



UNIVERSITY OF KWAZULU- NATAL

AWARENESS AND UNDERSTANDING OF DEMENTIA AMONG WOMEN IN  
RURAL AREAS. HA-SEPHAPO, MOHALE'S HOEK, LESOTHO.

BY

MAMATSIE MOKHOSI

217043813

Supervisor: Dr. Nokwanda Nzuza

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of Humanities, University of KwaZulu-Natal, Howard College Campus.

## DECLARATION

I, Mamatsie Mokhosi, declare that the reported research in this dissertation, except where referenced is my original research.

Signature

Date

...  .....

...August 27, 2020.....

Mamatsie Mokhosi (217043813)

## DEDICATION

I dedicate this dissertation to my grandparents, Mapita Florence Mphale and Tlale Alexis Mphale, to my mother and aunt, Makapari Cecilia Mokhosi and Mathabo Susan Mphale and my children, Lebohang Karabo William Mokhosi and Relebohile Liteboho Winifred Mokhosi.

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## ABSTRACT

Dementia is increasingly becoming a health issue that must be prioritised in national policies. With the increased life expectancy in both developed and developing countries, there is a high percentage of demented patients as it is highly associated with ageing. However, the prevalence is higher in ethnic communities in developing countries, especially amongst elderly women. As a mental health illness, dementia is not only a public health problem but is also linked with social challenges: dementia patients are victimised and stigmatised because of the symptoms presented by dementia. The purpose of the research was to assess awareness and understanding of dementia amongst women in the community of Ha-Sephapo. It investigated measures taken by the Lesotho Ministry of Social Development in raising awareness and understanding of dementia as a whole, and explored the understanding of dementia among women of Ha-Sephapo. The research study employed both an evaluative and qualitative research design and gathered data using semi-structured interviews, with open-ended questions for the participants. From the findings of the study, it was discovered that the Ministry of Social Development is not doing much to raise awareness and understanding of dementia in rural areas and to keep older women safe. It was also revealed from the participants' narratives that little is known about dementia as a mental health condition, and that they have not linked the illness to normal ageing. This lack of knowledge puts women in danger as some of the symptoms are related to witchcraft, in the minds of the community. Therefore, the researcher recommends that more programmes should be developed, not just by the Ministry of Social Development but also by involved stakeholders, to raise awareness and understanding of dementia among women in rural areas. This will help combat the victimisation and stigmatisation of older women showing some symptoms of dementia.

Keywords: Dementia; Ageing; Elderly Women; Awareness and Understanding; Rural Areas

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# 1 CHAPTER ONE: INTRODUCTION AND BACKGROUND

## 1.1 Introduction

Lesotho is a small country landlocked by the Republic of South Africa found in the Southern Africa. It is a mountainous country, and more than 70 percent of the people reside in rural areas where more than half of the population is poor. Lesotho is classified among the Least Developed Countries (World Bank, 2012), and like many other countries that are classified as Least Developed, poverty is increasing at a very alarming rate where people live below the national poverty line. The cause of poverty is mostly linked to lack of income and employment opportunities. Therefore, most of the households in rural areas of Lesotho are headed by women as most men have left to look for job opportunities in the mines of the Republic of South Africa.

Even though Lesotho has made great progress in education by being one of the highest literacy rates in Sub-Saharan Africa, disadvantaged communities remain largely outside of the school system. This also applies also to the community of Ha-Sephapo, where most women have gone as far as primary level while some did not even complete primary school. Most women in rural areas are forced to leave school to get jobs and support their families while some get married at a very young age. In rural areas of Lesotho, caretaking is left in the hands of the women as men consider it to be more of a feminine responsibility.

This research study aimed to assess the awareness and understanding of dementia among women in rural areas. Meanwhile, evaluating the effectiveness of the Lesotho Older Persons Policy in raising awareness and understanding of dementia as a mental health condition experienced mostly by ageing people. The research assessed how the implementation of the policy had changed the perceptions of communities in rural areas towards women living with dementia.

The research study is qualitative and uses evaluation research design. The unit of analysis is women in the community of Ha-Sephapo village. The sample of the research study consists of 15 participants, and the researcher made use of a key informant to identify 12 participants. At the same time, the other two are officials from the Ministry of Social Development in Lesotho. The key informant is also a caretaker and has been residing in the community for more than ten years.

Purposive sampling was used to select the first participant in the village of Ha-Sephapo followed by snowball sampling. Data will be collected through individual semi-structured interviews with open-ended questions. To keep data secure, interviews were recorded using a tape recorder with



the participant's permission, in the case where the participant is not comfortable with being recorded, a field notebook was used to write the answers. Since the researcher is fluent in both Sesotho and English, interviews were conducted in both languages depending on the interviewee's choice and translate where necessary.

This chapter includes the background to the research study, the research problem, research objectives as well as the research questions, the statement of the problem, the significance of the research and lastly, the structure of the dissertation.

## 1.2 Background of the Study

Dementia describes the progressive, permanent condition of memory impairment, as well as other mental abilities triggered by illnesses affecting the brain (Kurrle, Brodaty and Hogarth, 2012). According to the United Nations (2015), people associate dementia with old age, and although there are many causes of dementia, Alzheimer's Disease is the most common. Globally, demographics have indicated a significant increase in life expectancies where people live beyond the age of sixty years, and it is argued by the United Nations (2015) that life expectancy will increase in the coming decades. In as much as this may be a positive indicator for developing countries, population ageing puts pressure on health systems, increasing the demand for care services and technologies to prevent and treat non-communicable diseases and chronic conditions such as dementia (Wimo, et al., 2013).

However, the U.S Department of Commerce (2007) stated that, given this transition of the increasing elderly population, there seems to be less attention given to the needs of the elderly, especially women. Therefore, to prepare the people of developing countries to age gracefully and feel safe in their old age, Dong, Chen, and Simon (2014) argue that active initiatives and policies that target the well-being of older persons with dementia are essential. The Government of Lesotho, through the Ministry of Social Development (MoSD), developed The Lesotho Policy for Older Persons in 2014, to advocate for the "observance of rights and respect to older persons. It established structures that will improve the status of older persons and their well-being while being sensitive to gender and age difference of older persons" (MoSD, 2014: vii). Section 4.3 of the Lesotho Policy for Older Persons stated that ageing is associated with mental impairments leading to discrimination and abuse by family as well as the community.

This policy section, therefore, urges the Lesotho government and relevant stakeholders to promote public awareness and understanding of mental health associated problems to combat the stigma associated with decline and Alzheimer's Disease and provide mental health services to older persons with mental illnesses and support their families. Section 4.6 of the policy aims at promoting supportive environments, which facilitate adequate care and support for older persons (MoSD, 2014). The literature indicated that it is mostly women who live longer than men (Bamford, 2011; Carter et al., 2012). Hence, women are at a higher risk of being affected by dementia and its effects since the essential hazard factor for dementia is age. According to Alzheimer's Disease International (2015), worldwide, forty-four million people live with dementia, where 61 per cent of them are women, and 39 are men.

The effects of dementia may involve things such as stigmatisation and elderly abuse. In severe cases, people living with dementia are labelled witches due to episodes caused by dementia (Prince et al., 2016). More at risk are individuals in rural areas which are characterised by a dispersed population over a large geographical area and low literacy rates, as this makes it more challenging to deliver services targeting the diverse needs of older people and their caregivers/carers (Blackstock et al., 2006). The research, therefore, aimed at assessing the awareness and understanding of dementia among women in rural areas while, at the same time evaluating the effectiveness of the Lesotho Policy for Older Persons (MoSD, 2014) in raising awareness and understanding of dementia among women in rural areas.

### 1.3 Dementia as a Public Health Issue

According to De Jager et al. (2015), dementia is a growing public health concern globally, particularly in less-resourced countries and amongst indigenous populations, with total estimated worldwide costs per year at USD 604 billion in 2010 (Arkles et al., 2010; WHO, 2012). De Jager et al., (2015) further assert that despite older age being a significant risk factor for dementia, the rising number of older adults worldwide will increase demand for diagnosis, treatment and care services for people despite dementia. The WHO (2019) indicated that almost 60 per cent of people with dementia live in low-middle-income countries (LMICs). However, people in the LMICs know very little about the prevalence of dementia or its impact on older adults living in low- and middle-income countries. Beliefs around the illness and ageing, low awareness and knowledge of dementia

and stigma prevent help-seeking for dementia care and negatively impact on the human rights of people with dementia (Batsch and Mittelman, 2012; WHO, 2017).

Older adults with dementia are more susceptible to abuse (Dong, Chen and Simon, 2014). Elderly abuse is an alarming public health and human rights issue. Among the rankings, dementia is the twentieth-leading cause of global disease burden. Dementia may have enormous social and economic impacts and impose physical, psychological and financial stress on the patients as it causes a loss of independence for them, their caregivers and family members. It is an overwhelming experience to live with people with dementia, as well as resulting in increased financial costs for the government (Dong, Chen and Simon, 2014; De Jager et al., 2015; WHO, 2019). Worldwide, dementia's health and financial impact underline dementia as a global public health priority. It requires appropriate investment and action from individual countries to ensure appropriate policies and systems are in place to support individuals with dementia and their caregivers, particularly women (Alzheimer's Disease International, 2015; Wortmaan, 2012).

Abuse of older adults with dementia is under-reported because the detection of abuse is complicated by various biological, pathological, ethnic and cultural factors. For instance, common physical signs of and reactions to abuse may be difficult to distinguish from dementia symptoms. In community settings, older adults with dementia appear to experience different types of abuse simultaneously. There are significant challenges for governments to adapt to the increasing number of people living with dementia. A comprehensive approach to public health is needed to improve the treatment and quality of life of people living with dementia and the care of their families (WHO, 2017). The comprehensive approach will, therefore, increase awareness and understanding, especially in rural areas. Also, it will reduce the stigmatisation of older women living with dementia as treatment will be improved.

#### 1.4 Outline of the Research Problem

Dhemba and Dhemba (2015) state that the population of the world is ageing rapidly, especially in low-income countries, including those in the sub-Saharan region and Lesotho is no exception. With this trend, it is compelling for most countries to deal with every aspect of the ageing population (Eide et al., 2015). Tran (in Dhemba and Dhemba, 2015) contends that population ageing is a

phenomenon found in all countries, and it is happening fastest in the developing countries. He supports this by indicating that life expectancy at birth has risen substantially across the world and it that by 2045-2050 life expectancy will have risen to 83 in the developed countries and 74 in developing countries.

Lesotho is a member of international and regional organisations that have specific declarations on protecting the rights of the elderly population. As a member state, it has to enact policies addressing the aspects affected by ageing. Such effects include mental health conditions and social security (Yenilmez, 2015). One of the effects of ageing experienced globally is dementia, which is a mental health condition and is commonly caused by Alzheimer's Disease (AD). Not many policies have been made in Southern Africa to address the issue of dementia directly. However, most countries have developed national strategies directed towards the needs of the elderly persons in alignment with the guidelines on international and regional organisations like the World Health Organisation (WHO) (Ndabeni, Mbandazayo and Hlatswayo in Dhemba and Dhemba, 2015).

Unfortunately, the Lesotho Policy for Older Persons has not shown any identifiable positive outcomes in rural areas regarding raising awareness and understanding of mental health conditions associated with ageing, especially dementia. Low levels of awareness and understanding of dementia in communities can result in discrimination, isolation and violence, especially among women. Previously conducted studies do not say much about women and dementia in rural areas. The overall purpose of this research was to realise the degree of understanding and awareness of dementia in rural areas and how this can be improved.

### 1.5 Research Objectives

Below are the research objectives that guide this research study. The research study also examines the challenges faced by the Ministry of Social Development of Lesotho in raising awareness and understanding of dementia in rural areas.

- To determine the measures taken by the Ministry of Social Development in raising awareness and understanding of dementia amongst women in rural areas.
- To explore the understanding of dementia in rural areas.
- To explore the perceptions of community members towards women living with dementia.

## 1.6 Research Questions

The research study addresses the following key questions:

- What is being done by the Ministry of Social Development to raise awareness and understanding of dementia in rural areas to ensure that the elderly are well taken care of and feel safe in their old age?
- To what extent do women in rural areas know and understand dementia as a mental health condition, especially care-takers and women approaching the age of 60?
- What are the perceptions of the community members towards women living with dementia and experiences of care-takers of older women in rural areas, and how do they react to the effects of dementia?

## 1.7 Significance of the Study

Lesotho is experiencing an increase in its ageing population. This increase in the aged population puts pressure on the health systems and social welfare as it is associated with mental health conditions. One of the mental health conditions related to age is dementia, and it is most prevalent among women. The experiences of the ageing population differ in rural and urban areas. The assumption is that there is a lack of information dissemination or assimilation due to a lack of infrastructure and the size of the geographical area. Thus, communities in rural areas lack knowledge and understanding about conditions such as dementia and mistreat older women with this condition, either by discriminating, isolating or abusing them. Hence it is essential to do this research study as it will attempt to unpack the degree of understanding and awareness of dementia in Lesotho's rural areas. Also, assess how far the Ministry of Social Development (MoSD) in the country has gone in raising awareness of the mental health issues associated with ageing. The anticipation is that the findings of the research study will shed light on the MoSD's progress, on what is known and not known about the condition, help in the evaluation of the Lesotho Policy for Older Persons, and contribute to the existing body of knowledge. The research study also recommends action to improve awareness and care for those affected by the condition.

## 1.8 Dissertation Structure

### Chapter One: Introduction

This chapter consists of the research study's background and outline. It also provides a clear presentation of the research objectives, highlighting the research study's significance and the researcher's reason for undertaking this research study. Lastly, it states how the research contributes to the existing literature.

### Chapter Two: Literature Review and Theoretical Framework

In this chapter, the definition of dementia is given, and how the Lesotho Policy for Older Persons responds to the condition is discussed. The chapter also reviews the existing literature on international and local dementia policies and discusses how dementia is understood. Additionally, the chapter focuses on the conceptual framework, which guides the research and explains the public policy implementation framework and liberal feminist theory as to how they informed the research study.

### Chapter Three: Research Methodology

This chapter discusses the research methods used to collect data for this research study. Included is the research design and data collection methods used to obtain data by the researcher. The chapter also discusses the techniques that analysed the data, the sampling methods used to select the participants and the sample size for the research study.

### Chapter Four:

This chapter discusses the outcomes and findings of the research study. It gives the results of this research study undertaken to explore the awareness and understanding of dementia among women in the rural area of Ha-Sephapo village, Mphahlele's Hoek, Lesotho.

### Chapter Five: Conclusions and Recommendations

This chapter provides the conclusions based on the previous chapter and the contribution that this research study made to the existing literature and lastly, it presents recommendations of the research study for policy improvement.

## 2 CHAPTER TWO: LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

### 2.1 Introduction

Literature review, according to Bolderston (2008) can provide a concise examination and discussion of evidence in a particular area. Therefore, literature review is essential for comparing results of earlier findings in order to determine what further research may be necessary on the chosen topic (Polit and Beck, 2007). While writing this chapter, the researcher accessed information utilising relevant books and journals from past studies using libraries and google scholar.

The literature reviewed focused on old age, policies in addressing the needs of older persons, dementia understanding, women and dementia, community perceptions on women living with dementia. The literature reviewed further highlighted on experiences of dementia caregivers and dementia in developing countries. The keywords gathered from the literature reviewed were: dementia, normal ageing, older women; dementia awareness and understanding and rural areas and caregivers.

### 2.2 Older Persons

Older persons tend to have complex needs that put them in danger of maltreatment, neglect, poverty and institutionalisation and they are also more prone to experience chronic as well as physical degeneration because of the ageing process. According to Sung and Dunkie (2009), older persons experience a variety of social and psychological issues that present new needs and challenges for the social welfare of the elderly. They further assert that older persons often rely on service providers to resolve these issues. Given the increase in health issues globally, there is a recognition of dementia and other Non-Communicable Diseases (NCD) in the political declarations of many international bodies as the essential causes of ill health contributing to the global NCD problem. Furthermore, the NCD prevention programmes and health care interventions provide equitable access to effective programmes for these illnesses (Mensah and Mayosi, 2011).

