Department of Public Health and Nursing

MASTER THESIS IN PUBLIC HEALTH

AFRICANS AND DEMENT

Caregivers’ experiences of nursing homes placement for an elderly family member with dementia

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Experiences of African-Norwegian immigrants’ caregivers with placement of an elderly family member with dementia living in a nursing home in Norway. This study adopted a Qualitative study approach, using semi-structured interviews, with four individuals who have their elderly relative with dementia living in the nursing homes. Analysis: Interpretative Phenomenological Analysis (IPA) by Smith, Flowers & Larkin (2009).

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Preface

I have always dreamed of getting a master's degree in health sciences. I have worked in dementia care for a total of 14 years and have become involved in matters relating to elderly care especially with people with immigrant background. I strongly believed that the experience of living with dementia can be improve where people live in the municipality by contributing to better elderly care not only to the majority but to people with immigrant background with dementia and their relatives. The process of this thesis has been an exciting and educational journey. The work on the master's thesis has been long and demanding notwithstanding, I have acquired a lot of new knowledge about a study that is little explored in Norway, which I see as very useful in my future work. I would like to thank everyone who has been with me on this journey, and who has contributed to this study becoming a reality.

First and foremost, I would like to give thanks to the Lord for seeing me through this journey. For without Him, I would not have made it to this point. I started this master's degree at a very vulnerable time in my life but then I knew God was going to help me through it all. He provided me with the peace and clarity that I needed to complete it.

My sincere appreciation goes to Professor John-Arne Skolbekken my supervisor, at NTNU, Trondheim for his support, dedication, and generosity in ensuring this work is a good piece. I thank you also for your availability and for sharing knowledge from your research experience.

I would like to extend my gratitude to my participants for their time, cooperation, and valuable contribution to this research.

I thank all my lecturers in the faculty of Medicine and Health Sciences for their support and encouragement. Finally, I dedicate this thesis to my parents Mr. and Mrs. Anthony Jones who taught me that education is important. To my two boys Matthew Jr. and Perez who supported and encouraged me all the way even when I nearly gave up. Love you guys.

Trondheim, date
Joyce C. Jones

List of abbreviations

NSD – Norwegian Social Science Data Service
NH – Nursing home
IPA – Interpretative Phenomenological Analysis
SSB – Statistics Norway
SSA – Sub-Saharan Africa
PLWD – People with dementia
NASEM – National Academics of Sciences, Engineering, and Medicine

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Abstract

People with an immigrant background are a complex group, it is important to have knowledge about their living conditions, state of health, health challenges and the use of health services. In this way, professional healthcare workers can provide good and equal health services and reduce health differences through health promotions and preventive measures. Immigration to Norway has significantly increased Africans living in Norway, due to several pre- and post-migration factors, they are considered to have an increased risk of developing dementia. Migrants from Sub-Saharan Africa (SSA) are often from countries where people believe in traditional and spiritual practices. Furthermore, few studies have shown there is lower use of nursing homes facilities among African migrants than in the Norwegian population in general. In addition, Africans are face with barriers and challenges when it comes to seeking and accessing not only nursing homes but also health services. Then again very few studies have been conducted on subjective understanding of nursing home placement among Africans, which indicates a clear need to generate more knowledge.

With increased cultural diversity, professional health workers are challenged to obtain relevant cultural knowledge in the care of an aging immigrant population.

The purpose of the study has been to explore the experiences of African caregivers have had when close family members are moved and live in a nursing home. Data was collected by conducting individual semi-structured interviews with four participants. Four themes emerged during the interview and each of these themes produced sub-themes. The four themes are as follows: 1) Participants' attitudes towards professional health workers, 2) feelings of guilt transferred to their loved ones, 3) Feelings of shame because of the decision they have made by moving them to a nursing home and 4) lack of dementia knowledge, access to and receipt of information and language barriers. Caregivers described experiences that suggested health professionals were sometimes reserved, while the relatives themselves seemed to be afraid of causing disturbances when they complained when visiting their loved ones. The biggest challenge among other challenges was receiving care adapted to the needs of the elderly family member with dementia, difficulties in understanding and expressing themselves, and that they lack knowledge about dementia and its symptoms.

Keywords: Family caregivers, African minority family, dementia, qualitative study sub-Saharan Africans.

Sammendrag

Personer med innvandrerbakgrunn er en sammensatt gruppe, er det viktig å ha kunnskap om deres levekår, helsetilstand, helseutfordringer og bruk av helsetjenester. På den måten kan vi som helsepersonell og sykepleiere yte gode og likeverdige helsetjenester og redusere helseforskjeller gjennom helsefremmende og forebyggende tiltak.

Innvandring til Norge har økt afrikanere som bor i Norge betydelig, på grunn av flere pre- og post-migrasjonsfaktorer anses de å ha økt risiko for å utvikle demens. Migranter fra Afrika sør for Sahara (SSA) er ofte fra land der folk tror på tradisjonell og åndelig praksis.

Videre har få studier vist at det er lavere bruk av sykehjem blant afrikanske migranter enn i den norske befolkningen generelt. I tillegg står afrikanere overfor barrierer og utfordringer når det gjelder å søke og få tilgang til ikke bare sykehjem, men også helsetjenester.

Men igjen er det utført svært få studier på subjektiv forståelse av sykehjemsplassering blant afrikanere, noe som indikerer et klart behov for å generere mer kunnskap. Med økt kulturelt mangfold utfordres profesjonelle helsearbeidere, sykepleiere til å skaffe seg relevant kulturkunnskap i omsorgen for en aldrende innvandrerbefolkning.

Formålet med studien har vært å utforske erfaringer afrikanske omsorgspersoner har hatt når nære familiemedlemmer flyttes og bor på sykehjem. Data ble samlet inn ved å gjennomføre individuelle semistrukturerte intervjuer med fire deltakere. Fire temaer dukket opp under intervjuet og hvert av disse temaene produserte undertemaer. De fire temaene er som følger: 1) Deltakernes holdninger til profesjonelle helsearbeidere, 2) skyldfølelse overført til sine nærmeste, 3) Følelser av skam på grunn av beslutningen de har tatt ved å flytte dem til sykehjem og 4) manglende demenskunnskap, tilgang til og mottak av informasjon og språkbarrierer. Omsorgspersoner beskrev erfaringer som antydet at helsepersonell noen ganger var reservert, mens de pårørende selv så ut til å være redde for å forårsake forstyrrelser når de klaget når de besøkte sine kjære. Den største utfordringen blant andre utfordringer var å få omsorg tilpasset behovene til det eldre familiemedlemmet med demens, vanskeligheter med å forstå og uttrykke seg, og at de mangler kunnskap om demens og dens symptomer.

Nøkkelord: Familieomsorgspersoner, afrikansk minoritetsfamilie, demens, kvalitative studieafrikanere sør for Sahara.

Contents

CHAPTER ONE: INTRODUCTION

1.1 Introduction

This study explores experiences of African immigrants' caregivers moving their elderly with dementia in the family into nursing home in Norway. The main areas considered in this study are guided by the experiences of the participants. This study adopted a qualitative research approach, using semi-structured individual interviews, with four family caregivers who have their elderly relatives living in a nursing home. All participants in this study have no prior knowledge about dementia and its symptoms, knowledge and understanding about the health system or placement in nursing homes.

Though the sample is small, the interviews highlight areas of particular interest in the decision-making including cultural differences about transitioning into nursing home care for the elderly with dementia. It is important to note that due to sample size, however, findings from this study cannot be representative of the general caregiver's experience. The rest of the chapter begins by presenting the background of this study; a short overview on nursing home services in Norway, followed by a description of sub-Saharan Africans caregiver's role, dementia, and dementia in Norway. The aims and objectives of this study, my personal interest and the research questions, and end with an outline of the study.

1.2 Background

Around the world, different countries are experiencing seismic demographic changes due to rapid increase both in the elderly population, especially those from 60 years of age and above, although many studies performed in sub-Saharan Africa (SSA) have failed to provide age-adjusted rates of dementia (Trojanowski, Arnold, Karlawish, Xie & Deerlin, 2014). The African continent including sub-Saharan regions has cultural diversity, made up of different languages and cultural beliefs in relation to dementia illness (Oguniyi et al., 2016; Guerchet et al., 2017). Understanding and appreciating these cultural differences, as well as recognizing older adults of African descent as a polylithic subgroup, are important aspects of professional care for older African adults living in Norway (Olaniyi & Mbuyi, 2014).

Information on dementia and nursing home placement for elderly families living in Norway is scanty. Most of the studies are on immigrants in general (Sagbakken, Ingebretsen & Spilker, 2020). For example, there are four recent reports on dementia incidence from Western Africa, and one each from Central and Northern Africa respectively. Notably, most of the data on incidence is from Nigeria, and current incidence estimates from sub-Saharan Africa

(SSA) are likely to be the same for other low and middle-income countries (Ojagbemi & Bello, 2020).

Further, healthcare professionals are crucial in providing dementia healthcare to this group. Although sub-Saharan Africans might much less likely to use NHs than their Norwegian counterparts, several studies have examined predictors of placement for elderly immigrants in general (ibid). And with increased in cultural diversity, professional healthcare workers will be challenged in achieving relevant cultural knowledge in providing appropriate nursing care for elderly immigrants in Norway.

According to the World Health (2021), there are 55.2 million individuals living with dementia globally and 1.9 million in Africa. Global mortality rate in 2019 was estimated to be 1.62 million (Global Burden of Disease, 2012), and studies indicate that in low countries such as sub-Saharan Africa, prevalence rates are expected to increase by 70-90 % (ibid, 2012). Considering the economic perspective, this was translated into an estimated worldwide cost of US 818 billion in 2015, which is equivalent to 1.1% of the world's gross domestic estimate (World Health Organization, 2021).

With ageing of the population across the world, the question of rising needs for care has become of paramount important in many countries including Norway, where the ageing population along with high life expectancy means that there will be a substantial proportion of older adults in need of professional care in the future (SSB, 2021). The experience of falling sick and living in an unfamiliar environment can be challenging not just to the elderly person directly affected by dementia, but also to those involved in the process (caregivers, the whole family members) (Spittel, Maier & Kraus, 2019). This can be especially challenging when family members as well as the community do not know or understand what dementia is.

Migration

Migration is a universal phenomenon, has been a constant and persistent feature in the environment of mankind, being among the most important and pressing global issues of today (Hanssen, 2019). According to the world migration report, there was an estimated 281 million migrants in 2020 (International Organization for Migration, 2023). Recently, the process of globalization has significantly increased international migration, especially to developed countries.

Numerous empirical studies (Hanssen, 2017) have defined migration as the crossing of an administrative unit's border for a certain minimum period. This category includes refugee migration, economic migration and migration of people who move for other purposes or under the influence of other factors such as war or better life, a change of place where they carry out their professional activity and a change of social relations (entry into a new community) (Hanssen, 2017).

In addition, studies show that individuals or groups who migrate are varied and constantly changing (International Organization for Migration, 2023). These individuals' migrants are not easily classified because they come under different circumstances, different environments, individual characteristics, and different cultures (ibid).

Migration can be both internal and international. Internal migration refers to moving from one area (province, country, municipality) to another area within the territory of the same country. While international migration is a territorial relocation of people between countries (Berry, 2012 & Berry, 2007).

There are many reasons why people around the world who seek to rebuild their lives in a different country. Some people leave in search of greener pasture or education. While others are forced to flee from armed conflicts or other crisis or violence. An important group of these migrants worth mentioning are the refuges.

Furthermore, the process of migration has been described as taking place in three stages: pre-migration, migration itself, and post-migration. pre-migration involves making the decision and preparation to move. Migration, which is the second stage in the migration process, involves actual relocation. While post-migration is defined as absorption of the immigrant within the social and cultural lifestyle of the new society (Berry, 2012 & Berry, 2007).

There are many reasons why people around the world seek to rebuild their lives in a different country. Some people leave, in search of greener pastures or education. Others are forced to flee from armed conflicts or other crisis of violence. An important group of these migrants worth mentioning is the refugees.

Within the European Union, the term *'refugee' refers to 'any third country national who, owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, political opinion or membership of a particular social group, is outside the country of* *nationality and is unable or, owing to such fear, is unwilling to avail himself or herself of the protection of that country, or a stateless person, who, being outside of the country of former habitual residence for the same reasons as mentioned above, is unable or, owing to such fear, unwilling to return to it, and to whom Article 12 does not apply* (Directive 2011/95/EU).

According to this regulation, the definition of the term 'refugee' involves three elements: physical, psychological, and causal refugee. Meaning that from a physical point of view, a refugee is a person who has left the territory of his country and is in the territory of another country. From the psychological point of view, the granting of the refugee status is determined by proving a fear of persecution for well-defined reasons in the text (belonging to a race, religion, political, nationality or social group) (ibid).

The challenges of migration today involve finding ways to manage migration that can create benefits both for the migrants and the receiving country. This is particularly difficult when people have different cultures, different religions, and customs, or have different ways of taking care of the elderly embers in the family with dementia. This challenge is to find a balance between inequality and paths that lead to good ways of handling migration, diversity, and differences (IOM UN Migration, 2020). This involves studying processes that seem inclusive or exclusionary in relation to different groups living in the new society, which could be a way to address the problem. Different groups have different adaptation strategies and opportunities that policymakers need to understand to facilitate good inclusion process.

Acculturation and adaptation along with the time of transition are the three basic elements of any migration (Berry, 2009), meaning migration often involves deconstructions, reconstructions of cultural belief systems of the migrant (Sam & Berry, 2010). The cultural identity as migrant is redefined during the acculturation process and a new cultural identity is sometimes forced on them without their own doing but from the host community (ibid).

The IOM UN migration (2020) defines a migrant as: any person who is moving or has moved across an international border or within a State away from his/her habitual place residence, regardless of 1) the person's legal status; 2) whether the movement is voluntary or involuntary, 3) what the causes for the movement are, 4) the length of time.

In addition, compare to the general population within a country, immigrants face more challenges in accessing healthcare services in terms of dementia care needs and nursing home placement (Debessay, Arora & Bergland, 2019). Factors leading to these challenges could be explained by the different cultural barriers within the country's healthcare systems, lack of knowledge of dementia symptoms for example, lower education level a few to mention (ibid).

Torres (2004) describes immigration process as a trying period, not only because of the various challenges it poses for migrants' behavioral repertories, but also because it questions the very essence that gives them their preferred behavioral patterns and meaning. Breaking up with home country and close relationships often means that a migrant's life course is marked by discontinuity, instability, and different loses including opportunity to communicate in one's own mother tongue with the majority population, loss of the opportunity to understand social norms, loss of relatives, local environment including professional status and social prestige (Sam & Berry, 2010).

