I. & Herman, K. (1998). Narrative intentions: Listening to life stories in Alzheimer's Disease. *Journal of Aging Studies, 12,* 185–197. https://doi.org/10.1016/S0890-4065(98)90014-7

Vernooij-Dassen, M., Moniz-Cook, E., Woods, R., De Lepeleire, J., Leuschner, A., Zanetti, O., de Rotrou, J., Kenny, G., Franco, M., Peters, V. & Iliffe, S. (2005). The INTERDEM group: Factors affecting the timely recognition and diagnosis of dementia in primary care across eight European states: a modified focus group study. *International Journal of Geriatric Psychiatry, 20*, 1–10.

Velakoulis, D., Walterfang, M., Mocellin, R., Pantelis, C., & McLean, C. (2009). Frontotemporal dementia presenting as schizophrenia-like psychosis in young people: Clinicopathological series and review of cases. *British Journal of Psychiatry, 194*(4), 298-305. doi:10.1192/bjp.bp.108.057034

Vanhoutte, B., & Nazroo, J. (2014). Cognitive, affective and eudemonic well-being in later life: measurement equivalence over gender and life stage. *Sociological Research Online, 19*(2), 1–14. https://doi.org/10.5153/sro.3241

Vidhya, B., & Arjunan, A. (2015). Characterisation - an intrinsic aspect of dramatic text. *Journal of Humanities and Social Science*, *20*(3), 76–78.

Wall, S. (2016). Toward a moderate autoethnography. *International Journal of Qualitative Methods, 15*(1). https://doi.org/10.1177/1609406916674966

Wamwayi, M., Cope, V., & Murray, M. (2019). Service gaps related to culturally appropriate mental health care for African immigrants. *International Journal of Mental Health Nursing, 28*(5), 1110–8. https://doi.org/10.1111/inm.12622

Wei, Y., Simoni-Wastila, L., Lucas, J. A., & Brandt, N. (2016). Fall and fracture risk in nursing home residents with moderate-to-severe behavioral symptoms of Alzheimer's disease and related dementias initiating antidepressants or antipsychotics. *Journals of Gerontology Series A, 72*(5), 695–702. https://doi.org/10.1093/gerona/glw095

Weiner, M. F., Martin-Cook, K., Svetlik, D. A., Saine, K., Foster, B., & Fontaine, C. S. (2000). The quality of life in late-stage dementia (QUALID) scale. *Journal of the American Medical Directors Association*, *1*(3), 114–116.

Williamson, G., & Christie, J. (2009). Aging well in the 21st century. Challenges and opportunities. In C. Snyder & S. Lopez (Eds.), *Oxford handbook of positive psychology* (pp. 165–169). Oxford University Press.

Willig, C. (2001*). Introducing qualitative research in psychology: adventures in theory and method.* Open University Press.

Wimo, A., Guerchet, M., Ali, G.-C., Wu, Y.-T., Prina, A.M., Winblad, B., Jönsson, L., Liu, Z. and Prince, M. (2017), The worldwide costs of dementia 2015 and comparisons with 2010. Alzheimer's & Dementia, 13: 1-7. https://doi.org/10.1016/j.jalz.2016.07.150

Wint, E. (2011) Reflexivity in practice: developing a new attitude as part of teaching and engaging in participatory research and development. *Journal of Progressive Human Services, 22*(1), 68–83.

Wood, T. (2011). Author's characters and the character of the author: The typical in fiction. *Journal of Literary Semantics, 40*(2). https://doi.org/*10*.1515/jlse.2011.009

World Health Organisation. (1992). *The ICD-10 Classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. WHO.

Young, A. & Dinan, S. (1994). ABC of sports medicine. Fitness for older people. *BMJ*, *309,* 331–334.

Xu, W., Ferrari, C. & Wang, H X. (2013). Epidemiology of Alzheimer's Disease. In I. Zerr (Ed.), *Understanding Alzheimer's Disease* (pp. 329–358). Intech.

Young, K., & Saver, J. (2001). The neurology of narrative. *SubStance, 30*(1 & 2), 72–84.

Zarowitz, B., O'Shea, T. & Nance, M. (2014). Clinical, demographic, and pharmacologic features of nursing home residents with Huntington's disease. *Journal of the American Medical Directors Association, 15*, 6, 4.

APPENDICES

Analysis of the Autoethnography Process

Book Title: Dear Toriola, Let's Talk About Perimenopause					
Abstract	Orientation	Complicating Action	Evaluation	Resolution	Coda
This book is an epistolary narrative of my battle with perimenopause.	Many of the books on perimenopause at the time I was writing were full of medical jargon, while others were condescending.	I was keen on reaching women in third-world countries, many of whom may not have access to good medical care. I created two women, one in Devon and the other in Nigeria. They exchanged letters through which we got a glimpse of non-pharmacological approaches to having symptom-free perimenopause.	My book allows me to question conventional and authoritative narratives (Toloyan, 1987) about perimenopause which is not empowering for women.	After analysing my data, I decided to share my findings in an accessible format. I wanted my audience to be immersed in the narrative, even though the book is non-fiction. Therefore, I chose the epistolary form and used elements of fiction, such as characterisation and an engaging setting.	My message was that many health problems have roots that need to be examined; this helps people to understand how to start their healing journey. In the chapter titled 'April 2013', there is a true story where the narrator (me) explains how the sudden death of her father led to her food allergies and intolerance.

Book Title: Trickster Tales for Telling					
Abstract	Orientation	Complicating Action	Evaluation	Resolution	Coda
I heard these stories growing up in Nigeria; many of them are only available as oral narratives, so I had to rely on my imagination each time I tried to retell them in school.	A few years ago, I decided to write and publish some of them so that the next generation of storytellers could access them.	When I was young, I was bullied, and I dreaded going to school because the bullies took my lunch money and sometimes beat me up. The other students saw what was happening but did nothing, and I was too frightened to tell my parents.	I translated and adapted the stories in this book for publication because of my fascination with how tricksters negotiate the bends and curves of life. Their quick wit sometimes amuses me, but I also see how their actions mirror the natural world. It is rare to find a creature that sits by and allows itself to be destroyed by another without putting up a fight.	As a storyteller, telling these tales is my way of assuring my audience that they can learn survival skills from tricksters whether they are battling a disease or any other life challenge. They teach us how to challenge the negative chatter and mini-narratives that occupy our subconscious mind and render us helpless and immobile.	Illnesses or diseases can be a metaphor for life's bully. I used this theme in the play that I created in this thesis. Beatrice later uses the story as a 'prophetic' metaphor that though there is no cure for her FTD, she sees herself overcoming some of her challenges, just as the trickster overcame the problem that would have destroyed him and the other animals.

Book Title: How to Enhance Your Storytelling With Music					
Abstract	Orientation	Complicating Action	Evaluation	Resolution	Coda
This book is a resource for storytellers, teachers, community workers and parents who wish to create an engaging storytelling experience and connect more effectively with their audience.	Music gives a sense of satisfaction. The audience feels that they have been part of the whole narrative experience. A sense of 'community' is built as the emphasis shifts from the storyteller to the group having a storytelling experience.	Music is a universal language that everyone connects with, irrespective of age, culture or race.	Songs can be used to stir the emotion of an audience, thereby creating a high level of rapport between the teller and the listener.	The book offers practical call-and-response storytelling examples that could take storytellers' performances to a new level.	The theme of call-and-response storytelling features in the play '*My Name is Beatrice*'. There are researches that explore the efficacy of music as a person-centred approach to dementia care; music performance, which includes drumming, dancing and singing, helps to release endorphins.

Book Title: The Legendary Weaver: New Edition					
Abstract	Orientation	Complicating Action	Evaluation	Resolution	Coda
This is my first young adult novel.	The story is set in Nigeria, where Kike, the protagonist, lives with her mother, Aduni, in a remote village.	A serious bout of fever leaves Kike weakened. She recovers slowly but gradually loses her hearing until, in her early teens, she is totally deaf.	The structure of The Legendary Weaver as a frame narrative was deliberate. I wanted it as a storytelling novel with a narrator, hence the use of a prologue and epilogue. A grandmother was telling the story of the origin of a hair design known as Cornrows that enables young African girls to use their hair as a canvas to create intricate designs that tell artistic stories.	After a period of deep depression, she (the protagonist) turns her disability into a challenge as she advances from her lowly station to a symbolic house on the hill.	This experience was valuable in creating the protagonist for my play – '*My Name is Beatrice*'. In the play, Ireti, Beatrice's daughter, is the protagonist, though Beatrice is the woman who has frontotemporal dementia. I want to show the plight of a young carer to buttress the fact that families of people with dementia suffer a great deal, especially young carers.

Book Title: The Goshen Principle…					
Abstract	Orientation	Complicating Action	Evaluation	Resolution	Coda
This book is a typological allegory that explores the narrative of the Israelites' deliverance from slavery in Egypt.	According to the narrative in the book of Exodus in the bible, certain supernatural events occurred in Goshen that cast a metaphoric spotlight on the name.	The biblical account talks about a man named Moses, who was called by God to lead the Israelites out of slavery; however, the Pharaoh, at that time, would not let them go. Therefore, following the instruction that God gave to Moses, he performed some wonders in the presence of Pharaoh to convince him.	Using this story as a typology, I wrote an exegesis of the narrative. The main purpose was to explore the symbolism of Goshen and draw significant parallels about how to experience God's deliverance even when people appear to be in the 'darkest places' as they journey through life.	The country (Egypt) suffered from plagues, twelve in total, and the last plague was the death of all the firstborn Egyptians. After this, Pharaoh released the people. The miraculous event, however, was that none of these plagues was seen in Goshen, where the Israelites lived,	The challenge of not finding publications on my theme for the book was frustrating, but I persevered and found other books that talked about spiritual growth. This experience came in handy when I was struggling with finding data on my current research question. I have learnt how to look further afield for similar materials.

Stage Play Title: Legal Stuff					
Abstract	Orientation	Complicating Action	Evaluation	Resolution	Coda
The play is about immigration issues relating to legal documents and their associated problems.	Some people (immigrants) were doing unscrupulous things like arranged marriages with people who had European passports to obtain their legal papers.	When I was doing my initial research for this play, I found that many people did not want to discuss their immigration status, let alone how they plan to overcome their challenges.	My data gathering process for 'Legal Stuff' was through desktop research and being immersed in the culture. Being an immigrant and a member of the Nigerian community, I had access to people who were going through tough times concerning their immigration.	I did not conduct formal or semi-formal interviews. Our conversations were friendly chats, and they were forthcoming with information, though they knew I was writing a play on the topic. However, they were assured that the characters in my play would be totally anonymous.	Dementia is still a taboo subject in many Nigerian immigrant communities; families do not talk about their relatives' mental health issues. I had informal chats with people and asked questions about their knowledge of frontotemporal dementia. Many people that I spoke with had never heard of FTD. However, when I explained the symptoms, some felt they had relatives presenting with the symptoms but did not know how to help them.

The Play: My Name is Beatrice

This is a play in three Acts. It is a full-length play exploring frontotemporal dementia from the point of view of a young carer who is caring for her mum, an immigrant nurse.

CAST

- Beatrice, aka Bee: 43-year-old nurse. She is Ireti's mother. A Nigerian immigrant
- Ireti: A 16-year-old girl. Bee's daughter
- Eileen: Bee's best friend. A white Irish woman
- Ladun: Bee's sister-in-law
- Wolii: Leader of a spiritualist church. A Nigerian man in his early 50s
- Dr Baines: A white doctor
- Professor Tola Omole: A Consultant Neurologist and Geriatrician at Wellington Hospital – she is a Nigerian immigrant

NOTE:

The use of a forward slash (/) indicates interruption when a character cuts into another's monologue. This is prominent in the plays of Caryl Churchill's plays.

The play should move swiftly between scenes, which means the very barest of scenery so that scene changes can happen quickly.

Bee is showing signs of mild progressive non-fluent aphasia (PNFA), whereby there is difficulty in producing words even though a person knows what they wish to say. Subsequently, words come out distorted.