Lesotho is a member of various international bodies that promote the rights and welfare of the elderly population and urge member countries through declarations to protect the elderly through policies or acts. Some of those bodies include the United Nations, the African Union (AU) and the

Southern African Development Community (SADC). The Lesotho Policy for Older Persons was guided among others by the AU Policy Framework and Plan of Action on Ageing of 2002 and the WHO Global Action Plan on the Public Health Response to Dementia to respond to the psychological and social needs of the elderly (MoSD, 2014). To raise awareness and understanding of age-related issues such as dementia, the MoSD has opened the Department of Elderly Care Services, aimed at leading the development and implementation of the policy. It has also informed media houses, churches and other social organisations to make public the commemoration of International Day for Older Person on the 1<sup>st</sup> of October.

### 2.3 Global Action Plan on the Public Health Response to Dementia (2017-2025)

Some described the WHO's Global Action Plan on the response of public health to dementia as the beginning of a new era for people living with dementia, and it was released at the Seventieth World Health Assembly in May 2017 by the WHO. The plan identifies seven public health priority areas for dementia action, namely: (i) dementia as a public health policy; (ii) dementia awareness and friendliness; (iii) dementia risk reduction; (iv) diagnosis, treatment and care; (v) dementia carers' support; (vi) dementia information systems; and (vii) research and innovation on dementia. The Global Action Plan sets targets for each priority area over nine years (2017-2025) and requires governments around the world to commit to and prioritise all seven actions and regularly report to the World Health Organisation on their progress. According to the WHO (2017), to effectively implement the action plan on the public health response to dementia, the action is required by the member states, the WHO's secretariat, and international, regional, national and sub-national partners. The action plan (WHO, 2017: 6) clarifies that:

Depending on the national context, these partners include but are not limited to development agencies like the World Bank, regional agencies like bilateral aid, academic institutions, and research agencies including a network of WHO collaborating centres for mental health, ageing and disability. Civil society, including people with dementia, their carers and families and organisations that represent them, the private sector and the media.

The key focus of the Global Action Plan is on increasing dementia awareness to promote understanding as well as acceptance, thus improving the environment and communities in which people with dementia and caregivers live (WHO, 2017). Therefore, understanding the



conceptualisations of dementia is an essential aspect of policy development and providing culturally similar care and support to people with dementia, their family and caring professions.

The literature on dementia perceptions and beliefs and their impact on experiences for ethnic minority immigrants are significant (Mukadam, Cooper and Livingston, 2011; Sayegh and Knight, 2013; Kenning et al., 2017). However, there is currently no synthesis of the literature on dementia perceptions and beliefs and their impacts in the context of less-resourced countries or indigenous populations (Johnston et al., 2019)

### 2.3.1 Lesotho Policy for Older Persons

The Lesotho Policy for Older Persons was adopted and implemented in 2014, basing itself on the guidelines provided by the WHO Global Action Plan, and other declarations on ageing developed by the organisations of which the country is a member. The chief goal of the Lesotho Policy for Older Persons is to promote the observation of older persons' rights through the establishment of structures that will improve the status of older persons as well as their wellbeing while being sensitive to the gender and age differences of the older persons (MoSD, 2014). The Lesotho Policy for Older Persons (2014) defines an older person as anyone who is 60 years and above. Five principles guide the Lesotho Policy for Older Persons, based on the eighteen United Nations Principles for Older Persons, and they include independence, participation, care, self-fulfilment and dignity of the older persons. The policy aims to create awareness and understanding of mental problems related to ageing as a means of providing mental health services to older persons, as well as preventing the stigma attached to ageing due to dementia and related problems (MoSD, 2014).

Before the adoption of the Lesotho Policy for Older Persons in 2014, there was no specific policy for older persons in Lesotho. According to the MoSD (2014), the objectives of the Policy are to advocate for the observance of the rights and respect of older persons and to establish structures and programmes to promote their well-being. Unfortunately, however, Dhemba and Dhemba (2015) state that the achievement has not been great in terms of this policy in 2015, and the current research study will ascertain if the policy has been making more progress to date. Milne (2010) argues that such policies have a pivotal role to play, and by adopting such policies, governments acknowledge the discrimination that older people face, including those with dementia, as well as the negative impact it has on their lives and health. Improving the quality and range of services for

people with dementia and the treatment and care they receive is an essential component of addressing discrimination. There is also an associated challenge relating to supporting the carers of people with dementia. It is thus unfortunate that policy implementation is lacking in Lesotho.

#### 2.4 Dementia Awareness and Understanding

Generally, dementia is a term for a gradual progressive decline in an individual's memory and other mental abilities, or a set of brain disorders characterised by significant neurodegeneration leading to progressive loss of cognitive function, which usually starts in the later stage of life (Karantzoulis et al., 2011; Scerri, 2014; Fong, Inouye and Jones, 2017). Alzheimer's Disease and other dementias slowly steal all memories and abilities that have been learned since early life and are thus a process of progressive, permanent amnesia. Progressive brain failure characterises all dementias due to brain cell deterioration and brain cell death. As the brain deteriorates, the person's ability, understanding and behaviour go through many changes. Often people with dementia such as Alzheimer's Disease are seen as individuals with behaviour problems (McKeith and Cummings, 2005). The WHO defined dementia as:

A syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied and occasionally preceded by deterioration in emotional control, social behaviour, or motivation (WHO in Davis, 2004).

Dementia is a global public health issue that disproportionately affects, either through developing the condition or as a caregiver for someone with dementia. There is an estimation that around two-thirds of people with dementia live in their community in their own homes, with a higher proportion in LMICs (Prince, Jackson and Alzheimer's Disease International, 2009; Alzheimer's Society, 2011; Alzheimer's Association, 2014). Amongst many diverse illnesses that can cause dementia, Alzheimer's Disease is the most common, in agreement with this is George-Carey et al., (2012) who states that dementia affects one in twenty people over the age of 65. Addressing the needs of people with dementia and their family caregivers in rural areas in LMICs have to be a public health priority. Priority should be given since there are few health and social care services available, and are often difficult to access due to factors such as lack of infrastructure and difficulties associated with transport.

Erol, Brooker, and Peel (2015) argue that women need to be made aware of the assistance that is available to them through greater awareness-raising and better representation by health and social care organisations of the formal and informal services available and how to access them. Johnston et al. (2011) add that influences related to aspects of social location may have an effect when concerning the commitment of dementia services and may be reflected in the demographic patterning of patients as well as carers attending services such as memory clinics.

Over two-thirds of people with moderate to severe dementia live in their community and one third live in long term care. In total, over two-thirds of all care home residents have dementia, and one in three people aged over sixty-five will die from the condition, according to Denning and Milne (2008). Given the growing awareness that the socio-political position of people with dementia is full of drawbacks and that more has to be done to enhance consumer and carer services, the negative role of stigma has only recently been recognised (Milne et al., 2008). The disclosure of dementia presents a significant challenge because it entails emotionally charged communication about a life-threatening, incurable and stigmatised Disease that is associated with enormous societal, familial and personal costs (Werner, Karnieli-Miller and Eidelman, 2013). Stites, Rubright and Karlawish (2018) agree that dementia presents a significant challenge, as it is the only top ten cause of disability that does not have a therapy to slow down its progression.

Stigma to AD can take the form of one or more of a collection of beliefs, behaviours and attitudes. The assumptions made about AD and people with the Disease often reflect those that confirm a stereotype about symptoms of functional abilities (Werner, Goldstein and Buchbinder, 2010). These stereotypes often depict the later stages of disease when the person is most impaired and entirely dependent upon others for care. Stigma may prevent a person from finding a diagnosis, educating themselves about the condition, and engaging in research as a result of these negative expectations. It can also cause people to react negatively, such as patronising a person with the disorder, isolating them and discriminating against it.

## 2.5 Women and Dementia

Gender differences are apparent in terms of prevention and delaying the onset of dementia. In most studies, dementia is associated significantly with female sex, mainly due to their longer life span.

The above statement is conforming to nearly all the reviews in the LMIC, confirming that women are marginally more likely to develop dementia, particularly in old age based on the greater longevity in women. Despite compelling evidence of a disproportionate and distinct impact on women, gender blindness is widespread in understanding and responding to dementia (Ingram, 2016). In most countries, national dementia strategies for dealing with dementia do not include gender as a critical consideration. It is not known, the exact number of men and women living with dementia. As with all other health conditions, not everyone with dementia has seen a health practitioner, and not everyone who has sought help for symptoms has been diagnosed (Kalaria et al., 2008). By combining all forms of dementia, dementia is the leading cause of women's deaths. Dementia causes 13.27 per cent of all deaths of women of any age, according to Alzheimer's Research UK (2015), which is more than heart disease or strokes and equivalent to the number of who women die from all cancer forms. Dementia is the third cause of death for men, that is, more than twice as many women as men die from dementia (Alzheimer's Research UK, 2015).

According to Pinder (2008), physical activity and body weight seem to have a positive impact on the risk of future dementia and cognitive decline. These factors, however, do not appear to slow or reverse dementia once women reach their seventies (Godfrey and Warshaw, 2009). Mental activity such as reading, attaining higher education (Ochayi and Thacher, 2006), socialisation, and an active lifestyle have the highest potential for reducing the risk of developing dementia. Women in LMICs, however, are less likely than men to have access to education or spend fewer years in school (Ochayi and Thacher, 2006). As the population ages and the prevalence of dementia increases, in both LMICs and HICs, and adequately skilled and sufficiently large dementia care workforce is essential to meet long-term care needs (Bruckner et al., 2011; Elliott et al., 2012; WHO and Alzheimer's Disease International, 2012). As with informal caregivers, women make up over 85 per cent of this workforce for the majority of professionally paying health and social care for people with dementia (Cummings et al., 2013; Alzheimer's Association, 2014). As a result, the role of gender in dementia is increasingly recognised, with emerging evidence indicating the need to treat dementia as a global issue of women's health (Savitch, Abbott and Parker, 2015).

However, the voices of women are missing from the research and literature given that most of the people affected by dementia are women, with an estimation of sixty-one per cent of those affected being women and thirty-nine being men (Savitch, Abbott and Parker, 2015; Barlett et al., 2016).

There is a need, therefore, for all countries to understand the existing as well as the anticipated prevalence of dementia and admit that dementia disproportionately affects women (Erol, Brooker and Peel, 2015). The estimation that more women than men have Alzheimer's Disease and other dementias is mainly clarified by the fact that women live longer on average than men. Bearing in mind that and old age is the most significant risk factor for Alzheimer's Disease or any dementia (Alzheimer's Disease, 2014). Having a different view are Vina and Lloret (2010), arguing that the increased incidence in persons at ages 60- 68 cannot be attributed to the higher longevity of women versus men because, at those ages, the death rate is too low to be a significant factor in the pathogenesis of the disease. They argue that there must be a specific pathogenetic mechanism to explain the higher incidence of AD cases in women compared to men.

A possible explanation for the increased incidence of dementia in women is that they suffer higher rates of obesity, diabetes and other conditions which increase the likelihood of developing AD. Alzheimer's Disease International (2015) adds that the symptoms that women with dementia live with are more severe than those of men living with dementia and that the proportion of dementia is much higher in LMIC countries. Alzheimer's Disease International (2015) indicates that there is very little research in any context involving women with dementia as participants, which focuses on the gender issues of dementia. Much of the research about the impact of dementia on women has been conducted in higher-income countries. Nevertheless, it suggests that the problems facing women in LMICs need to be better understood, both in how they perceive dementia and how they are cared for (Alzheimer's Disease International, 2015)

## 2.6 Perceptions of the Community Members towards Women with Dementia.

Lanting et al. (2011) claim that different cultures vary in the way that people understand and behave towards dementia. Culture's behavioural dimension, which is how individuals relate to others, varies in different contexts and circumstances. The importance of understanding cultural beliefs about normal ageing and dementia is illustrated by Henderson and Henderson (2002:199), who states that the "talk of each individual about dementia reflects biomedical input and cultural understanding framed within the context of the unique circumstances and understanding of the individual's own experience". Since culture is an essential aspect of any disease's experience,

understanding possible differences in dementia perceptions and care-giving practices is crucial in providing adequate, culturally competent health care services. More attention has also been paid to perceptions of dementia as a stigma: in other studies, the general public suggests that general practitioners also consider dementia as a stigma (Cahill et al., 2008; Blay and Peluso, 2010).

Thus, understanding the composition of the general public's beliefs, attitudes, and expectations of dementia could assist in informing specific strategies to moderate stigma as well as its consequences. For instance, members of the general public are not only concerned that a dementia person faces discrimination but are also explicitly worried that a confirmatory genetic test for dementia might make a person vulnerable to discrimination by health insurance providers. This knowledge would be valuable in informing how to direct public education about specific policies (Stites et al., 2016).

According to Mkhonto and Hanssen (2018), in some developing countries, dementia is still associated with 'madness' as well as 'witchcraft', causing the affected individuals as well as their families to be in an extremely vulnerable position and stigmatised. In some instances, individuals with dementia are taken to traditional healers in an attempt to heal their condition, however (Chandra, 2006) states that this further preserves the isolation and stigma. Furthermore, Riley (2012) states that "people who have been diagnosed with dementia at an early stage indicate that dementia is a predominant concern, where the stigma of dementia seemed to be perpetuated by negative societal attitudes and misconceptions of the disease".

Dementia is not only a public health issue but also a socio-cultural issue, as the communities lacking understanding of dementia attach a stigma to it. In most cases, it is women who suffer more than men as they are labelled as witches. This labelling comes with bullying, physical abuse, or being killed (Leff, 2014). Krug et al. (2002) point out that while men are also accused of witchcraft, in many sub-Saharan societies, the low status of women "means that women are overwhelmingly the main target". Older women living alone with depression or dementia symptoms are particularly at risk of being charged with witchcraft (Ferreira and Kalula, 2009), and Hari (2009) describes this as "the hidden war against women in Africa."

De Jager (2015) argues that education is required at all levels, including communities so that people with dementia can better manage and live a life that has meaning and purpose. Severo, Gaio and

Barros (2010) add that knowledge contributes to changes in behaviours and attitudes that directly impact the health status, and relevant information can help in self-management skills essential for managing an illness. Illness perceptions have long been recognised as a crucial factor in response to symptom recognition, seeking a diagnosis, and disease self-management. For example, the perceived threat of Disease predicts willingness to seek out preventive and screening options. In contrast, beliefs about causes, course, and severity can influence coping with illness and disease self-management. In the case of AD, illness perceptions and misconceptions may hamper efforts in the areas of risk reduction and early diagnosis, making an increased understanding of public views about the Disease a priority (Roberts, McLaughlin and Connell, 2014).

## 2.7 Dementia Caregivers

Caregiving for dementia is stressful, the level of burden on caregivers is relatively high, and it is mostly family members or informal carers who care for dementia patients (Dang, Badiye and Kelkar, 2008; Collins and Swartz, 2011). On the other hand, due to rural-urban migration and the impact of HIV/AIDS on the younger population, older people with dementia have additional responsibility to care for themselves as well as grandchildren. The burden for women with dementia is even more prominent because they have other domestic responsibilities (Mushi, 2014). Without caregivers, people with dementia would have a lower quality of life and need quicker institutional treatment, and the advancing population tidal wave will sweep national economies (Brodaty and Donkin, 2009). Most people with dementia live in communities, and most of these individuals are cared for by family and friends. Patients with dementia may depend increasingly upon informal caregivers, typically close family members, to help them with activities of daily living, when displaying challenging behaviours and when facing safety issues (Allen et al., 2017).

Brodaty and Donkin (2009) state that the typical profile of a dementia caregiver is a middle-aged or older female child or spouse of the person with dementia, with the most significant proportion of dementia caregivers being spouses, followed by children and children-in-law. The Alzheimer's Association (2007) asserts that, although male caregivers are becoming more frequent in the US, at least 60 per cent of unpaid caregivers are wives, daughters, daughters-in-law, granddaughters, and other female relatives. According to the Alzheimer's Association (2007), in 2007

approximately ten million Americans were caring for persons with Alzheimer's Disease or another form of dementia and the most significant proportion of those caregivers were female.

Caregivers are facing many obstacles, as they balance caregiving with other demands, including child-rearing and careers. These demands further put them at an increased rate of burden, stress, depression and a variety of other health complications when they cannot cope with the difficulties they experience (Cassie and Sanders, 2008). Although the negative aspects of caregiving for people with dementia receive much attention, caring itself is associated with positive feelings and outcomes. Sanders (2005) reports that between 55 per cent and 90 per cent of caregivers experience positive experiences such as enjoying togetherness, sharing activities, spiritual and personal growth, increased faith, and feelings of accomplishment. Several studies report that caring for a person with dementia is more stressful than caring for a person with a physical disability. Mannion (2008) explores the physical and psychological effects of caring for a person with dementia by family caregivers, and the results revealed that a significant proportion of carers reported poor self-rated health, depression, restless sleep and decreased tolerance of pain. Hence, Roach et al. (2008) emphasise the importance of home visits by nurses to support the caregivers.