Globalization

Globalization is an important concept in the context of migration. Globalization is not a state, but a process and some claim that this process leads to the flow of people and culture equal, meaning equality between ethnic and cultural groups. Others claim that such a flow leads to a greater need to confirm their own culture in relation to that of others.

Globalization has involved increasing human mobility of not just refuges and migrants but also visiting other countries, the result of which has increased diversity among country population and sharing of cultures (IOM, 2020). The complex underlying processes driving migration and its effects have attracted significant and growing attention globally.

Norway's immigration began following the discovery of oil resources at the North Sea in the late 1960s and according to Statistics Norway (2018), the population data show that immigrants add up to about 14% of the population in Norway. Most migrants living in Norway are from countries such as Eritrea, Iran, Somalia, Syria a few to mention (ibid). Among this group of immigrants are people from sub-Saharan African countries (SSA) (ibid, 2018).

According to the United Nations (2017), countries in this region are noted for their political instability and low economic status and health problems. In addition, migrants in Norway form a heterogeneous group, and their health condition depend on several factors: before, during and after migration, reasons for migrating; whether they are refugees or migrant workers, place of origin and whether they came from urban or rural areas, gender, class and age imply significant variations about health and incidence of disease (Ministry of Health and

Welfare, 2013; Kumar et al., 2008 Rudmin & Ahmadzadeh, 2001; Blom, 2010 & Bhugs, 2004; Hanssen, 2005; Fauske & Høgmo, 2010).

Also, migration into Norway has grown in the past two decades, particularly with immigrants from sub-Saharan Africa (SSA) (Statistic Norway, 2019). Presently, 112,786 (Statistic Norway, 2019). Immigrants from SSA countries constitutes part of the total Norwegian population today and with increasing aging among elderly people, the risk of developing diseases such as dementia is also increasing (Spilker & Kumar, 2016). Immigrants as well as sub-Saharan Africans are vulnerable to dementia including other diseases. Due to problems such as underdiagnosis and access barriers, the care of this population is becoming a public health challenge not only in Europe, even though many countries are issuing care guidelines, a systematic overview of their reference to migration is lacking (Lien, Nafstd & Rosvold, 2008).

Additionally, there has been little effort in this (SSA) areas, especially how dementia impact sub-Sahara Africans. Today however, there is a growing interest in acquiring a better understanding of the health status and healthcare needs of not only sub-Saharan Africans but immigrants in general and the elderly with dementia (Spilker & Kumar, 2016).

Finally in this chapter, the migrants in this thesis have changed their place of residence permanently for over a year. The term sub-Saharan Africans, Africans and migration are used interchangeably in this thesis and have the same meaning permanently. Sub-Sahara Africa is an area that lies south of the Sahara Desert of the African continent (Bogueva, et al., 2018), including Nigeria, Ghana, Liberia a few to mention. Migration, and its consequences in receiving societies today, is among the major societal issues (IOM, 2023).

Nursing home services in Norway

Like other countries in Europe (Saltman et al., 2007) nursing home in Norway is part of the public health care system and are intended for long-term care services for frail older people. In other countries for example, United States, NH may be private institutions. Most NH offers regular units or a special unit for people with dementia (Kirkevold & Engedal, 2010). Nursing homes are intended for elderly people needing chronic and daily care that the home nursing services cannot deliver. In Norway, local boards decide admission to private and public nursing homes. Although nursing homes have a special care unit for dementia, the great majority of residents who are mentally impaired or have dementia live in a general ward together with other residents' who are not mentally impairment (Debessay, Arora & Bergland, 2019).

Nursing homes (NH) share environments such as dining room and living room even though some studies have indicated that the sharing of these common within the institution can be a challenging for the patients, caregivers', and the professional healthcare workers (ibid, 2019). Older adults who move to care homes are experiencing higher levels of dependency including eating, dressing, brushing of teeth, etc. (Livesey et al., 2011). About 80 percent of older adults in care homes including immigrants have dementia or another form of cognitive impairment (Alzheimer's. 2013). Nursing homes services constitute a central part of this study. Equality is one of the underlaying principles of the Norwegian health system, that is the right to equal access to health services (Debessay, Arora & Bergland, 2019).

Further, in Norway, the cost of public dementia care is about 28 billion NOK annually and residents account for approximately 70% of the total cost (Diaz, Mbany, Gele & Kumar, 2017). In addition, most NH offers regular units for people with dementia (Kirkevold & Engedal, 2006). Long-term care facilities aim to provide care that enables residents to attain or maintain their maximal functional capacity and health-related quality of life (Kirkevold & Engedal, 2006).

Approximately 28 000 persons are living in nursing homes in Norway including a few numbers of immigrants and approximately more than 80% are diagnosed with dementia (ibid). To provide for best possible care especially for immigrants including Sub-Saharan Africans, the need for more knowledge about migrants' caregivers and what they experience with nursing home placement for their elderly is important. Generally, all nursing homes are staffed with doctors, nurses, and professional and nonprofessional healthcare workers (Halvorsen, Ruths, Granas & Viktil, 2010).

Sub-Saharan Africans family caregiver's role

Family caregivers occupy an ambiguous place, being providers for the elderly in the family. In most sub-Sahara African regions, family members are primarily responsible for providing care and support to older adults (Mkhonto & Hanssen, 2018). The dependence is a reciprocated act, and one related to an African adage that roughly translates to: *'because your older parents' / mama has taken care of you (as a child) to grow teeth, than you must also take care of them until her teeth falls out'*. African family life is known for large, extended kinship groups which are more complex and nuanced than conventional Western ideas of the nuclear family (ibid: 2018).

In addition, raising a child or children by someone other than the child's biological parents have been a common practice across many African countries and traditionally children are often view as precious gifts from God and the entire extended family (Olaniyi & Mbuyi, 2014). A study on the family involvement in urban Kenya and South Africa, suburban, Ghana, and rural Tanzania found that relatives are actively involved in developing care plans with social service agencies such that they integrate caregiver's roles and contributions. But dependence on families alone results sometimes in unreliable quality care and places economic, psychological, social, and physical burdens on the family caregivers, who tend to be women in the family (Ogunniyi et al., 2005).

Furthermore, most African family caregivers provide care with little and no guidance on how to address complex health issues. For example, few caregivers understand the nature of dementia, how it can influence behavior, and how they can improve the lives of older people. This lack of knowledge increases the risk for elder abuse, either physical, or financially from corrupt caregivers who help themselves to older people's assets (Ogunniyi et al., 2005).

And in addition, given the challenges and complexities facing family caregivers, many sub-Sahara African researchers and policymakers believe this will no longer be feasible to rely just on the extended families for long-term care of older persons but rather organized and paid long-term care services that are needed to supplement and strengthen the care of older adults (Agyemang, 2014).

Research studies about Africans indicate that generally Africans remain faithful to the notion of the family-orientation. Africans believe in the importance of family as an essential source for support and caring. It becomes a sense of shame and guilt to the family when family caregivers fail to provide care to their relative with dementia. Family responsibility appeared to be understood by a sense of pride and honor, which is mainly expressed in terms of how the family was perceived within the community (Agyemang, 2014).

In addition, minority ethnic groups including sub-Saharan Africans (SSA), when it comes to making decisions about healthcare are sometimes collectively made, an approach that is not incompatible with the Western culture like Norway which embraces self-determinism in healthcare decision-making (Koffman & Higginson, 2007). However, the differences between older relative’s expectations of care and the caregivers’ role, is seen as an obligation to provide care for the elderly relative (ibid).

Dementia and dementia in Norway

The World health Organization (WHO, 2021) defines dementia as a syndrome in which there is deterioration in cognitive function beyond what might be expected from the usual consequences of biological ageing. According to WHO (2021) dementia is because of various diseases that primarily or secondarily affect the brain. Alzheimer’s disease is reported to be one of the most common forms of dementia and is currently the seventh leading cause of death among all other diseases and one of the major causes of disability and dependency among older people globally (World Health Organization, 2021). Other subtype of dementia is dementia due to Parkinson’s disease; Lewy Body dementia; frontotemporal dementia; dementia due to traumatic brain injury; and dementia due to Huntington’s disease (ibid).

Dementia symptoms are characterized by impairments in memory loss, reasoning, intellectual function, speech, and spatial-temporal awareness (ibid, 2021). These changes are often small to start with but can become severe enough to affect their daily lives. Currently in Norway, persons with dementia were estimated to be 101,118 in 2020, and it is currently projected that the number of PLWD in Norway will reach double by 2050 (Gjora, Strand, Bergh, Braekhus & Engedal et al., 2022).

Indication shows that improving and delivering quality care for PLWD in Norway has always been an overarching priority in the Norwegian government institutions and related bodies (ibid). It is the government’s five-year plan (2021-2025) to improve services for people living with dementia including Sub-Saharan Africans and the immigrant population (Dementia Plan, 2020, nursing homes). Recently, both health literature (Hanssen, 2019), parliamentary messages (Ministry of Healthcare, 2006) and reports (Spilker & Kumar, 2016), indicate how dementia care for elderly immigrants can be handled. Parliamentary notices back to the beginning of 2000 are written guidelines on how healthcare services for older immigrants in general and when diagnosis for dementia could be carried out (Hanssen, 2019). Much has improved since the first plan was implemented and many municipalities have carried out educational programs for family members and support groups for people with dementia (Engedal, Haugen, & Brækhus, 2009).

There is limited information or studies about nursing home placement for elderly Africans living with dementia in Norway. Why is this so? Could it be because of the lack of culturally appropriate dementia services, food, language barriers, lack of dementia knowledge, culturally appropriate care within the various health institutions or the stigma that comes with dementia? Some research studies indicated that there is no local term for dementia in most of the Sub-Saharan African regions and such information may suggest that there are places where dementia is not regarded as a sickness or disease but due to old age, witchcraft activity, a curse, or a white-man disease (Ogunniyi, et al., & Adebiyi et al., 2016). Cultural beliefs influence the way in which dementia is recognized and understood, which may influence health-seeking behaviors (Alzheimer's report, 2013).

Prior literature emphasized that Sub-Saharan Africans and their family members with dementia are vulnerable to the stigma and 'witchcraft of dementia'. Further, Africans elderly adult with dementia and with migration background are in most cases cared for at home by family members (Chaouni, Smetcoren & De Donder, 2019). The norms of family-oriented model can lead to exhaustion and stress, especially with African caregivers in Norway who do not have the support of the extended family around to help (Sagbakken, Spilker & Ingebretsen, 2018). In addition, results from different research in regions of Sub-Saharan Africans for example, Liberia, Nigeria, Ghana, Serra Lone a few to mention, underlaid the cause of dementia-like symptoms to be 'normal aging' with both grief and stress (Goffman, 2006).

A research study in Nigeria for understanding the different types of stigmas associated with dementia discovered that participants had inadequate knowledge about dementia (Adebiyi et al., 2016). As a protective gesture, family caregivers feel obliged to hide relatives suffering from dementia and refrain from seeking further assistance (Spittel, Kraus, Ther & Maier, 2021). This could be the same belief system that might be influencing most African immigrants in Norway and keep from seeking the necessary help needed for their relatives with dementia. This will be further discussed in the discussion chapter.

1.2 Aims and objectives of the study

The main research question of this study is to explore the experiences of African immigrants' caregivers for placement of an elderly family member with dementia into Norwegian nursing homes.

Key research objectives include:

1. *To identify challenges and barriers encountered during and after palcement in Norwegian nursing homes and what are the strategies did they adopt in dealing with these challenges and barriers?*

2. *To explore the attitudes and perceptions of caregivers about nursing home after placement.*

I hope that the results from this study will increase knowledge and understanding including interest for both the elderly with dementia and caregivers with a background other than Norwegian. An important point to take note of here is that the assignment was not to find an absolute truth or an explanation, but it was to understand and interpret African caregivers' experiences with nursing home placement of their loved ones. This knowledge goal of the study is to gain insight into caregiver's lived experiences with professional healthcare workers in the nursing home where their elderly family are living. Finally, this understanding will in turn help me to meet caregivers of ethnic minorities as well as sub-Saharan Africans in my practice. It will also be interesting to compare findings from this study with other research studies as well.

1.4 My personal motivation

My personal background and interest in the study of African caregivers stemmed from three main reasons, which purely for the sake of analysis, term as personal, practice and academic. I considered both an inseparable part of myself. The academic reason is derived from the desire to fill the gap in current academic literature on African caregivers' experiences on placement of their elderly relative with dementia in a nursing home in Norway. When speaking of Africans, I am referring to countries from sub-Sahara regions (Nigeria, Ghana, Serria Leon, Liberia etc.). I had a preconceived notion that collaboration between immigrant caregivers and professional healthcare workers can be challenging in terms of communication and cultural differences.

My second reason is my experiences from practice as a healthcare worker in a nursing home/residential care home. At the personal level, the reasons for the choice of research group can be primarily linked to my own identification as an African migrant living and working in Norway. I have a bachelor's degree in social work and specialization in dementia care.

Since I moved to Norway, I have experienced immigrants also including taking steps to blend within the Norwegian society. All of these require a whole lot of effort and hard work. When elderly Africans are moved into the nursing homes, professional healthcare workers need to take steps that are relevant for this group of citizens.

Last but not the least, before taking up this study, I had the opportunity to meet and discuss with a friend from a Kenyan family who is a caregiver to her mother with dementia. She was in the process of taking her mother back home to Kenya because she refused to move her into the nursing home. Her reasons were that her mother would not be happy living there, but the food and eating aspect she feels it would be difficult to practice some of her cultural norms. Therefore, according to her, she never sought professional help. Even though at the end she moved her mother to give it a trial and it ended up that her mother was more depressed and sicker than ever. This got me interested and wanted to find out more about this phenomenon.

Furthermore, apart from my personal motivation for this study was my preconceived notion that cultural understanding for healthcare personnel was of great importance for caregivers' elderly members with dementia living in the nursing homes. I had a preliminary notion that the caregivers' experiences for placing elderly relatives with dementia in nursing home was going to be challenging, especially in relation to communication, cultural differences, and norms.

Another assumption about the participants was that they might not be willing to take part in the research study because of the sensitivity of the research question. Another assumption was that participants might lack knowledge and understanding about dementia and its symptoms. In addition, I tried unconsciously by not influencing the data with my prejudices. Van Manen (1999) indicated that our understanding and interpretations should play out in their own terms because we seek for an understanding in the phenomenon being explored.

For any situation to emerge depends on one's awareness of one's own prejudices and understanding of that situation. In this study, this was a continuous and conscious process in all stages. I was aware of my professional status, my background as an African and pre-understanding of dementia and nursing home placement, how this could affect the phenomenon regarding all phases of the process before, during and after the interviews. This is important in qualitative research, where the researcher is in a special position, because it is the researcher him/herself who carries out the data setting, the analysis and interpretation of the results Van Manen, 1999).