ACT 1: Scene 1

We are in Bee’s living room on the first floor of a two-bedroom flat in Lewisham, London. The year is 2015, and it is mid-November. Beatrice is bending over her daughter, Ireti, and she is braiding her hair. She is singing and swaying to the Yoruba song, ‘Kulumbu Yeye’, on CD.

Ireti: Maami, it’s getting a little embarrassing now, you singing that song to me every time you make my hair. I’m going to be 16 soon.

Bee: My darling, a child is never too old to be pampered by her mother…

Bee continues singing and swaying.

Ireti: Phew!

Bee pinches Ireti’s cheeks playfully.

Ireti: Mum, you never finished that story you started telling me last weekend.

Bee: Story?

Ireti: Yup! The Tortoise and the One-Eyed Lion story.

Bee: Oh, yeah… Where did I stop?

Ireti: You only just started… Um… The animals living in Adawa village heard a loud strange roar and gathered the mountain lion was still alive, blah, blah…

Bee: Ah, yes. So, the following day, the owl called the animals to a meeting at the village centre. “My friends,” he said, “yesterday, we all heard the rumbling and the roar of the one-eyed lion.” “What shall we do?” asked the bush rat, almost in a whisper. The monkey clams…class… I’m sorry, I mean, cleared his throat and addressed the animals. “Since the owl knows so much about the one-eyed lion who lives on the mountain, why doesn't he go and ask him what he wants?" All the animals nodded in agreement, and the owl reluctantly agreed to fly out to the mountain. The animals waited patiently for him, and later that evening, he came back with a message from the lion. "It's bad news," the owl announced. "The one-eyed lion wants us to draw up a food rota. He said we must come to him one by one so he can eat us for dinner." "What a terrible idea," said the monkey. "Why should—" "Please be quiet for a minute and let me finish my message!" the owl scolded before continuing with his story. "According to the lion, if we come to him on a regular basis, he won't need to roar loudly and send us all into a panic, and he won't hunt us down fiercely. He will stay on the mountain and wait patiently for his dinner. So, all we need to do is go to him one by one." The monkey yelled, "Ha! He must be out of his miserable mind. He is not eating me for dinner, and that's that!" The other animals were pals…palliss… I'm sorry, what's that word when you, like, freeze up 'cos of fear

Ireti: Paralysed?

Bee: Thanks. The animals were paralysed with fear because they knew that they wouldn't be able to escape the fierce lion. If they didn't go to him, he would eventually hunt them down one by one. The question on everyone's mind was, who would be the fist…fost/

Ireti: /First?

Bee: (nods) …first animal to go to the lion? They all looked at one another in silence. Ijapa the tortoise was the first to speak. "My fellow animals, I am prepared to go to the lion. I am happy to be the first on the rota." "You?" the animals chorused. "Yes, me. Why is everyone surprised?"
Everyone was quiet. They were relieved that…

The doorbell rings offstage.

Ireti: I’ll get it.

Ireti exits stage and comes back with Eileen.

Bee: Hi, darling.

Ireti curls up to her mother on the sofa.

Eileen: Hey, you, what’s up?
Bee: Nothing much, we just had dine…diner… Oh, bother, dinner!
Ireti: You missed Mum’s cooking tonight. Jollof rice and fried plantain.
Eileen: No need to rub it in. I can smell it a mile away.

Everyone laughs.

Look at you, all curled up. You guys make me want to rethink my decision not to have a child.
Bee: Too late now, my love.
Eileen: There’s something called adoption, sweetie.
Bee: Ah, well.
Eileen: Are you looking forward to your birthday, Ireti?
Bee: She said all she wants is money.
Eileen: What?
Bee: I know. All my hopes are shattered.
Eileen: So then, I can let the cat out of the bag. You silly girl, your mother was planning a surprise for you. In fact, that’s why I’m here—to help her draw up a list of/
Ireti: (Sits up) /Maami, is that true?

Bee nods.

Ireti: I’m sorry to spoil your plans, but I’d rather have money.
Eileen: Kids, hey? What do you need money for?

Ireti: Saving up.

Eileen: For?

Bee: I asked her, but she said it’s a secret.

Eileen: Okaaaayyy. Anyway, how’s prep for your assessment and interview at Bath? It’s coming up soon.

Bee: In two weeks.

Ireti: Ummm, it’s going well, I guess.

Eileen: What do you mean, “I guess”? C’mon girl, go break a leg in Bath and do us proud. First girl in the family to go private ed., innit?

Bee: “In the family” did you say? In my entire generation. Hehehe…

Everyone falls about laughing.

I couldn’t believe my ears the day she came back from school and told me she got a letter from Mastai…Matai… I mean, Matilda Girls School saying she was shortlisted. How did that even happen?

Eileen: I’ve always told you she’s a prodigy. Just look at her... See, my girl? See how/

Ireti: /Yikes! Can you guys just stop already?

Eileen: Blushing now, are we?

Ireti: That’ll be the miracle of the century—a brown girl blushing!

Eileen: (To Bee) On a more serious note, have you even thought of how amazing it will be if Ireti gets that scholarship?

Bee: Are you telling me? Hmm… I’ll forever be grateful to her biology teacher, Mrs Adedeji. She pulled me aside one day after Ponto and said/

Eileen: /Ponto?

Bee: I mean Pont…pit…

Ireti: PTA?

Bee: Yeah, PTA. She said, “Do everything you can to get your daughter out of this school. I just hate to see great minds waste away.” Initially, I was shocked, but when I went to see her later, she told me the school failed another Ofsted and is likely to close. She was the one who got the Mazda Girls form for us.

Ireti: Matilda Girls School…

Bee: Yeah, whatever. She said, on average, only about ten per cent have five GCSEs, and many of their students don’t come back for A Levels.

Eileen: My goodness! What sort of school is that? How did Ireti end up in that ramshackle of a school?

Bee: Catchment area. Remember?

Eileen: Hmm, yeah. Anyway, God puts angels everywhere around us. That teacher is one. And honestly, Ireti, I’m so proud of you that you got one leg in. In two weeks, we will get both legs in and start a posh private school next year. Whoop whoop!

Bee: I will pray and do marathon fasting for her. We applied for a full scholarship. Mrs Adedeji said that if Ireti wants to fulfil her career dream, she must leave that school.

Eileen: Well, I agree. Ireti, are we still going for a career in medicine?

Ireti: Yep.

Bee: That’s all she’s ever wanted to be since she was five. It’s the only thing she talks about.

Eileen: Cool.

Bee finishes braiding Ireti’s hair.

Bee: There you go, my princess. You look smashing!

Ireti: (Hugs Bee) Aww, thanks. Love you.

Bee: I love you too, my darling. Very much.

Ireti: (Looks at her hair in the mirror above the fireplace) That’ll last for another month.

Bee: A month? I’m redoing that hair in two weeks, just before you go to Bath.

Ireti: Mum, I’ll show my gratitude by cooking dinner tomorrow.

Bee: Nope! I’ll cook, and you’ll help.

Ireti: Hmmm… That’s why Aunty Ladun says you’re spoiling me.

Bee: Did she now? And what does she know about raising a child, the miserable woman?
Ireti: Mother!
Eileen: (Tries to change the subject) So, Bee, how was your meeting tonight?
Bee: What meeting?
Eileen: Your Thursday meeting at church.
Ireti: Didn’t she tell you?
Eileen: Tell me what?
Ireti: We haven’t been for over a month.
Eileen: What? You’ve never missed a meeting, Bee.
Bee: Let’s joist…jest…just say they’re a bunch of gossips, and I leave…I mean, I’ve left them to it.
Eileen: You’re not making sense.

Bee is showing signs of mild progressive non-fluent aphasia (PNFA).

Bee: Can’t be bothered with a bunch of hypostrites…hypdri…hypocrites.
Bee: (To Ireti) Darling, get Eileen a cup of tea.
Ireti: (Goes out) Okay.
Bee: (Calling out to Ireti) Remember how she likes it. No…um…em…whatchmacallit…no…
Eileen: (Calls out to Ireti) No sugar, darling.
Bee: Yeah, no sugar.

Ireti exits stage.

Eileen: Bee, what’s happening?
Bee: Pass. Don’t want to talk about it.
Eileen: If you say so. You do look tired, though. Are you okay?
Bee: Just work stress.
Eileen: Take some time off work.
Bee: Like that’s even possible.

Eileen: If you don’t feel well, you/

Bee: /It happened again.

Eileen: What?

Bee: This time, it was a child, Eileen—an eight-month-old baby. I mixed up her drug with…with…um, that of a girl on chemo.

Eileen: When was this?

Bee: Last week.

Eileen: But I saw you two days ago.

Bee: I know. I was still…still… Oh, bother!

PAUSE

Eileen: I’m so sorry.

PAUSE

Have they said anything?

Bee: Who?

Eileen: The department.

Bee: Tribunal, they said.

Eileen: Oh no!

PAUSE

I think what you said earlier about seeing a specialist… I think you should, really.

Bee: Specialist like whom?

Eileen: I’m not…/

Ireti comes back on stage with a mug of tea for Eileen.

Bee: /That’s my girl. Do you want to make a start on that assessment and interview practice? I’ll join you as soon as Eileen is gone.

Eileen: Thanks, darling.

Ireti gives the mug to Eileen and exits stage.

Eileen: What do you want to do?

Bee: Wish I knew.

Eileen moves over to sit next to Bee.

Eileen: Listen, I am right here for you. Always remember that.

Bee: I am worried about my daughter.

Eileen: Ireti? Ha! That one has her mother’s resilience. You worry too much. You worried when that monster left you, and you worried you wouldn’t be able to cope, but look at you now. You worried that/

Bee: /Eileen, Eileen, that was different. I was wordy…worried, but I was in control of my life. Presently, I feel I am in a quicksand. Do you know how that feels?

Eileen: No, but I/

Bee: /Like I’m sinking fast, and I can’t stop myself from/

Eileen: /A trip to your GP then, don’t you think?

Bee: I’m just wordied…word…worried they’ll place me on antidepressants again.

Eileen: It’s a step off the quicksand, though. You just need to explain to your doctor what’s been happening. I think it’s anxiety brought on by constant worry. You could enter a worrying competition for England, and you’d beat anyone hands down.

Bee smiles wearily.

Now, that’s the smile that I’ve missed.

PAUSE

You have been to Hell and back. You’ll pull through this one, too, I know.

Bee: You reckon?

Eileen: I know so.

LONG PAUSE

Better be on my way. I just dropped by to see how my two favourite girls are doing and to help you with planning for Ireti’s party, but it looks like that’s off the agenda now.

Bee: Thanks. She wants money, and money she'll get. I'll do the usual birthday morning ritual for her anyway.
(Calls to Ireti)
Ireti, Eileen is leaving.
Ireti: (OS) Bye.

Lights dim as Bee and Eileen exit stage.

ACT 1: Scene 2

A week later, at a bus stop in front of the hospital where Bee and Eileen work. Bee is sitting awkwardly and looking agitated. Eileen enters stage.

Eileen: Bee?

Bee: Hm?

Eileen: What are you doing here? Where's your car?

Bee: I…I…had to park it at the…the…the place where we put cars here.

Eileen: Hospital car park?

Bee: Yeah.

Eileen: Why? Can't remember the last time I saw you taking the bus.

PAUSE

Bee?

Bee: Nothing. I'm just tired.

Eileen: Who's picking Ireti from swimming this/

Bee: /Oh dear!

Eileen: /afternoon. She still goes swimming on Tuesdays, doesn't she?

Bee: She'll kill me, that girl. I…just… I'm just very tired and…and… I drove and drove around, but I couldn't find my way.

Eileen: Find your way from where to where?

Bee: I don't know!

Eileen: Calm down. You're not making sense.

Bee: Like I said, I've been driving around and/

Eileen: /For how long?

Bee: (Checking her watch) I finished my shift at three, and I…I…went to take my…my…the…the…whachmacallit to go and pick Ireti but had to come back after about one hour.

Eileen: That's strange.

Bee: Been very stressful with the tribunal and all, innit?

Eileen: Oh yes, I meant to call you last night. How did it go?

Bee: How did what go?

Eileen: The tribunal.