Caregivers in the developing world face a different set of challenges than those faced by caregivers in the developed world and are worth considering in intervention programmes. LaFontaine et al. (2007) assert that people from ethnic minorities, including indigenous groups, are less likely to have access to and to use mental health services because of the contributing factors such as; lack of understanding about dementia. Additionally, language barriers or other communication barriers, ethnocentric attitudes and incorrect assumptions. According to Dlas et al. (2008), most people perceive dementia to be part of normal ageing. Consequently, making families less likely to present dementia symptoms to health services, which in any case are often ill-equipped to meet their needs, especially in Low Middle-Income Countries (LMICs). As health care costs continue to soar, and the global population ages, caregivers are becoming increasingly responsible for patient care (Lynch and Lobo, 2012). The National Dementia Strategy for England (2009) identifies family carers as the most valuable resource for people with dementia, with six hundred family carers providing £8 billion per annum of unpaid dementia care in the United Kingdom alone.



## 2.8 Dementia in Developing Countries

Limited research has been conducted on dementia in Less Developed Countries (LDCs); however, lack of primary knowledge about the Disease in these countries detracts from awareness of the policy responses to dementia, as well as the management of the clinical and care burden that arises (Kalaria et al., 2008). Although dementia is a dangerous and disabling disease, its diagnosis and management predominantly prevalent in the older population is not a priority for LDCs health care systems, unlike other conditions such as cancer and HIV/AIDS (Prince et al., 2009; Kalula and Petros, 2011). In Sub-Saharan Africa (SSA), authors have found that awareness and understanding of dementia are still lacking and stigma is extensive around neurological and psychiatric diseases (Dlas et al., 2008).

Therefore, family members hide or do not report dementia cases as a way of protecting the demented family members and this could be linked to lower prevalence rates reported from developing countries (Mushi et al., 2014). Maestre (2012) adds that various factors contribute to the limited diagnosis of dementia in resource-poor areas. Kalula and Petros (2011) add that in some parts of Africa, people who have the signs and symptoms of dementia are labelled as witches, particularly older women who live alone and have certain physical features. Maestre (2012) identifies three major obstacles; low health literacy, limited access to health care and the stigma associated with dementia, with limited access to health care being a universal problem in LMICs.

Unlike Western countries, where there are special programmes for people with dementia such as memory clinics and carer support programmes (Kalula and Petros, 2011), most African countries do not have such facilities to diagnose or help those who have dementia. The majority of people living with dementia in the developing world are poor and do not have access to even primary care (Jolley and Moniz-Cook, 2009). According to Feinleib (2008), the literature indicates that health care systems in less developed countries do not have adequate capacity, both human and technological, to address the increasing demand for chronic diseases and mental health conditions, especially dementia. Sufferers are usually undiagnosed and receive inadequate support from informal carers such as family members (Paddick et al., 2013).

## 2.9 Conceptual Framework

The research study is informed by the liberal feminist theory and the public policy implementation framework to understand the factors that have contributed to the realisation or non-realisation of the policy objectives (Pressman and Wildavsky, 1973) and to evaluate the implementation process of The Lesotho Policy for Older Persons. The evaluation of policy implementation involves the examination of inputs, activities, and outputs involved in the implementation of a policy. It can also assist in the provision of important information about the perceptions and awareness of stakeholders and barriers to and facilitators of implementation (Southern California Injury Prevention Research Center [SCIPRC], 2008). Knill and Tosun (2008) state that the implementation of public policy is also the stage in the process of public policymaking where several actors and policymakers engage with each other to facilitate the implementation of public policy.

### 2.9.1 Policymaking process

Harold Lasswell initially proposed the policy cycle, or sequenced policy process, in the 1950s (Howlett and Ramesh, 2003), and others later adopted the cycle. The term ‘policy cycle’ relates to the recurring pattern of processes that eventually lead to the formulation of public policy (Savard and Banville, 2012). Progress through the policy cycle is deliberately iterative (Freeman, 2013) in the sense that policy operations are recurring, and tools are repeatedly used to address the urgent issues efficiently. Policies are developed through a policy process involving stakeholders in the institutional development of new or modified policies (Maetz and Balie, 2008). According to Knill and Tosun (2008), policymaking is characterised by multiple constraints, such as time and resources shortages and public opinion. The existence of different policy processes and an endless cycle of decisions and policies whereby the last stage leads back to the first stage, indicating a continuous and infinite policy cycle (Mwije, 2013).

Everett (2003) states that the policy cycle is a mechanism to help the manager of the public sector smooth a complex policy process as well as to inject consistency into the process. Thus, providing a useful heuristic for breaking policymaking into different units to illustrate how the implementation of policies takes place (Knill and Tosun, 2008). The policy cycle has five main stages: agenda setting, policy formulation, public policy decision making, policy implementation,

as well as policy evaluation (Howlett and Ramesh, 2003). Other scholars like Dye (2008) treat problem identification as a separate stage.

### 2.9.2 Problem identification

The first stage of a policy cycle is to identify public issues requiring intervention. Societies are facing a vast number of socio-economic and political problems that need resolutions to improve lives. Identification of problems takes when individuals or groups, such as mass media, interest groups, citizens' initiatives and public opinion make demands on government (Dye, 2008). The need for a new policy or new policy provisions within an existing policy is identified and confirmed using the heuristic policy cycle to guide the policy process (Freeman, 2013). Through publications, social issues are recognised and prioritised, mainly using the media, but mostly depending on public demands that require intervention (Mwije, 2013).

### 2.9.3 Agenda setting

Once the issues are recognised, public attention is attracted, compelling government officials to react to the discussion agenda (Dye and August, 2008). Agenda setting is a process by which problems and alternative solutions gain or lose the attention of the government or elite attention (Birkland, 2017). It represents public issues that are selected and acknowledged in the political system by decision-makers. Stone, Maxwell and Keating (2001) claim that it is possible to identify two distinct elements of the setting of the agenda; the public agenda and the official agenda, the public agenda relies on public views. In comparison, the official agenda depends on decisionmakers or representatives and politicians in any government segment or level (Cobb and Elder, 1972). Consequently, the setting of the agenda can be either bottom-up (by public opinion) or topdown (by authorities or elites).

Howlett and Ramesh (2003) argue that setting the agenda is not automatic. It includes creating public interest in an issue that makes it a socially constructed process, whereby actors and institutions affected by ideologies play a significant part in choosing what issues are to be decided and resolved by the government and is mainly determined by elites (Savard and Banville, 2012). Hill and Varone (2014) add that the agenda-setting describes how important actors functioning within a specified institutional framework can push one policy issue to the front line of an extended range of other issues that a given state wants to address.

Many societal issues need attention; however, there is scarce room on the agenda of public policymaking; hence some agenda-setting includes prioritising non-decision and decision-making and choosing those issues that need immediate intervention (Stone, Maxwell and Keating, 2001; Dye, 2008). It is at this stage of the policymaking that most of the policy choices never get any further; that is, agenda-setting results in a selection between diverse problems and issues (Stone 2017). Knill and Tosun (2008) also add that legislators and executives will give few issues, proper attention, and policy will be formulated depending on those issues decided on the agenda (Baumgartner, 1993). Therefore, it is essential that the issue captivates governments and public attention to compel action, as not all current problems receive the same amount of attention and some are not acknowledged at all (Benoit, 2013).

#### 2.9.4 Policy formulation and adoption

Howlett and Ramesh (2003) describe policy formation as a process of defining, considering and accepting or rejecting alternatives for addressing public issues. As soon as the attention of the government is awakened, the research's focus is on finding a solution to the public issue (Stone, 2017). At this stage of a policymaking process, concrete and detailed actions on how to address an issue are debated and discussed. It is also in this stage of the policymaking process that stated problems, proposals and demands are altered into government programmes (Dye, 2008). Dye (2008) points out that policy formulation takes place in governmental bureaucracies; parliamentary committee rooms, meetings of special commissions and policy planning organisations, otherwise known as 'think tanks'. Usually, these organisations are established as non-governmental organisations (NGOs), but some are either semi-governmental agencies or units within the government (Stone, 2017).

#### 2.9.5 Policy legitimisation/ decision making

Decision-making is the process through which governments act or decide not to act, choosing among a relatively small number of alternative policy options to resolve public issues (Howlett and Ramesh, 2003). Possible alternatives designed in the policy formulation stage are legalised as policies but are much more dependent on the public, interest groups, and agencies or organisations accepting these proposed solutions (Mwije, 2013). It is at this stage of the policy process where a

proposal is selected, and its political support developed. The proposal is then passed into law, and its constitutionality decided upon, resulting in its adoption after the policy decision has been acknowledged and constitutionalised (Dye, 2008). Unlike the earliest decision-making stages, the final adoption of a policy alternative is determined by government institutions that are affected by many factors under which key policy actors operate (Howlett and Ramesh, 2003; Knill and Tosun, 2008).

#### 2.9.6 Policy implementation

Implementation is a significant stage in the process of policymaking. It relates to the execution of a law, in which different stakeholders, as well as organisations, work together with the use of procedures and techniques to implement measures to achieve objectives (Stewart, Hedge and Lester, 2008). Paudel (2009) claim that policy implementation is considered as the process of carrying out a government decision. Implementation is regarded as a process, output and outcome, involving certain actors, organisations and techniques for control. It is also a process of interactions between setting goals and the actions directed towards achieving them Khan and Khandaker, 2016).

According to Van Meter and Van Horn (1975, pp. 445-488):

Policy implementation encompasses those actions by public and private individuals (or groups) that are directed at the achievement of objectives outlined in prior policy decisions. This includes both one-time efforts to transform decisions into operational terms, as well as continuing efforts to achieve the large and small changes mandated by policy decisions.

A choice is made through the application of government directives, and then later challenged with reality (Savard and Banville, 2012). At this point, resource allocation and assignment of duties are essential in achieving policy efficiency and effectiveness and are two reasons why policy implementation often needs the bureaucracies to develop official rules and regulations. Organisations and agencies are formed to translate laws into operational rules and regulations through systematic monitoring of activities and resources (Dye, 2008). Implementation is purely technical and therefore exposed to rapid change, and it involves much more than merely implementing previous decisions or matching goals with means (Howlett and Ramesh, 2003). Bureaucrats make policy as they participate in the tasks of implementation, creating laws and

exercising their discretion (Dye, 2008). Thus, according to Knill and Tosun (2008), the success of the policy depends on the extent to which bureaucratic structures implement government decisions; otherwise, all policies are destined to fail.

#### *2.9.6.1 Approaches to policy implementation*

##### *2.9.6.2 Top-down approach*

The Top-Down model of implementation, as stated by Mazmanian and Sabatier (1983); Brynard and Erasmus (1995); and Sabatier (1986 in Cloete and Wissink, 2008) they view implementation actions of officials and target groups as being consistent with the objectives embodied in the authoritative decision located at the central level of government. This view typically begins with the central government's authoritative policy decision (Sabatier, 1986). Top-down theorists like Van Meter and Van Horn (1975) claim that for the effective implementation of policy objectives: clear and consistent objectives should be set; there should be adequate causal theory; the process of implementation should be structured legally to improve compliance by implementing officials and target groups (Khan and Khandaker, 2016); officials implementing the policy should be committed and skilled as their commitment to policy objectives, and their ability to use accessible resources is vital (Lipsky, 1971); interest groups should be supportive; and finally, there should be changes in socio-economic conditions which do not significantly undermine political assistance or causal theory.

According to Elmore (1979); Hjern and Hull (1982) and Hanf (1982), the fundamental defect in the top-down approach is that key decision-makers' view tends to ignore other actors. The topdown approach to implementation assumes that the policy decision-makers, namely the statute, are the main actors and that others are impediments, which in turn leads top-downers to neglect private sector strategic initiatives from the street-level bureaucrats, or local implementing authorities. It is criticised for being difficult to use in situations where there is no dominant policy law or agency, but rather a multitude of governmental directives or actors and none of them is preminent. Moreover, this is often the case, especially in the delivery of social services. Lastly, it is criticised for being likely to disregard or at least underestimate the tactics employed by streetlevel bureaucrats and target groups to move around policy or divert it to their ends (Weatherly and Lipsky, 1977; Elmore, 1978; Berman, 1978).

### *2.9.6.3 Bottom-up approach*

A bottom-up approach is mainly a reaction to the top-down approach, based on identifying its flaws and proposing solutions to solve them (Cloete and de Coning, 2011). Hjern and his colleagues created this approach; they dedicated themselves to training the workforce, involving a variety of government and private organisations. It focuses attention on the formal and informal relationships that constitute the policy subsystems engaged in policymaking and implementing (Howlett and Ramesh, 2003). According to Paudel (2009), this approach has as its starting point a problem in society, and the focus is on individuals' behaviour. Hence street-level bureaucrats are at the centre of the political process as bureaucrats have a better understanding and knowledge of what clients need as they who have direct contact with the public (Lipsky, 1980; Winter, 2003).

In contrast to the top-down approach, which begins with a policy decision, and focuses on the achievement of its objectives over time and why. The bottom-up approach of Hjern (1987) begins by defining the network of service delivery actors involved in one or more local areas, asking them about their goals, strategies, operations and contracts. The contacts are used as a tool to develop a network technique to identify the local, regional and national actors engaged in the planning, funding and implementation of the appropriate governmental as well as non- governmental programmes, offering a mechanism for shifting from (the bottom) street-level bureaucrats to the top policymakers in both the public and private sectors (Hjern and Porter, 1981; Hjern and Hull, 1985; Hjern et al., 1987).

### *2.9.7 Factors influencing implementation success*

In terms of policy implementation, success means achieving the anticipated functionality needed by an identified stakeholder (Giacchino and Kakabadse, 2003). According to DeGroff and Cargo (2009), policy implementation is a change process characterised by multiple organisations and shaped to some extent by administrative practice but also influenced by politics. Successful implementation requires the implementation of a policy to be executed in such a way that it will produce results, and attain the goals as well as the objectives of the policy. Therefore, if the policy is implemented effectively, the design and planned development goals and objectives are attained (McConnell, 2010; Ungwuanyi and Chukwuemenka, 2013). Anderson et al. (2011) indicate that at any point in the implementation process, a policy is practical if the elements for carrying out the

policy directives are present and functioning and these elements include people, resources and organisations. Thus, policy success, according to Van Meter and Van Horn (1975), relies on how well the bureaucratic structures implement government decisions and the characteristics of the implementing agencies including economic, social and political environmental factors and the disposition of the implementers. Successful implementation is a strategic action taken by the government to deliver the policy decision designed and to attain intended outcomes.

#### *2.9.7.1 Availability of funding and resources*

The availability of funds, according to Pearce, Robinson and Subramanian (2010), includes tangible and intangible assets as well as organisational capabilities. These consist of staff and skills information, authority and sanctions, and physical facilities and equipment which affect the efficiency and effectiveness of policy implementation (Ugwuanyi and Chukwuemeka, 2013). Although funding alone does not generate success, other aspects of an implementation strategy are often unable to be mobilised without it, meaning access to available funding and resources is, therefore, a requirement for successful implementation (Signe, 2017). Additionally, stable funding is a requirement for successful implementation according to Durlak and DuPre (2008) and to effectively implement policies. The implementing agency requires resources in an appropriate and timely manner. In any case, inadequate financial resources have resulted in situations where policies cannot be enforced, and lack of service provision and reasonable regulation not developed and implemented (Makinde, 2005). Sometimes, though governments give out enough funds, corrupt activities within public bureaucratic organisations do not allow for their judicious use to effectively implement policy programmes, which then results in policy failure (Ugwuanyi and Chukwuemeka, 2013).

Brynard (2009) argues that continued successful policy implementation often involves substantial financial, institutional and technical inputs. Therefore, public organisations are inclined to look for resources and project finance elsewhere. Developing partners such as private institutions or NGOs is one way to address the resource challenge. In this regard, successful policy implementation often results from a high level of co-operation and a realisation that each party has a stake and interest in the other (Luthuli, 2007).



### *2.9.7.2 Stakeholder involvement and cooperation*

Another external factor that policy-makers must take into consideration while formulating and implementing public policies is international public opinion. Any public policy to be initiated must comply with international norms, values and standard (Aliyu, Alabi and Adeowu, 2018). Abubakar et al., (2013) stresses that, regardless of how public policies are, they must not violate human rights, the rule of law, good governance, transparency, budgetary planning and economic reforms. Any public policy made in defiance of the above invaluable democratic components may warrant the country being sanctioned or isolated by the international community (Kech, 2014).