1.5 Outline of the study

Chapter Two: Literature review of African caregivers including immigrants generally about nursing home placement research. This chapter consider literature review on topics of African caregivers and nursing placement for an elderly relative living with dementia both in Norway and other countries. It begins by explaining what a caregiver is supposed to be and follows by a systematic literature search using the PICO-frame Table.

Chapter Three: Theoretical framework for the current study. This chapter consider culture in relation to caregivers and introduces the theoretical model culture, put forward by Leininger & McFarland (2009), including cultural competence in dementia, assimilation, amalgamation, ethnic identity, acculturation, integration, and communication. Finally, this chapter consider four strategies which acculturation is distinguished.

Chapter four: Methodology

This part of the thesis discusses the methods employed in this study to collect and analyze data. The selection of the research design is rationalized according to the research question and objectives. The chapter continued with research the research samples, inclusion/exclusion, selection, the research instrument data collection, data analysis and ethical issues.

Chapter Five: Findings

In this chapter, the findings are presented from the semi-structured interviews with the various participants. These findings are arranged by themes, which are divided into sub-themes to bring out key topics from the interviews.

Chapter six: Discussion

This chapter discusses the findings from the individual interview. These findings are discussed in terms of the theoretical framework.

Chapter seven: Conclusion

This chapter concludes the research study. Included in this chapter are recommendations for future research and practice, limitations encountered during the study and strength of the study

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This chapter presents the literature review on the topic of African caregivers and nursing placement for an elderly relative living with dementia both in Norway and other countries. Research study on this topic is currently under-researched and not well-defined area in Norway. It begins by explaining what a caregiver is supposed to be and follows by a systematic literature search using the PICO-frame Table.

2.2 Caregiver

Any person who cares for an individual with dementia most of the time at home. They provide both physical and emotional support for the elderly in the family. For this study, it means a son or daughter who has been living with a mother, father, or grandmother for more than two years or since the start of the symptoms of dementia.

2.3 A systematic literature search

A systematic search for literature, journals and research studies was conducted in the different databases: PubMed, BMC, Norwegian Institute of public health. The combinations of keywords were ‘African formal caregivers’, ‘ethnic minorities’, ‘nursing homes’, ‘home care’, ‘long-term care facilities’, ‘immigrants/immigration’, ‘elderly/old people’, ‘African relatives’, ‘sub-Saharan Africans,’ ‘culture’, ‘dementia/illness’, ‘cultural sensitivity’, ‘cultural competence’ and ‘cross-cultural terms’ including ‘witchcraft’, ‘stigma’, ‘spirituality’.

In addition to the lack of literature specific to sub-Saharan African immigrants using nursing homes facilities in Norway and abroad, I then narrowed my search into databases for ‘transcultural care and dementia’ on immigrants and minority in general, ‘acculturation’, ‘care in nursing home among Africans’, and ‘cultural differences’ with the option of excluding interesting articles or research that does not contain selected search term. The collected literature/journals had been published between the years 1994-2024 except for few sources that were published before that period because the researcher found these journals as significant in this study.

The literature search strategy was structured using PICO-framework as shown in the table below (Higgins & Green 2008).

Table 1: PICO-frame

P: Patient / population	I: Intervention/Exposure	C. Comparison	O: Outcome
Dementia, cognitive impairment, **Residential/nursing home, Immigrants/immigration', Migrants, sub-Saharan Africans & dementia, elderly relative, family member, informal long-term care**	Program social stigma, shame, attitude, belief, and perception, witchcraft, magic, and religion	No restricted search terms were applied to the categories of comparison	cultural sensitivity dementia care, stigma, shame increase cultural competences or cross-cultural terms dementia, lack of language, communication

Cultural variations in the understanding of dementia and nursing home facilities

Research studies have shown that in many societies, dementia is often regarded as the result of normal aging and not as a disease (Morhardt m.fl. 2010; Gonzaelez, Gaona, Quintero, Chavez, Selga & Maestre, 2014). In addition, dementia may be seen as madness and often associated with shame and taboo (Ingebretsen Spilker & Sagbakken, 2015).

African caregiver and their relative with dementia may have a different understanding of dementia (ibid, 2015). Because sub-Saharan Africans have a different medical understanding than the biomedical one, they present dementia symptoms in a way that professional healthcare workers might not understand (Hanssen, 2020). For example, research was carried out in one township in South Africa showing dementia is often perceived as connected to witchcraft rather than a disease (Mkhonto & Hassen (2017).

This could probably be the reason Africans caregivers are reluctant to seek help from healthcare system when problems relating to cognitive changes problems are observed. Instead, Africans families try to deal with the situation within the family by keep the elderly family member with dementia away and lock up in some cases (Hanssen & Tran 2018; Morhardt mfl. 2010). At the same time some families are quite tolerant to the situation and find means to help the loved ones with dementia.

Witchcraft activities in most African countries has been associated with the use of supernatural powers or magic to achieve certain outcomes (Mkhonto & Hassen, 2017). In some cultures, witchcraft is seen as a form of religious or spiritual practice. While in others, it is viewed as occultism or sorcery. It is also important to understand that witchcraft interference in the natural community lifestyle and behavior is a subjective interpretation and may not be accurate or applicable to all cultural beliefs (Jayeola-Omoyeni, Oyetade, & Omoyeni, 2015). Different societies and communities have their own unique perspectives on dementia, and these may vary widely depending on factors, cultural norms, religion, and geography (ibid).

Stigma is another aspect surrounding dementia and is reported in numerous cultures and in different ethnic groups (Ogunniyi et al., 2005; Adebiyi et al., 2016). For example, 'madness', 'witchcraft', and unintelligent' are words said that are commonly used in describing dementia in some African countries (ibid).

A study conducted in Nigeria found that the knowledge of dementia is limited, and people tend to respond differently towards the elderly with dementia (Adebiyi et al., 2016). In addition, stigma in relation to dementia has numerous implications, including impending help-seeking, quality of life, increased isolation, and loneliness, not only for the one with dementia but the entire family members (Jacobs, Schneider, Farina, Toit & Evans-Lacko, 2022). People with chronic conditions such as dementia are often stigmatized according to an article written by Idemudia et al., (2018) for the following reasons: a) poor understanding of the condition as a chronic and progressive health condition, b) cultural beliefs about its causes and c) social interaction problems associated with memory impairment (Mukadam & Livingston, 2012).

For example, 'madness,' 'witchcraft', and 'unintelligent', are words commonly used in Nigeria to describe dementia (Adebiyi et al., 2016; Ogunniyi et al., 2005). Another study conducted in Nigeria found that some people had limited knowledge about dementia (Adebiyi et al., 2016), and because of the different beliefs about the causes of dementia, Africans tend to respond differently towards the person with dementia (ibid).

Furthermore, spirituality and religion has interested researchers in gerontology for some time, particularly because spirituality and religion in the elder person are essential issues insofar as they can have a positive role in individuals health and well-being (Koeing, 2012).

According to Olayinka et al., (2014), a survey conducted by the Harvard School of Public Health and the Alzheimer's Europe Consortium on Alzheimer's disease concluded that dementia is a significant cause of health concern among adults. According to several public health research on dementia in developed countries McParland et al., (2012) conducted a study focusing on the community of Norther Ireland in which dementia knowledge and attitude were explored.

Studies on migrant beliefs about dementia, its symptoms, and role of caregivers serve predominantly as barriers to the diagnosis of dementia (Sagbakken et al., 2018; Mkhonto & Hassen, 2017). Professional healthcare workers see migrants including Sub-Saharan Africans, Latinos and black Americans hold beliefs about dementia as a curable and shameful condition that have various impact on the community in general (ibid). Also, some hide the status of their elderly with dementia for fear of prejudice and negative attitudes towards them (Mkhonto et al., 2018). A research report from the UK found that 33% of those living with dementia had lost friends following the diagnosis, and 39% felt lonely and not included in their communities (Alzheimer*s Society, 2019).

Migration and dementia

Quite a lot of elderly immigrants including Africans, as mentioned by Heikkila & Ekman (2003), wish to be in familiar surroundings and be with people to whom they are well-known. This is mentioned as an important necessity to immigrant care and migration. Several studies show that family carers do not understand the causes of dementia, life expectancy linked to the disease and other clinical topics (Hanssen, 2020), and living in environments sometimes unknown to them with European system makes it more difficult for them to ask for help.

In the study of Mazaheri, Eriksson, Nasrabadi, Sunnvisson, and Heikkila (2014), new insight into understanding the experience of dementia in older immigrants is now focusing more on the immigration experience then the disease.

Furthermore, several research studies show that more elderly immigrants as indicated by Heikkila (2003), wish to be in familiar surroundings and be with people to whom they are well- known. Physical, social, and cultural environment has been an important focus for the well-being of elderly people including sub-Saharan African elders who need care in a different socio-cultural environment.

The findings from these studies indicate that the development of dementia in countries different from one's own country (Africa), where cultural differences and situational awareness are different, produces different understanding of living with dementia in a new environment (ibid). This report describes results from a three-year sub-project on older immigrants and their relatives for increased knowledge and attitudes towards dementia, and how health related service can be offer including how healthcare personnel can meet their needs.

Furthermore, in a systematic review of ethnicity and pathways in dementia care on minority ethnic groups, Mukadam, Cooper & Livingston (2011), shows beliefs about the causes of dementia is because of normal ageing. Barriers such as personal reactions that is denying there is a problem, community stigma; shame, a sense of family responsibility and healthcare related barriers including language barriers, feeling discriminated against, thinking dementia has a spiritual, psychological, physical, and social causes and believing nothing can be done to help relatives with dementia were cited Mukadam, Cooper & Livingston, 2011; Sagbakken, Spilker & Nielsen, 2018).

It can be argued that Africans including some ethnic minority groups and the family caregivers do everything in their power to look after their elderly member with dementia for as long as possible, and that the healthcare system is consulted when the situation becomes completely impossible to handle at home. In addition, one can also argued that this could be one of the main reasons there are still few immigrants including sub-Saharan Africans among residents in Norwegian nursing homes.

The shame and humiliation of not fulfilling the family obligation for taking care of the relative with dementia the same way that the mother and father took care of one when one was a child, thus honoring the elderly as is culturally required (Hanssen, 2020).

Nursing Home Care

Several research highlights the importance of health and social care professionals' collaborating with family caregivers (Unnde, Vatne & Ytrehus, 2021). Nevertheless, the involvement of and support for sub-Saharan African family caregivers have not developed into a common practice, and research has identified professional barriers to collaboration with family caregivers in several areas. It is also well documented that family members need support to prevent negative consequences of caregiving (Sagbakken, Spilker & Neilsen, 2018). In addition, in Norway, most of the research studies on adjustment and challenges of healthcare services for elderly immigrants were conducted by Norwegian Social Research (NOVA).

In 2007, NOVA published 'The elderly with minority background, adjustment of long-term care services. This report sought to answer how the elderly with a minority background can benefit from healthcare services with the majority population. This research also indicated use of nursing homecare services among elderly immigrants is lower compared to age groups in the majority population.

Review of Nordic, Norwegian and international literature shows that several similar problems recur in studies on elderly immigrants' use of nursing home care services which does not provide clear results to whether it is best to develop culturally appropriate care services.

Similar finding from Norway suggest that migrants' patterns of health care usage differ to that of natives (Straiton, Reneflot & Diaz, 2014). Health data from Statistics Norway's living conditions survey, shows that migrants evaluate their health more negatively with increasing age than other populations, and generally report poorer health (Blom, 2016; Debesay, Arora & Bergland (2019).

African caregivers in Norway face a different set of challenges involving professional healthcare workers knowledge base in intervention programs. Challenges such as language barriers, communication, lack of understanding about dementia are but a few to mention (Sagbakken, Spilker & Ingebretsen, 2018; Mkhonto & Hassen (2017; Jayeola-Omoyeni, Oyetade, & Omoyeni, 2015). To develop and implement cultural care, there is the need for implementing culturally competent understanding. Secondly, culturally appropriate care is important. And thirdly, professional healthcare workers ought to be culturally sensitive to achieve basic knowledge and useful attitudes towards the health traditions observed among immigrants generally including Africans.

In conclusion, a research report from NOVA (2008), 'Elderly immigrants and their use of nursing home care services', involving five municipalities sought out to investigate on how elderly with minority background use health care services and to also learn how the municipalities experience providing services to this group. The findings from this project indicated that elderly immigrants prefer home-based nursing home services rather than long term institutions.

CHAPTER THREE: THEORETICAL FRAMEWORK

3.1 Introduction

Chapter three presents the theoretical framework for this study. The conceptualization of nursing home experience of African caregivers for elderly relatives living in nursing homes with dementia in Norway might be attached to various attitudes and culture beliefs against the idea of nursing home placement. Older people having different ethnic backgrounds form diverse groups with different linguistic, cultural, and religious backgrounds and with different health, social and economic needs, and resources.

Cultural including traditional beliefs; cultural competence in dementia, assimilation, amalgamation, ethnic identity, acculturation, integration, communication was presented as the theoretical framework for this thesis.

3.2 What is Culture

According to Madeleine Leininger (2009), culture is defined as the learned, shared, and transmitted values, beliefs, norms, and practices that influence a group's thinking and behavior. It includes aspects such as language, religious practices, dietary preferences, family dynamics and perceptions of health and illness (ibid). Leininger proposed that nursing care has both universal aspects (those that are common across cultures) and culturally specific aspects (those that are unique to a particular culture).

Nurses and professional healthcare workers must be knowledgeable at recognizing these differences and similarities to provide holistic care across culture (Narayanasamy & White, 2005). It is therefore important to have a good understanding of the complexities and cultural factors associated with dementia care in nursing homes that can form the basis for proper understanding of the physical and psychological health outcomes of the elderly with dementia (Heikkila & Ekman, 2003).

The concept of culture focuses on helping individuals maintain their cultural practices and values related to health and well-being. Professional healthcare must workers aim to support both patients and caregivers in adhering to their cultural rituals and beliefs while at the same time receiving healthcare services especially, in relation to nursing home and dementia care (Madeleine Leininger (2009). Meaning, for one to understand an individual or a group, one must look at that individual/group considering his/her cultural background. Leininger's main point was to focus on something more than medicine, disease symptoms and nursing knowledge but to focus on the holistic of care for patients through cultural diversity.

People’s experiences and interpretations of reality are rooted in cultural contexts and the term has often been used in relation to race and ethnicity, but at the same time encompasses a wider range of similarities and differences than race and ethnicity (ibid). For example, to provide care for one’s family or community amongst Africans is deeply rooted in the cultural subconsciousness arising naturally without conscious thought.