Bee: (Gets up) Long story. I’ll come to yours later today if my legs can move me around. Got to pick my daughter now.

Eileen: I’ll come with you.

Bee: But your shift starts in five minutes.

Eileen: I’ve never seen you like this.

Bee: I’ll be fine. I’ll take the bus to…to…

Eileen: Bus? Do you know the one that goes to the sports centre where she swims?

Bee: I’ll ask.

Eileen: Who, the bus driver? I’m coming with you.

Bee: But you’ll be late for work.

Eileen: I’ll go to my ward now and tell Matron I have an emergency and that I’ll be back soon.

Eileen pulls Bee up and they exit stage.

ACT 1: Scene 3

A few days later, we are in Bee's dimly lit bedroom. There are cartons and boxes under the bed, on the table and in every available space. Other items include an old sewing machine, an exercise bike and boxes of old shoes. There are clothes everywhere. Beside the double bed are a dressing table and chair. A nurse's uniform is on the chair. Bee is sitting on the bed, staring absentmindedly at her right palm and holding her nurse's badge in the other.

Ireti enters stage wearing pyjamas. She stumbles over a milk carton near the bed, and she kicks it to the side.

Ireti: (Cheerily) Good morning, Maami.

I'm greeting.

Bee: (Slowly turns around) Did you sleep well?

Ireti: Like a log.

PAUSE

Maami?

Bee: Hm?

Ireti: Are you okay?

Bee nods.

Ireti: It's just that…um… You didn't wake me up this morning and…

Bee: Sorry, I didn't sleep well in the night.

Ireti: (Smiling) Well?

Bee: Well, what?

Ireti: (In a sing-song voice) Someone's forgetting what day it is…

Bee: What? Forgetting what?

Ireti is disturbed by the agitated look on her mother's face.

Ireti: Never mind. I'm just going to the bathroom.

Bee: (Quietly) Okay.

Ireti exits stage, and Bee continues to stare at her palm. She looks around, gets up and paces the room. Then she goes on all fours, searching for something and looking under the bed.

Ireti comes back on stage dressed in her school uniform.

Ireti: What are you looking for?

Bee: (gets up slowly) Hmmm?

Ireti: Have you lost something?

Bee: My badge. I had it a minute ago.

Ireti: Your badge is in your hand!

Bee: (Gets up and sits on the chair) Oh.

Ireti: You look very tired. Shall I call the doctor?

Bee: No, don't! I'm fine.

Ireti: You sure?

Bee: Just too much stress at work. Been given time off.

Ireti: Time off? You've never taken time off work. Anyway, got to go now. I'm late.

Ireti stops at the door and stares at her mum's bed. Bee stands up slowly and covers the bed sheet with her duvet. She sits at the foot of the bed and fiddles with her badge.

Ireti exits stage.

Bee: (Muttering) Beatrice… My name is Beatrice.
Beatrice… My name is Beatrice

Ireti: (OS) Maami, do you need anything from the shop?

Bee: No.

The mobile phone on the table in Bee's room rings. She stares at it until it stops ringing. The phone rings again, and she picks it up.

Bee: Hello. Aunty Ladun, is that you? No, not really… Worse, I think, no change. I know… Well, I thought…

PAUSE

Pardon? Hmm… Can I think about it and get back to you? Hmm… Hmm… If you say so. Okay… That's fine. Tonight? That's…that's… Okay… Alright then. It's okay. Yeah… Ireti? She's gone to school… What time? Okay… I'll be here… See you later. Bye.

Lights dim on Bee as she puts the phone down.

Lights back on stage.

Later that day.

Bee is sitting on her bed. Wolii and Ladun are standing beside her. Each guest is wearing a long white robe with wide yellow belts tied to the waist. Wolii is holding a wooden cross that is tied to a candle. The room reeks of incense.

Wolii: (To Bee) Arabirin (Woman), the prayer warriors in the church have prayed, and they sent us to bring you a message.

Wolii is interrupted by the sound of a door slamming offstage.

Ireti: (OS) Hellooo. anybody home? Maami?

Ireti enters stage and begins to choke on the incense smell.
She goes to her mum and puts her arm around her.

Ladun: (Pulls Ireti away) Come, my dear. Sit down here.
Wolii: (Gives Bee the wooden cross) As I was saying, Arabirin, you're to take this cross and candle to a crossroad near your house and place it there with three eggs. Then, go to Brighton and swim in the sea. When you come back, take one of the candles that we have used here today and rub your entire body with it. Then, every morning, put the same candle in a bucket of water, add a few drops of this perfume and bathe with it. (He gives Bee a tiny bottle of perfume)

Bee nods.

Within seven days, the evil spirits waging war against you will disappear, and you will be well again.

Bee nods.

Now, let's sanctify this house.

Wolii takes a jug from the table and pours some water into a bowl. He then begins to chant into the water.

Wolii: Ya si mimo, ya si mimo, ya si mimo, holy Michael. (Sactify it, sanctify it, sanctify it, holy Michael)

Ladun: Ya si mimo, ya si mimo, ya si mimo, holy Michael.

Wolii sprinkles water round the room as the chant intensifies.

Wolii: Ladun, show us around Beatrice's house so we can sprinkle the holy water.

Ladun and Wolii exit stage. Ireti gets up.

Bee: (Sternly) Sit!

Ireti: Maami!

Bee turns to face the wall.

Wolii and Ladun: (OS) Ya si mimo, ya si mimo, holy Michael.

The two come back on stage.

Wolii: (To Bee) Arabirin, kneel and let's pray.

Bee kneels

Wolii: Mimo, mimo, mimo… (Holy, holy, holy…)

Ladun: Holy Michael…

Ladun begins to shake vigorously, chanting louder than Wolii.

Wolii sprinkles Bee with water.

Wolii: Yaa si mimo, yaa si mimo, yaa si mimo.

Ladun: Amin! Amin! Amin! (Amen! Amen! Amen!)

Bee is shivering because of the cold water. Ireti jumps up and grabs Wolii's arm.

Ireti: Stop it! Stop hurting my mum! (To Ladun) Aunty, do something!

Ladun: (To Wolii) I'm so sorry, Elder.

Wolii: Who is she?

Ladun: She's the woman's child.

Wolii: How dare you hinder the work of the holy angels, child? Ladun, take her out of here!

Ladun grabs Ireti's hand.

Ireti: Leave me alone. I'm staying with my mum!

Ladun drags her off the stage.

Ireti and Ladun are in the living room.

There is a double sofa in the corner. A computer desk with a laptop and chair are near the sofa. Ireti is pacing the room; Ladun sits on the sofa.

Ireti: I keep asking who that man is, but you're/

Ladun: /Is this the first time anyone has come to your house to pray?

Ireti: No, but it's the first time some weird people in flowing white garments have come here, holding candles over my mum's head.

Ladun: That's the leader of the afadurajagun in our/

Ireti: /Afajaja… who? What's that in plain English?

Ladun: Prayer warriors. All we're doing is praying for your/

Ireti: /You call that praying?

Ladun: What do you call it then since you know everything?

Ireti: But why is that man splashing Maami with water. Who asked you to bring him here?

Ladun: Your mum!

Ireti: Maami?

Ladun: Yes, I called her this morning to find out how she's doing. She didn't sound too well… I've been telling her she should let me bring my afadurajagun group to wade off the evil spirits tormenting her, but/

Ireti: /She hasn't got an evil spirit! What she needs is a doctor, not a freaking Wolii and some smelly water…

Ladun: (Arms akimbo) Ehen? From your mouth, Ireti? 'Freaking Wolii'?

PAUSE

And you're calling holy water smelly water? I don't blame you, London girl.

We hear the chant off stage.

Ireti: I'm not going to sit here with you, while that weirdo hurts Maami! She's ill and you're freaking her out.

Ladun: (Stands in front of her) Where do you think you're going?

Ireti: To save my mother from you horrible lot!

Ladun: Shut your mouth, you rude girl!

Ireti stands still.

Ladun: Freaking this, horrible that… Do you think your mother hasn't been to see the doctor?/

Ireti: /No, she hasn't been lately/

Ladun: /Why haven't they helped her?

Ireti: /and I'll phone our GP tomorrow. So, if you don't mind, please tell your leader to leave, or I'll go and do it myself!

Ladun sighs and moves closer to Ireti. She attempts to put her arm around her, but Ireti pushes her away.

Ladun: She doesn't want you to be worried. You know what she's like. I had to call her several times to even get any information from her. Listen, Ireti, I'm as worried as you are. What we're doing now is the last resort.

Ireti turns to face her.

Ireti: What do you mean last resort?

Ladun: You're a child. You wouldn't really understand.

Ireti: Try me.

Ladun: (Holds Ireti's hand and leads her to the sofa) My dear, your mother is… Her…

PAUSE

What I'm trying to say is that she has a disturbed mind and/

Ireti: /Ha! Anyone would have a disturbed mind, surrounded by freaks dancing around her with candles, and pouring cold water on her head!

Ladun: Enough!

Ireti: I'm not going to shut up until you leave my mum alone! She needs to see a doctor. She's had depression before, but she used her medicine, and she was fine.

Ladun: This is different.

Ireti: She said it's work stress.

Ladun: (Lowers her gaze) I don't know, Ireti. Nobody knows what it is. This is different from the depression she had then. When your mother called me up a few months ago, about this issue, I/

Ireti: /A few months ago? She only started feeling unwell some days ago. In fact/

Ladun: /Goodness! Is that how you interrupt your teachers when they talk to you at school?

PAUSE

Listen, I promised your mother I'll do everything I can to help her; and I'm standing by my promise.

Ireti: (Grabs her aunt's long yellow belt – amure) Then help her; let's take her to hospital. If the drugs ain't working, they'll change them. I know they will.

Ladun: (Pulls her amure away from Ireti) Aren't you even listening to me, child! What I've been trying to tell you is that your mother needs spiritual help… she's going mad.

Ireti: (Stares menacingly at Ladun) Who's going mad?

Ladun backs off.

Ladun: Calm down. She’ll be alright.

Ireti runs out of the living room and exits stage.

ACT 2: Scene 1

We are in Eileen’s Kitchen. *A wrapped present is on the table. Eileen is wearing a nurse’s uniform, and she checks the watch on her pocket flap. We hear a doorbell off stage.*

Ireti enters Eileen’s kitchen.

Ireti: Your front door was open.
Eileen: Hello, you! Happy birthday, darling.
Ireti: Thanks.
Eileen: Tea?
Ireti: No, thanks.

Eileen cocks her head to the side.

Eileen: Something wrong?
Ireti: Maami is not well. You’ve got to come and see her. Today, she forgot my birthday and didn’t even say anything about it… She’s never forgotten my birthday. She dances into my room on my birthday and sings for me… There’s something wrong, Eileen.

Eileen gently picks up the present from the table and gives it to Ireti.

Ireti: Thanks.
Eileen: I was going to bring this to you on my way to work.
Ireti: Eileen, you’re the only one I can talk to and/
Eileen: /Ireti, I know your mum has been unwell.
Ireti: You knew?
Eileen: (Wearily) She’s been having this depression for a while now and/
Ireti: /It’s more than depression. Aunt Ladun says so/
Eileen: /Darling, there are various forms of/
Ireti: /But when she had depression a few years ago, she didn’t forget my birthday. She still went to work.
Eileen: /depression. I know, child, but it comes in different guises.

Ireti: (Quietly) Depression does not make your speech slur, does it? Depression does not make you…make you wet the bed.

Eileen: What are you talking about?

Ireti turns her back to Eileen.

Ireti: She tries to hide it from me, but I saw it. I saw the big wet stain on her bed… I saw the frightened look on her face.

Eileen: (Quietly) I didn't realise it had gone that far.

Ireti (Turning around sharply) What do you mean gone that far?

Eileen What has your mum told you?

Ireti: Nothing.

Eileen: Well then…
PAUSE

Ireti: You and I are the only people she's got. Dad's family would have nothing to do with us. Only his brother's wife, Aunt Ladun, comes once in a while. You know the story.

Eileen sits on the chair and motions for Ireti to sit.

Eileen: About a year ago, your mother came to my house one day—after we had her 40th birthday bash. You remember the one we did for her at the Aston hotel?