### *2.9.8 Critical variables for studying policy implementation: the 5-C protocol*

According to Brynard and De Coning (2006), policy implementation is essential in developing and developed countries. However, there are different practices between developed and developing countries. Even though the implementation process is complicated, scholars in different countries at various levels of economic development have identified standard variables that are critical for policy implementation. There are five essential variables for studying policy implementation; they are referred to as ‘the 5-C protocol’ by Cloete, Wissink and De Coning (2006), and they comprise of the content, context, commitment, capacity, and clients and coalitions. It is worth remembering that when implementing a policy, the five critical variables are interlinked and affected by others based on the scenario and conditions under which the policy is being implemented (Wittrock and De Leon in Cloete and Wissink, 2000).

#### *2.9.8.1 Content*

The original typology of policy content is provided by Lowi (1963), who characterises policy as either distributive, regulatory or redistributive. In general terms, distributive policies create public goods for the general welfare. Whereas regulatory policies specify laws of conduct with sanctions for non-compliance, and redistributive policies seek to allocate wealth or authority to specific groups at the cost of others (De Coning, Cloete and Wissink, 2000; Jewett, Anderson and Gilchrist, 2005). Critical points about this assertion by Lowi is that policies determine politics and that “the most significant political fact is that governments coerce” (Lowi, 1963:181). The amount of and the extent to which the government coerces communities and societies determines what then

becomes the policy content. There are different means of power that the government uses to force, such as those that are remunerative or regulatory (Ahmed and Dantata, 2016). The significance of policy content is not restricted to the means used to attain the policy objectives alone; the way the goals are determined and achieved are as vital as achieving the policy objectives (Cloete and De Coning, 2011).

Cloete and De Coning (2011) assert that policy implementation is influenced by the interest that affects a policy's content, to the extent that the policy implementation seeks to bring about changes in social, political and economic reforms. Therefore, those whose interests are threatened by such policies are bound to oppose it, and those who stand to benefit are bound to push for such policy, and this sometimes leads to a dispute and competition and can make implementation more problematic (Egonmwam, 2009). The main focus of this research study is on the Lesotho Policy for Older Persons, which is distributive. One of the aims of the Lesotho Policy for Older Persons is to raise awareness and understanding of dementia as a mental health issue, especially in rural areas, while acknowledging gender and age differences, and the policy has detailed strategies on how it aims to implement its objectives.

#### *2.9.8.2 Context*

Policies are not developed and implemented in context-free environments; that is, some policies address specific areas such as economics, politics, social and legal settings (Brynard, 2005). Public policy implementation comprises of numerous actors at numerous levels, each having an interest in the programme. Thus, the power base and strategies of actors engaged in the implementation of a policy can have an impact on the course of its implementation. The characteristics of the different institutions and regimes, as well as the people's compliance culture, correspondingly affect the implementation process and response of the people towards policy implementation (Egonmwam, 2009). O'Toole in Cloete, Wissink and De Coning (2006) puts it sufficiently when implying that, implementers should pay attention to challenges that arise from the contextual influences, which have an impact on the effective implementation process, and the passages which implementation go through. They argue that such challenges reflect the realities of the systems which shape the policy and its implementation.

Sometimes implementers need to bargain and accommodate different perceptions to build effective working relations to allow for a successful implementation process (Brynard, 2005). In the context of this research, The Lesotho Policy for Older Persons aims to protect the rights and dignity of the elderly; thus, it is a social policy. Therefore, it is primarily affected by the economic, political as well as legal settings of Lesotho.

### *2.9.8.3 Commitment*

Commitment in this context refers to an apparent political and administrative will to implement a policy. That is, the support from the political elites for the implementing agency is very important in policy implementation (Egonmwan, 2009). The quality of interest, commitment and support from implementers or actors, as argued by McLaughlin and Scott (1978), determines the success of policy development as well as its implementation. Kech (2014) argues that there will be a lack of commitment to the policy implementation process if the elected or appointed representatives are adversely affected by the policy. Usually, when the government establishes feasible policies for the state, the faction that holds the highest rank of government is guaranteed at any point in time to frequently frustrate the implementation process of well-formulated policies (Akinwumi, 2010).

Therefore, any policy that is not in alignment with the interests of the actors or implementers is bound to be opposed. In contrast, supportive behaviour of political elites for the policy implementing agency may imply accessibility to resources and a possibility to successfully implement a policy (Hussein, 2018). Sharing the same sentiments is Kech (2014), stating that the success of policy implementation can also be affected by the implementer's attitudes and behaviours, which is referred to as the 'political will of the implementers'. In the implementation of the Lesotho Policy for Older Persons, with its focus on raising awareness and understanding of dementia through the Ministry of Social Development. The lack of commitment by the officials, other involved ministries (Ministry of Health and Ministry of Gender). Both international as well as local actors, for instance, Help Age International, Maseru Women Senior Citizens' Association and Dementia Lesotho can affect the implementation of the policy adversely.

#### *2.9.8.4 Capacity*

The capacity of the public sector, as viewed by Mukamunana and Brynard (2005), could generally be regarded as the structural, functional and cultural ability to deliver the necessary services. The success of public policy implementation is therefore subject to the civil servants' professional skills, interest and attitudes (Brynard, 2005). Therefore, these office-bearers, including managers and supervisors, are appointed based on their ability to manage or supervise the duties of those reporting to them (Cloete and De Coning, 2011). Public servants' ability to deliver public policy should not be based solely on party affiliations, but also on the expertise and knowledge of the policies involved. The reason is that the capacity to implement a policy includes both tangible resources as well as intangible requirements. The intangible capacity to implement implies the political, administrative, economic, technological and social environment in which action is taken and should be concerned with or beneficial to successful implementation (Brynard, 2001).

The core focus of this research is on the institutional capacity of the Ministry of Social Development in Lesotho in implementing the Lesotho Policy for Older Persons in raising awareness and understanding of dementia and the effectiveness of mechanisms for monitoring and evaluation that are in place to oversee the process of implementation

#### *2.9.8.5 Clients and coalition*

Cloete, Wissink and De Coning (2008) assert that for effective policy implementation, and in the interest of efficiency and efficacy, the government must join coalitions of interest groups, opinion leaders, actors and parties who support a policy implementation process. That is, the influence of external influence must be taken into consideration, and Rein and Rabinowitz in Cloete, Wissink and Coning (2008) alert that power shifts in the implementation process should be observed. It is essential to determine the external forces as they could be favourable or unfavourable, as unfavourable influences could impede the implementation process and lessen the effect that the policy may have (Cloete and De Coning, 2011). It is, therefore, necessary to identify those stakeholders with whom coalitions should be established that can have an impact on policy implementation. Also, to be cautious of the policies adopted as they do affect not only the public but also have a direct or indirect effect on several actors who actively support a specific implementation process (Magoro, 2010).

### 2.9.9 Liberal feminism

The feminist theory offers a perspective for understanding human behaviour in the social environment, by centring women and issues that women face in contemporary society. Feminism reflects a world view that values women, and that confronts systematic injustices based on gender (Chinn and Wheeler, 1985). Liberal feminism, therefore, is mostly associated with the rights of women, as in access to education, the right to vote, the economic independence, citizenship and other issues of equality (Saulnier, 1996). Many women benefit from the strategies of liberal feminism and its focus on the public lives of women. Liberal feminists point out that society violates the value of equal rights in its treatment of women, primarily by restricting women as a group, rather than treating women as individuals. They argue that women should have the same rights as men.

In liberal feminist theory, Rossi (1970) argues that through legal as well as political avenues of the mainstream, women are capable of changing laws and politics to attain gender justice. Liberal feminists' emphasis is on the importance of an ideal state that respects all its citizens, where the rights and opportunities of women and men are equally granted and protected (Sarikakis et al., 2014). Barlett et al. (2016) state that in matters concerning people with dementia, gender is an ignored dimension in public discourse, in that people living with dementia is typically represented in policies in gender-neutral terms as 'people with dementia' as it gender does not matter who is affected. According to Bowen and Wyatt (in Sarikakis et al., 2008), feminism is concerned with women's lives and how knowledge is generated and legitimated. Wright and O'Connor (2018) state that political, economic and environmental aspects are addressed sparsely throughout policy documents. Politically, most people talk about the importance of treating dementia as a priority for public health, and economically there is always a need for substantial financial investment in documents. However, there is no articulation of how investment can be raised or made available and how its distribution across different areas will take place. Calls for political action and monetary investment assume that there are political will and financial means to invest in dementia care, whereas these are rarely demonstrated (Wright and O'Connor, 2018)

## 3 CHAPTER THREE: METHODOLOGY

### 3.1 Introduction

The main objective of the research study was to explore the awareness and understanding of dementia in rural areas. Therefore, the appropriate way to explore this was through collecting primary data qualitatively so that the extent of dementia understanding and awareness could be explored in-depth, instead of using secondary data and a quantitative method of collecting data. This chapter discusses the research design and research methods used to conduct the research study. In the discussion, the research sample, sampling technique used to identify the participants, validity and reliability, ethical issues considered during the research study and the research's limitations will also be included.

### 3.2 Research Design

Research design is tied in with discovering things systematically, rather than research which is just about discovering things, and if appropriately arranged, whatever discoveries are made should be valuable and contribute to knowledge. According to Rugg and Petre (2007), a research design is a framework that is created to seek answers to the research questions used. Selltiz et al. (in Akhtar, 2016) define research design as the arrangement of conditions for the collection and analysis of data in a way that intends to combine significance with the research purpose with economy and procedure. Akhtar (2016) adds that research design not just foresees and determines the vast choices associated with completing data collection and preparing an analysis; it also shows an intelligent reason for specific decisions. Research design is crucial as it makes possible the smooth sailing of the numerous research processes and stands for advanced planning of the methods to be adopted for data collection and analysis (Kothari, 2010). Therefore, the research design helps the researcher to organise ideas in a form whereby it will be possible to look for errors.

This research study is evaluative as the primary research question was to assess the awareness and understanding of dementia among women in rural areas and at the same time evaluated the effectiveness of The Lesotho Older Persons Policy in raising awareness and understanding of dementia in rural areas amongst women. According to Babbie and Mouton (2001), evaluation research refers to a research purpose rather than a specific research method, of which that purpose is to evaluate the impact of social interventions and is appropriate whenever there is the planning

of some social intervention. It is also defined by Rossi and Freeman (1993) as the systematic application of social research procedures for assessing the conceptualisation, design, implementation and utility of social intervention programmes. Evaluation research is the process of determining whether a social intervention has produced the intended result.

### 3.3 Research Setting

The research study was conducted in a rural village of Ha- Sephapo, which is found in the district of Mohale's Hoek, Lesotho. The village consists of dispersed households of which most are headed by women as men have left for employment to the Republic of South Africa. Some of the households were said to have been left unoccupied for more than a year, as the family has relocated to the urban areas to have access to better opportunities. The village of Ha-Sephapo is about 17km for the main road and about 40km to Mohale's Hoek. Women who reside in this village are married Basotho women and are taking care of their in-laws. Most women have gone as far as primary school while some did not even complete primary school.

### 3.4 Methodology and Methods

A research methodology, according to Reid, Greaves and Kirby (2017), is a set of rules and procedures about how research should be conducted. They argue that, even though there are many methodologies articulated in the literature and the vast and growing body of literature, most research methodologies fall into one of two categories: qualitative and quantitative. This research study used qualitative research methods to collect data as it aimed at exploring the extent of awareness and understanding of dementia among women in rural areas. Mertens (2014) asserts that qualitative methods are used in research that is designed to provide a clear description of a specific programme, practice or setting.

Cohen and Crabtree (2008) argue that qualitative research occurs in natural settings. It attempts to make sense of or interpret phenomena in terms of the meanings people bring to them, often requires multiple methods, is grounded in lived experiences of people and is naturalistic, emergent and evolving (Babbie and Mouton, 2001). Qualitative researchers are concerned with how people think and act in their everyday lives (Denzin, 2012; Rallis and Rossman, 2012; Creswell and Poth, 2018).

According to Denzin and Lincoln (2011), qualitative research involves the use and compilation of a range of analytical resources, such as case studies, personal research, experience, introspection, life stories and interviews describing routine as well as challenging moments and meanings in individuals' lives. Maxwell (2012) indicates that qualitative research methods allow for the inclusion of participants' differences in beliefs, and social, cultural and physical contextual factors that affect casual relationships. The goal of qualitative research is to examine how things look from different vantage points (Taylor, Bogdan and DeVault, 2015).

Qualitative research differs from quantitative research and mixed-method research in that in qualitative research; the researcher collects open-ended, emerging data with the primary intent of developing themes from the data. While in quantitative research, the researcher employs strategies of inquiry such as experiments and surveys and collects data on predetermined instruments that yield statistical data. The mixed-method research uses strategies of inquiry that involve collecting data either simultaneously or sequentially to understand research problems and data collection best. It also suggests a gathering of both numeric information as well as text information so that both qualitative and quantitative information is represented in the final database (Creswell and Creswell, 2017).

### 3.5 Sampling and Sampling technique

Sampling, according to Babbie and Mouton (2001), is the process of selecting observations and in agreement with this definition are Landreneau and Creek (2009), they define sampling as a selection of a sample of the population in the researcher's research area which will be a representation of the whole population. Therefore, a sample is a subset of the people, selected to be representative of the broader population. According to Acharya et al. (2013), sampling techniques are broadly classified into probability and non-probability sampling. They indicate that probability sampling allows the investigator to generalise the findings of the sample to the target population. A sampling frame is crucial in probability sampling because if the sampling frame is not drawn appropriately from the population of the interest. Random sampling from that frame cannot address the research problem and generalisations can be made only to the actual population defined by the sampling frame.



The goal of the researcher was to interview 20 participants, but only 15 participants were interviewed because some of the participants that the researcher was referred to were unavailable.

The unavailability of some participants was because of the ongoing road construction that was taking place nearby, and most women were employed there. At the same time, some had to herd the cattle while their sons were at school during the day. In addition, there were very few households in the village of Ha-Sephapo. The participants were selected through purposive sampling and snowball sampling. Purposive sampling, which is also referred to as convenience sampling, is a nonrandom technique that is a commonly used sampling method, according to Babbie and Mouton (2001). Just as the name indicates, the sample is chosen based on 'convenience' for the investigator, and often, participants are selected because they are at the right place at the right time (Acharya et al., 2013). According to Tongco (2007), the researcher determines what needs to be known and identifies individuals who can and are willing to provide information based on their knowledge or experience, and the key informant technique exemplifies it. Key informants are observant, insightful community members of interest who know much about society and are willing and able to share their knowledge (Tongco, 2007).

Snowball sampling, which is also referred to as chain-referral-sampling of a hidden population, begins with a convenience sample of an initial subject (Heckathorn, 2011). It is a non-probability method of survey sample selection that is commonly used to locate a hidden population. According to Johnson (2014), this method relies on referrals from initial sampled participants to other persons believed to have the characteristics of interest. Out of the 15 participants who were interviewed, 13 were women from Ha- Sephapo village and 2 were officials from the Ministry of Social Development. The 12 participants from the village were identified with the help of the key informant who was a woman who had been staying in the village for more than ten years and was also interviewed. Snowball sampling was then used to locate other participants that were not known to the researcher.

This research study chose women in rural areas as the unit of analysis because women are more vulnerable to dementia as compared to males. Most women who were interviewed were caregivers, either taking care of their in-laws or parents. However, few were not caretakers but women in their middle- age. According to Akpinar, Kucukguclu and Yener (2011), "varying estimates across different countries indicate that 57per cent to 81 per cent of all caregivers of the elderly is women

who are usually middle-aged”. Therefore, the research study focused on women aged 35-45 years. Prince (2014), added that the prevalence of dementia is high amongst women because they experience high life expectancy and age is considered as one of the risk factors of dementia. Moreover, Bamford (2011) and Barlett et al., (check2018.) adds that women are more exposed to dementia as care-givers, as various studies suggest that in most countries up to three-quarters of family caregivers are women.