Leininger & McFarland (2006) tries to standardize healthcare in such a way that would be appropriate, respectful, and decent for everyone that may find themselves in a globalized beliefs and actions shared by a particular group influencing thinking, decisions, and actions (Leininger & McFarland, 2006). People’s experiences and interpretations of reality are rooted in cultural frame. On’s culture serves as a platform for cultural reasons, which are defined in this discussion as the expressions and meanings, as derived from culture, that direct behaviors such as why African caregivers express negative attitudes towards nursing home placement.

In addition, I am not purporting that caregivers who are experiencing nursing homes placement for an elderly family member with dementia do not have positive attitudes towards nursing home placement or that cultural reasons are uniform within any cultural group; instead, there is likely variability within cultural groups regarding how they express the cultural reasons for nursing home placement or not.

Therefore, understanding cultural complexity from the perspective of caregivers and their relatives with dementia living in nursing homes is critically important because culture permeates all aspects of care and living (Leininger & McFarland, 2006). In addition, to understand and provide cultural congruent care for immigrants including Africans, professional healthcare workers must be influence by several factors. Studies have shown culture, attitude, and knowledge play a key role in delivered care (Berry, 2008 & Leininger, 1998).

Caring for family members including the elderly among Africans is generational and traditional (Agyemang, 2014). Children grow up in households/families where they see their parents care for their parents, and family members care for each other. Sas noted earlier, the family plays an important role in the perpetuation of cultural values and belief and family networks have served as social service system, community-based intervention systems (Burton & Dilworth- Anderson, 2010). So, caring for elderly family members is expected and viewed as a cultural norm for continuity and mandates family members to provide care for older adults and the shame associated with the failure to do so can be a barrier to professional care-seeking (Agyemang, 2014).

Furthermore, research done in sub-Saharan countries like Nigeria found that cultural differences, negative attitudes, and lack of knowledge about dementia in communities were big issues when it comes to dementia illness (Adebiyi et al., 2016).

3.3 Cultural Competency in Healthcare

The notion of cultural competence has been defined in several ways in literature studies, though all seem to concur on that it relates to the way which professional people and organizations respond dutifully and effectively to persons who are from different cultural and ethnic backgrounds (Leininger & MacFarland, 2006).

Furthermore, the notion of competence in culture is a never-ending practice of self-exploration and continued pursuit of understanding of others. Considering the diversity of the Norwegian society, it is important for healthcare professionals to become culturally competent to provide effective care across a variety of cultures (Leininger & MacFarland, 2006).

This includes recognizing the diversity of people's beliefs, religious, traditional norms and values in a way which enables them to feel their worthiness is being respected (Leininger & Mc Farland, 2006). While it is generally agreed that cultural competence training can result in better access to and increased quality of care for migrants and ethnic minorities including sub-Sahara Africans (Sorensen, 2017).

Further, in accordance with Leininger's 'Theory of Cultural Care', This theory seeks to standardize healthcare in such a way that would be appropriate, respectful, and decent for everyone that finds themselves in a globalized healthcare system regardless of the origin of culture (ibid). An assumptive premise of Leininger's Theory of Cultural Care states that "knowledge of meanings and practices derived from world views, social structure factors, cultural values, environmental context, and language usage can be essential to guiding nursing decisions and actions in providing cultural congruent care" (Leininger, 1988). In addition, research suggests a lack of cultural competency in nursing homes and that culturally competent programming has a positive effect on treatment and quality of life of the patients, however, the question of how cultural competency impacts people with dementia and their caregivers is left still left unanswered.

In Norway for example, efforts are being implemented to better cultural awareness in the healthcare system, referred to as 'Cultural Competence' to revolutionize healthcare by incorporating, supportive, facilitative, or enabling acts or decisions that are mostly tailor-made to fit with individual's groups or institution's cultural values, beliefs, and lifeways (Leininger & McFarland, 2006).

3.4 Acculturation

The study of the processes of acculturation started at the beginning of the 20th century by three American cultural anthropologists R. Redfield, R. Linton, and M. Herskovits (1936). Acculturation comprehends those phenomena which result when groups of individuals having different cultures come into continuous first-hand contact with subsequent changes in the original culture patterns of either or both groups (Berry, 1997). Meaning, individuals generally act in ways that correspond to cultural influences and expectations (ibid). Immigrants including sub-Sahara Africans migrated to Norway via four main types of vises: Humanitarian/Refugee, skilled, student and family/spouse (Berry, 2002).

The acculturation experience of African families is limited but should be recognized as essential factor to consider when looking at health behavior and outcome of family members. Within sub-Sahara families, the father is the primary caregiver and influences the health of all family members (Berry, 2002). The elder and women in the family serve as co-consultants to the father when questions of health issues or illness are asked (ibid).

When examining and understanding the culture care meanings, expressions, patterns, and practices in the family, professional healthcare workers can begin to understand how to impact health and well-being of the elder more effectively in the various nursing homes (Leininger & McFarland, 2006). Although acculturation is a neutral term in principle (that is, change may take place in either or both groups), in practice acculturation tends to induce changes in one of the groups than in the other (Berry, 1990).

However, one of the most relevant questions pertaining to most groups of migrants is that which acculturation strategy to pursue. Specifically, this question relates to two issues: first, to which extent do they prefer cultural continuity? And second, to which extent do they have preference in getting involve and participating within the larger society by getting alone with other ethnocultural groups (Berry, 2017).

In addition, acculturation research suggest that the integrated acculturation strategy has the most favorable psychological outcomes (Berry, et al., 2006), for individuals adjusting to a host culture while marginalization has been the least favorable outcomes (ibid). For example, African caregivers adjusting to the use of nursing home facilities. When these two issues mentioned above are crossed, four ways of acculturating are distinguished: Assimilation, integration, separation, and marginalization. Understanding these four strategies is very important for the purpose of this thesis.

3.5 Assimilation

The absorption of culture and social structure of an incoming group into the dominant society is referred to as assimilation (Reitz & Sklar, 1997), meaning total acceptance of norms and values of another culture and do not wish to keep his or her own cultural identity. When one is considering dominant groups, this strategy sometimes called 'melting pot,' includes adaptation, incorporation, inclusion, integration, and acculturation (Berry, 2006). There are two forms of assimilation: 1) new immigrants change their socio-cultural structure to conform to that of dominant culture and society, (the true melting pot) 2) intermixing or blending of the dominant culture with sub-cultures of immigrants in such way, a new culture result (Reitz & Sklar, 1997).

The most common indicators often cited are language, attachments, and social system patterns. Most Africans living in Norway would have preferred to live in residential areas with same ethnic background for mutual support which further symbolizes the values of traditional African life (ibid). Living and being together, and the sense of solidarity is the basis of extended family system in Africa (Agyemang, 2014).

This guarantees individual obligations within communal a relationship including access to the extended social support and community networks, especially, when an elderly family member has dementia (Agyemang, 2014). Meaning community ties reinforce ethnic identity and help ensure stable assimilation in the new society. As Africans assimilate both in language and identity, they also sometimes un-assimilate from their own native language and birthplace to find themselves in special and unknown situation.

3.6 Integration

This acculturation strategy includes identification with both home and the host culture. This is perceived as a gap between assimilation and segregation, with its intent being cultural diversity and inclusion, instead of removing the original cultural and ethnic identities to benefit the larger system thereby trying to exclude those who are culturally different from the majority in a country (Berry, 2011). However, according to Berry’s definition, the term integration expresses an individual’s interest in retaining one’s original culture including interacting with other people in the same society. A degree of cultural integrity is maintained while seeking to participant as an integral part of the larger society (Berry, 2011).

Looking at Berry’s definition of integration, this point to a particular way of positioning oneself within a new environment characterized by belonging to a minority group, including a desire to contribute to the larger system that one is part of which is sometimes call ‘the cultural others. Interactions in society vary from impersonal relationships within economic and political institutions to more personal relationships.

In addition, Western European countries, Norway especially have a pressing need to strike a balance between equality and difference between unity and diversity as the government attempts to foster a fair and just society that includes both the Norwegians and immigrants (Eriksen, 2013). Throughout the Norwegian’s postwar history and especially under the leadership of the Labour Party, inclusion and values associated with equality have been seen as paramount (ibid).

3.7 Separation

In contrast to assimilation strategy, separation provides a rejection of a foreign culture and holding on to the original culture (Berry, 2011). Individuals wish to avoid contact with other cultural groups. Dominant groups see this strategy as an act of segregation or exclusion.

3.8 Marginalization

Marginalization strategy refers to the case where the individual is not interested in maintaining their culture as well as having less interest in relationship with other groups due to discrimination or exclusion (Berry, 2011). Such a situation arises because of lack of interest in obtaining a new identity.

3.9 Amalgamation

Cultural amalgamation; the blending of culture (Abebe, 2010). Today, we have the means to communicate with people from other countries more easily than before. Although it is physically easy to talk to someone from another country, things like language and cultural barriers make it difficult. Since the world is so intertwined, cultural amalgamation will need to occur for people with different cultural backgrounds to connect especially immigrants including Africans living in Norway.

In addition, the reasons Africans immigrants come to Norway among many other reasons, is to pursue opportunity for better life by adopt behaviors and attitudes to achieve their goals. An example of this is learning Norwegian language to become part of the Norwegian society and culture. For this to happen, it takes willingness and effort from all sides. Both parties need to be welcoming with each other. A basic understanding between individual cultures will lead to unity and acceptance (Abebe, 2010).

Expecting immigrants to completely change from what they believe especially with nursing home placement because they live somewhere different will make life difficult. The uniqueness of an individual or cultural norms is an integral part of being a human being and this should always be encouraged, respected, and embraced no matter where you come from. When this is done properly, there should be no negativity to amalgamation since it refers to the blending of cultures, rather than one group eliminating another (acculturation) or one group mixing itself into another (Assimilation) (ibid).

To add to this, I believe that humans have always left traces of their own activities in different surroundings and these activities sometimes constitute communal memory of past and present generations, ways of life many Africans including immigrants generally, constantly struggle to reconcile with and to maintain their distinctive cultural identity, with desires of not being perceived as too different from the mainstream society. Consequently, interactions are filled with the attempts to remain authentic and loyal to the identities of both their homeland and the social activities in their new homes in Norway.

3.10 Ethnic identification

Phinney (1990) identified ethnic identity to be related to an individual's identification to his or her ethnic culture and sense of belonging to that ethnic group. Ethnic identity in acculturation situations is described as a dynamic state, that is determined by three components: 1) by the degree of inclusion in the group of their cultural origin; 2) the tendency to assimilate (be included) in the group and 3) the complementary tendency to differentiate from one's own (Brewer, 1991; Phinney, 1990). In the same degree as inclusion intensifies, the tendency to assimilate decreases and the tendency to differentiate increases. Furthermore, if the tendency to assimilate increases, the tendency to differentiate decreases.

Therefore, a state of balance between the two complementary tendencies to assimilate and differentiate ethnic identity exists at an intermediate degree of inclusion (Brewer, 1991). Furthermore, acculturation may force an individual to address the aspects and degree to which one's ethnic identity will be retained. This is in accordance with sub-Saharan including the majority of ethnic minorities wanting to retain their cultural and traditional values in relation to family caregiving.

Ethnic identity can also be viewed through positive attitudes towards heritage culture, and a sense to belong to this culture, relationships with other members and acceptance of ethnic practices, for example music, language, food, and customs. In accordance with Berry's (1997) acculturation mode, individuals may choose whether to maintain their own ethnic identity or not and the state of ethnic identity could concede to different acculturation strategies. In this case some cultural values may change while some others often remain unchanged and could be called as more central and characteristic to a particular culture as in African attitude towards nursing home placement.

In most cases intercultural contact has an influence on migrants' health status. The level of acculturative stress increases together with acculturation problems. However, according to Berry (1992, 1997), acculturative stress can be avoidable. Finally, migrants who follow the assimilation strategies try to avoid conflicts between their beliefs and values, and those of the host society. The question of whether it is possible to combine two cultures has been answered affirmatively. Immigrants Africans can be, and often are, part of two cultures (Berry, 1990, 1994, & 2006).

3.11 Communication

Communication comes from the Latin word *communicare*, which means doing something in common, involving another in, having a connection with (Eide & Eide, 2007). Effective communication skills are crucial to any profession and professional duties. Ekeland (2007), points out that communication is a part of professional competence which we can learn. However, Ekeland clarifies that effective communication techniques are of little use if the other person taking part in the communication is respected and recognized as an important person in the ongoing conversation (ibid).

An important prerequisite for effective communication is that meeting must be seen as a three-part relationship, where there are two subjects interacting about an issue, which is the object (ibid), caregivers, the healthcare workers, and the nursing home (ibid).

Furthermore, communication theories express that behavior is an act of communication and that it is impossible for one not to be able to communicate with others. An important aspect of communication according to Eide & Eide (2007), is the way we communicate with one another, we are either understood or misunderstood.

Eide and Eide (2007), distinguished between two distinct types of communication: our daily communication and professional communication. With professional communication is the communication by virtue of our profession, the role we play by being a helper which in another term known as ‘helping communication’ and involves information and dialogue among other things (ibid). Another aspect of communication is face-to-face communication where both receiver and giver are communicating face-to-face about what is communicated to each other (Qureshi, 2009).

Furthermore, before communication is successful to promote good dialogue between caregivers and healthcare professionals in the nursing home, there should be certain balances between what is similar and what is different both in content and in relationship (Ekeland, 2007). The content of the message should be perceived and interpreted equally for equal understanding, and before a message can contribute to something new also, there must be an element of inequality (Ekeland, 2007).

Professional carers contribute to this inequality not only by knowledge, but through the ability to create distance through analytical reflection (ibid). The professional must also be able to listen to what family caregivers bring into the on-going conversation concerning their loved ones, without being critical in return (Ekeland, 2007).

Taking a person’ opinion seriously is like taking the other person’s opinions during discussion for reflection. This has an implication for interactions between the caregivers and healthcare workers. Through communication, we develop relationships with each other and with situation at hand. It should not be a one-sided situation (ibid).

Research studies have shown communication as an integral part of the clinician-patient relationship, especially with healthcare workers in nursing homes (Hashim, 2017). Within the context of healthcare encounters, high-quality provider-patient communication is most effective when it is bidirectional, patient-centered, and involves the use of active listening to engage patients and their caregivers understand their perspectives (Hashim, 2017).