Ireti nods.

She said she was forgetting things and finding it difficult to recall names. I told her she'd had too much to drink.
PAUSE
But earlier this week, the day we came to pick you from swimming, I found her sitting alone at a bus stop. She said she'd driven around and couldn't remember where she was going. But it wasn't the first time it's happened. Apparently, a few weeks ago, she got lost for more than two hours during a 15-minute trip home from work.

Ireti: What?

Eileen: Well, I really didn't understand what the problem was, but a few days ago, when she told me she'd been suspended from work/

Ireti: /Suspended? Like go home and don't come to work for a while?

Eileen: Oh dear, I thought you knew.

Ireti: So now you regret telling me. I came to you for help and/

Eileen: /Darling, if your mother wanted you to know all this, she would have told you, don't you think?

Ireti: I'm just a kid, aren't I? A dumb child who knows nothing, can't do nothing, has no/

Eileen: /Stop it!

Ireti: What if she dies? I…

Ireti breaks down in tears.

Eileen: I promise you/

Ireti: /Promise, promise, promise. Even Aunt Ladun is standing by her promise! Comes to see our house, reeking with smoke from incense and flooded with holy water.

Ireti stands up.

You can stuff your promise neatly into… Into…

Eileen: Ireti!

Ireti: I WILL find help for her!

She storms off and exits stage.

Eileen: Ireti… Please wait… I didn't mean… Ireti!

We hear the slamming of doors off stage.

Act 2: SCENE 2

The following day, in *Bee's dimly lit bedroom. She's wearing a long, oversized white robe and sitting on the edge of her bed.*

Bee: (Holding her badge and muttering) Beatrice, my name is Beatrice… Beatrice…

Ireti enters Bee's room.

Ireti: Morning.

Ireti moves closer and taps her mum on the shoulder.

Ireti: Hi.

Bee: Hmm?

Ireti: You alright?

Bee: Why are you not at school?

Ireti: I told you yesterday, I'm staying with you.

Bee: But I'm…I'm better today. I drank holy water and used some of it to bathe.

Ireti: Ha!

Bee: I set…said I'm fine. So now go to school.

She gets up suddenly and throws her badge on the floor.

Ireti: It's okay, it's okay, Maami. Yes, I know you're fine. I'll/

Bee: /Why you… Why the change of tone?

Ireti: I'm not here to fight.

Bee: Then off to school, you son of a bitch!

Ireti: (Backs off) What?

Bee: You heard!

Ireti: All I've come here to do is find out what want for breakfast.

Bee: And who saith…said I can't make my own foot…food?

Ireti: I didn't say that… I'm just/

Bee: /Shut your front door! You're like all them…all of them… Patronising!

Ireti: How can you say that? You didn't even tell me anything, and I heard about your work from Eileen. Whatever happened to our vow – "we must always be open, no secrets"?

Bee: You're smothering me with fussing. Lay off!

Ireti: Have it your way, MOTHER! I'll lay off from now on.

Bee: (Yells) Good!

PAUSE

Ireti looks around the dirty room and picks her mother's clothes from the floor.

Bee: Back again, are you?

Ireti: I never left, Maami. I was here all along and will always be here for you.

Bee shrugs.

Bee: Suit yourself, silly child. Very stubborn!

Ireti exits stage, taking her mother's clothes for washing.
Bee sits back on the chair, rocking herself, staring into space and muttering, "Beatrice, my name is Beatrice… Beatrice…"

Ireti comes back with a tray.

Ireti: I brought you food.

She places the food on the table and picks an empty carton of milk from the floor.

Ireti: Eileen said there's a car boot sale at the park on Sunday. Shall I take some of these things?

Bee: (Snatches the carton of milk) Get out!

Ireti: I was just trying to/

Bee: /And I've told you, leave my stuff al…alan…alone!

Ireti: You haven't used some of these things in years. At least let's get rid of the old shoes and clothes and make some money from them.

Bee: Did I tell you I need money?

Ireti: No, but/

Bee: /But nothing… They stay here!

Ireti plugs an air freshener in when Bee isn't looking.

Ireti: Okay, please eat your food. And… you need to have a shower. My friend is coming today.

Bee: What friend?

Ireti: Anna from school. We're just gonna hang out.

Bee: NO ONE is come…coming into this house. Understand?

Ireti: But you like Anna. You braided her hair once, remember? Anyway, she's already on her way.

Bee: Your mobile phone still working then?

Ireti: Yeah, why?

Bee: Then phone her, dumb ass! Tell her your mother said NO VISITORS!

Ireti: No! I won't call her. YOU will have to explain why YOU don't want her here!

Bee: You bet I will.

The doorbell rings offstage.
Bee and Ireti exit stage.
We hear commotion, a loud argument and door slamming off stage.
Bee comes back on stage, dragging her long robe behind her.

Ireti: (Screaming) Did you have to do that? I'm talking to you! I said, did you have to do that?
You know what, suit yourself. Live in your squalor and drown in your wee and holy water. I've had enough. Now everybody at school will know my mother is a lunatic. You've gone right ahead and exposed yourself to the world. It's…

The doorbell rings again and Ireti quickly exits stage.
Ireti and Eileen enter Bee's bedroom.

Eileen: Bee.

Bee: Eileen.

Eileen: Sorry to barge in on you. If it’s not a good time, I’ll/
Bee: /You’re right, not a good thai…time.

Eileen makes to leave.

Ireti: Why are you leaving? Are you afraid she’ll bite you?
Eileen: What’s come over you, Ireti?
Ireti: (Dramatically) What’s come over you, Ireti? Ha ha ha. I’ve been drinking holy water and…

Bee draws close to her and slaps her.

Bee: Get out! Bastard!
Eileen: (Drops her bag) Bee!

Ireti exits stage, crying.

Bee: (Calling after Ireti) Did I tale…tell you that man wasn’t your father? You’re a bastard.
Eileen: (Shrieks) Bee!
Bee: Yes. Can I help you?

Eileen picks her bag and exits stage.

Act 2: SCENE 3

The next evening. Ireti and Eileen are in Eileen's kitchen.

Ireti: I saw your text.

Eileen: I need to speak with you, and I don't want to upset your mum again.

Ireti: I'm sorry about last night. That's not even the worst of her.

Eileen: I'm really concerned about you.

Ireti: I'm fine. Honestly, I am, but thanks for your concern.

Eileen: Ireti, I'm not going to talk to social services. Just hear me out. Firstly, tomorrow is your assessment and interview at Bath and/

Ireti: /Not going!

Eileen: Over my dead body. You and I will go to Bath, even if I have to drag you!

Ireti: You had better get ready to do the dragging then. I ain't leaving London. I am not going for any damn assessment or interview. Don't/

Eileen: /Ha! Really?

Ireti: /you get it?

Eileen: And that decision to throw away all you've worked for is the right one?

Ireti: Do I look like I care?

Eileen: (Moves closer to Ireti) My darling, please, let's talk this through. I know your mum is ill, but what do you think she'd want you to do if she was in the right frame of mind?

Ireti: Watch my lips. I DON'T CARE! I'm staying with Mum, and I'm looking after her. And that's all there is to it!

Eileen: (Sighs) Okay, I really can't force you, but I want you to please think about what I'm saying. I've taken the day off so we can go to Bath tomorrow, and I've arranged for someone to look after your mum.

Ireti: Without consulting me?

Eileen: I'm sorry, my angel. I didn't think for one second that you would decide not to go.

Ireti: Well, take back your day off, and tell whoever you've asked to come to the house not to. I have called Matilda School to say that due to family emergency, I won't be coming. Do you even know how many days the program is? I'd be boarding for three days! I'm not leaving Mum for half a day, let alone three. And I’m certainly not in the frame of mind to do any assessment or interview. I’ll cry/

Eileen: /But we can…

Ireti: /throughout, and God help me if they don’t call a psychiatrist to bundle me away from the school. Ha!

Eileen: Okay, I hear you. Can they arrange another interview for you?

Ireti: Nope! That’s it for this year.

Eileen: (Very emotional) Oh dear, oh…

Ireti: Please don’t cry, Eileen. I can’t deal with that now.

LONG PAUSE

Eileen: (Blows her nose loudly into a handkerchief) Anyway, okay, let’s think about how we can work together to help your mother. That’s not her there in that house.

Ireti: Tell me about it. She now swears, eats junk, does not bathe, she…she…

Eileen: That apart, no child should have to go through this.

Ireti: Did you say you could help us to book an appointment with a neuro doctor?

Eileen: A neurologist.

Ireti: Yeah.

Eileen: Problem is, how would we get her there? She may not want to go.

PAUSE

Ireti: I’ll think of something.

PAUSE

Eileen: She… Your mum is in a dark place, where…where things don’t make sense to her. She’s confused and can’t control what’s happening to her.

Ireti: She’ll be fine. She only gets upset when people argue with her. I’ll just say yes to everything, then. No problem.

PAUSE

Is it true that she’s losing her mind?

Eileen: What?

Ireti: Aunt Ladun said she’s going mad.

Eileen sighs.

You can talk to me, Eileen. I’m now her carer.

Eileen: No, my child. Your mother is having some health issues, which we will find treatment for.

Ireti nods absentmindedly as she and Eileen exit stage.

ACT 2 SCENE 4

Bee’s bedroom the next day. *She’s standing in front of her table; she lifts the CD player to her ear as if trying to listen to music, then she puts it on the floor, takes a jug of water and tries to pour water into a glass cup. She clumsily pours water all over the floor in the process. Then she tries to carry the jug and the full cup of water back to the bed, but she trips over the CD player and fell, smashing the jug and cup.*

Ireti: (OS) Maami, Maami!

Ireti enters stage.

What is it?

Bee: (Muttering) I gjooze wa…wan…waher… I’m fai…fai…fine.

Ireti: Oh my God!

Bee: I…I seez…I seezzz…said I’m fai…fine. Thaaar’s note…notin srong weee meee… Leave me be… Go now. Go twa twa…to your room.

Ireti looks at the wet carpet and shattered glass.

Bee: I slips…slipped on…on… Um…

Bee points to the CD player on the floor.

Ireti: How did that get on the floor?

Bee: Zee Dee?

Ireti picks the CD player and puts it back on the table.

Ireti: I’ll get this cleaned up. Let’s get you on the bed.

Ireti hesitates.

Ireti: Actually, no! Stay where you are. I’ll be back in a sec.

She exits stage.

Lights dim on Bee, who is whining in pain and holding her foot.

Ireti: (OS) Hello, please help me… I'm right by her side. Yes, I said she fell and hit her head… She's not unconscious… No, she's not bleeding… She's on the floor… No, she can't speak with you, and she's not alright. I need an ambulance! She's 41… She can't get up… I'm 16. No, there's no other adult in the house. Just me and my mum. Thanks, I'll stay with her.
(In a hushed voice) Please don't let my mum die. Please hurry.

Lights dim on stage.

Lights back on stage.

At the hospital, *in Dr Baines' office. He's sitting behind a large desk, dressed in a smart grey suit. Three case notes and a paper tray are on the desk. Dr Baines takes one of the case notes and reads.*

Bee, Ireti and Eileen come on stage, and Dr Baines stands up to greet them.

Dr Baines: Beatrice, you look much more relaxed.
Looks like you've been able to catch up on sleep.

Bee offers a bar of chocolate to Dr Baines.

Dr Baines: No thanks. How are you?

Bee: (With a mouth full of chocolate) Good as new.

Dr Baines: The tests we did are inconclusive at this stage, but we're doing the best we can to make sure you're given the right diagnosis.

Bee: Thank you.

Dr Baines: After our chat earlier, I think I'll put you on Prozac.

Bee: What?
(To Eileen) Say something.

Eileen: Um… Prozac?

Dr Baines: Mood swings, suicidal thoughts, bad judgement, especially the errors that/

Bee: /I'm not depressed! I am just stressed to the bone.

Dr Baines: I know you've/

Bee: /NO! You can look for another patient to drug up to stupor. I'm out of here!

Bee throws the rest of her chocolate on Dr Baines' table and storms off.

Eileen: I'm so sorry, doctor.

Eileen goes after Bee.