### 3.6 Methods of Data Collection

Interviews can be used as a primary data gathering method to collect information from individuals about their practices, beliefs, or opinions. They can be used to gather information on past or present behaviours or experiences. Interviews can further be used to collect background information or to tap into the expert knowledge of an individual. According to Rosenthal (2016), semi-structured interviews are used often in policy research. Raworth et al. (2012) assert that a guide with questions and topics to be covered is used in semi-structured interviews. The interviewer has some flexibility about the order in which questions are answered. However, the questions are consistent, and probes can be made to ensure that the researcher is covering the right material. This method of interview gathers detailed information in a conversational style.

On the 6<sup>th</sup>-10<sup>th</sup> of January 2020, the researcher used semi-structured face-face interviews to collect data, using open-ended questions. From the 6<sup>th</sup> to the 8<sup>th</sup>, 12 interviews were conducted in Sesotho at Ha-Sephapo village in the comfort of their own homes and both the Ministry of Social Development officials were interviewed on the 9<sup>th</sup> and 10<sup>th</sup>. The Ministry of Social Development officials were interviewed in both Sesotho and English at their offices in Maseru, Lesotho. Some participants’ interviews at the village of Ha- Sephapo were recorded using a tape recorder, with the most extended recording lasting for eight minutes. However, most participants from the village were not comfortable with being recorded, and field notes had to be taken. Likewise, one official from the Ministry of Social of Development who had just been appointed in the Elderly Department was not recorded as she believed she did not have enough information to offer, so in that case field notes were also taken.

Semi-structured interviews were used to allow the researcher to investigate the participants' understanding of dementia so that detailed information could be obtained. Semi-structured interviews are regularly used when the researcher wants to explore deeper into a topic and to understand thoroughly the answers provided (Harrell and Bradley, 2009). The responses of the interviewee determine how the interview is being conducted. Cohen and Crabtree (2006) state that semi-structured interviews are often preceded by observation and informal and unstructured interviewing to allow researchers to develop a keen understanding of the topic of interest, necessary for developing relevant and meaningful semi-structured questions.

The researcher benefited a lot from semi-structured interviewing as it increased their level of flexibility and was not structured. The flexibility allowed the interviewee to respond on their terms using their language (Sesotho). The researcher was, therefore, able to modify the style, speed, as well as the arrangement of questions to stimulate the fullest responses from the interviewees. More meanings and understandings were created during the interaction, which resulted in the construction and reconstruction of knowledge (Edwards and Holland, 2013). Qu and Dumay (2011) add that semi-structured interviews are more capable of disclosing essential and often hidden facets of human and organisational behaviour.

The standardised open-ended interview, in terms of the wording of the questions, is too structured. Participants are always asked the same questions, but the questions are written in such a way that the answers are available (Gall, Gall and Borg, 2003). Such open-endedness encourages participants to provide as much detailed information as they want, as well as allowing the researcher to ask questions as a follow-up tool. Standardised open-ended interviews are probably the most popular method of interviewing used in research due to the nature of the open-ended questions, allowing participants to express their views and experiences entirely (Turner, 2010).

### 3.7 Data Analysis

Thematic analysis was used to analyse the collected data. Thematic analysis is a method for systematically identifying, organising and offering insight into patterns of meaning across data sets. Through focusing on purpose across a data set, thematic analysis allows the researcher to see and make sense of collective or shared meanings or experiences. Identifying unique meanings and

experiences found in a single data item is not the focus of thematic analysis. However, its goal is to identify themes, that is, patterns that are important or interesting and then to use those themes to address the research or say something about the issue (Maguire and Delahunt, 2017). This method then is a way of identifying what is familiar to the way a topic is written and of making sense of those commonalities.

There are six phases to Braun and Clarke's (2006) approach to thematic analysis. In phase I, the researcher must familiarise themselves with the data; in phase II, the researcher generates initial codes; in phase III, the researcher searches for themes. In phase IV, the researcher reviews potential themes; in phase V, the researcher defines and names the themes. Lastly, in phase VI, the researcher produces the report. The researcher adopted this approach to analyse the collected data manually. Firstly, the researcher transcribed the interviews and then read and re-read the interview transcripts to be familiar with the data. Secondly, the researcher generated initial codes from meaningful data and then reduced them into smaller chunks of data. Thirdly, the researcher searched for relevant data from the generated codes. The researcher then reviewed and refined the themes identified and after that defined and named the themes and created sub-themes. Lastly, the researcher transformed the analysis into interpretable writing.

### 3.8 Trustworthiness

Babbie and Mouton (2001) indicated that another approach in clarifying the notion of objectivity as it is manifested in qualitative research is found in the highly influential work of Lincoln and Guba (1985). According to them, the key principle of good qualitative research is found in the notion of trustworthiness, that is the neutrality of its findings. Pilot and Beck (2014) defined the trustworthiness of a study as the degree of confidence in data interpretation and methods used to ensure the quality of the study. It was argued by Gunawan (2015) that a study is trustworthy if and only if the reader of the research report judges it to be so. Therefore, in establishing trustworthiness, Lincoln and Guba created stringent criteria in qualitative research known as credibility, dependability, confirmability and transferability (Lincoln and Guba, 1985).

### 3.8.1 Credibility

Credibility refers to the degree to which the research represents the actual meanings of the participants, or the “truth value” (Lincoln and Guba, 1981). In ensuring the credibility of the research study, the researcher engaged in persistent observation, prolonged engagement and referential adequacy

#### *3.9.1.1 Persistent observation*

According to Babbie and Mouton (2001), credibility can also be achieved by consistently pursuing interpretations in different ways, in combination with a process of continuous and cautious analysis, that is searching for what counts and what does not count. Therefore, the development of codes through the transcribed interviews helped examine the characteristics of the data. The researcher read and re-read the data and analysed it to generate initial codes from the meaningful data.

#### *3.9.1.2 Prolonged engagement*

Credibility can further be guaranteed by collecting data related to the study questions and having a direct, reliable connection with the concepts and theories under examination (Moser and Korstjens, 2018). Thus the participants were asked diverse questions regarding topics related to the subject. Furthermore, the researcher, as the interviewer, encouraged the participants to give examples to support their statements, and the interviewer asked follow-up questions.

#### *3.9.1.3 Referential adequacy*

This procedure achieves credibility through the availability of materials to document the research findings (Babbie and Mouton, 2001). To document the data, the interviewer recorded interviews. Thus the correctness of the information acquired through the interviews was assured using a recording device.

### 3.9.2 Transferability

Refers to the degree to which the phenomenon or findings described in one study are applicable or useful to theory, practice, and future research (Lincoln and Guba 1985), that is, the transferability of the research findings to other contexts.

### *3.9.2.1 Purposive Sampling*

To ensure transferability, purposive sampling was used to select informants that differ from one another to maximise the range of specific information that can be obtained from and about the context (Babbie and Mouton, 2001)

## **3.9 Ethical Issues**

According to Edwards and Mauthner (2002), ethics is about the nature of human behaviour.

Throughout social research, it refers to the researchers' moral deliberation, choice and responsibility throughout the research process. In alignment with the ethical issues in social research, the researcher obtained permission from the village chief of Ha-Sephapo, Mohale's Hoek to collect data in the village. Sarantakos (2012) states that codes of ethics have been formulated within research institutions, professional associations and tertiary institutions to ensure that inquiry is conducted according to professional and ethical standards. Therefore, permission was also granted by the University of KwaZulu-Natal Higher Degree Committee to pursue the research study.

According to Babbie and Mouton (2001), if a social study is to be carried out, the researcher must be mindful of the universal agreements among researchers regarding what is proper and what is not appropriate in the conduct of scientific inquiry. These may include voluntary participation, no harm to the participants as well as privacy, anonymity and confidentiality. During the research study, the researcher observed social research ethics and protected the rights of the participants. Participants were issued with a consent form, and the researcher explained its content to them. The way the research was to be conducted, how long the research would take and the importance of their contribution to the research study was explained in detail to avoid deception. Participants were made aware that their participation was voluntary, and that they could withdraw from it at any time if they wished to. Participants' identities were not used anywhere in the data; instead, pseudonyms were used in the research study to observe anonymity, privacy and confidentiality. Participants were not harmed or put in danger by the researcher, interviews were conducted in the participants' homes for comfortability, and if the participants did not feel comfortable continuing with the research study, the interview was stopped.

### 3.10 Study Limitations

#### 3.10.1 Availability of participants

The researcher initially intended to interview 20 participants. However, only 15 participants were interviewed; therefore, took the researcher four days to do the interviews. In the community of HaSephapo, like most villages in rural areas, most middle-aged women had left for jobs in the urban areas of Lesotho. Some of the potential participants who were available only answered half of the questions and decided to withdraw from the interview, which resulted in no further probing. Some of the interviewees asked not to be recorded, and a field notebook was used in those instances. For some of the interviewees who approved of the recording, the researcher had to go back to the field and ask for clarification as some of the Sesotho terms were not clear, and some parts of the recordings were not audible. The missing information from the participants who could not be interviewed could have contributed significantly to the research study and shed some light on unknown experiences faced by women affected by dementia (both patients and caretakers) in rural areas.

#### 3.10.2 Improper response

The responses from some of the participants were not in alignment with the research objectives, which resulted in no further probing by the researcher.

#### 3.10.3 Location of the study

Data was collected at Ha-Sephapo village in the district of Mophale's Hoek, Lesotho. This village is characterised by dispersed households, with about a five-minute walk from one house to the other, as was common in the country. Added to this was the fact that most middle-aged women had left for urban areas to look for jobs or had left for other villages because of marriage. Thus the village itself did not have enough family households, which made it difficult to get the anticipated number of participants.

#### 3.10.4 Time

Time was one of the factors that the researcher had to consider during interviews, as most of the available participants had other duties. For instance, two of the participants that the researcher was referred to had been awarded a feeding scheme tender at the local primary school. They had to go there immediately after their interviews as they had to cook and dish up for the students. Other participants were in a bit of a hurry to cook for shepherds who had left in the very early hours of the morning. With more time, the researcher believes that the interviewees would have provided more information that would have benefited the research study.

#### 3.11 Conclusion

In this chapter, the research design and methodology were presented. Qualitative research methods were utilised to guide the research study. Purposive sampling was used to select officials from the MoSD, while both purposive and snowball sampling were utilised to identify participants from the community of Ha-Sephapo. The researcher solely collected data through semi-structured, face-to-face interviews with open-ended questions were used to collect in-depth data from both the participants at the MoSD and the Ha- Sephapo community. Trustworthiness was ensured through credibility and transferability by the researcher explaining to the interviewees in detail the purpose of the research study, and why it was being conducted before the interviews were conducted. This was done to avoid deception or answers that were not truthful. The primary limitations that the research study faced were time constraints and the availability of participants.



## 4 CHAPTER FOUR: RESEARCH FINDINGS AND DISCUSSION

### 4.1 Introduction

This chapter discusses and analyses the findings of the research study using thematic analysis.

There are four main themes. The first theme is; Lesotho's government intervention in raising awareness and understanding of dementia in rural areas. The second theme is; understanding of dementia in rural areas. The third theme is; community perceptions towards women living with dementia. The last and fourth theme is; caregiver's experiences. The first theme has two subthemes, the first one covering the measures taken by the government of Lesotho in raising awareness and understanding of dementia among women in rural areas in Ha-Sephapo village. The second subtheme covers the challenges faced by the Ministry of Social Development in raising awareness and understanding of dementia. It discusses the implementation challenges that the Ministry of Development faced while implementing the Lesotho Policy for Older Persons as a tool used by the Ministry to raise awareness and understanding of dementia. Such challenges include; lack of funding, lack of political commitment and stakeholder participation.

The second theme has three subthemes; the first subtheme covers dementia causes among women. The second subtheme covers the prevalence of dementia, and the last subtheme covers the gender issues around dementia. The third theme has one subtheme, which covers the safety of women with dementia and how older women showing symptoms of dementia can be kept safe. The last theme explores the caregivers' experiences in dealing with older women with dementia symptoms. Section four investigates what the government does to protect older women with dementia symptoms from abuse, victimisation and stigmatisation.

### 4.2 Government Intervention

Participants were asked if they thought there was anything that the government was doing to protect older women who could be showing signs of dementia, especially in rural areas. Few participants indicated that the government was doing anything to help women with symptoms of dementia. They stated that help could come in the form of medicine to help reduce some of the symptoms such as forgetfulness, which they believed was caused by high blood pressure. Another measure could be to arrest those who abused the older woman. Leseli and Kekeletso indicated that:

There is, the government usually help people when an older woman has been beaten and arrest the person who did that (Leseli).

Yes, the government is doing something. They give free medicine to health facilities. The medication puts high blood pressure under control; it also helps them not to forget a lot (Kekeletso).

Nthati also believed that the government was something doing via the MoSD. She stated that she had heard the now former Minister of Social Development (Ms Doti) on the radio, making the public aware of mental health conditions that affected people as they aged. Nthati also indicated that from what she had heard, this condition mainly affected women negatively, as they were stigmatised because of it and labelled as witches and then killed or abused. She further elaborated that Ms Doti would often visit villages where women had been killed or abused to address the issue. Nthati argued that the government could do more, by having regular radio talk shows on ageing and what could be expected as people aged, to raise awareness of such conditions.

I have heard about issues on elderly abuse on the radio. That the elderly, especially older women severely beaten, their body parts are cut off and even get raped in rural areas because they are accused of witchcraft. I have heard the Minister of Social Development make the public aware that as one age, there is the illness that they develop. They mainly affect the brain, which presents itself in symptoms that may be associated with witchcraft. She sternly ordered the public at large to protect the elderly by making sure that they are safe. I have also heard that she would go to the communities where such events have taken place, and people who have abused the elderly would be arrested; however, I wish this wasn't a once-off thing that we hear about when there is something that has happened. There should be a radio show that talks about issues concerning the elderly, to make people aware of such health conditions (Nthati).

In her speech, while commemorating International Day of Older Persons which is celebrated annually on the 1<sup>st</sup> October, the former Minister of Social Development, Ms Doti, alerted the public that “ill health also puts older persons at the risk of abuse and killings. We have also heard cases where women are accused of witchcraft and are murdered, and that is wrong” (Doti, 2018). She further appealed to the public to care for and protect older people as they were champions of human rights. She delivered the speech after the ruthless killing of an 83-year-old woman, allegedly for ritual purposes in one of the districts in Lesotho called Mafeteng (Doti, 2018).

Some of the participants had different opinions and argued that the government was not doing anything to protect demented or older women showing signs of dementia in rural areas. These

participants were asked what they believed the government should do to protect these women. When perceived as associated with witchcraft, dementia could lead to fear of the persons afflicted by it, which could lead to their stigmatisation, discrimination and social isolation, possibly even resulting in violence against them or their murder (Hari, 2009; South African Pagan Rights Alliance 2014).

Bohlale shared that:

No, I haven't seen them do anything...only if there was a place where they can all be put for their safety and to be cared for (Bohlale).

'Mabatho further explained that:

A a, ka nnete! Ha ke so utloi. Ntse ba bolaoa, ba thungoa ho thoe ba loea...mmuso o ka ba bokella nqa e le ngoe be etsetsoe lehae hobe le batho ba tla ba thusa, beo e leng litsibi tsa lefu lena ('Mabatho).

Honestly, no! I have not heard. Older women are still being shot and stabbed because they are accused of witchcraft...The government should put them in one place where they will get help from people who have the expertise for this condition ('Mabatho).

Sharing the same sentiment was Matumisang, who added:

To be honest, I have not heard anything. Here in Mohale's Hoek? Or other surrounding villages? Honestly, I have not heard of anything that the government is doing to help elderly women...to help people with this condition. Just like the government of South Africa, the government of Lesotho can build nursing homes where they will be taken care of. But then, we keep saying things, we give answers, but they are implemented ('Matumisang).

Having a different opinion about primary care was (Relebeletsoe), advocating for both institutionalised care and home care. She argued that, for the safety of older women with this condition, they should not be left to stay alone. They should either be institutionalised or have someone taking care of them in the community.

She suggested that:

If only there were a possibility that they should not stay alone. The government should get specialised people to take care of these older women in their communities or should be taken to nursing homes (Relebeletsoe).

One participant believed that the government was doing something. However, it had only acted at a very late stage when women had already been abused or killed because of this mental health condition.

Government officials? The government doesn't take action if nothing happens. They only take action after they get alerted that some older women have been killed somewhere because of witchcraft accusations. But if something of that sort does not happen, they don't. That is, they only take action after the damage has been done (Relebohile).