Immigrants including African caregivers' experience with communication have been found to influence negative interactions and trust with professional healthcare workers. At the same time, challenges, such as lack of interpersonal communication, limited information and disclosure about dementia and language barriers have especially dominated the experiences of not only African community but immigrants generally when accessing healthcare services in Norway (Sagbakken, Spilker & Ingebretsen, 2020).

CHAPTER FOUR: METHODOLOGY

4.1 Introduction

This part of the thesis discusses the methods employed in this study to collect and analyze data. The study design, sampling, data collection and analysis are discussed in this chapter. Interpretative Phenomenological Analysis (IPA) is used to interpret the data collected from individual interviews. Furthermore, the chapter discusses the characteristics of the study's participants, details of the interview, coding, reliability, trustworthiness, ethical considerations, and challenges encountered in the research.

4.2 Research design

The study employed a qualitative research design. Qualitative research seeks to understand experience that is being explored, rather than to measure (Kvale & Brinkmann, 2009). Meaning that, it led to an exploratory experience, attitudes, understanding and values from the perspective of the participants. This approach is used to explore how African immigrants' caregivers experienced placement in nursing homes for a family member with dementia?'

Semi-structured individual interview was further employed to this design to find answers as to how participants experienced their everyday life with healthcare workers in the nursing homes, and a greater understanding on how they encountered challenges and barriers alone the way. It was fruitful to conduct qualitative research interviews with participants than to conduct a superficial survey aimed at a larger number of participants (Kvale & Brinkmann, 2009).

A qualitative approach means that the researcher strives to understand participants' life world based on their own terms, for example through interpretation of semi-structured interviews, participant observation or field interviews. Even if the aim is to interpret the material based on the understating of the participants' lifeworld, such a method will basically facilitate a subjective interpretation (Kvale & Brinkmann, 2009). To avoid situations where the text helps to exoticize 'the others', it is important to reflect on how one present him/herself as a researcher in the text, and how one can relates to the stereotypes that are presented to the researcher. This does not apply to the image of society's stereotypes as they are expressed but also to the stereotypes of the participants as these appear in participants' narratives (Kvale, 1997).

With the explanations given above, I could find a connection between my research aims and qualitative research framework. Therefore, a hermeneutic phenomenological approach was considered to explore this social phenomenon from the perspective of individuals within their social context. This approach leads to a constructivist rather than realist epistemology. It is situated within the interpretive and constructivist/relativist paradigms which are concerned with how people make sense of their social world and the belief that, by obtaining their subjective experiences, we can, through interpretations make sense of meanings embedded in their social world (Smith, Flowers & Larkin, 2009).

4.3 Phenomenology and Hermeneutics

Phenomenology is a philosophical approach to the study of experience (Smith, Flowers & Larkin, 2009). It has been described as both a research approach and a philosophical movement (Van Manen, 2014). The founding principle of phenomenological inquiry says that experience should be examined in the way that it occurs by its own terms and identify the essential qualities of that experience (Smith, Flowers & Larkin, 2009). There are two types of phenomenological research, transcendental or objective phenomenology and hermeneutical phenomenology. Further, the transcendental phenomenology research, the researcher separates him/herself from the study and sets aside their personal beliefs and experiences to remain bias-free (Van Manen, 2014) According to Husserl's (1927), this involves stepping outside of one's everyday experiences, (natural and attitude) to examine our everyday experience. Husserl (ibid) also suggested that we need to consider the consequences of our taken-for-gotten ways of living in the familiar everyday world of objects.

This is called bracketing and is important so that the research remain objective and is not influenced by the researcher (Husserl, 1927). Hermeneutic phenomenology is a method of textual analysis with an artful form of understanding and a process of exposing hidden meanings (ibid). Hermeneutics initially developed as an approach to interpreting Biblical text (van Manen, 2014). The key aspect of hermeneutics in the interpretation of the human experience is the consideration of the part in the context of the whole and how the whole relates to the part which enhances the depth by which the researcher engages in and understand the embedded meanings in the experience. By this, the hermeneutic phenomenological attitude uses reflection to make visible fore- meaning, horizontal of understanding, the texts alterity, and intentional character of experience as the researcher came to understand being a caregiver for elderly relative with dementia and living in a nursing home is (Husserl, 1927). In addition, hermeneutical phenomenology looks at the essential themes that are uncovered through the foundation of the lived experience being explored. This is known from individual experiences (Moustakas, 1994). implied that the unique source of our absolute existence is based on what the person thinks, feels, and perceives.

The bulk of the material from this project has been obtained through semi-structured interviews. A semi-structured interview attempts to understand themes of the lived everyday world from the participants own perspectives (Brinkmann & Kvale, 2009). In addition, this kind of interview seeks to obtain descriptions of the participants' lived world with respect to interpretation of the meaning of the described phenomena (ibid). An interview guide was then used as a tool to have an overview of topics covered and to keep a common thread throughout the conversation (ibid). But there has been room for the participants themselves to bring up topics they feel are important to the topic, but which I had not anticipated.

Field interviews can be useful for eliciting information that the researcher had no prerequisites to ask for. Field interviews are more like a normal everyday conversation, and not an arranged interview. As field interviews are not agreed upon but occur in an everyday situation, there have been limited opportunities to make use of this in the current research study. This is because there have been few situations in which it has been natural to participate in the participants' daily lives.

4.4 Research Sample and selection

Sampling must be theoretically consistent with the qualitative paradigm in general, and with IPA's orientation, this means that samples are selected purposively. Participants are described as persons who are thoughtfully selected and perceived to be knowledgeable about the topic and the domain of inquiry, which in this study is the experiences of African caregivers with nursing home placement for their elderly relatives (Smith et al., 2008).

Participants in this study were sought out through social media (Facebook, the African communities, and African Churches) and snowball sampling. Snowball sampling was chosen due to the inclusion criteria for a specific trait, African immigrants living in Norway and the difficulty in identifying this population. One limitation of this method is that all subsequent subjects will relate in some way to the initial contacts made. Therefore, it was important to make entry into the community through reliable channels, free from special interests and unknown bias.

Snowball sampling uses a networking approach where data is collected from participants, who are asked to identify and forward the letter of solicitation to other people in the community, churches and gatherings who fit the criteria for the study. This process continues until the required number of participants is gathered. Even though two of the participants dropped out later because of family issues.

Initially, six participants were selected who met the research criteria for the study and were able to describe and provide useful information about their experiences, unfortunately two dropped out of the study for personal reasons. Data was gathered from four individual interviews with each one lasting one to two hours each. A continuous process of data collection, data analysis and confirmation with participants was conducted until consistencies were revealed and information became repetitive. At this point it was determined that saturation of the data was obtained.

Table 2: Participant's demographics

Participants	**Gender**	**Person being cared for**	**Number of years living in Norway**	**Competence in Norwegian as will be defined by participants**
Alpha	Male	Mother	10	Very little
Sarah	Female	Mother	12	Average
Rebecca	Female	Father	12	Average
Kantoka	Female	Grandmother	12	Average

4.5 Research Instrument

In qualitative research, it is noted that there is a rang of instruments involve and such instruments are interviews, structured and semi-structured; focus groups, In-dept and individual interviews and participant observation. In this study, data collection strategies included the use of a semi-structured individual interviews of participants with an open-ended inquiry interview guide.

Kvale (2007) mentions that an interview should be drawn up so that it reflects the research problem of the study. My interview guide contains questions that were relevant to the research questions. Participants were also advised that the interview would be audio-taped, and data would be confidential and anonymous. False names were given to participants to protect the identities of all participants. Primary sources of recruitment were referrals from family friends, church members, Street conversation and co-workers. They all agreed to assist with the study participants by identifying potential candidates and providing contact information of the Researcher if they felt they matched the criteria and distributing letters of solicitation via emails to potential candidates. In this study, age was not an important variable in relation to the research study and therefore wanted to keep the age range wide from 30-60 years.

During the interview sections participants were asked a series of open-ended questions congruent with the research inquiry and developed by the researcher in the form of an interview guide (Appendix D). Questions were developed to be open and ended questions, to learn more from participants and reduce possible bias or etic points of view. The questions served as prompt to help the researcher during the interviews in a conversation rather than in a questionnaire format.

Table 3: Inclusion and Exclusion

Inclusion	**Exclusion**
Peer reviewed empirical papers. Qualitative papers, including case studies. Quantitative and mixed methods studies.	Non-African immigrants' peer-view journals. Opinion papers to the researcher.
Papers written in both Norwegian and English	Papers not written in both Norwegian and English.
Papers whose primary focus was the experiences/ views/ needs of family members (informal caregivers).	Papers whose primary focus was not the experiences/views/needs of family members (informal caregivers).
Paper whose primary focus was decision making on behalf of the family member with dementia.	Papers was not.

Papers in which the setting of care for the family member with dementia was a nursing home, residential care home or equivalent.	Was not a nursing home.
Age group: not necessary.	Not necessary.
Papers with sub-Saharan Africans including immigrant generally.	Papers that do not including Africans.

4.6 Conducting the interviews

The four participants had previously been sent an information letter about the project and interview questions via email (Appendix B). The interviews started with information about the study and research principles such as voluntaries, the possibility of withholding anonymity and obtaining informed consent with a signature (Appendix B). I chose to submit the interview guide to participants in advance and handed out the sheet before the commencement of the interview sections to create security around the interview sections. During the interviews, participants were active and engaged and considered the importance of such a study. They had a great need to be heard because as one of them said and I quote: *I am afraid nurse do not understand my mother when she wants tomatoes for breakfast!*

I asked a few follow-up questions, for example: *Can you say more about this? Or can you explain what you just said again? Can you tell me more about what you refer to as good care?* addition, I was constantly on the lookout for body language that expressed participants experiences, by not making any comment on the content of experiences but repenting the participant's last comments and using an active listening technique. In this way, I showed each of them recognition for their lived experiences, without influencing the interview content (Smith, Flowers & Larkin, 2009).

Furthermore, after each question, I briefly summarized by using a field diary and asked participants to confirm or deny since I followed Smith, Flowers & Larkin (2009) Interpretative Phenomenological Steps analysis. The interviews session ended by thanking each one of the participants and a reminder that participants had the right to withdraw after the interview section. But surprisingly it turned out to be productive as I expected it to be and perceived my participants as being more open and relaxed.

4.7 Data analysis

The aim of IPA studies is to gain an understanding of the social world of participant (s) and apply meaning to the experience that they have narrated during the interviews (ibid). There were several reasons for my choice or Interpretative Phenomenological Analysis (IPA) for this study. I was specifically interested in the subjective experience of experiencing nursing home placement for elderly relative with dementia and how meaning might be derived from it. Not much research has been conducted into the experience of nursing home placement with African background as a topic in contrast to several research on immigrants generally. I therefore felt it was important to explore this area of research, which would support my curiosity about what the participants were experiencing, rather than being constrained by assumptions about what I would find.

The four individual interviews were transcribed verbatim by the researcher. Listening to the tone and accent of the voices helped the researcher understand the meaning of what the participants were saying. To ensure the analysis was transparent and limit possible biases i.e., influence of the researcher's pre-conceptions. The analysis was performed by following Smith, Flowers & Larkin (2009) six steps analysis.

4.8 Applying the Interpretative Phenomenological Analysis Approach

Reading and re-reading

The data analysis was conducted as an iterative process that included multiple reading of the transcripts from the audio recording (Smith, Flowers & Larkin, 2009). The purpose of this reading and re-reading was to familiarize the researcher with the data to ensure that no errors were made while creating the transcripts (Smith, Flowers & Larkin (2009). This approach allowed the researcher to become immersed in the collected data and gain an overall understanding of the interviews. Notes were taken to focus on the central points in each interview (ibid:2009). Each re-reading can come up with new themes including deepen our engagement in the participants' lifeworld (ibid). During a second reading, comments and first impression of the contents were captured in the researcher's journal.

Initial noting

My aim here is to try and understand what participants were saying and not use what they were saying as a springboard for my own personal reflections on the topic. This is because, it is important to think about whether a particular point that participants were making seems to flow together, or whether there is a sense of disruption to that flow (ibid).

Transforming notes into Emergent Themes

Furthermore, the researcher worked more with transforming her notes into emergent themes, rather than with the transcript by trying to formulate a concise phrase at a higher level of abstraction which may refer more psychological conceptualization (Smith, Flowers, and Larkin, 2009). Nevertheless, this was still grounded in the detail of the participant's narrative. In this stage, the researcher might have been influenced by annotating the transcript which is a good example for the hermeneutic circle (ibid: 2009).

Next, the text from each interview was organized into meaningful units, which involved separating the text into words and sentences related to each other through content and context (ibid). This means practically, organizing the meaning units in themes and sub-themes. In this stage some of the themes were dropped because they did not fit well with the emerging structure. The final list comprises of four main themes such as attitude towards professional healthcare workers, Guilt-feeling towards the relatives, lack of knowledge about dementia, and language difficulty and communication. 18 sub-themes emerged from the main themes which together reflected the experiences of caregivers with nursing home placement for the elderly family member with dementia.

One basic element of exploratory commenting is analyzing the transcript to describe content (Smith, Flower, & Larkin, 2009). The descriptive comment, according to Moustakas (1994) states that in descriptive stage there is room for free imaginative fancy with reflective explication giving body, detail, and descriptive fullness to the search for essence (ibid: 1994). Essence serves here as the basis of the overall experience of interviewees (caregivers) and conflict because of nursing home placement. Finally, the researcher tried to reflect on and include textual and structural description from each interview as shared by all participants.

4.8 Ethical consideration

The protection of research participants thorough the application of appropriate ethical principles is important in all research studies. Ethical practice is a process that should be strictly monitored throughout data collection and data analysis (Smith, Flowers, and Larkin, 2009). As within any research, qualitative research requires the researcher ability to look after the research participants' physically, psychologically, and emotional well-being by ensuring that they are not at risk of any harm because of being a research participant (ibid).

The researcher conducted the study in such a way that there were minimal risks for all participants. The only possible risk that was noted were possible feelings associated with participant's caregiving including family issues of the loved ones living in the nursing homes. Participants were asked to answer questions related to their caregiving, about the reason they moved to Norway in a one hour to a one-hour individual interview.

During the preparation and cause of the research while analyzing data, the researcher was sensitive about the questions being asked in relation to the research and the possible vulnerability of each participant. Finally, previous experience has shown that the present topic can be of great interest to the public. Participants were then encouraged to contact with the researcher for question (s) if the need arises.

Ethical clearance was obtained from the Norwegian Social Science Data (NSD) (Appendix A), which states that professional conduct should be based on four principles: respect, competence, responsibility, and integrity. Data collection with the four participants commenced once ethical clearance was obtained. During the data collection process, the following ethnic guidelines were followed.