Ireti stares at Dr Baines, who looks at her and shrugs as he fidgets with the case notes.

Ireti: Are you sure it's just depression?

Dr Baines: I'd rather speak with your mum.

Ireti: I know I'm not an adult, but I'm her carer.

Dr Baines: I understand, but…

Eileen and Bee come back on stage.

Dr Baines: I'm really sorry to/

Eileen: /My friend has something to say to you, doctor.

Eileen nudges Bee.

Bee: I'm sorry, doc.

Dr Baines: That's alright.

Dr Baines writes on a prescription sheet.

Take this to the pharmacy on your way out.

Bee: Thanks.

Bee stands up and shakes Dr Baines' hand and then places her left palm on top of his hand.

Bee: You've very kind.
Dr Baines: I'm just doing my job.
Bee: I'm available, you know.

Dr Baines wipes his brow with his free hand and tries to release his other hand from Bee's hold.

Bee: You married?
Dr Baines: Yeah, I am.
Bee: Shame… Would you like a second wife then?
Eileen: Bee!
Dr Baines: (Agitatedly) Ha ha ha. I'm perfectly okay with the one, thank you, Bee.

He tries again to release his hand from her grip, but Bee is non-relenting.

Bee: What's the matter, doc? Here's one exotic fruit throwing herself at you. Pick it, pick it, pick it.
Eileen: (Takes Bee's hand off Dr Baines') Okay, Bee, we should be on our way now. It's/
Bee: /Stop interrupting me, Eileen. The good doctor hasn't said a definite no. Though, he hasn't said yes, either.
(To Dr Baines) Look, doc. I'll do anything. I'll even get myself under the knife to look sexier.

Bee touches her breasts inappropriately.

Eileen (Grabs Bee by the elbow) That's it! Come on!

Eileen and Bee exit stage.
Dr Baines looks drained.

Ireti: You sure it's depression?

Dr Baines: Beg your pardon?

Ireti: I said… Oh, never mind.

Dr Baines: Shouldn’t you be on your way?

Ireti is not budging.

LONG PAUSE

Dr Baines: My next patient is waiting.

Ireti: It’s always about the next one and the next one. Why aren’t you interested in knowing more about her condition?

Dr Baines: We’re doing our best.

Ireti: Yeah?

Dr Baines: Okay, I’ll speak with Eileen.

Ireti: Eileen isn’t even her carer. I am!

Dr Baines: I have read through your mum’s medical report, and I see that she has a history of depression.

Ireti: That was when my dad died, but they gave her medicine, and she got better. I’ve never seen her like this.

Ireti’s voice was shaking with emotion.

Dr Baines: We can stop this conversation anytime.

Ireti: I’m fine. I just want help for my mum.
It’s horrible seeing her like that… Slurred speech, profuse sweating and occasional jerking…

Dr Baines: She seems better today, though, and she’s communicating better. I think it was good we admitted her to hospital for a few days to run some tests.
PAUSE
You are a very brave girl. I promise you, I’ll do everything I can…

Eileen enters Dr Baines’ office.

Eileen:	There you are, Ireti. I thought you followed us. Come on, darling. Your mum's alone downstairs. (To Dr Baines) I apologise for my friend's behaviour.
Dr Baines	I'll send a note to her GP, and we'll send her a date for the next appointment.

Ireti and Eileen leave Dr Baines' office.
Lights dim on Dr Baines as he picks another case note.

ACT 3 SCENE 1

It is late evening on the same day. Ireti and Bee are in Bee's bedroom. She's lying on the bed, and Ireti is combing her hair and plaiting it into two ponytails. She's humming Bee's favourite song, 'Kulumbu Yeye'.

Ireti: All done, Maami. If you need anything in the night, just knock on the wall. Don't you start getting up.

Bee: Thanks. Now ga…gat…go to sleep now. You stay too long on laptop.

Ireti: I just want to find out more about…about…

Bee: (Smiling) Found anything yet?

Ireti: For starters, your symptoms, though, some of them are similar to depression, they're not quite.

Bee: Ha ha ha… Dr Ireti!

Ireti: I'm dead serious, though.

Bee: I'm just happy I'm a bit better.

Ireti: It's the tranquilizers they gave you at the hospital. Those things numb the brain, and you were able to sleep for two days. That was more sleep than you've had in this house in a week!

Bee: So now/

Ireti: /Besides, they didn't do a brain scan for you.

Bee: Ireti, I just want/

Ireti: /Maami, I've been reading stories of people who have been wrongly diagnosed with/

Bee: /Okay, okay, we'll talk tomorrow.

Ireti: Whatever.

Bee: Love you.

Ireti: Love you, Maami.

Bee: We'll go to the park tomorrow. I mean, after school.

Ireti: I'm not going to school tomorrow.

Bee: Why?

Ireti: We broke up for Easter, remember?

Bee: Oh.

Doorbell rings off stage.

Bee: At this time of night?

Ireti: I'll see who it is.

Bee: No, ignore it. It's late.

Ireti: Maami, I won't open the door. I'll just ask who it is through the latch. Could be Eileen. She may be coming from her night shift.

Ireti exits stage and light dims on Bee.
Lights on Ireti and Ladun.

Ireti and Ladun are in the living room. Ladun is frantically holding on to a cockerel that is flapping its wings.
Ireti keeps her distance.

Ladun: So, what are you waiting for? I said, tell your mum I'm here.

Ireti: And I just told you, she's sleeping.

Ladun: But I called her a few days ago when she didn't get back to me about the prayer vigil that Wolii said she should do. I told her I'll come later this week.

Ireti: Well, she may have forgotten all about it. Anyway, she's not going anywhere tonight 'cos/

Ladun: /I said, call your mother. Are you deaf?

Ireti: /the doctor said she must stay in bed after she's taken her medication. She's now seeing some specialists and doesn't need your fetish/

Ladun: /Why am I even standing here talking to you?

Ladun is about to go to Bee's bedroom.

Ireti: (Stands in her way) Don't even try or I'll/

Ladun: /Or you'll what?

Bee: (OS) Ireti, who was it?

Ireti: (To Ladun) Sh…sh… If you say a word, I swear I'll call the police.

Bee: (OS) Ireti!

Ireti: Maami, it's just some Halloween people.

Bee: (OS) Halloween in summer?

Ireti: Um… yes. They now do it twice a year. In October, it’s the white witches, and in summer, it’s the black witches, wearing long white robes, carrying live cockerels.

Ladun raises her hand at Ireti who quickly steps back and takes a photo of Ladun with her mobile phone.

Ladun: Shut up, you stupid girl! You’re the witch, not me!

Ireti: (Whispering calmly) Sh…sh… Aunty, didn’t I tell you not to raise your voice? I said I’ll call the police. Now I even have your picture as proof. Here, see?

We see a projection of the picture that Ireti took on the wall. Ladun is holding a cockerel in one hand and raises her other hand as if about to strike someone. She looks weird.

Ireti: Just imagine the headline: “A Nigerian woman goes to her nieces’ house with a live cockerel to conduct ritual killing. She was about to kill the little girl, who quickly dialled 999 on her mobile.”

Ladun swallows hard, holds on to the flapping cockerel and heads to the door.

Ladun: Evil child. You’re now raving mad, but you don’t know it yet.

Ireti: Old news, Aunty. Have you forgotten that madness runs in the family? Anyway, what’s the cockerel for? Has your water-sprinkling, candle-lighting family abandoned you? Now it’s cockerel sacrifices?

Ireti laughs sarcastically.

Ladun: (Sucks her teeth loudly as she exits stage) If I ever set my feet here again, cut both off. But mark my words, one day, you and your mother will come begging me to bring my prayer warriors to your house, and then we’ll see who will have the last laugh!

Ireti: And when that time comes, slam the door in our faces. But for now, leave my mum alone!

Bee: (OS) Ireti!

Ireti: Maami.

Bee: (OS) Haven't the Halloween people gone?

Ireti: They've gone now.

Bee: (OS) Okay, make sure you lock the door.

Ireti: I will.

(*Soliloquising) I can't believe she came here to take my mum to their fetish place again. She won't be back… Well, not for a very long time.*

Lights dim on Ireti.

Later in the night. The stage is dark, and we hear the sound of someone retching. Light comes on, and we see Bee rolling around on the bed. She sits up and staggers offstage.

Offstage, we hear Bee vomiting. She staggers back to her bedroom, but a few seconds later, she hurries offstage again.

Bee: (OS) (Moaning) Oh… Hmmm… Oh god!

We hear her vomiting, and we hear a loud crash, and more moans follow as the light goes off on stage.

Ireti: (OS) Maami? Maami, is that you?

Ireti rushes to Bee's bedroom, and the stage is illuminated.

Ireti: Maami, where are you?

We hear Bee's muffled groans and moans as if in pain, and she walks slowly back to her bedroom.

Ireti: Oh my god! What happened?

Ireti grabs her mother's mobile phone and dials 999.

Ireti: Hello, ambulance, please? It's my mum. She fell… I don't know, I-I just heard a loud noise… Okay… I think she's conscious, but she's not opening her eyes…

Bee: But…but…but my eyes are open. You're lying!

Ireti: (To her mum) Mum, sh…sh… Mum.

(Back on the phone) No… okay. Yes, her eyes are still closed… Yes, number 9 Gangarine Court, Lewisham…

Ireti throws the mobile on the bed and holds Bee, who has now collapsed on the bed.

Ireti: Maami? Maami!

We hear the siren of an ambulance in the distance as the light dims on stage.

ACT 3: Scene 2

Late evening the following day. *Bee is on a bed with drips inserted into her forearm at Wellington Hospital. Ireti is sitting on a chair beside her, holding her hand. Eileen comes on stage; she's wearing her nurse's uniform.*

Eileen: (Hugs Ireti) Darling!

Ireti: (Whispering) Sh… She's just gone to sleep.

Eileen kisses Bee's forehead.

Eileen: (To Bee) Haven't you been through enough?

Ireti: I specifically told her last night that she must call me if she needed anything, but she didn't even wake me up.

Eileen: Not surprised. The stubborn woman!

Ireti: I told the paramedics that she knocked her head on…on the sink and…and they did a scan.

Eileen: She knocked her head?

Ireti: (Looks away) Ummm… Yeah.

Eileen: I'm sorry you couldn't reach me earlier. I was in theatre all day. Has anyone seen her?

Ireti: Yeah, Dr Baines. He said… Well, I told him he shouldn't have given her that medication.

Eileen: You what?

Ireti Maami doesn't have depression.

Eileen: Now wait/

Ireti: /Why isn't anyone listening to me?

Eileen: I'm just…

Ireti: Why didn't you support me when I pleaded that the hospital do a brain scan for her when Dr Baines saw her?

Eileen: Because it wasn't necessary then.

Ireti: But you said she needed to see a neurologist. That was why I lied three days ago when she fell and hurt herself.

Eileen: What do you mean you lied? She fell, didn't she?

Ireti: Of course she fell, but she didn't hit her head. I only said that so that they'd do a brain scan for her.

Eileen: Now, listen to me, child, you can't go around lying to doctors because you want them to do a scan for your mother. It's not right.
PAUSE
So, what happened this time? Did you lie again? Did she really hit her head on the bathroom sink?
SILENCE

Eileen: Answer me, child!
SILENCE
I don't believe this!

Ireti: If you look closely, you'll see her swollen forehead. She fell.

Eileen: Ireti, your mum is seeing specialists. These people have years of experience and/

Ireti: /How come she's been misdiagnosed more than three times by the 'specialists'? Anxiety, stress, depression… And now…

Eileen: Calm down, Ireti.

Ireti: Did you just tell me to calm down? If my mother dies, who's going to look after me? Some white garment relative coming with cockerels to sprinkle holy water on my head? I can just hear Aunty Ladun…

Ireti becomes animated and mimics Ladun's Nigerian accent.

Her grandmother, lunatic, tick. Her mother, mad, tick. And now what have we here? Oh, the daughter… Okay, where's the Wolii? Holy water, holy water… Fire… Burn, you demon. Fire, Fayaaa…

Eileen: (Grabs Ireti) Ireti!

Ireti breaks down in tears.