On behalf of the MoSD, when answering this question, Ms Tsuinyane indicated that:

We are still at the beginning, so when you speak of taking care of women with dementia, the only thing we do when we see that they are in danger from the society is to remove them from the community and put them in a care facility of which they are not that good because they do not have skilled personnel to deal with dementia patients... There are two care facilities in Lesotho, Catholic nuns own one in [Pitseng] and the other in [Mazenod]. Apart from that, is to talk to families, families that have women with dementia...to sensitise them toem...how? The main thing we talk about is that they should make sure that they are safe... You will find that people come because they are beginning to be aware that the behaviour of older women is not linked to witchcraft, but it is a mental health condition (Ms Tsuinyane).

#### 4.2.1 Measures taken by the Government of Lesotho to raise awareness and understanding of dementia among women in rural areas

Ms Tsuinyane indicated that an increase in life expectancy had resulted in a rise in the number of older people in communities. Therefore, under the guidance of the WHO, the Government of Lesotho, like other member states, had to develop and implement a policy protecting the rights and welfare of older people. The Ministry of Social Development developed the Lesotho Older Persons Policy in 2014. She indicated that one of the objectives of the Lesotho Older Persons Policy was to raise awareness and understanding of mental health issues associated with ageing. Therefore, to achieve that, the Ministry of Development had developed sensitisation programmes. It opened the Department of Elderly Care Service and launched a Campaign Programme on Dementia. It is also working closely with NGOs such as Dementia Lesotho and the Lesotho Age Network and was still in the process of creating collaborating bodies to engage stakeholders and working towards a law protecting the elderly.

The government, through the Ministry of Social Development, has launched a campaign programme called 'Campaign Programme on Dementia'...In 2014, the highest powers of government made attempts that communities in rural areas understand about dementia. There are sensitisation programmes developed to sensitise the counsellors, local authorities, chiefs... We don't only sensitise them, but the main thing is to train them so that they understand better since they are custodians of vulnerable people such as older women, isn't it? We train them so that they can understand and in the absence of structure that should currently be in place, they should make sure that they protect the older women...There are vigilantes in some communities to protect people. We also train young people and make them aware and understand dementia, especially boys because in most cases, they are the ones killing their grandmothers, accusing them of witchcraft. The main thing is that we are working towards the law protecting older women. If we have a law, it will make the policy enforceable. That is, one cannot accuse someone with a policy but can do so with a law. So these are the things that are still in the pipelines (Ms Tsuinyane).

#### 4.2.2 Challenges in Raising Awareness and Understanding of Dementia

Several challenges are preventing ethnic, and minority people affected with dementia from accessing appropriate services (Parveen et al., 2015). These include the absence of the word 'dementia' in most African languages, as instead words such as 'madness' are used to refer to dementia (Lawrence et al. 2011). Mrs Tshabalala, an official at the Ministry of Social Development in the Elderly Department, indicated that there were many challenges that the Ministry faced in raising awareness and understanding of dementia as it was still a new phenomenon but the fastestgrowing epidemic. Two of the problems that she mentioned were that of explaining dementia to rural people, as some of them were not literate, and dementia did not have a name in Sesotho. Instead, dementia could only be explained in terms of its symptoms. She stated that through the Lesotho Policy for Older Persons, the Ministry had formulated an initiative to raise awareness of the mental health issues associated with getting older, not just amongst women but amongst men as well. However, the MoSD had realised that mental conditions such as dementia were stigmatised in rural areas, and those most affected were women, with some having been killed because of their dementia.

There are many challenges that we face as the ministry. But the main one is that of ways on how we make people aware and understand mental health conditions, such as dementia. With dementia, it is not easy to disseminate information as some of the words are very scientific, with no lay terms.

Remember also that literacy rates in rural communities are not high, so educating rural communities on mental health is very challenging. We, the Ministry of Social Development, or let me say, the Elderly Department, don't only focus on mental health issues among women, we also include men. That is, the Lesotho Older Persons Policy includes all the older people above 60 years.

However, we have realised the need to put more focus on women as they are more negatively affected by this condition (dementia) than men. You have heard of the elderly women killings because of witchcraft accusations, isn't it? So, yes, although it is a very new phenomenon (dementia), we have to act fast to protect the elderly from the stigmatisation of women because of mental health conditions caused by ageing which results in killings (Mrs. Tshabalala).

#### *4.2.2.1 Lack of funding and resources*

According to Durlak and DuPre (2008), for implementation to be successful, accessibility to available funding and resources is a requirement. They argue that, although funding alone will not ensure implementation success, it is impossible to mobilise other aspects of an implementation strategy without it. Both officials from the MoSD argued that lack of funding was a considerable challenge that their department was facing regarding the implementation of the Lesotho Older Persons Policy. When answering this question, Ms Tsuinyane asserted that the budget given to their department was not sufficient to reach some parts of the country, mainly the rural areas. Most of the rural areas in Lesotho are found in mountainous regions, where there is a lack of infrastructure; therefore, to get there, there should be enough available funding.

According to Ms Tsuinyane:

In terms of implementation of the policy and making sure that the elderly are protected, the biggest issue is lack of resources. The budget given to the department is not enough to get to some remote areas and raise awareness and understanding of dementia (Ms Tsuinyane).

According to Hussein (2018:356): "The lack of expertise and skilled personnel translate into reduced capabilities by the public bureaucracy to effectively implement policies and projects". Mrs Tshabalala also shared the same sentiments and attested that funding was not the only type of resource they were challenged with, as they also lacked human resources (experts) to implement the Lesotho Older Persons Policy. This lack of expertise specifically relating to dealing with the needs of the ageing population, forced the MoSD to use social workers who had not studied this

aspect in-depth when training. Thus these social workers were not able to address the ageing population's needs effectively.

My dear, our country does not have enough money. The government does not have money, and there are no donors. So, going to the rural areas to make people aware of this condition (dementia) means that we do not have enough money as the department. Unfortunately, the department is allocated an insufficient budget. Except that, the other challenge we faced with is regarding skilled people when it comes to dealing with elderly issues. We only have one person who is an expert in dealing with elderly issues. Therefore, we are forced to work with social workers (Mrs. Tshabalala).

#### *4.2.2.2 Lack of political commitment*

Dementia has become a global health priority, especially in the resource-constrained low-and-middle-income countries, where the speed of ageing is faster (Zaidi et al., 2018). According to the WHO (2012), governments are faced with substantial challenges to respond to the increasing numbers of people with dementia. Hussein (2008) argues that one of the problems that the public bureaucracy face in implementing policies is the tendency of suspending the previous regime's policies by political leadership after government changes, without a sound basis.

The problem is that this programme is not taken as a priority, you know! It is not a national priority. There are other priorities like poverty, like health issues and education. Those are the priorities, are still fighting that this should also be taken as a national priority like other programmes. That is, we still have a long way to sensitise the government itself, the highest powers of the government to make older person's programmes a national priority. Actually, we want it to fall within the national agenda, which is a national priority (Ms Tsuinyane).

Mrs Tshabalala added that:

It has not been long since African countries got to know about the condition of dementia. When someone showed symptoms that are associated with ageing, those symptoms used to be associated with ageing. It is only now that most African countries are formulating policies addressing the issue of dementia with the recommendation of WHO. As such, it is still not considered a national priority as other illnesses such as HIV/AIDS and cancer and others. So, there are some few challenges in the implementation of this policy on addressing dementia because the government does not treat it as a priority like other diseases or illnesses (Mrs. Tshabalala).

#### 4.2.2.3 *Stakeholder participation*

In most cases, to raise awareness of dementia, the involved ministries and NGOs carry out campaigns that focus on increasing the knowledge of dementia and reducing the stigma and discriminatory behaviour towards people living with dementia (WHO, 2012). However, for such campaigns to be effectively implemented, the whole of civil society should be organised (WHO and ADI, 2012). In this research study, both the officials narrated that dementia was not only a problem faced by the Ministry of Social Development (Elderly Services); it was also a problem that affected other ministries and NGOs.

The issue of dementia is not only the MoSD's problem but also involves the Ministry of Health, as it a mental health condition. It also involves the NGOs, the one that we work closely with is Dementia Lesotho. It is playing such a huge role in raising awareness and understanding of dementia (Mrs Tshabalala).

Ms Tsuinyane further elaborated that:

When it comes to stakeholders, in terms of collaboration, we have few stakeholders. Mainly, we have Lesotho Age Network (LAN) which is a body established to coordinate all these other organisations working with older people. So, in particular, there is this other organisation called Dementia Lesotho (DL) which is part of LAN. So, coordination works in such a way that we have established an umbrella body for all organisations, including the government which is ex-officio of that body. Actually, the government facilitated the existence of the LAN. So, it is mainly used to collaborate with other stakeholders. The government is still in the process of establishing coordinating mechanisms from the policy to the implementation level.

We are still in the process of having a coordinating body at a policy level, that will trickle down to the district level up to the community level. But then, those processes are still in the pipeline [...] because elderly issues, especially women with dementia, is not only the problem of the Ministry of Social Development alone but affect many other ministries like the Ministry of Health and the Ministry of Gender, mainly because it disproportionately affects women. So, we need mechanisms that will make a solid collaboration in which every stakeholder will know and understand their role as well as the reporting mechanisms where we meet and hold each other accountable, you know! (Ms. Tsuinyane).

#### 4.2.2.4 *Summary*

This section discussed the measures taken by the GoL through the MoSD to raise awareness and understanding. From the above narratives, most participants argued that the government was not



doing anything to protect the lives of older women showing symptoms of dementia. They stated that the government only took action after something had been done to older women. Some participants believed that the GoL intervened by supplying medicines to local clinics to help suppress some of the symptoms of dementia. Van Meter and Van Horn (1975) argued that successful implementation relied on how well the bureaucratic structures implemented government decisions, on the characteristics of the implementing agencies including economic, social and political environmental factors, and the disposition of the implementers. Based on Van Meter and Van Horn's (1975) statement, it was difficult for the MoSD to effectively implement the Lesotho Older Persons Policy's objective of raising awareness and understanding of dementia. The reason for this was that its implementers were not experts on dementia issues and that dementia was not being treated as a national priority.

Moreover, the implementation challenges faced by their department in raising awareness and understanding of dementia through the Lesotho Older Persons Policy were discussed in this section. From the narratives, both officials mentioned that the main challenges that they were facing were the lack of funding and resources, lack of stakeholder participation and lack of political commitment. They argued that the budget that their ministry was allocated was not enough to allow them to raise awareness and understanding of dementia fully. In addition to the insufficient budget from the government, there was also no funding from international donors to help the department in achieving the goal of the policy regarding dementia and other mental health illnesses associated with ageing. Lack of skilled labour was also a challenge in addressing the issue of dementia among the elderly.

The other challenge limiting the implementation process of the policy was the lack of stakeholder participation. From the narratives, both officials argued that other ministries should be involved in raising awareness and understanding, as the issue did not only concern the Ministry of Social Development. However, these ministries were not as engaged, as they should have been putting more pressure on the MoSD. However, there was one NGO called Dementia Lesotho that had contributed significantly in raising awareness and understanding of dementia. Lastly, lack of political commitment was also mentioned as a challenge that affected the implementation of the policy, as the government did not view this issue as a priority. Instead, it focussed its efforts on other issues such as education and food insecurity.

### 4.3 Understanding of Dementia in Rural Areas

Despite the growing impact globally, lack of understanding of dementia contributes to the fears and stigmatisation and leads to social isolation (Alzheimer's Association, n.d). In many societies, dementia is perceived as normal ageing (Erol, Brook and Peel, 2016), or linked to spiritual beliefs, for instance, caused by 'fate' or retribution for earlier wrongdoing (Mukadam, Cooper and Livingston, 2011). According to Lawrence et al. (2011), in most African languages, the word dementia does not exist; instead, words such as 'madness' are used to refer to dementia. The *World Alzheimer's Report* by Batsch and Mittelman (2012) adds that, in some languages, the term dementia can be offensive to an extent where people are ashamed to accept dementia. Therefore, in many cultures, symptoms of dementia are perceived as normal ageing and linked with behaviours that are heavily stigmatised.

In this section, awareness and understanding will refer to issues such as knowledge about dementia, behavioural changes in older women, causes of dementia, the actual prevalence of dementia and the safety of women living with dementia in rural areas. This section will discuss at length the extent to which women in rural areas are aware and understand dementia as a mental health condition, while also examining their perception they hold of demented people.

It is argued by Kalula and Petros (2011) that in some African countries, medical doctors at the primary care level lack awareness of and training on how to treat dementia and are often therefore disinclined to investigate symptoms of dementia. They too ascribe the symptoms to old age. Health care providers also often lack the education and training necessary to recognise caregiver burden and help families manage the behavioural problems in patients with frontotemporal dementia (Wong and Wallhagen, 2012; Filippiet al., 2013). Education for health care providers related to neurocognitive disorders should also include information on frontotemporal dementia. There is existing evidence proving that knowledge and understanding of dementia in some 'black and minority ethnic' (BME) communities are often low and the levels of knowledge and awareness of dementia among BME communities vary. Therefore, collecting data on awareness and understanding of dementia from women in Ha-Sephapo was a bit challenging as the term dementia was not known to them.

Berwald et al. (2016) argue that there is no equivalent word for dementia in most African and South and East Asian languages, and instead terms such as 'madness' are used to refer to dementia.

Furthermore, some symptoms of dementia such as memory loss as well as misrecognition of faces and places may be assumed as normal ageing or as the consequences of mental illness (Berwald et al., 2016). As a result, dementia had to be briefly explained to the participants before starting their interviews. When asked about their knowledge about dementia, few women claimed that dementia was a normal part of ageing. Their responses were similar to the study results of Cations et al. (2018), as most women from the Ha-Sephapo village believed that dementia was a normal and inevitable part of ageing. However, they thought that there was a possibility for potential medical improvement towards prevention over time. Some participants further added that dementia was a mental condition that affected people when they reached a certain age.

Most of the participants did not know about dementia. Still, they admitted to realising a change in behaviour as people aged and how differently older people were treated because of those behavioural changes, especially women. They referred to some behavioural and cognitive symptoms of dementia as mental illness or only as normal ageing, and some were not knowledgeable and aware of dementia as a mental health condition. Erol, Brook, and Peel (2016) indicate that in many societies, dementia is perceived as normal ageing. Cahill et al. (2015) add that for years, there have been misconceptions about dementia, including the belief that dementia is a normal part of ageing, and there is no value in pursuing treatment. This misconception is found across studies, such as the one done by Cations et al. (2018), where most of the participants believed that dementia is just part of ageing. Even though some participants in this research study believed that dementia was a normal part of ageing, they also believed that by using modern medicine, the symptoms of dementia could subside. One of the participants indicated that as people aged, they started acting like they had lost their minds.

In most cases, I have realised that as people grow older, their memory does not function very well because of age. They start behaving weirdly, what can I say? They act in a way that they have not been behaving like all their lives (Leseli).

Sharing the same sentiments was Relebohile, who also stated that the behaviour of people as they aged surprised her every day. She further explained that the very same person who used to be so strict, neat and active started changing altogether and behaved like a different person.

What I know about this illness of the elderly is that it is an illness that affects people when they reach a certain age...when they reach old age. The way

they do things and the way their brain functions changes. That is, the way their brain functions changes, it starts functioning like that of a child (Relebohile).

With dementia as a general condition that causes damage to the brain, its impact depends on the functions of the brain that are affected. The changes in a demented person may then include loss in memory, creating difficulties with recognition of familiar objects and faces, learning new skills or routines and understanding time and language (Ingram, 2016). Dementia also affects feelings and mood, personality and behaviour. The damage has an increasing impact on whether the person with the condition can carry out daily living activities independently and eventually affects the parts of the brain that coordinate the things people need to do to stay alive. For instance, mobility, maintaining continence, eating and drinking (De Jager et al., 2015). The cognitive decline in persons with dementia gradually creates a significant reduction in the ability to perform everyday activities and social functioning (De Jager et al., 2015). People with dementia may develop confusion and personality changes (Mkhonto and Hanssen, 2017). Mukadam, Cooper and Livingston (2010) indicate that in some studies, caregivers and those without direct caregiving experience recognised dementia symptoms such as memory loss and disorientation, but did not conceptualise them as being part of an illness.

As they age, they do not only forget but do and say things that do not make sense. They start saying things that might put them in danger or make people believe that they are witches (Relebohile).

Motho ekare oa hlanya ka nako tse ling, o batlana le ntho a ntse a e ts'oere ka letsohong ('Mabatho)

It is as if someone has lost their mind; they start looking for things somewhere while holding them in their hands ('Mabatho).