4.8.1 Information sheet and informed consent

The information sheet and informed consent form were given to potential participants. The forms were written in English to ensure that respondents fully understood the nature of the study and the content of the informed consent. The use of the English language ensured that the participants could comprehend the information and were thus adequately informed about the research in which all four participants were happy. Participants had the freedom to choose whether to participate in the study or not. Participants' agreement to participate in the study was thus obtained only after a thorough explanation of the research process. In addition, contact details of NSD, supervisor and researcher were available in the informed consent form.

4.8.2 The issue of Trustworthiness

In a qualitative study trustworthiness requires establishing credibility, confidentiality, transferability, as well as dependability, and confirmability (Smith, Flowers & Larkin, 2009). For the present study, the researcher established credibility by restating comments, statements made and responses from participants to confirm my understanding of participants experiences. I employed self-reflection to avoid biases due to personal and professional interpretations. I was mindful of my perceptions ideas, and attitudes as an African immigrant and as an expert in the field of dementia and nursing home. To address bias, I maintained reflective notes to acknowledge or recognize any prejudice or personal perspectives that may interfere with the data gathering and analysis Smith and White, 2014). I maintained my notes to document my biases, perceptions, and assumptions. Failing to recognize these factors could have impacted the study (Kvale & Brinkmann, 2009). Learning by maintaining my notes improved the study's trustworthiness throughout the process.

4.8.3 Credibility and Dependability

Credibility was ensured by adopting research methods that could elicit information about the phenomenon studied. This study chose qualitative research to understand African caregiver's experiences with nursing home placement of a relative with dementia living in the nursing home. The researcher ensured that all the planned processes were described in detail. For example, details of data collection were described.

CHAPTER FIVE: PRESENTATION OF THE FINDINGS

5.1 Introduction

This study explored the experience of African caregivers for a family member with dementia living in the nursing home employing an Interpretative Phenomenological Analysis (IPA). By employing an Interpretative Phenomenological Analysis new insights were revealed. The sample consisted of three women and one man, all from different African countries. All had a minimum educational background and little understanding of the Norwegian language both orally and written. A total of four main and sub-themes emerged: attitudes towards professional healthcare workers, guilt feelings towards the relative, lack knowledge about dementia and language difficulty in communication.

Each of these themes generated a set of sub-themes and offer an understanding to how African caregivers are experiencing nursing home placement for their loved ones. They also offer some understanding of how these experiences influence their daily lives. In cases where the same topic was described the researcher used the notation (…) to link the speech and expressions that there was a change on topic therefore the notation (…). In addition, the notation (…) helped to preserve the integrity of participants, safe guiding participants' anonymization.

Table 4: The main and sub-themes generated from the analysis

Main theme	Sub-theme
Attitudes towards professional healthcare workers	Decision-making, fear of healthcare workers lacking cultural care education, culturally appropriate care, negative perceptions of nursing homes
Guilt-feelings towards the relatives	Feeling guilty and shame, living with decision, eating and food habits and hygiene and acceptance of caregiving role
Lack knowledge about dementia	Access to dementia care, stigma in African community, traditional beliefs, and taboo
Language difficulties in communication	Language barrier, inability to express messages in Norwegian language.

5.2 Attitudes towards professional healthcare workers

Attitudes towards professional healthcare workers emerged as a fear towards healthcare workers lacking cultural care education, including culturally appropriate care and negative perceptions of nursing homes care. Caregivers mentioned that in most African culture, family members are primarily responsible for providing care and support to elderly relative in the family, the caregivers mentioned that this was one of the many reasons why it was difficult initially to place their loved ones into nursing homes. Individuals expressed how it was their duty to care for the elderly.

> *'… notice here in Norway it is very different and not understandable. It is very different from where I come from in Africa and what we do culturally. Back home the family will never think of putting our parents in care home and think about a professional worker to take care of them'* (Sarah).

Because of her limited experience with dementia before leaving her home country, Sarah tends to view the conditions of her mother differently regarding nursing home placement.

> *'… what is difficult for me is that nursing home workers are the one taking care of my father instead for me.' I do not believe they can do that, because you see we are different'* (Rebecca).

Participants described their experiences in terms of their differences between what they know from their cultural beliefs for caring to that of the nursing home where their relatives are dwelling.

5.2.1 Decision-making, fear of healthcare workers lacking cultural care education, culturally appropriate care, negative perceptions of nursing homes.

In the sub-theme decision-making, fear of healthcare workers lacking cultural care education, culturally appropriate care and negative perceptions of nursing homes, participants mentioned that the decision to place the loved ones in nursing homes was painful and culturally difficult. This means that nursing home placement is not part of their belief and up bringing in caring for the elders in the family. Despite what was expected of them, caring for the elderly with dementia in Norway was exhausting without any help from other family members. Participants talked about the difficulties it took them to make the decision for nursing home placement for their elderly relative as was expressed by Sarah.

> *'… The decision to put my mother in nursing home was a difficult one … but it helped me a lot … regards of what my family said back home to me not to … They are not living in Norway with us … I and my brothers and sisters are the ones taking care right now. We must ask for help from the health people you know'. (Sarah)*

Sarah said that the decision to place her mother in a nursing home was one of the most painful and morally difficult decisions she had ever experienced. Even though she had to do this without the extended family involved.

> *… it is difficult. But my decision helped me very much. Regardless that I come from Africa … and I am supposed to take care of my relative… I am not living in African right now, so mmm eeh … I must make a quick decision' (Alpha).*

> *'… My friend advised me to put my mother in a nursing … I did and I am happy I did it … because I now have time to do something else even though I visit her regularly. She is not happy, but she is not sad you know…' (Kantoka).*

> *'Extended family is too … important … you know but what do I do …living in Norway. One thing is important, if we were in Africa today my father will be ok … nothing to worry me … you say dementia? my big family do not know dementia. they know only sickness. Is dementia sickness?' (Alpha, Sarah, Kantoka, and Rebecca).*

Participants narrated that the pre-decision phase in caregiving is highly dependent on their cultural and personal perceptions of what they know as dementia. According to participants when the elderly relative (s) becomes more difficult and affects everyday life in the family, they had no option but to seek help. Even though the decision to move their loved ones was one of the most painful and morally difficult decisions they had even made. Thus, living in Norway without family support of the larger family evoked in them a sense of being the sole decision maker for their elderly relatives. Participants expressed their worries about the extended family network back home including the African community in Norway playing important role in the decision-making process of placing their relatives in nursing homes.

5.3 Guilt-feelings towards the relative

A theme that was conveyed by all the participants was Guilt-feelings. The shame of living with the decision after nursing home placement of their elderly relatives was described as multifaceted and a myriad of different emotions including concern over relinquishing their home care role. The feelings of unpreparedness and loneliness were great. Thus, living in Norway without the extended family around evoked in caregivers the sense of being the sole carer for their elderly ones. Even though, all carers reported a sense of responsibility and a desire to continue caring for their loved ones.

> *'I miss my aunties, uncles, and other family members. If they are in Norway I … don't think I will have trouble … they will take care of the elderly… you know. It is big, big, big challenge for me now…'* (Sarah)

> *'I do not think you can repay your parents for all they have done by bringing you up as a child. So, showing you care for them goes a long way. Not to just put them in nursing home and forget them there. I think you do what you can do at home let them know you love them' (*Kantoka).

Kntoka believed that showing love to his grandmother and being there for her in numerous ways will help her know that she is not alone in a strange place.

> *'My main concern was for the best possible care for my mom. I do not see anything bad or wrong ...you know. With placing my mother in nursing home if it is in her best interest. You see here the problem is nursing home placement is not our culture thank you' (Rebecca).*

Rebecca, in her opinion, did not have any guilt feeling for putting her mother into the nursing home. This shows that not all the participants experienced guilt-feeling. Despite improvements in most nursing homes facilities, Africans (SSA) living in Norway still tend to feel that placing their elderly family member with dementia isn't ideal for them. On the same note, could it be because of healthcare workers lacking cultural competence, lack of cultural appropriate food habits or again could it be that caregivers have to change their attitudes and believe about nursing home facilities and accept the help that they can get from the services offer in nursing homes? These remain questions that could be taken further to research on.

5.3.1 Feeling guilty, shame, living with the decision, eating and food habits and acceptance of caregiving role

The findings under this sub-theme shows that participants experienced shame, they felt guilty for sending their loved ones to the nursing home.

> *'… In our culture children or the family at large do not send the sick away to a place for others to take care of them. I would probably have tried to nurse my old relative for as long as I am able to. I grew up in a family where outsiders are not very welcome to interfere in what is going on in the family you know … I feel so guilt that she over there.' 'How do African-Norwegian immigrants' caregivers experience placement in nursing homes for an elderly family member with dementia'?* (Rebecca, Kantoka, Sarah and Alpha).

> *'It is not a question'. You know, it just comes naturally, that has been in our family a long time. We have several caregivers in the family and community'. It is our obligation, and it shows our elderly that we love them'* (Rebecca, Sarah, Alpha & Kantoka).

> *'Sister, I do not have any choice. My big family are in Africa … they do not know whether grandma is sick … I do not tell them. I tell them grandma is happy, eating well. I cannot tell them grandma is living in an old people home' me and my children together take care of grandma. But now she lives in sykehjem. I can't stop wondering what more I could do. Why is it that I can't shake the feeling that I had let grandma down?'* (Kantoka)

> *'During visits we could see that she ate half a slice of bread. They gave her coffee, what! coffee for old woman who do not drink coffee before … me I do not even drink coffee how much more my mother. I feel so guilty right now. Do you know that African people think that it is when your father or mother in her old age is misbehaving that people in the community starts to call her 'madwoman' crazy in the head or she has lost her mind' (Alaph).*

> *There was no reaction in a way, true nothing. We told them that our elders are eating too little and asked for other type of food … nurse just say ok, that they will see… because we have given different suggestions on what can be done but still the same'. No … no … no … follow-up with our older family members the way we thought it was*

> *going to be after placement. Sometimes we carry our African food that they like to eat every time we go to visit them. They enjoy it good and feel very happy* (Alpha, Rebecca, Kantoka and Sarah).

Dissatisfaction with healthcare workers was repeatedly mentioned among caregivers. Healthcare workers were often perceived as unprofessional and sometimes unhelpful to them.

5.4 Lack of knowledge about dementia care

To begin with the participants in this study had no prior understanding of dementia and its symptoms. Participants could not name the symptoms as dementia and knowledge would have been satisfactory if participants could discern appropriate health care assistance should the need have been. Overall, as the research literature suggested, participants associated dementia symptoms with normal aging, witchcraft, or madness. The four participants expressed themselves as attributing dementia to normal aging.

> *'… she is old and that is while she is behaving like that. It is not sickness. You will get old too. Will your children say you have … what it is again, dementia! will they say you get dementia?' (Rebecca).*

> *'Mother forget thinks so easily. And I think it is not good because I don't know what to do with her… I must take care of her very well… maybe ask them for help' (Sarah)*

> *I know if we were in Africa back home, she will heal because there are many witchdoctors to take of her, because when we pray God hear us'*(Kantoka).

5.4.1 Access to dementia care, stigma in the African community, traditional beliefs, spirituality and taboo

Three sub-themes were identified from the participants identifying dementia as growing old. These sub-themes were extracted from the main theme indicated dementia symptoms are perceived in traditional beliefs, stigma, spirituality, and taboo. When asked, caregiver Alpha was reluctant to elaborate on this, but later said that what was happening to his mother was caused by an ageing process and not sickness. He refused to see it in any other way.

> *'…I saw the signs of old age in my grandmother's … in my country we called it change of life into old age, or she is getting old.'* (Alpha)

Caregiver Sarah believes that her mother was suffering from a family taboo and was sent to her mother through a spiritual means (dark magic).

> *'When I notice mama was behaving funny … I say this is dark magic sent to kill her from Africa, but I was waiting to see what to do … old people home will not help her'.* (Sarah)

Caregiver Kantoka and Rebecca went on to say that they did not know what dementia is.

> *'Maybe it is head trouble, you forget everything, you walk around in circles until the traditional doctor tells you what to do, maybe taboo you know. Very bad but now she is in the old people home'*

The findings under this sub-theme shows that participants understanding of dementia varied they recognized dementia to be witchcraft and stigma symptoms, age symptom, and 'crazy' their loved ones were going through. Participants' understanding of dementia as they expressed was based on the perception that dementia is an inevitable, normal ageing and not a disease. Hiding symptoms, feelings of shame and disclosing it to a selected few were common and if disclosure did occur, only close family were told. Stigma was reported for those with memory problems.

> *'… someone has dementia, but they use to say this one has become old, ignore them. It is tradition and the way we know it'* (Kantoka)

Most African countries assumed that mental illness is because of the elderly being possessed by evil spirits (spirituality). Some viewed it as 'white person's disease' because they had not come across the condition as dementia in their countries of origin neither do they have ideas about the symptoms of dementia as it is being handled in the Western world including Norway.

Participants expressed that it was important for them as African immigrants to preserve their traditional ways of thinking, although they have adopted to the Norwegian lifestyle which included food and language. Participants further mentioned that male healthcare workers taking care of an elderly woman especially in the terms of bathing them is a tabu in their Africa culture. They mentioned that is the duty of a female cater to an elderly woman while a male take care of an elderly male unless the opposite sex are couples. They emphasized that African are straight in their culture practices, therefore, seeing anything contradicting their practice seems like tabu to them.

> *The first time my grandmother moved to nursing home she refuse to take her bath for about a week because a young boy came into bath her"* (Rebecca)

5.5 Language difficulties in communication

The largest category of challenges mentioned by the caregivers was associated with barriers due to language difficulty in communication. Participants viewed the Norwegian language as difficult and challenging between them and the healthcare workers in the nursing homes. Speaking and taking time to communicate was clearly voiced by all four participants.

'Do you know Norwegian is very hard to speak and understand? When I want to say something to the nurse, I bring my son … he speaks good Norwegian language and explain everything to me after' (Rebecca).

*'… I went to 'norskkurs' all I learn from there is how to say good morning, what is my name and plenty other things. I am tired … mother is living in the old people home … they take care of her there no worries.' I take one of my children every day. Visit mother from Tuesday to Friday and on Saturday … we talk good in our language. My mother is feeling happy when we speak our language' If I go alone, I just say yes …*yes to them (Alpha).

5.5.1 Language barrier, inability to express and communicate messages in Norwegian language

Participants expressed that they needed to have good experienced of language skills in Norwegian to communicate with healthcare workers. The participants mentioned that language problems, both spoken and written, were shown to impede understanding about the health system leading to frequent utilization of other family members, older children as interpreters when they were visiting their loved ones.

> *'… again, that feeling of anxiety and stress arises when you think you have explained to the nurse what you want them to do and how they should take care of my grandmother.'* (Sarah).