Eileen: Your mum is not going to die! She'll be fine, and she and I will be here for you.

Ireti is sobbing loudly.

Go on, child, let it out. You've been too strong for your own good.

Ireti: I'm-I'm sorry…

Eileen: Sh…sh… Don't be silly.

Professor Omole comes on stage.

Professor Omole: Morning.

Eileen: Good morning.

Professor Omole: I don't think I've seen you on this ward?

Eileen: Oh no, I don't work here. I'm here to see my friend. I didn't have time to go home and change my uniform. (Pulls Ireti closer) This is Ireti, Bee's daughter.

Professor Omole: Beautiful name, Ireti. Is your family Yoruba?

Ireti: Yes.

Professor Omole: My name is Tola Omole.
(To Eileen) I am the consultant neurologist on call. My colleague spoke to me about Beatrice.

Professor Omole takes Bee's hospital note and reads.

Professor Omole: Hmmm… (nods) Overdose.

Eileen and Ireti: Overdose?

Eileen: She tried to kill herself? Oh, Bee…

Professor Omole: Who can I talk to about her? Family? Partner?

Eileen: Ireti and I are her only carers. In fact, Ireti is her carer. I only support them when I can. You can talk to us.

Professor Omole: Would you mind stepping into to my office?

The trio leave and light dims on stage.

The stage is illuminated to show Professor Omole's office. She is sitting behind a desk. Eileen and Ireti are sitting on the chairs in front of her.

There's a screen on the wall behind Professor Omole, and it is elevated so that the audience can see the pictures that are projected on it as the trio converse.

Eileen: I didn't realise it was overdose. I thought she was reacting to something.

Professor Omole: Well, she was lucky that she quickly became sick and most of it is out. But I'm concerned about her mental health.

Ireti is crying.

Professor Omole: Ireti, come with me. I'll take you to my other office where you can have a drink and wait while I speak with…with…

Eileen: Eileen.

Ireti: No! I'm okay. I want to be here.

Eileen: She'll be okay, Prof. She's with her mum most of the time. She may be able to answer more questions than I can.

Professor Omole: Okay, if you're sure. A CT scan was done for Bee when she was taken to A&E earlier today, and I have the results.
My colleague was looking for things like subdural hematoma, but he saw something else that is a bit alarming. I have also looked at the scan, and I can confirm that it is rather unusual.

Eileen: Alarming? Unusual?

Professor Omole: There is evidence of Frontotemporal Lobar Degeneration, so I sent for Bee's hospital record. When it arrived, I saw that she had presented with some of the symptoms, but it hasn't been diagnosed.

Ireti: (Jumps up) I knew it! She was treated for anxiety, depression, demonic oppression/

Professor Omole: /Demonic oppression?

Ireti grabs professor Omole's hand.

Ireti: Please, help my mum. I know it’s not depression. If she’s not properly diagnosed, she’ll be given the wrong medicine again, and she’ll die.

Eileen tries to release Professor Omole’s hand from Ireti’s.

Eileen: I’m so sorry, Prof. Ireti has been under enormous stress lately. She’s/
Ireti: /I’m not under enormous stress. I know what I’m talking about!

Professor Omole waves at Eileen to leave Ireti alone.

Professor Omole: Talk to me, Ireti. How do you know that your mother doesn’t have depression?
Ireti: From online.
Professor Omole: Online?
Ireti: I’ve been looking up her symptoms.

Professor Omole nods.

Ireti: My mum recognises us, but she sometimes can’t find the right words even for simple things, and she slurs. She also behaves strangely.
Professor Omole: Strangely?
Ireti: Aggressive, confused—she even swears now.
Professor Omole: Hmmm…
(To Eileen) Wellington Hospital is a neurological centre, and I head the brain and spine unit. Since we set up the Dementia centre 18 months ago, we have seen a number of patients. Would you mind if I take an FBI from you both?
Eileen: Yes, absolutely. Anything to help my friend.
Ireti: What’s FBI?
Professor Omole: It stands for Frontal Behavioural Inventory. We take this from carers to assess behaviour and personality changes in patients.

Although your mum is not officially diagnosed, I suspect Frontotemporal Dementia. We usually don't do this inventory when patients are present as many are in denial, and it could be difficult for carers to be truthful about their situation. When Bee wakes up, I'll do a SPECT brain scan and a thorough examination.

PAUSE

Professor Omole: Ireti. if I ask you to tell me about your mum, what would you say?

Ireti: My mum…

She is brilliant—the kindest person I've ever known. Strong, positive and independent…

Light dims on the trio, and we see the picture of a young woman – Bee – on the screen behind Professor Omole. She's wearing a nurse's uniform, and she's in a children's ward.

…and she likes her job. She married my father when she was just 19, and they came to England. She didn't have me until she was 25, and I am their only child. My mum said the day she gave birth to me was the happiest day of her life.

We continue to hear Ireti's voice as we now see on the screen the picture of Bee, holding Ireti who was a few days old.

Ireti: My mum and dad were very happy. When I was little, we had fun and went everywhere together when they were not working.

Another picture appears on the screen – there are three people holding hands. Bee is on the left, a man – Ireti's father – is on the right, and 5-year-old Ireti is in the middle. They look happy.

Trouble began when father started travelling back to Nigeria very often. He'd come back moody, and they'd argue. Once he hit my mother so many times I ran out of the house, and then he stopped. But he continued to call her names… like infertile.

Lights back on the trio.

LONG PAUSE

Professor Omole: Take your time. We can continue this another day.

Ireti: No, no, I'm fine.

One day, he travelled to Nigeria, and three days later, a phone call came that he'd had an accident. Apparently, he went to marry a woman, whom his family had found for him, so he could have another child – a male child – but my mum didn't know. On his way back from the village, his car collided with an overloaded truck whose break had failed, and he died instantly. He was the only one who died in the accident.

Professor Omole: I am so sorry.

Ireti: My mum struggled to finish her nursing training, and she did evening and weekend shifts, but she still took care of me and bought me gifts. We were happy.

(Turns to Eileen) Weren't we, Eileen?

Eileen nods and pats Ireti's hand.

Professor Omole: When did you first notice that something was wrong?

Ireti: (Tilts her head to the side) Hmm… On the day I turned 16. She always comes into my room to sing for me—first thing on my birthday. Then she would buy me loads of presents and take me out for dinner… and throw a party. But that day, I went to her room, when she didn't come to sing happy birthday for me, I found her looking confused. She sat on her chair and repeated the words, "Beatrice. My name is Beatrice."

PAUSE

Looking back now, there were weird signs before then.

Professor Omole: Weird signs?

Ireti: She hadn’t been going to work for a few days. She said she was on sick leave. But everything made sense when Eileen told me she’d been laid off work.

Professor Omole: (To Eileen) Was she?

Eileen: She gave the wrong medication to a patient. It wasn’t the first time. It had happened twice previously. She went before a tribunal…

Professor Omole: (Writing notes) I see.

Ireti: Sometimes her hands shake. Also, she slurs her speech when talking. She also repeats her actions.

Professor Omole: (To Eileen) Like OCD?

Eileen nods.

PAUSE

Eileen: And the junk in her room!

Ireti: But she’s been hoarding for many years.

Professor Omole: Has she shown aggression or hurt anyone physically?

Ireti: My mum rarely raises her voice, except for when I used to be naughty… But now, she shouts at me, and twice she’s thrown things at me and swore…

Ireti wipes her eyes with the back of her hand.

Professor Omole: Do you know the meaning of your name?

Ireti: (Smiles) Yes. My name means Hope.

Professor Omole: And rightly so. I’m going to keep your mum here for a while, and we’ll run all the necessary tests. I promise that, this time, she’ll be properly diagnosed.

Ireti: (Beaming) Thank you very much. Thank you.

PAUSE

I want to ask a question.

Professor Omole: Go ahead.

Ireti: What is *SPECT?* You mentioned it earlier.

Professor Omole: *SPECT* stands for Single-Photon Emission Computed Tomography. It is a non-invasive way of looking at brain function.

Ireti: (nods) Okay, thanks.

Eileen and Ireti exit the stage.

ACT 3: Scene 3

Two days later, Bee and Ireti are in Professor Omole's office. Bee shows signs of aphasia as she converses with Professor Omole.

Professor Omole: Rough ride lately, hey?

Bee: (Opening a packet of sweets) More than a rot…roof…rough ride. Have you ever had a plumbing issue in your house?

Professor Omole shakes her head.

Bee: (Stuffing her mouth with sweets) Well, it is like the plumbing in a kitchen exploding 'gbuuu', and nothing can hold the water back. It is just gushing out from the front and back door.

Bee points to her mouth and bottom.
Ireti cringes.

Professor Omole: (Takes Bee's hospital note) After the tests, we've come to a conclusion that what you have is a condition called Frontotemporal Dementia.

Bee: Fronto what?

Professor Omole: A progressive dysfunction of the frontal lobe and/or the temporal parts of the brain.

Bee: I know, I'm just surprised. I'm only 41!

Professor Omole: As you know, unfortunately, this type is not an old age dementia. In fact, typically, the age group of people with frontotemporal dementia is below 65.

Bee: I've heard about FTD, but I've never seen anyone with it in my many years of nursing. What causes it?

Professor Omole: About a third of cases seem to be hereditary, but we still don't know what causes the non-hereditary cases.

Bee: (Shakes her head vigorously) I don't smoke, I don't drink, and I eat sensibly… I…I even do crosswords.

Professor Omole: The disease strikes many intelligent professionals who are in their prime.

Bee: The curse of Job.

Professor Omole: Pardon?

Bee: Job 3:25. “What I feared has come upon me. What I dreaded has happened to me.”

Professor Omole: I see.

Bee: Did you say some cases are hereditary?

Professor Omole: Yes. Why?

Bee: My mother suffered from depression and was eventually institutionalised when she was about 45.

Professor Omole: Is she still alive?

Bee: No, she died eight years after she was locked up in a mental home. By then, she had degenerated into a vegetable. I always knew my pathway through life would be similar.

Professor Omole: Now wait a/

Bee: /Is there a cure?

Professor Omole: No, but there are medications that can help patients cope with the behavioural symptoms. I’m also researching non-/

Bee: Prof. /What’s going to happen to me?

Professor Omole: Like I said, we’ll continue to/

Bee: /I need to know!

Professor Omole: (Lowers her gaze) The damage is done to that part of the brain, and it will continue to degenerate.

Bee: You mean there’s no medication that/

Professor Omole: /Early intervention does help, though. As in your case, with/

Bee: /Mortality?

Professor Omole: /the help of… What did you say?

Bee: How long do I have to suffer this before…

Ireti gets up and leaves Professor Omole’s office.

Professor Omole: I’m sorry. I did ask if you’d like us to discuss this privately, but you said/

Bee: /She'll be fine. She's the only family I've got. She's a brave girl, you know.

Professor Omole nods.

She'll be making decisions for me…very soon. I didn't think… I didn't…

Bee breaks down in tears.
Professor Omole hands her some tissues.

Bee: What's the average life span after diagnosis?

Professor Omole: Presently, about 8 to 15 years. No one can say. Some live with FTD for many years, while others lose the battle more quickly. However, through research, we are gaining insight into how it affects the brain and, more importantly, how we can tailor medication to slow progression.

Bee paces Prof Omole's office.

Bee: I didn't really ask for too much in life, just a happy home full of children. But life is like the grave! INSATIABLE!

PAUSE

I had plans for Ireti. I wanted her to be well-educated, marry well, and be happy. But look at her. All I see is in her face is pain. Makes me want to end it all.

Professor Omole: The Ireti that I see just wants her mother to get the right diagnosis, and she is achieving her aim. So, to make her happy, you have got to keep fighting and not give up.

Professor Omole places her hand on Bee's shoulder as she cries into the tissue.
Light dim on stage.

ACT 3: SCENE 4

Four weeks later at Professor Omole's office. Bee is there for a routine check-up. She is lying on the patient's couch bed. The screen is not fully drawn. Professor Omole examines her, and Ireti sits on the chair by the desk.

Professor Omole: I'm happy to hear you're sleeping well without the tranquilizers. How are you feeling in yourself?