Sharing the same sentiments was Bohlale, who narrated that:

They have this tendency of forgetting, you can call it, and they have this disease of forgetting. So, as the people age, some forget. Why? It is because of stress, some have stress, and some is simply because of age (Bohlale).

According to Johansson et al. (2013), research confirms that mid-life stress is a significant cause of dementia in later life among women. Women's lives in the last century have been more stressful in many cases than men's, and most of the time, older women do not discuss their experienced stresses (Andrews, 2015). 'Matumisang and some of this research study's other participants believed that cognitive impairment as a symptom of dementia was linked to the type of work

women did while still able-bodied. The literature argues that some jobs can be very stressful and psychologically damaging, affecting the health of women in the long run (Rivera-Torres, AraquePadilla and Montero-Simó, 2013). Bickel and Kurz (2009) assert that a higher risk of dementia seems to be linked with lifetime careers that do not require higher education or professional vocational training. As education and higher mental stimulation are likely to have a direct protective effect by enhancing the reserve capacity of the brain (Katzman in Bickel and Kurz, 2009).

While sharing her thoughts, 'Matumisang stated that:

.... According to my understanding, this condition of forgetting, I think, it is because this person used to work a lot as they were ageing. So the same brain function under pressure gets tired and can no longer function like it used to...to an extent where she can't remember where she has put some things and then she forgets ('Matumisang).

According to the Alzheimer's Society (2014), one of the most common behaviours among people with dementia is making accusations against people around them. It indicates that these accusations are based on an illusion on the part of someone with dementia. In most cases, they accuse people of trying to steal from them or causing them harm. The accusations can be very stressful and challenging to handle for some caregivers (Dimond, 2016). Thabileng, a caregiver in this research study, indicated that taking care of an older person was difficult because they sometimes seemed ungrateful, said hurtful things and in some cases accused their carers of stealing.

I know of some people who are very old and forget a lot, some even get lost. This mere yesterday, I was at a clinic in [Makotomane], there was an aged woman who forgets, she likes accusing people of stealing her things while she still has them with her. There is another one who was telling us that she got lost, that she was supposed to jump off at [Ha-Moeletsi] but only realised when she got here that she forgot to say to the taxi driver where she was supposed to jump off. She blames the taxi driver and believes he did it intentionally (Bohlale).

Sharing the same opinion was Moratuo, who had also been accused of stealing by her grandmother. She explained:

Unlike most of the aged people here in our village, my grandmother does not drink alcohol, but she sometimes behaves like she is drunk. Even though she doesn't drink alcohol, she often forgets where she has put things, and

when she doesn't find them, she starts blaming me for stealing them (Moratuo).

It is argued by Kalula and Petros (2011) in *Global Ageing* that in some parts of Africa, medical doctors, mainly at the primary care level, lack awareness of and training on how to treat dementia and are often therefore disinclined to investigate symptoms of dementia. They too, simply ascribe the symptoms to old age (Wong and Wallhagen, 2012; Massimo et al., 2013). Khonje et al (2015) assert that, in severe circumstances, the lack of knowledge and awareness around dementia can cause communities to classify symptoms of dementia as mystical. As a result, the community labels demented individuals as 'witches', and in this way, women appear to be much more likely to be stigmatised (Corfield and Global Alzheimer's and Dementia Action Alliance [GADAA], 2017). Mushi et al. (2014) further indicate that a study in Tanzania on dementia knowledge and education found that most people with dementia and carers do not know what dementia is, but relate it to a stroke, high blood pressure, old age curses or witchcraft.

According to Mkhonto and Hanssen (2018), in some developing countries, dementia is still associated with 'madness' as well as 'witchcraft', causing the affected individuals as well as their families to be in an extremely vulnerable position and stigmatised. Some of the participants who were caregivers indicated that the first thing they did when they observed some of the symptoms in the persons they were caring for was to take them to a health facility. However, there the nurses attributed the symptoms to old age, which is in agreement with the findings by Kalula and Petros (2011) about the lack of knowledge and care at primary health care facilities.

Ingram (2016) states that dementia might bring intense memories of past occasions which are heavily influenced by gender; for instance, low paid work, marriages as well as domestic violence. Nthathi was a carer who took care of her mother who had worked for a white family in the Free State, South Africa. She asserted that, although her mother had not been diagnosed with dementia, she had high blood pressure, and she presented with some of the symptoms of dementia. She believed her mother's behaviour was associated with the work she did in her early years and how she was treated.

She indicated that:

The nurses haven't diagnosed my mother with dementia. However, after your brief explanation about what dementia is, I believe my mother might

have dementia as she has some of the symptoms. My mother forgets a lot; she spends most of the time talking about the time she was working for a white family in the farms, in Free State. Sometimes in the morning, she gets completely blank and forgets where she is. At times, she wakes up in the middle of the night and tries to clean the house. That scares me a lot because some of the people who are not used to the behaviour might think she is a witch. I thought the behaviour is related to the kind of work she was doing or the way she was treated while working (Nthati).

Research shows that stress among women in midlife is a significant cause of dementia in later life (Johansson and Guo, 2013). Some of the participants indicated that they did not know about dementia as a mental health condition and were not aware of it. However, they attributed the symptoms of dementia to tension and worries.

(Shakes head) No! I do not know anything about dementia, the only thing I have realised is that as people age they start forgetting and I believe it is because they have lots of things on their mind, so they forget (Kekeletso).

I do not know anything about dementia (Tiisetso).

#### 4.3.1 Dementia Causes among women in rural areas

In many societies, dementia is perceived as normal ageing (Erol, Brook, & Peel, 2016), or linked to spiritual beliefs, for instance, caused by ‘fate’ or retribution for earlier wrongdoing (Mukadam, Cooper and Livingston, 2011). Most of the research participants believed that dementia was simply caused by ageing; when asked about what they thought caused this condition most of them rhetorically asked, “ha se ho hola?” translated “is it not ageing?” Adding to the belief that dementia was caused by normal ageing, some participants argued that dementia among older women was caused by stress, which led to hypertension. Participants used the words “high blood” to refer to hypertension. Stress has been associated with hypertension and other vascular factors that are related to different types of dementia and Alzheimer’s disease (Sparrenberger et al., 2008). One of the participants further elaborated that most women got dementia because of “high blood” which was triggered by stressful situations in midlife, either at their workplaces or by their roles as wives. According to Zilberman et al. (2015), 25 per cent of adult women were affected by hypertension worldwide.

I think it has to do with age, old age (Leseli).

It is caused by old age (‘Mabatho).

In her assertion, Tiisetso believed that some symptoms of dementia, such as forgetfulness were caused by stress.

Is it not because they think too hard in their age? The brain also gets tired as you age, so thinking too hard might affect it, which will then result in this disease associated with forgetting (Tiisetso).

Although Relebohile agreed with other participants that dementia could be caused by stress, she also believed that dementia could also be caused by the type of food people ate. She argued that “Ache mohlomong e baka keng? Nna nka re ke stress. Nqengoe le mefuta ea lijo tseo batho ba lijang” (Relebohile).

#### 4.3.2 Dementia Prevalence

According to Jorm and Jolley (in Hugo and Ganguli, 2014), the prevalence of dementia increases exponentially with increasing age. Age, according to the Alzheimer’s Association (2014), is the most significant risk factor for dementia; therefore it argues that many people with dementia are women as their life expectancy is higher than that of men globally. Participants were asked at which point they thought that dementia was likely to present itself in women and in which gender it was most prevalent. Most of the participants believed people were most likely to get dementia around the ages of 60 and 70. Some were of a different opinion, with the belief that dementia could affect people at any age, from as early as 35. When discussing gender prevalence, most participants believed that dementia was most common among females, while one thought that dementia equally affected women and men.

I think around 60 and it most common among women (Relebeletsoe).

Other participants narrated that:

At what age? I believe from 60 upwards and affects women more than men (Nthati).

Is it not at 35? It is women who are more likely to get it (‘Mabatho).

‘Matumisang was also of the opinion that women could get dementia at a young age. She believed that people got dementia at a young age because of the lifestyle they lived during their youth, which subsequently affected their brains when they tended to overthink matters.

Ba bang le e aba potlakela, lebitsong lang? lebitsong la bophelo bona bo ba hohla ho feta tekano a ba nahanise kelello ea hae ka boima. Eo o fumane



ngoanenoa a lilemong tse nyane empa o se a lahlehelo a ke kelello...Empa ho motho a hotseng hantle, e mo tlela ha a se a ea lilemong tsela tsa ho latela bo 60, ba bang ho ea ho 80 joalo joalo...hore na le ts'oara bo mang haholo, ache, nna ke bona ho ts'oana...moo ke tla re ho oa ts'oana hobane ntate o tla be a setse a le mong, mme a hlokaetse. U tla fumana ntate enoa a setseng a le mong e se ka re kelello ea hae ha e sa ts'oara ('Matumisang).

Some get it at a very young age; why? Because of the kind of lifestyle, they are living. It terribly affects them, and then they end up thinking a lot. You will find that this person is still young, but already they are starting to lose their mind. However, on someone that lived a good life, it comes at a later stage around the age of 60, some around the ages of 80. As to whether it affects more men or women, I think it is the same. I am saying this because you will find that the man is now a widower and the wife has been deceased. You will find this widower, who is left alone, acting like someone delusional ('Matumisang).

When answering the question on prevalence, Ms Tsuinyane further explained that:

It is a condition that can affect anyone at the age of 65 and above since the concepts of dementia state that. So, everybody should understand that with age, people age in different ways and women also fall within people who can age with dementia and present behaviours that people associate with witchcraft (Ms Tsuinyane).

#### 4.3.3 Perceived gender issues in dementia

In sub-Saharan cultures, the cause of dementia is believed by many to be witchcraft, rather than a disease (Mushi et al., 2014). In South Africa, this is also the case, especially in townships and rural areas (Mukadam et al., 2011). This belief is described as prevalent, widespread and deep-rooted by ActionAid (2013). The question around the gender issues in dementia was best articulated by Ms Tsuinyane, she is the Director of the Elderly Care Services and a gerontologist by profession and is well informed with issues affecting the elderly, both male and female. According to Ms Tsuinyane, this was also the case in the rural areas of Lesotho, as culturally women had always been associated with witchcraft. Therefore some of the behaviours presented by dementia among women put them more at risk of being victimised and discriminated. She further argued that the labelling of older women as witches was placed in an African child's mind at a very young age, so when they grew up, they started treating older women as witches.

...of course, it has gender disparities because in most cases when we talk about dementia...or the general feeling is that it affects females more...

because it is a condition that presents itself through behaviour. Cultural practices and beliefs have always been like, females are associated with witchcraft. So, when they get older and fall into these mental conditions like dementia, they become even more vulnerable because of the very gender issues that have been prevailing, that they have always been discriminated against... eh, so gender issues have always been there and they are now rising because of dementia because it exposes females to the behaviours that make-believe and confirm that they are witches...Mostly, older women are killed by boy children, their grandsons because they are taught that older women are witches...it's nothing else but witchcraft, and they grew up in a society that believes in witchcraft. You will never hear of a man being accused of witchcraft. Instead, they are referred to as a traditional doctor (Ms Tsuinyane).

#### 4.3.4 Summary

This section discussed dementia understanding among women in Ha-Sephapo village. From the narratives, it was discovered that women in Ha-Sephapo were not aware of the word 'dementia' but were aware of its symptoms, which they collectively associated with old age. Participants indicated that the most common symptom of dementia they had observed among older women was cognitive impairment which resulted in forgetfulness and disorientation, as well as a drastic change in behavioural patterns. Although most participants were not aware of the word 'dementia', they seemed to have a slight understanding of behavioural changes that took place as people aged. This section discussed dementia causes among women, its prevalence among men and women, gender issues around dementia and the safety of women with symptoms of dementia living alone in communities.

From the above narratives, it could be established that most participants assumed that dementia was caused by ageing, midlife stress and stress caused by thinking a lot in old age, as well as hypertension. One participant indicated that food could be one of the risk factors for dementia. When discussing its prevalence, most participants argued that dementia was most common among women around the ages of 60 and above. However, one participant had a different view and argued that dementia affected both genders the same and that people could be affected with dementia at an early age, depending on the kind of lifestyle they had lived during their younger and midlife years. When discussing gender issues around dementia, Ms Tsuinyane indicated that women were

more affected by dementia than men as African cultural practices had long created an environment which perceived older women as witches because of dementia behaviour.

#### 4.4 Community perceptions towards dementia

The importance of understanding cultural beliefs about normal ageing and dementia is illustrated by Henderson and Henderson (2002:199), who states that the “talk of each individual about dementia reflects biomedical input and cultural understanding framed within the context of the unique circumstances and understanding of the individual's own experience”.

##### 4.4.1 Safety of women with dementia living in the communities

People with dementia living alone or with their spouse alone may be more vulnerable as there is no family member available to help care for them (Miranda-Castillo, Woods and Orrell, 2010). The availability of family members in LDCs to assist with caregiving has declined due to internal and global migration of employable members and increased involvement of women in the workforce (Prince et al., 2007). According to the Australian Institute of Health and Welfare (2012) and the Alzheimer’s Society (2012), it is best for people with dementia to live at home as they are known to friends and residents in a healthy, familiar environment. The familiar environment will help a demented person to be less disoriented, as changing places and being introduced to new people may result in more confusion. There is a high likelihood that more women are living alone with dementia than men, due to trends in living arrangements, life expectancy and rates of dementia (Alzheimer’s Society, 2012).

Tierney et al. (2007) report that according to clinicians, people with dementia living alone in their homes are at risk in many ways, including in terms of money management and nutrition. In HighIncome-Countries (HIC), people with dementia living in care homes contribute substantially more to the total cost of illness than in LMICs, where several studies suggest that few such facilities exist. Mostly, in LMICs, a vast majority of people with dementia are informally cared for in the community (Wimo et al. and Alzheimer Disease International, 2013). According to Eliopoulos (2013), ensuring the safety of people living with dementia is one of the primary care considerations as their poor judgement and misconception may lead to severe behavioural problems and accidents. When asked if women who presented with the symptoms of dementia could stay alone, all participants indicated that older women with symptoms of dementia should not remain alone but

rather have someone with them and taking care of them. Their reason was mainly because of dementia symptoms such as forgetting and disorientation, as they believed these would put the lives of older women with dementia symptoms in danger, not only from the community but also from themselves.

Leseli and 'Mabatho elaborated that:

Honestly, no! She can't stay on her own because she won't be able to do a lot of things; she might get injured and is not safe at all on her own (Leseli).

No! someone of this condition is not supposed to stay alone. She might quickly try to stand then fall or wander around and get lost, which might result in her being abducted. Therefore, she needs someone to take care of her at all times ('Mabatho).

Elaborating further was Relebohile, who stated that:

No! It's not safe for her to stay alone because she forgets a lot. She might get injured. She might try and cook then forget that she is cooking and then burn the whole house down. It's just not wise. Sometimes she might even get lost because of forgetting where she is at a particular time. So, she might walk and get lost, not knowing if it is safe to be there because she doesn't know the place (Relebohile).

Bohlale also stated that an older person showing these symptoms couldn't stay alone because some of the things used daily in the household were not safe, and could cause accidents. "Honestly, no! Because sometimes they will open the gas and some other things. You know these things are hazardous" (Bohlale). Although Tiisetso indicated that she wasn't aware of dementia and its symptoms in older women, after the researcher briefly described dementia and its symptoms to this participant, she emphasised the issue of primary care, as argued for by Eliopoulos (2013). Adding to the importance of caregiving for older women with dementia, she also believed that it was not safe for someone who had such a condition to stay alone as they needed someone to remind them of necessary things. Protect them from wandering, as well as to help them with other basic things such as taking medication, cooking and cleaning.

#### 4.4.2 Summary

When discussing the issue of safety among women who had symptoms of dementia, all participants agreed that such women should not stay on their own. The participants indicated that there were household and environmental safety hazards associated with them being alone, as well as the

potential threat of them being killed because their symptoms could be misconceived as being associated with witchcraft. Baehr (2018) points out that liberal feminism claims that violence and the threat of violence undermine the dignity of women and their autonomy by reducing their scope of action for them to avoid harm. Goergen and Beaulieu (2010) add that abuse breaks the self and takes away the sense of self-respect from women, so the threat of violence adds to the burden of people living with dementia.