> *'All I am thinking about is the language and what I am going to say to the nurse. Look eh – eh mmmm … I hope she will talk very slowly for me to understand her because I can only try to understand slow Norwegian. … she tries to speak English to me but it was bad'* (Kantoka).

Participants expressed their deficient knowledge of the Norwegian language makes communication an important issue between them and healthcare workers in the nursing homes. They expressed that this language barrier seemed to be associated with fluency not only in the Norwegian language but also in English as the elderly relatives only remember to speak their native language (mother tongue and English) and not in the third language (Norwegian language). Participants expressed that the need for professional interpreters will be of help and was vital in working together with healthcare workers to help their loved ones instead of taking the children to interpret on their behave.

> *'The workers at the old people home make me say things repeatedly … maybe I am speaking wrong Norwegian or maybe they just don't know what I am saying. I get so tried to explain the same thing over again. It is hard'* (Sarah).

> *'But now we see that Norwegian is important if workers at the nursing home can help us get people who can translate whenever we come to visit'* (Sarah, Kantoka, Alpha & Rebecca).

These statements are consistent with the findings from other studies that reported communication and language importance for understanding health problems of immigrants (Adebiyi et al., Ogunniyi et al., 2016 Kumar, Spilker & Sagbakken, 2016).

CHAPTER 6: DISCUSSION OF FINDINGS

6.1 Introduction

With an increase in life expectancy, we can expect an increase in age related conditions, such as dementia and nursing home placement. In this understanding, the experience of African caregivers for elderly relatives with dementia becomes the corner stone to understand the challenges, needs and caregiving role that come alone with nursing home placement of loved ones. This study explored the experience of African immigrants' caregivers for an elder relative living in nursing home with dementia. The interpretative data established central aspects of the experience of caregivers, which held great importance for the participants. This chapter will discuss findings from the individual interviews in relation to the theory presented in this study.

6.2 Summary from the Results

The summary from the results yielded four main findings. When compared to existing literature on ethnic minorities few mainly on sub-Saharan Africans. The participants' views were presented under four main themes and sub-themes of attitude towards professional healthcare workers, guilt feelings transferred towards their loved ones, lack knowledge about dementia, and language difficulty in communication.

Sub-themes included feeling ashamed because of the decisions made to move their loved ones into a nursing home, fear of healthcare workers lack cultural care education, culturally appropriate care, negative perceptions of nursing homes, living with the decision, eating and food habits, hygiene, and the acceptance of the new caregiving role. In addition, access to dementia care, stigma in African community, traditional beliefs, and taboo; language barrier, and inability to converge messages in Norwegian language.

These findings were influenced by caregivers' inability to become familiar with nursing home systems before placement of their loved ones. This is in line with other research studies from countries like Norway, Denmark, Sweden, Nigeria, South African, Ghana to mention just a few (Adebiyi et al., Ogunniyi et al., 2016; Kumar, Spilker & Sagbakken, 2016). The results indicated that participants' strong feeling of obligations to take care of their elderly relatives with dementia was a strong barrier to how they felt towards professional healthcare workers in the various nursing homes (Adebiyi et al., Oguniyi et al., 2016).

Second, studies on sub-Sahara Africans reveal fear of losing respect as caregivers, tabu and shame for moving the elderly relative into nursing homes (Petersen, Venter & Hoffman, 2024).

6.3 Cultural care

Leininger & McFarland (2006), assume that people from different cultures perceive, know, and practice care in different ways by acknowledging that there are some commonalities about care that cut across all cultures of the world. Cultural care emerged among other key findings in this study. From the findings participants described how they were obligated to carry on their roles as caregivers even though their relatives were moved into nursing homes. According to caregivers, caregiving starts from the time they were born to growing up into the position of a caregiver. The fear that their loved ones might not be taken care of properly was also expressed even though the importance of the social environment in nursing homes is strongly present in other studies (Sagbakken, Spilker & Kumar, 2016).

Caregivers' attitudes towards healthcare workers emerged as a fear towards healthcare workers lacking cultural care education, including culturally appropriate care and negative perceptions of nursing home care. This poses some difficulties in how they relate to healthcare workers in nursing homes. Because most caregivers have limited experiences with dementia, they tend to view the conditions of their family members in nursing homes differently regarding how they are treated by Nurses in various placement units. They felt that their family member should be taken care of by the Nurses instead of they, the caregivers, doing the most. This brought about the sense of feelings that the healthcare workers lack knowledge culturally appropriate care. This in essence can be reflected as negative feedback by caregivers to Nurses and healthcare workers in dementia placement homes.

In addition, people's experiences and interpretations of reality are sometimes rotted in cultural contexts and the term has often been used in relation to race and ethnicity, but at the same time encompasses a wider range of similarities and differences than race and ethnicity (Sagbakken, Spilker & Kumar, 2016). Providing care for family member or community amongst Africans are researched to be deeply rooted in the cultural subconsciousness arising naturally without conscious thought (Oyetade, & Omoyeni, 2015).

In addition, transition from home to nursing home is a difficult process and this process not only narrates the experiences of caregivers but also provides deeper understanding of the reason why during this process it was difficult for caregivers to finally accept and placed their loved ones in nursing homes (Boots et al., 2015). Different studies have shown that African caregivers might be less likely to use nursing homes for their elderly relatives (Kumar, Spilker & Sagbakken, 2016). Efforts to understand why most Africans living in Norway are less likely to utilize nursing homes facilities have targeted understanding influence of culture on service utilization (Sagbakken, Spilker & Kumar, 2016). For Africans in this study culture represents the values, beliefs, customs, behaviors they grew up in and this has structured their identities in caring for their elderly relatives. Findings show participants heightened value of being able to stand in the role as caregivers for their elderly relatives despite facing controversies and challenges such as language, communication, etc. (Hanssen, 2020).

My study show that caregivers did everything in their cultural and traditional power to look after their elderly relatives for as long as possible, and the healthcare system is consulted when situations became impossible to manage and when decisions have been made with other family members before placement into the nursing homes. I would like to argue here that this might be one of the reasons why there are still few Africans including immigrants among residents in Norwegian nursing homes (Hanssen, 2020).

Furthermore, Leininger (1991) in her culture care diversity and universality theory, stated the need for professional healthcare workers to be culturally competent in providing culturally congruent care that carter for needs of the increasing diversified population. These two concepts of Leininger's (2003) 'Culture care diversity and universality', should be considered when caring for diverse cultural groups including sub-Saharan Africans. In effect, elderly Africans and their caregivers have different views as to how they view health, causes of illness and even who and how they prefer care or treatment as expressed by participants in this study. We should also remember that for many elderly people and their caregivers with immigrant background, institutional care is something new and not yet accepted in sub-Saharan region. Caregivers also do not have a clear role model to show when it comes to how they should and can relate to large care obligations, especially with the healthcare workers.

Participants described their attitudes towards professional healthcare workers as due to ill knowledge about how the system works and that the nursing homes were not setup to meet the needs of their loved ones dwelling there (Sagbakken, Spilker & Ingebretsen, 2018). With this description, it became evident that arriving in an unknown environment with different culture and lifestyle brings about fear of what is expected of them as caregivers (Berry, 2008), and fear of leaving their loved ones alone in the nursing home. Complaints from the relatives of being left alone with strange people around 'the clock', feelings of powerlessness and lack of autonomy highlighted uncertainty in the caregivers whether they have made the right decisions with placement in the nursing home. This might be another reason caregivers felt an emotional burden, as they perceive placing their elderly relative in nursing home might have been a failure.

In addition, comes the shame and humiliation of not fulfilling the special obligations that lies in taking care of the elderly in the same way that the elderly relative took care of them when they were children, thus honoring their parents as culturally and traditionally required of them (Hanssen, 2020). These principles subsequently encompass the characteristics of informal care provision for older individuals (ibid).

Participants emphasized the importance of educating immigrant communities including Africans not only about the basic information about dementia, but also its available services to remove negative attitudes towards healthcare workers lacking cultural education. In addition, concepts and values including cultural knowledge have aided several healthcare professionals in managing healthcare to diverse groups including Africans (Leininger & McFarland, 2002). According to the findings caregivers responded to nursing home placements for their elderly when they could not manage the situation anymore. It is therefore important to maintain a family perspective on care tasks in accordance with several literature and research studies on nursing homes in Norway, Norway have assumed greater responsibility for a larger number of older patients including immigrants from different countries (Kjelvik, Rokstad, Stuebs, Thingstad, Deckers, Kohler and Selbæk, 2022).

Furthermore, caregivers' involvement for their loved ones with dementia is an integral part to nursing home care, particularly in specialized dementia care homes (Selbaek, Engedal & Benth et al., 2014). Caregivers could contribute substantially to helping professional care workers understand how to provide care for their loved ones in the nursing homes (ibid). This is because allowing caregivers to participate as much as they want in the daily activities of the elderly relative will result in more positive expectations and more fully individualized care for them (ibid).

6.4 Integration

Traditional food constitutes an important element of cultural integration and is linked to regions and sensory qualities (Hanssen & Kuven, 2015). Findings from the data collected show that caregivers believe most nursing homes have not learn the preferences of immigrants including Africans food habits. Some studies have shown that traditional food constitutes an important element of integration, identity, and heritage (McAuliffe, 2022). Participants expressed nutrition was a challenge for their loved ones living in the nursing home. Participants expressed that their elders are finding it difficult to eat most of the Norwegian food offered to them and are stress when they must eat 'bread' and drink 'kaffe' or 'tea' every morning and evening.

They also expressed that serving some traditional food can improve quality of life for their loved ones. In addition, several studies have pin-pointed to the fact that serving of traditional meals in nursing homes demands extra planning and resources, knowledge about how to prepare the food, and patients' personal preference. Meals such as 'fufu', 'potatoes-green, with goat meat', 'yam porridge', 'African-fish and vegetables are meals that are not available to serves to this group of patients in nursing homes, but only Norwegian food such as 'bread', 'potatoes with tomatoes-soup' or pig-meat a few to mention, were served to them.

Relatives tell their family caregivers that they were not happy whenever they visited them and complained that they would prefer to go back to their home countries instead of living in the nursing home. One participant expressed traditional foods create a feeling of belonging and joy. Familiar tastes and smell awake pleasant memories in and boast their sense of well-being. As a part of the integration process for African immigrants' caregivers, it is important that healthcare workers understand the nutritional needs of their loved ones, as well as their preferences and perceptions related to food habits (Hanssen & Kuven, 2015).

In addition, Food is not only important for health and in physical sustenance, but it is also linked to an individual's personality, cultural, social practices, and religious beliefs, in addition to generating enjoyment. In a previous study conducted among British Bangladeshis has shown that behaviors surrounding the preparation and consumption, of ethnic food are some of the most resilient aspects of migrant culture and integration (Mu'Min Chowdhury, 2011, Berry, 2011). Although Africans immigrants' patients tend to adopt the food habits of the host country

(Hanssen & Kuven, 2015), the opportunity to have access to traditional food and preserve familiar meal patterns is deemed important.

6.5 Communication Strategy

Communication and language barriers have been said to constitute major challenges in intercultural healthcare, particularly in relation to immigrants including African patients with dementia living in nursing home facilities (Sagbakken, Ingebretsen & Spilker, 2020; Czapka & Sagbakken 2016). This has led to misunderstandings and stress when it comes to receiving information from healthcare workers and giving out information from caregivers (Hanssen, 2019). From the findings, language problems in healthcare settings were found to contribute to misunderstandings and led to serious communication breakdown between healthcare workers and participants. This has contributed and created a significant impact on delivery of appropriate cultural services to immigrants, quality of life, and effective health care in nursing homes facilities in Norway. Most importantly, studies have shown healthcare workers' lack knowledge about patient's culture in relation to care and language (Sagbakken, Ingebretsen & Spilker, 2020; Czapka & Sagbakken 2016; Hanssen 2019).

Participants expressed that they need to have good experienced of language skills in the Norwegian language to be able to communicate with healthcare workers in the nursing homes where their family members with dementia are living. Some of the participants mentioned that language problems, both spoken and written, were shown to impede understanding of the health system and confidence towards healthcare workers, leading to frequent utilization of other family members for example older children as interpreters. This language barrier was seemed not only associated with fluency in Norwegian but also English as some family members with dementia only remember to speak their native language (mother tongue) and not the second language they have learned. This brings into play the need for an interpreter, which one of the participants said was very vital in helping with his father situation.

An example of misunderstandings in communication was indicated in the findings between one of the relatives who reported to her daughter that she was served very little food and when she asked for more, she was taken to her room because the care-worker thought she had finished eating her food and wanted to be taken to her room. In addition, there are also specific norms for how to communicate and cooperate with fellow human beings regardless of which cultural background one comes from. From finding, participants expressed views about healthcare workers not understanding different cultural codes especially with communication (Hanssen, 2020).

Nevertheless, little is known about the interactions and relationships between African caregivers and professional healthcare workers in nursing homes. But at the same time, previous research found that strong ties in relationships are helpful in creating new ways of communication. The use of body language when verbal communication becomes difficult as was indicated by caregivers (Cronfalk, Norberg &Ternestedt, 2018).

Several studies have indicated that communication and language expressions are not exclusively verbal but also non-verbal (Sagbakken, Ingebretsen & Spilker, 2020). Every act from facial expressions, food, eye contact, voice tone, body language, clothing and gesture are useful means of communication and can play key roles during conversation between healthcare workers as was expressed by participants (Czapka & Sagbakke, 2016; Eide & Eide, 2007, Hanssen, 2020).

6.4 Acculturation and marginalization

African family caregivers in Norway, how well do they acculturate?

An extensive amount of literature has explored the determinants of health behaviors among immigrants generally, including acculturation. From the findings participants learn how to acculturate by developing their own strategies for handling the challenges associated with their interactions with care workers at the various nursing homes through the lens of traditional values and beliefs and sometimes from the majority groups (Ingebretsen, R. 2006; Mbanya, Gele, Diaz & Kumar, 2019).

When discussing how well African family caregivers and their elderly family members acculturate, this should be seen in the long-term outcome of psychological acculturation (Berry, 1997). Adaptation is not synonymous with acculturation, but it follows from the change. Adaptation in the context of acculturation has been defined variously, including health status, communication competence, self-awareness, stress reduction, feelings of acceptance, and culturally skilled behaviors (ibid).

According to what participants have expressed, they uphold social norms, and moral obligations as a cultural perception for family duty. Phinney et al. (2001) argues that most studies have proven strong ethnic identity combined with strong national identity as means of acculturation strategy that promotes best adaption thus leading to psychological and physical good health (Berry, et al., 2006; Phinney et al., 2001).