Bee: My thinking is a little clearer, but my tongue is still heavy, and words elude me.

Professor Omole: How about the occasional dystonia?

Bee: Still there, but I'm trying to control it with my mind.

Professor Omole: (Leaves Bee) Get dressed and come.

Bee joins Professor Omole and Ireti.

Professor Omole: I'm going to keep you on Valproic acid since you don't have any complaints about it. Do you have any questions?

Bee: No.

Professor Omole: Have you been to any of the meetings that your counsellor recommended? Did you find any of them helpful?

Bee: Yes, I've been. No, not helpful.

Professor Omole: Not even the 'Photoshop' one?

Bee: Absolutely terrible.

Ireti: Maami!

Bee: I hated it! The youngest person there must be 100 years old!

Ireti: You know that's not true and/

Bee: /Hey, shut your front door!

Ireti: Sorry…

Bee: Oh, be sorry for yourself!
It was called photo reminis…remi…reminence…

Professor Omole: Reminiscing?

Bee: What part of my life do I want to remember? My depressed and suicidal mother? My unfaithful husband who died in the act? Or my newfound dementia?

Professor Omole: I’m sorry that you found the program/

Bee: /The worst part is, the facilitator turned to me and said, “How about a picture of your beautiful daughter on the day she was born?” I told her not remind me of/

Professor Omole: /Oh dear.

Bee: /my guilt, bringing a child into the world to become a carer for her crazy mother at the age of 16! How many girls of her age don’t have a life?

Ireti: I have a life!

Bee: Yeah, some life. Hospitals, medication, illness, disease.

Professor Omole: I guess you didn’t bother with the other meetings then.

Bee: Well, Eileen dragged me to a singing group.

Professor Omole: And?

Bee: Worse than the remi-remini one. Sad, boring songs.

Bee is becoming more animated but also anxious.

One of the facilitators asked us to dance. I… I asked her why, and she just stared at me like I had horns peeking through my frontal loi…loib…lobe…

Bee is speaking very fast now; she’s on her feet.

Professor Omole: (Gestures to Bee to sit back on the chair) Ha ha ha, serves them right for trying to force their songs on you, hey?

Bee sits down.

Did you ask them if they had Ebenezer Obey’s songs?

Bee and Professor Omole laugh at this.

Or Sunny Ade’s?

Bee: Ha ha ha, or Ayefele?

Professor Omole: To be honest, I’ve lost touch with the Nigerian music industry.

Bee relaxes.

LONG PAUSE

Professor Omole: You don’t have to go to any of the meetings, Bee.

Bee nods.

Bee: I need the loo.

Professor Omole: There’s one opposite us. Once you step out, just look straight ahead of you.

Bee exits stage.

Professor Omole: Ireti, how are you getting on with school and everything else?
Ireti: (Shrugs) Okay.
Professor Omole: Are you sleeping well?
Ireti: Sure.
Professor Omole: I told you earlier that I’m happy to contact social services anytime you need a second person to look after her.
Ireti: We’re doing fine. Eileen comes almost every day after work. She’s really good with her.
PAUSE
Professor Omole: Did you read the leaflets I gave you, especially the one on managing behaviour?
Ireti: They’re very useful, thanks.
Professor Omole: Your mum is not being annoying or aggressive on purpose.
Ireti: Is there no medication that can cure it?
Professor Omole: No. Sorry.

Professor Omole picks a leaflet from her table and gives it to Ireti.

My research unit is looking at cognitive stimulation and a few non-pharmacological approaches. There's a centre here in the hospital that I think your mum may like since she's not responding positively to the community groups.

Ireti: Isn't that just another group?

Professor Omole: Well, it's a beautiful space where people can come and chill. Having said that, there are mini courses. Here, check out the leaflet for more information. They have an open mic once a month. I've only been once. One of my clients invited me the day he shared his collection of short stories.

Ireti: Really? Did you know that my mum also has…

Bee comes back on stage.

Professor Omole: Are you okay, Bee?

Bee: Yes.

Professor Omole: You are free to go now.

Bee holds Ireti's hand and pulls her up gently.
Professor Omole writes a prescription.

Professor Omole: Take this to the pharmacy on Level 5. I'll see you in four weeks. Don't forget to book your appointment at reception.

Bee: Thank you.

Professor Omole: (To Bee) By the way, I meant to say that I like your new haircut. Suits you.

Bee: I don't suppose you have any young men that you can introduce me to?

Professor Omole smiles.

Bee: I'm dead serious, you know. I've/

Ireti: /Prof, I was about to tell you earlier that my mum has started writing poems.

Professor Omole: Really? That's brilliant!

Ireti: She's never written a line of poem until recently, and now she can't stop.

Professor Omole: What do you write about?

Bee: Oh, this and that, nothing special.

Ireti: She's just being modest. She's written funny ballads, and now it's Haikus.

Professor Omole: Haikus! That's another level, Bee!

Bee: (Smiling) I'll bring them to my next appointment.

Professor Omole: Great! I'd love to see them.

Bee: Bye for now.

Professor Omole waves at them as they exit stage.

ACT 3: SCENE 5

In Wellington Hospital’s Dementia Care Unit in a brightly lit room with multi-coloured sofas. There is a centre table with a red vase that has marigold flowers in it. There are two computer desks and chairs in the corner. Bee is using one of the computers.

An alarm goes off on Bee’s mobile phone. She picks her bag up from under the table, takes out her medicine and resumes typing. Professor Omole comes on stage.

Professor Omole: Hey. Good to see you here. How are you?

Bee: I’m good.

Professor Omole: Where’s Ireti?

Bee: At school. She’ll be here to pick me up later.

Prof Omole: What are you up to?

Bee: Just editing my new poem before the show tonight.

Professor Omole: How exciting! What time is the event?

Bee: 7 pm. Right here in this room.

Professor Omole: Are you reading your poems?

Bee: Oh no, not me. Ireti.

Professor Omole: I finish at about 6:30. I’ll come straight over. I’d like to hear your poems live. Do you like this place?

Bee: Yes. I just want to come here every day now.

Professor Omole: (Smiling) So, the muse whispers creative verses into your ears here.

Bee: Nice environment.

Eileen and Ireti enter stage.

Eileen: There you are.

Bee: Hi, troubles.

Professor Omole: Ireti, I hear you’re performing tonight.

Ireti: I’m dead nervous, though. I haven’t even seen the poems that I’m performing.

Eileen: We’ve put leaflets around, and the local radio did a clip. Our Ireti was on radio last night.

Professor Omole: Hey, why isn’t anyone telling me anything?

Eileen: I recorded it. You can hear it later.
And I just thought of something. Why don't we practice your mum's poem, Ireti? Prof, do you have a wee minute?

Professor Omole: Of course. I still have ten minutes.

Eileen: Bee, you have to let go of those babes now and/

Bee: (Looking confused) /Babes?

Eileen: Your poems. They'll never be perfect, but you can at least hear them and then do more corrections before tonight if you really need to.

Bee reluctantly hands the papers over to Eileen.
Eileen clears her throat and starts to read.

Eileen: This collection is titled *Haiku in Three Parts,* written by my friend Beatrice and I will perform it with Ireti, her daughter.

Eileen:
The tree has blossomed
But alas a big bad hole
Threatens the branches

Ireti:
Waves crash around me
Just a brand-new experience
On a flooded bed

Eileen:
As the night crawls in
Cherubim and Seraphim
Ring their bells and dance

Ireti:
Oh, crazy seasons
What, no summer? No autumn?
Winter! You're early

Eileen:
Machines' ceaseless beeps
Mirror my old restless soul

That needs to be calmed

Ireti: What magic, what joy
A tree surgeon's breath of life
Health for the branches

Eileen: The grey skyscrapers are gone
And now we have luscious green
Here on London streets

Ireti: Beautiful cadmium
So colourful in the sky
I have just seen you

Eileen: Daughters, friends, healers
Agates, Rubies, Kyanites
Love keeps me alive.

Eileen and Ireti bow as Professor Omole and Bee clap.

Professor Omole: Brilliant and symbolic. I'm sure your audience will love it!
Bee: You think it's good? I haven't even edited/
Ireti: /Mum, it's great! And you've been editing this one for almost a week. You got to let go now.
Professor Omole: I agree.
Eileen: Thanks for staying to listen, Prof.
Professor Omole: My pleasure.
Bee: Prof, would you like to come for…for dinner at ours? I'm not doing the cooking. Ireti and Eileen are. Trust me, their food is fantasy…fan…fantastic.
Professor Omole: When?
Bee: Any Saturday that you're free.
Professor Omole: Thanks, I'd love to, and I'll let you know when I'm free.

Professor Omole exits stage.

Bee: Now what have I done?

Eileen: What?

Bee: Inviting her. It was Ireti's idea, she set…said to show our grant…gratutue…grat… Oh, never mind.

Ireti: But she's a friend now.

Bee: People like that don't become friends with people like us. She's just doing her research, and we're cooperating bitches.

Ireti: Maami!

Eileen: Does anyone smell fresh muffins? Look, guys, I need a hot cup of cocoa with them muffins. Who's coming?

Ireti: I'm starving. Didn't have much at school.

Bee: Yeah, why not?

They exit stage.

Act 3: Scene 6

Bee's living room on a Saturday evening. Professor Omole, Bee, Ireti and Eileen have just had dinner.

Professor Omole: Thanks for that lovely meal.

Bee: Hope it wasn't too hot for you?

Professor Omole: You seem to forget I'm a Yoruba woman. Hot is what we do.

Everyone laughs.

How did it go at your event? So sorry I couldn't make it eventually. I had a last-minute emergency. Did many people come?

Eileen: Fifteen in total. People were very generous with their feedback. Ireti created a feedback sheet, and we gave them out.

Bee: I was very proud of my daughter…and…Eileen, too.

Eileen: Don't be silly. You wrote the poems. Someone said in their feedback that they cried all the way through.

Professor Omole: Aww… That'll encourage Bee to keep writing. So, have you produced another set of Haikus?

Bee: Um…um…

Ireti: She's got loads.

Professor Omole: Really?

Ireti: I'll get your laptop, shall I, Maami? So, we can read some to Prof.

Bee: Oh, go on then.

Eileen: She's good, our Bee. You'll be proud of her and all.

Ireti jumps up and exits stage.

Bee: I don't think Prof has the time to listen to poems.

Professor Omole: Of course I have the time. I love poetry, especially ones written by a very clever woman.

Eileen: I grew up with stories in Ireland. My grandma, mother, sisters, aunts—all great storytellers. Shame we don't have time for stories now.

Bee: I do—and poems.

PAUSE

Eileen: Now, where's that girl? She's been gone for ages.

Bee: Trying to find anything in my room takes special grace.

Eileen: Yeah, but it's a laptop we're talking about, not a needle.

Bee: Ha!

Eileen: Oh well, I'd better go find her.

Eileen exits stage and lights dim on Professor Omole and Bee.
Lights on Ireti in Bee's bedroom.

Eileen comes on stage.

Eileen: There you are. So, what's keeping… What are you doing, Ireti? What's that in your hand?

Ireti: (Startled) What?

Eileen: Ireti!

Ireti: It's nothing. I've got headache, that's all.

Eileen moves closer and takes the pouch containing medicine bottles off her.

Eileen: Headache? But this ain't Paracetamol or Ibuprofen… And this, and what's this one? Oh my goodness, child!
When did this start?
I'm talking to you, Ireti!

Ireti: Sh…sh… Lower your voice, please!

Eileen: You've got to start talking, or I'll go out there right now and show your mother and Prof all these.

Ireti: YOU WILL NOT! You'll send her to an early grave!

Eileen: Your mother is stronger than you think. She won’t die, but she’ll agree with me that we need to get you help. So, what’s/

Ireti: /I don’t need help!

Eileen: Not what I asked you, girl!

Ireti: Okay. Alright. They are just a precaution.

Eileen: Against what?

Ireti: Did Maami not tell you what the doctor said about her disease?

Eileen: What?

Ireti: It’s hereditary!

Eileen: (Calms down) Oh, dear child…

Ireti: You don’t have to feel sorry for me. I’m/

Eileen: /I’m don’t feel sorry for you. I’m upset that you couldn’t come and talk to me about this.

Ireti: Talk to you?

Eileen: Yes.

Ireti: Right.

Eileen: But… I just wish you’d shared your fears with me, that’s all.

Ireti: I’m not afraid of anything! I just want to take care of myself so I don’t end up like Maami and my nan.

Eileen: You won’t end up like your mother. You/

Ireti: /What do you know?

Eileen: I… I…

Ireti: You don’t live with us. You don’t know.

Eileen: Now that’s not fair, child.

Ireti: Nothing’s fair. The world’s not fair. Life’s not fair, otherwise it wouldn’t take my father and slowly kill my mother.

Eileen: Okay, calm down. If you don’t trust me, there’s nothing I can do about it, but I can ask Professor Omole to talk to you. What you’re doing is really dangerous. All these supplements can harm your liver!

Ireti: They say they are/

Eileen: /Who’s they?

Ireti: I researched online.

Eileen: But those people just want to sell their supplements.

Ireti: Eileen, they're just multivitamins. You make it sound like I'm drugging myself/

Eileen: /Look, let's do a deal. I won't tell your mum, but you must promise you'll speak with Prof. She's a lovely woman, and she really likes you.

Ireti: Okay, if you promise not to tell my mum.

Eileen: Deal.

Both of them exit stage.
Back in the living room.

Bee: We were about to send out a search party.

Eileen: Like you said, looking for something in your room is a nightmare. Anyway, we are here now.

Ireti: (Hurriedly) Here you go, Mum. I just remembered, I'm giving a presentation tomorrow, and I've not finished it.

Ireti gives Bee her laptop and leaves the sitting room.

Bee: Hey, Ireti!
(To Eileen) Is she okay?

Eileen: Yeah…um… Yeah, she said she's got work.

Bee: You sure? I'll go check on her.

Eileen: Let her do some work and then check her later. She's fine.

Professor Omole: Perhaps I should be heading back home now. I have lots of reading to catch up on too.

Eileen: Umm… Prof?

Professor Omole: Yes, Eileen.

Eileen: Can I call your secretary to book an appointment for Ireti?

Professor Omole and Bee: Ireti?

Eileen: Umm…umm… Yes. They are going to do this um…um… What's that thing again? Yeah, placement. She really wants to do it at the hospital, at your unit. But she needs to um…um…speak to…interview a specialist and we…we thought since we know you/

Professor Omole: /That's okay. Call my office and book the appointment. I'll be more than happy to see Ireti. Thanks again for a lovely evening. Bee, keep writing. I'll see you at your next appointment.

Bee: Thanks very much for coming.

Lights dim on stage.
Lights come on stage.
Ireti is in Professor Omole's office.

Professor Omole: Eileen called me today. What's this that I hear? You're self-medicating?

Ireti: I am not self-medicating. I'm only using multivitamins, and Eileen saw me and freaked out.

Professor Omole: That's not what she told me. She saw you with a pouch full of all sorts of medicine and/

Ireti: /Well, what would she know?

Professor Omole: Seems there's more to this then.

PAUSE

Please talk to me. I can help if you want me to. This is not an appointment, just a friendly chat.

Ireti: Multivitamins are good for you, aren't they?

Professor Omole: Perhaps the odd multivitamin a day. But from what I hear, you take a whole lot more than that.

Ireti: I really don't want to be… Well, like I said, I'm taking them 'cos they say we don't get enough vitamins daily.

Professor Omole: Is that what this is really about?

Ireti: I've been reading about my mum's condition. It is hereditary. If she's got it and my nan had it, what's stopping me from getting it?

Professor Omole: I see.

Ireti: That's what I was trying to tell Eileen.

Professor Omole: I understand what you're trying to do, but that's not the way to go about it.

Ireti: Can you give me just one strong drug that will prevent me from having dementia?

Professor Omole: I'm sorry, there's nothing like that… Yet.

Ireti: So, I'll continue with my own plan. I have enough to take care of every area. I didn't just go and pile any nonsense up. I researched each/

Professor Omole: /How many are we talking about? I mean that you take daily.

Ireti: Enough.

Professor Omole: As in…?

Ireti: Five… Six… Well, some days about nine.

Professor Omole: You're too young to be taking nine different vitamins daily! Some can be toxic for your liver.

Ireti: If the liver is ruined, you get a transplant. There's no brain transplant.

Professor Omole: Your brain isn't going to be damaged.

Ireti: How do you know that? I thought it…this thing my mum has would continue to run in the family?

Professor Omole: If that's what you think, why are you using vitamins? You said they are precautionary.

PAUSE

Okay, my point is, there are other ways of achieving your aim.

Ireti: Like?

Professor Omole: Less worry, maybe, and good nutrition. If you wish, I can arrange for you to visit our counsellor.

Ireti: Okay.

Professor Omole: In the meantime, here's an assignment for you. Write down all the foods and exercises that are good for brain health and show me when next I see you.

Ireti: When can I see the counsellor?

Professor Omole: I'll call her today. I know this is important to you. But like I said earlier, a crucial point is not to worry too much. Being agitated has a negative effect on the brain.

Ireti gets up and hugs Professor Omole.

Ireti, do you believe in prayer?

Ireti: Ah, like an exorcism and sprinkling holy water?

Professor Omole: What?

Ireti: That’s what my aunt does to my mum. She has this prayer warrior group, and they come to the house and chant things to my mum.

Professor Omole: No, my dear, I don’t mean that. I mean prayer whereby you connect with God and meditate.

Ireti: Do you?

Professor Omole: Yes.

Ireti: So, doctors also believe in God?

Professor Omole: Everyone has a personal journey.

Ireti: True.

Professor Omole: When you feel overwhelmed and feel there’s no hope, try to pray and meditate on good things.

PAUSE

Listen, I really want you to believe you’ll be okay.

Ireti: Thanks for helping my mum…and me.

Light dims on Professor Omole and Ireti.

Act 3: Scene 7

Ireti and her mum are in their living room. Ireti gives Bee a glass of vegetable juice.

Bee: I said I didn't want this horrible stuff. How…how many times have I told you?!
Ireti: /But, Maami, it's/
Bee: /I don't want it!
Ireti: It's healthy. I didn't like it at first, either, but/
Bee: /So why bother?
Ireti: It's living food and/
Bee: /You've been surfing the net again.
Ireti: It isn't just about the Internet.
Bee: Here, you drink it. I'm not interested.

Ireti sips her drink.

Ireti: This one is better than yesterday's. It's nice juice—even has pineapple. Take a sip at least.
Bee: Okay, it's just 'cos you've been working hard, plus I don't want to waste my money.

Bee chokes down the green juice.

Ireti: Not as bad as you think, is it?

Ireti places the cups on the table, takes a comb and begins to comb her mum's hair. She hums Bee's favourite song, 'Kulumbu Yeye'.

Ireti: Ah, Mum?
Bee: Yes, Ireti?
Ireti: What happened to the animals in that story about the one-eyed lion?
Bee: The one-eyed lion?
Ireti: Yes, that story you never finished telling me before.
Bee: /Oh, I remember… Hmmm…

I think I should be able to finish the story, but I may be slower than usual.

Ireti: (Excited) Thanks, Mum! Take your time. I just want to hear you telling me stories again.

Bee: I may skip some bits. I'm not sure I remember the whole story now. Anyway, where did we stop?

Ireti: The tortoise volunteered to be the first to go to the lion to be eaten, and the other animals were surprised.

Bee: So, they said, "Thank you for doing this, Ijapa. We promise to take care of your wife and children until it's their turn to go to the lion."

Bee pauses.

The photoing…follows… I mean, the following day, the one-eyed lion waited patiently for his first meal, but nothing…none… No animal came. He waist…wasted…waited for two days and became upset. He was about to start his terrible roar when he heard the voice of the tortoise. "Ah, Ijapa. Are you my fast…floss meal?"

Ireti: First meal?

Bee: Yeah, he said that, and Ijapa answered, "Indeed, I am."
I can't remember the conversation they had, but the long and short of it is that the tortoise tricked the lion. He said he wiid…wood…would have come earlier, but another great lion living inside the river stopped him, saying he was the king of the jungle.

Ireti: Oh dear! The one-eyed lion must be furious now.

Bee: He was limpid…livid! "Take me to him at once," he yelled. Okay, Ireti, what do you think happened next?

Ireti: Did the tortoise lead him to the river?

Bee: Yep! And…?

Ireti: I think the tortoise told the lion to look inside the river where the fake lion was, and the one-eyed lion saw his reflection and jumped in to fight the fake lion, not knowing it was his own reflection.

Bee: (claps) Look at you, girl. You’re a brilliant storyteller!

Ireti: So, was that how the story ended?

Bee: Yeah, the animals overcame the bully, and they lived happily ever after.

Bee and Ireti are laughing.

Bee: So, what did you learn from the story?

Ireti: We didn’t do the chant, Mum, and you’re asking me about the moral of the story.

Bee: Well, you lead the chant then.

Ireti: No, Mum, we’ll sing it together.

Bee and Ireti: Itan yi ko wa wipe, itan yi ko wa wipe (This story teaches us that…).

Bee: Well?

Ireti: Hmmm… What did I learn from the story? I think the tortoise is one badass ninja!

Bee: Hey?

Ireti: (Giggling) Innit, though?

Bee: (Shaking her head) So, that’s what you…you…learnt from the story.

Ireti: Mum, what did you learn from the story?

Bee: I love tricksters… They teach me how to deal with bullies.

Ireti: Bullies? Who’d bully you, Mum? You’re a ninja!

Bee: (Smiles) Bullies come in various shapes and forms, child.

Ireti: Hey? Such as?

Bee: Don’t worry, my darling. You wouldn’t understand.

Long pause.

Bee: Ireti?

Ireti: Maami?

Bee: Are you happy?

Ireti: I'm happy when you tell me stories, Mum. I'm happy you can write your poems and…and… I'm happy you got the right diagnosis, and you can take some medication that helps you relax a bit… I'm/

Bee: /You're going on about me. I want to know if YOU are happy.

Ireti: But that's what makes me happy. That you are happy.

Bee: You remind me of my mother. She'd say, "My child, I'm happy when you are happy." She was a very beautiful woman.

Ireti: That photo of her dancing at a party was nice. She looked really happy.

Bee: That was before her illness.

Ireti: Did your dad have other children? I know Mama had only you.

Bee: Yes, my dad had zree…free…three wives, and we were eight children.

Ireti: Three women in the same house!

Bee: People just got on with it. My mother was the last wife, and the other two made her life hell!

Ireti: Really?

Bee: Oh yes. One day, the…

The doorbell rings off stage.

See who…who's there.

Ireti: (OS) Eileen. Please come in.

Eileen: (OS) Hi, you look cheery today. How's your mum?

Ireti: (OS) She's alright.

Eileen and Ireti enter stage. Eileen sees the remnants of Bee's green smoothie.

Eileen: What on earth is that gooey stuff?

Bee: Ireti's new recipe. She's been blending odd stuff since that…that day she went to interview Prof.

Ireti: It's not blending. It's juicing.

Bee: Whatever.

Ireti: Anyway, what's Prof got to do with it?

Eileen and Ireti exchange glances. Eileen winks at Ireti.

Eileen, would you like some?
Eileen: No, thanks. I'm just fine. What are you guys up to? Do you want to go out tonight?
Ireti: Maami was just about to tell me the story of her childhood in a poly-marriage home.
Eileen: Errm… What's that?
Ireti: It happens a lot in Africa, you know. It's when a man marries many wives and…and/
Eileen: /Ewww…
Bee: Po…polny…polygamy, not poly-marriage.
Eileen: Oh, polygamy. I've heard of it.
Ireti: Eileen, my granddad was a polygamy man. Is that even grammatically right, a polygamy man?
Eileen: It's called a polygamist child. Well, I'm glad I came. Okay, Bee, take us on that journey down memory lane.

Ireti continues combing her mum's hair.
Bee clears her throat.

Bee: My mother was the thread…third fife…wife in her marriage, and I was her only child…

Lights dim on them as Bee continues her story.

THE END