According to one of the participants, he had to learn to integrate himself with the Norwegian language because he experienced lower language proficiency was going to become a barrier as a core challenge to navigating the system and acquiring necessary information to help his mother. In addition, unfamiliarity with and suspicion of formal institutions, has been correlated with lower usage of healthcare services in ethnic minorities including black Africans.

Furthermore, on the basis with the concept on collectivism and individualism from a cross-cultural concept, for example, the Norwegian culture emphasis high on individualism, whereas ethnic minorities including sub-Saharan Africans, cultures place greater emphasis on collectivism, such as the welfare of one's family (Olayinka et al., 2014). As predisposing of factors, negative perceptions held by participants toward nursing home services, in terms of their quality, respect, dependability, cultural sensitivity, trust may deter caregivers from seeking them out which leads to difficulty of not coping well with integration and acculturation. Obligations towards providing care to the elderly, especially for women who are caregivers, has been suggested among other reasons. Participants believed in both their cultural values and Norwegian values in assisting them to acculturate with some difficulties.

Another important finding in the study indicates that relationship between acculturation and ethnic identity in experiencing nursing home placement, indicated caregivers feeling the push to assimilate into the new society and its social norms yet, a pull back towards their own ethnic norms was higher. The simultaneous push and pull of where to identify themselves resulted in difficult acculturation and stress in most part (Berry et al., 2006).

It is widely accepted that the best outcomes are achieved when care for the elderly is person-centered, where care is informed by knowledge and understanding of the unique needs and preferences to ease for cultural influence (Berry et al., 2006). Even though little is known about the experience of African caregivers for a relative with dementia, and families and how these transitions should be supported. The findings in food habits, hygiene and practice of spirituality are integral part for continuity as was identified by caregivers. From the findings participants' strong feelings of being obligated to care for the elderly relative was a strong barrier in seeking nursing home placement even after moving their loved ones into the nursing homes.

The findings also reveal that the caregivers position themselves both in their traditional healthcare and the dominant healthcare system by amalgamating (sammenslång) to the culture of nursing home placement. According to Berry's et al. (2006) framework of acculturation, there is evidence that proposes independent dimensions of adoption in the majority culture and maintenance of the heritage culture. However, it also seems clear that there may be many ways for African caregivers to integrate culture of healthcare into the nursing home system. This can be done by cultural competence. Being culturally appropriate, relates to underlying background knowledge to give the elderly family member with dementia the best possible health care in the nursing home.

6.5 Related stigma and ethnic identity

In African society, stigma can directly or indirectly affect family status in a larger community. Two participants expressed that being stigmatized by the African community was one of their greatest fears for which it took them long to make the decision for their relatives to move into the nursing homes. They also emphasized that this is one of many reasons that Africans families and their elderly living in Norway do not want to know more about dementia resources and how best it can help the elder. The participants further expressed that collective understanding of how stigmatization is highly concentration in their African culture. They mentioned that people tend to scare away elderly people with health problems thinking they are witchcraft or wizards. They feel that the person with dementia is connected to evil or spiritual spirit. As such, other family members and friends tend to distance themselves from the family of the person with dementia.

The participants expressed 'isolation of family' due to health problem as dehumanizing and comes with trauma. As a result, African caregivers will prefer to send the elderly relative back to African where they will be taken care of behind closed-door or in secret. The fact that family friends and close neighbors are aware of the elderly member with dementia, coupled with the stigmatization of placing the elderly into a nursing home, makes it difficult for most African families to move their relatives into nursing homes.

Goffman (1963), defined stigma as a circumstance where an individual is disqualified from society, he/she is living by excluding the person (s) from social inclusion. Findings from the collected data show that the stigma experienced was related to traditional beliefs in witchcraft and spiritual possession including negative attitudes towards the elderly family member with dementia. Participants expressed fear which sometimes led them to go into hiding to protect their loved ones and make sure that the elderly person will not be seen through the African community as being violence. It is important to underline that participants in this study have little and no knowledge about dementia. The little knowledge of dementia has had comes from their understanding that when an elderly family member begins to act otherwise from their normal way of speaking or doing things is as a result of old age or that they are going crazy or witchcraft attitude is in play.

The many challenges brought forth by dementia have created a common narrative of this disease as an inevitable loss of self, a kind of death before death (Czapka & Sagbakke, 2016). As cognitive abilities continue to deteriorate, the person with dementia may be viewed as ‘not themselves anyone’, ‘less than’, or ‘the other’. The act of stigmatization is actively discrediting and thus stripes an individual of value, effectively reducing the person with dementia to one who is tainted and discounted as was expressed by participants (Czapka & Sagbakke, 2016).

Chapter seven: Conclusion

7.1 Introduction

This chapter concludes the research study. Participants contributed and described their experiences from four main sub-themes. Even though this was a small study, the findings are noteworthy, as four of the six caregivers interviewed described nursing home placement for their loved ones at the end as a positive experience.

The main objective was to explore the experiences of African caregivers with nursing home placement for elderly relatives with dementia living in nursing homes. The findings, which focused on these experiences are important, as there has been little research carried out particularly in this area from an African living in Norway.

Below are the following recommendations which resulted from the findings, including limitations encountered during the study. Lastly the strength of the study.

7.2 Recommendations

Although there is an array of literature generally on the topic of nursing home placement for elderly family member with dementia, literature exploring sub-Saharan African caregivers in Norway is still limited. More research studies are recommended to explore reasons most Africans are not using nursing home facilities. Apart from language and cultural barriers, could there be other reasons for this? In addition, professional healthcare workers should not only be aware of their patients, but the family caregivers as well.

The study contributed to the evidence base needed in Norway but also extends its relevance by contributing to a growing global evidence base on the limited knowledge about dementia in low-and middle-income countries including sub-Saharan Africa region.

7.3 Limitations encountered during the study

Limitation refers to the aspects of a study that the researcher cannot control, and which provides the context from the findings. This sometimes influences conditions, or shortcomings that place restrictions on selected methodology and conclusions (Smith, Flowers & Larkins, 2009). The limitation of this approach is first and foremost the researcher biasness. Could there be a possibility that the researcher's perceptions or opinions impacted the findings of the study? To avoid researcher bias, I implored the use of reflexive journaling, which is the process of documenting bias throughout the data collection and analysis process (Brinkmann & Kvale, 2015).

The second limitation was the truthfulness of the participants. Meaning that it might not be possible to verify that all four participants are truthful. I made every effort to ensure that the participants were comfortable during the semi-structured interviews. Another limitation was the sample size of four.

Could it have been better to enlarge the sample size to more than four? Samples in qualitative research tend to be small in supporting the depth of case-oriented analysis that is fundamental to this mode of inquiry (Kvale & Brinkman, 2009). Despite caregivers' in-depth information about their nursing home experience, the sample size made it difficult to generalize findings. Even though meaningful data was captured from participants in this study, the sample size limits generalizability. This limitation suggests future studies with a larger sample size of nine to twelve participants to further explore the experiences of African (SSA) caregivers.

Another limitation was that the study was limited to Africans immigrant caregivers and not the elderly family member with dementia living in a nursing home in Norway. Also, the quality of this study was dependent on the access to sufficient sample of sub-Saharan African immigrants that met criteria for inclusion and could deliver comprehensive experiences with the use of nursing home facilities. To address this limitation, I adopted a purposeful sampling and snowball method. Professional healthcare workers were also not interviewed in this study.

In addition, this study was conducted from caregivers' perceptions, attitudes towards professional healthcare workers in the various nursing homes where the elderly family member are residing. Structured training is needed for healthcare workers and other healthcare personnel to enable them to recognize dementia, understand patients and their caregivers needs and support them.

7.4 Strengths of the study

The strength of this study is that participants were able to provide in-depth information about the transition into the various nursing homes facilities in assisting their elderly relatives. Previous research on caregivers with relatives with dementia and living in nursing homes have focused on immigrants generally. Therefore, the biggest strength in the current study is that the study provided a chance to look at African caregivers' experiences of nursing home placement.

Specifically, this thesis raises the question about how it is to be an African caregiver for elderly relative with dementia living and living in Norwegian nursing home.

Interviewing African caregivers was not easy, but it was far more successful than I thought before the interview. With more time, being an African myself including the experiences I have acquired over the years, it will reduce stress and tension between researchers and the participants to discuss different issues and situations. This requires interviews, practical experience from working with people with dementia especially immigrants, and theoretical knowledge on culture, migration, acculturation including cultural competence and how dementia and other illnesses affects people from different culture and their caregiving role.

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Appendix A:

Appendix B: Information Letter to Participants

Please read this consent letter before you decide to participate in this research.

My Name is Joyce Jones, I am currently undertaking a master's degree in public health study at the University As part of my study I am required to undertake a research dissertation and I wish to explore on the experiences of African caregivers with nursing home placement for an elderly family member with dementia.

What is the project about:

The experience of having an elderly family member with dementia living in the nursing home can be challenging not just to the person directly affected by the disease, but to the family caregiver and the entire family. Furthermore, the elderly member with dementia suddenly becomes the family's center of attention which leads to larger family members, including children, uncles/aunties, and so on. It is hope that through understanding of these experiences, that services will be better placed to support African caregivers and their elderly with dementia living in nursing homes. Also, this study is hoped to contribute towards improving African immigrant caregivers' knowledge about nursing home placement and dementia.

Time required:

The research will be carried out through an interview with the researcher. This will require up to two hours of your time and will be audio recorded for late review by myself and my supervisor to ensure accuracy and reliability. You will be one of four caregivers who are expected to participate in this research study. This interview can be arranged at a time and place that suits you. During the interview you will be asked approximately 15 questions related to your experience as a caregiver of an elderly relative with dementia.

Primary risk of participation is low to nothing. The main benefit of participation is in assisting in the development of support systems for African caregivers and their relatives with dementia living in nursing homes in Norway.

Confidentiality:

Efforts will be made to limit the use or disclosure of your personal information and identity by giving you an imaginary name and will not appear on any documents. Your information will be assigned a code name and any personal identifiable information will be changed to protect your identity. All data collected will be gathered with the informed consent of the participants and participants can refuse involvement in this study with no negative consequences until the research is completed. All data collected will be treated with the utmost confidentiality and participants will receive complete anonymity.

Voluntary Participation:

Your participation in this study is completely voluntary. You can decide whether to participate or not to participate. You can choose to participate and then decide to leave the research at any time. Your choice will not be held against you and the researcher can decide to remove you from the research without your approval. Possible reasons for removal including inability to participate in the study or non-compliance with the study procedures. You may also refuse to answer any or all the questions that the researcher will ask you.

Contact information:

If you have questions, complaints about this research project, you can contact the researcher Joyce Catherine jones@ntnu.no in the department of Public Health or 92329108. The project has been notified to the Norwegian Center for Research Data. If you have any question (s) related to the Norwegian Center for Research Data (NSD) assessment for this project, you can contact them by email personverntjenester@nsd.no or by telephone: 55 58 21 17. You can also contact my supervisor Professor John-Arne Skolbekken.

Appendix C: Consent Form

Research's Name: Joyce Cathrine Jones	Title: Master Study
Faculty/Department: Public Health	
Title of Study:	
To be completed by the interviewee (delete as necessary	
3.1 Have you been fully informed/read the information sheet about this study?	YES/NO
3.2 Have you had an opportunity to ask questions and discuss this study?	YES/NO
3.3 Have you received satisfactory answers to all your questions?	YES/NO
3.4 Do you understand that you are free to withdraw from this study?	YES/NO
• At anytime • Without giving a reason (s) for withdrawing?	YES/NO
3.5 Will you be willing to take part in this study which are likely to be published?	YES/NO
3.6 Have you been informed that this consent form will be kept in the confidence of the researcher?	YES/NO
Signed:	Date:
Name in Block Letters	
Signature of Researcher	Date:

Appendix D: Interview Guide Questions

Introductory questions

- Tell me a little about yourself and your family.
- When did you and your family moved to Norway?
- What type of work experience do you have from the past?
- What is your relationship with a family member with dementia?
- What was involved in your decision-making for you in becoming a family caregiver for the elderly relative with dementia?
- How do you understand the word dementia? b) what do you know about dementia?
- How long have you been a caregiver for your family member with dementia?
- Have you experienced any challenge (s) if any since you became the family caregiver?

Follow-up questions participants were aware of:

- Can you say something more about…?
- How would you like to describe your attitude towards Norwegian nursing home?
- Can you please elaborate more on the barriers to accessing healthcare services for your relative with dementia?
- What is the most important thing you do as a caregiver? a) what were the challenges you experienced? b) have any of these challenges forced you to make changes to your caregiving role? please explain c) do you have any examples?
- Why did you choose to tell me about this experience? a) was it positive or negative?
- Does placing your relative with dementia change any family values or customs?
- How can you describe your working relationships with the healthcare workers where your family member is living? a) can you please give me some examples of what you are trying to say to me?

Conclusion of follow-up-questions

Is there anything else you want to add about nursing homes or dementia that you've not had a chance to say yet you would like to add?

Appendix E: Search table

Table 5: Search table

Data base	Search word	Combination	Number of hits	Titles	Authors
JSTOR	. Elderly . Caregivers	1	1	Consideration of nursing home care placement for the elderly in South Asian families	Rahsmi Gupta (2002)
Chinihl	. African immigrants' family caregivers	1	1	The experiences, priorities, and perceptions of informal caregivers of people with dementia in nursing homes: A scope review	Alexandre E. Haper, Lauren Terhorst and Marybeth Moscirella (2021)
BMC	. Minority ethnic Groups	1	1	It is always me against the Norwegian system. Barriers and facilitators in accessing and using dementia care by minority ethnic groups in Norway	Elzbieta Anna Czapka & Mette Sagbakken (2020)
Norwegian Institute of Public Health	. Dementia and Immigrants and nursing home care	1	1	Dementia and migrants: family care patterns merging with public care services	Mette Sagbakken, Ragnhild S. Spilker (2017)
Health and Social Care online	Dementia caregivers	1	1	What do family caregivers of people with dementia need?	V. Breassan, Chiara Visintini & Alvisa (2020)
SAGE	Family caregivers	1	2	Understanding the lived experiences of family caregivers of individuals with dementia in Soweto a South African Township	Ageela Mahomed & Chrisma Pretorius (2022)
BMC	Older people living with dementia	1	2	A systematic review & narrative synthesis of the experiences with caring for older people living with dementia in sub-Saharan Afica	Purity Mwendwa, Rrian Lawlor, Thilo Kroll & Aoife De Brun (2022) – A research article

Alzheimer’s Disease International	Sub-Saharan Africa/Africans	1	1	Dementia in sub-Saharan Africa – challenges and opportunities: The global voice on dementia	Alzheimer’s Disease International (2017)