#### 4.5 Caregivers' experiences

Dementia caregiving is stressful and presents a high level of burden for most caregivers and immediate family members (Dang, Badiye and Kelkar, 2008; Collins and Schwartz, 2011). Most of the caregivers in developing countries are there providing informal caregiving as patients of dementia are taken care of by their family members at home (Allen et al., 2017). According to Brodaty and Donkin (2009), most people who are caretakers are women, and they are predominantly middle-aged. Caregivers face many obstacles, including stress, depression and other health complications due to the difficulty of coping with the challenges they experience. During all of the interviews, participants were asked how they would feel and what they would do if they had an older woman with dementia in their family.

When asked how they would feel, most participants who were not caretakers said they would feel hurt. Most of them were heard saying, "Nka utloa bohloko" translated "I would be hurt". When responding to the question about what they would do, those who were not caretakers said they would help them or make the community aware of their illness, while some said they would take them to the clinics for medical assessment, with the hope that they would be given pills to help with the symptoms. 'Mabatho said, "nka mo isa ngakeng ea sekhooa, ho le kokobetsa le ske la tota" translated "I would take her to a medical doctor, to make the condition better so that it does not get worse". When asked this question, some of the participants who were caregivers said that it was not an easy task to take care of an elderly person. They often said, "It's not easy, it's so stressful to take care of elderly people". Therefore, in observing the research ethics, the researcher did not probe any further. Caregivers who were able to respond indicated that:

It is not easy to take care of an older person. It is the same as taking care of a child or a person living with a disability. They forget a lot, they even blame

you, the same person taking care and feeding them. Sometimes they also accuse you of not feeding them...Goodness! So, if you are the type of person who takes things to heart, you will get stressed and develop high blood pressure. But then, there is nothing that can be done; they are our burden (Moratua).

Thabileng mentioned that taking care of an older person had a negative emotional impact as the very same person that she took care of accused her of things. She further explained that it was more difficult as there were no other family members who came to help. She was the only one taking care of her mother, as was expected by her family since she was the only single female among her siblings. She further explained that her brothers worked in the mines in South Africa and made a good living while she was expected to take care of their mother alone.

I don't have a problem taking care of my mother; she is my parent. The only problem is when accuses me of stealing and not giving her food to her other children, my brothers. As much as they know that is an everyday story; it pains me to hear her accuse me of such. Apart from that, the most painful thing is the fact that my brother expects me to take care of my mother alone as I am the only daughter among my siblings. As for them, they work in the mines in the Republic of South Africa and earn a decent living while I can't and only home now and then...it is not easy, but then... (Thabileng).

Another participant indicated that:

The thought of having someone you know be in that condition of forgetting, being delusional is very scary. Some people are not accepting of this condition and some do not understand that as people grow up their brains deteriorate, hence some of the behaviours. They end up associating some of the symptoms with witchcraft (Relebeletsoe).

#### 4.5.1 Summary

This section discussed the perceptions of participants who were not caregivers, regarding how they would feel and what they would do if one of their family members were to get dementia. It also discussed the experiences of a few of the participants who were caregivers of older women who displayed symptoms of dementia. Most participants who were not caretakers indicated that they would feel hurt if one of their family members showed such symptoms and would take them to a medical doctor for an assessment. This suggested that most participants believed that dementia could be cured or managed with the use of modern medicine. Those who were caregivers reported

that taking care of someone who had such symptoms was not easy as they were accused of stealing by the people they were looking after.

Moreover, the fact that they did not get support from other family members made it more difficult as it was believed that it was the responsibility of a female child to take care of their elderly mother. This represented an unequal distribution of labour, as women were the only gender engaged in caregiving (Loewenstein2001). According to liberal feminists, such beliefs are a result of the gender system or the patriarchal nature of inherited traditions and institutions. Liberal feminists claim that the practice of personal autonomy relies on certain supporting factors that are insufficiently present in women's lives and that social arrangements frequently fail to respect the personal freedom of women and other aspects of equality for women (Baehr, 2018).

## 5 CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS

### 5.1 Introduction

The research study set out to assess awareness and understanding of dementia as a mental health illness among older women in the rural community of Ha-Sephapo in the Mophale's Hoek district of Lesotho. The establishment of the Lesotho Policy for Older Persons in 2014 by the MoSD, based on the WHO guidelines, had as one of its objectives the raising of awareness and understanding of mental health illnesses associated with ageing, with dementia as one of the associated illnesses.

To realise the main purpose of the research study, clear objectives were developed to direct it. Firstly, the research aimed at determining the measures taken by the MoSD in raising awareness and understanding of dementia amongst women in rural areas. Secondly, the knowledge of dementia in rural areas needed to be explored. Lastly, the research study aimed at investigating the perceptions of community members towards women living with dementia. In the previous chapter, the actual findings of the research study were presented, analysed and interpreted, and these are used to outline the recommendations and conclusions in this chapter.

### 5.2 Summary of the Study

Although there had been various programmes and initiatives undertaken to raise awareness and understanding of dementia, most of the rural areas in African countries still did not understand dementia. This was because of the non-existence of the word 'dementia' in their ethnic languages, the lack of infrastructure, lack of funding and resources, and the lack of political will to adequately address the issue as dementia was not treated as a priority like other diseases such as cancer and HIV/AIDS. From the data analysed in the previous chapter, to raise awareness and understanding of dementia, not only in rural areas but in the country as a whole. The MoSD had developed a campaign programme called the 'Campaign Programme on Dementia' to make sure that elderly people, or rather women in rural areas, understood that dementia was a condition, not witchcraft. Upon the recommendation of the MoSD, Lesotho commemorated the International Day of Older Persons on the 1<sup>st</sup> of October annually. During this commemoration, the MoSD usually made the public aware of the condition of dementia. The MoSD also sensitised the communities, both rural and urban, and trained them on elderly issues.



To keep the elderly women safe, especially those above the ages of 65 and those who had symptoms of dementia, the MoSD advocates for community vigilantes to keep older women safe in the villages. However, from the analysed data from the participants in the community of HaSephapo, it could be concluded that little was being done to protect the older women. The action was only taken when older women had been victimised or killed because of witchcraft accusations resulting from their symptoms of dementia. Moreover, it could be concluded that most of the women in the village of Ha-Sephapo were not aware of the word ‘dementia’ and associated its symptoms with normal ageing rather than with a mental health condition. They held the belief that it was caused by high blood, midlife stress, diet and the type of work that was done when they were middle-aged.

While exploring the perceptions of the community members towards the older women with symptoms of dementia, it was concluded from the narratives provided by caregivers from Ha-Sephapo that they feared for the safety of the older women they were taking care of, as their symptoms were suspicious of witchcraft, in the general community’s perception. The narratives agreed with the Alzheimer’s Association (2014), indicating that dementia was most prevalent among women and affected their safety. There was no law in place protecting older women; instead the MoSD used the Lesotho Policy for Older Persons to regulate the behaviour of the public and how they should treat older women. The MoSD was, however, working on formulating a law that would protect the elderly. The absence of a law that regulated the behaviour of the public towards the elderly, especially women, had resulted in many older women being victimised and killed and their abusers not being punished because no law outlined the punishment. The findings validate Barlett et al. (2016) statement that in matters concerning people with dementia, gender is an ignored dimension in public discourse, in that people living with dementia is typically represented in policies in gender-neutral terms as ‘people with dementia’ as it gender does not matter who is affected

The research study was carried out in alignment with the objectives of the study. In the first question, the measures taken by the Ministry of Social Development in raising awareness and understanding of dementia among women in rural areas were addressed. From the findings, empirical evidence was drawn, and it suggested that the Ministry of Social Development was not doing much to raise awareness and understanding. The main significant finding of the research

study relating to dementia awareness and understanding is that the ministry is faced with some implementation challenges making it difficult to raise awareness about dementia effectively. The challenges identified included lack of funding, lack of political commitment and stakeholder participation. Overall, the research study that the Ministry of Social Development is faced with some implementation challenges of the Lesotho Policy for Older Persons which has among its aims, to raise awareness and understating of mental health conditions such as dementia.

Secondly, the research study explored the understanding of dementia among women in rural areas. Although the participants were not aware of the term “dementia” as it does not, the investigation revealed that most women in rural areas understand dementia as a normal part of ageing and do not relate it to a mental health condition. Most of the participants revealed that the most common cause of dementia is ageing while some related it to hypertension or stress encountered by women before they reach old age. Generally, the findings of the research study confirmed that women in rural areas are not aware and do not understand dementia and its causes but associate its symptoms with normal ageing.

Lastly, the research study explored the perceptions of community members towards women living with dementia. The study established from the caretakers' narratives that most community members associated the symptoms of dementia, especially among women to witchcraft. It was further revealed that most caretakers, therefore, fear for the safety of the older women that they are taking care of, given the community's assumption. The study therefore established that even though there are few old age homes which do not have trained personnel to take care of dementia patients, women showing symptoms of dementia should not stay alone but with caretakers. Generally, the findings established that dementia symptoms in rural areas are stigmatized especially among women which lead to the victimization and discrimination of older women.

### 5.3 Conclusions about the research objectives

Presented below are the conclusions drawn in this research study and are in alignment with each research question.

### 5.3.1 Measures taken by the Ministry of Social Development in raising awareness and understanding of dementia among women in rural areas.

The first objective was to determine the measures taken by the Ministry of Social Development in raising awareness and understanding of dementia amongst women in rural areas. Below are the conclusions drawn from the findings.

- i. The research study concluded that the Ministry of Social Development is faced with some implementation challenges to effectively raise awareness and understanding of dementia through the Lesotho Policy for Older Persons.
- ii. It was established that the lack of funding from both the government of Lesotho and the international organisations affected the implementation process adversely.
- iii. The research study also concluded that the absence of relevant stakeholders makes it more difficult for it to raise awareness and understanding of dementia as a mental health condition does not only concern the Ministry of Social Development alone. However, dementia as a mental health condition also affects the Ministry of Health, Ministry of Gender and NGOs.

### 5.3.2 Exploring the understanding of dementia in rural areas

The second objective was to explore the understanding of dementia in rural areas. The following are conclusions drawn from the findings.

- i. The research study revealed that most women in rural areas do not know about dementia as a term and as a mental health condition. The research study confirmed that dementia symptoms are often associated with normal ageing leading to misdiagnosis.
- ii. The research study further confirmed that dementia symptoms are more prevalent among older women above the age of sixty.
- iii. The research study also revealed that dementia affects both genders differently. The research study discovered that women with dementia symptoms are victimised and discriminated against relative to their male counterparts.

5.3.3 Exploring perceptions of community members towards women living with dementia. The third and last objective was to explore the perceptions of community members towards women living with dementia. Below is the conclusion that was drawn from the findings.

- i. The study revealed that most people in the community associate symptoms of dementia among women with witchcraft. The research study, therefore, established that those perceptions held by the community about dementia put the lives of older women with dementia symptoms risk of being discriminated.

#### 5.4 Recommendations to the Government and the Ministry of Social Development.

1. The MoSD should develop a policy focusing on the protection of older women with dementia.
2. The Lesotho Policy for Older Persons should be gender-specific on how it will protect the welfare of older women with mental health illnesses, as dementia affects both genders differently.
3. The Lesotho Policy for Older Persons should be specific on how it will raise awareness and understanding of mental health issues, especially dementia.
4. Dementia awareness and understanding programmes should be developed and disseminate information in a language that communities in rural areas will understand.
5. There should be a full collaboration and participation of stakeholders; government ministries and NGOs to address dementia issues for effective implementation of the Lesotho Policy for Older Persons.
6. The Government of Lesotho should prioritise the training of dementia experts who will develop good policies for dementia and ensure that the Lesotho Policy for Older Persons is implemented effectively.
7. There should be memory clinics to diagnose older people with symptoms of dementia.
8. Elderly Care facilities should be built and equipped with people skills to deal with dementia patients.

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## APPENDICES

### Appendix One: Informed Consent in English

#### Informed Consent Document

Dear Participant,

My name is Mamatsie Mokhosi. I am a Masters candidate studying at the University of KwaZulu-Natal, Howard College Campus. The title of my research is: “Awareness and Understanding of Dementia among women in rural areas, Mohale’s Hoek, Ha-Sephapo”. As part of my study I am interested in interviewing caregivers of elderly women, as the aim of the study is to evaluate the awareness and understanding of mental illnesses related to ageing, especially dementia, among older women in rural areas. It is hoped that the information will be helpful in providing the concerned ministries with ways to address dementia as a mental health condition as it is highly prevalent in women, and raise awareness and understanding of dementia as a mental health condition.

I am interested in interviewing you to share your experiences and observations on the subject matter. If you are interested in helping me with this research please sign below and note that:

- As people age, their brain performance weakens, resulting in memory loss and decline in other mental abilities, the mental condition is termed as “Dementia”. This condition is more prevalent in women than in men due to the fact that women live longer than men. Lack of understanding and awareness of this condition puts those affected with the condition at risk of stigmatisation and discrimination by the society they live in as they experience episodes caused by the condition. Therefore, the aim of the study is to evaluate the awareness and understanding of mental related illnesses, especially dementia, among older women in rural areas.
- The researcher is interested interviewing women who are over the age of 35 as they are likely to be carers. The researcher was therefore informed by other participants that you are over the age of 35 and/or care for an elderly women.
- Your participation is entirely voluntary. You have a choice to participate, not to participate or stop participating in the research. You will not be penalised for taking such an action.
- The information that you provide will remain confidential to the researcher and be used for scholarly research only.
- Your views in this interview will be presented anonymously. Neither your name nor your identity will be revealed in any form in the study.
- The interview will take about 15-20 minutes.
- A voice recording device will be used to record the interview if permission is granted to do so. If not, a field notebook will be used to take notes. The recording, as well as other items associated with the interview, will be held in a password-protected file accessible only to myself and my supervisors. After a period of five years, in line with the rules of the university, it will be disposed of by shredding and burning.

- If you agree to participate please sign the declaration attached to this statement (a separate sheet will be provided for signatures).

I can be contacted at: School of Social Sciences, University of KwaZulu-Natal, Howard College Campus, Durban. Email: 2 1 7 0 4 3 8 1 3 @ s t u . u k z n . a c . z a

Cell: +27 63 591 9477/ +266 62043199

My supervisor is Dr. Nokwanda Yoliswa Nzuza, who is located at the School of Social Sciences, Howard College Campus, Durban of the University of KwaZulu-Natal. Contact details: email: nzuzan@ukzn.ac.za. Phone number: +27 73 903 0575

The Humanities and Social Sciences Research Ethics Committee contact details are as follows: Ms Phumelele Ximba, University of KwaZulu-Natal, Research Office, Email: [ximbap@ukzn.ac.za](mailto:ximbap@ukzn.ac.za), Phone number +27312603587.

Thank you for your contribution to this research.

#### DECLARATION

I ..... (*full names of participants*) hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to participating in the research project.

I understand that I am free to withdraw from the project at any time, should I wish to. I understand the intention of the research and hereby agree to participate.

I consent/ do not consent to have this interview recorded.

SIGNATURE OF PARTICIPANT

DATE

.....

.....

## Appendix Two: Informed Consent in Sesotho

Ke Mamatsie Mokhosi. Ke ntse ke nts'etsa lengolo la ka la "Masters pele Univesithing ea KwaZulu Natal, Howard College Campus. Sehloho sa lipatlisiso ke: "Katleho ea Lesotho Older Persons Policy: Tsebo le Kutloisiso ea "Dementia" har'a basali ba libakeng tsa mahaeng. Mohale's Hoek, Ha-Sephapo. Sepheo sa lipatlisiso ke ho "hlahloba katleho ea Lesotho Older Persons Policy tsebong le kutloisisong ea mafu a amanang le kelello har'a batho ba baholo, haholo-holo har'a basali ba mahaeng. Ke thahasella ho buisana le uena, ho arolelana maikutlo le lintlha tsa hau mabapi le taba ena.

Ke kopa u ele hloko hore:

- Lintlha tseo u fanang ka tsona li tla sebelisoa bakeng sa lipatlisiso tsa boithuto feela.
- Ha u oa qobelloa ho nka karolo boithutong bona. U na le khetho ea ho nka karalo kapa ho e se nke. U ke be oa tjamelo ke kotlo mabapi le khetho eo u tla e nka.
- Maikutlo a hao lipatlisisong tsena a sireletsehile, mme lebitso le hao le ke be la sebelisoa ho u amahanya le litaba.
- Ke tla hloka fela metsotso e leshome le metso e mehlano ho isa ho e mashome a mabeli ho u botsa lipotsa.
- Tlaleho ea khatiso ea likarabo tsa hao le tsohle tse tlang ho sebelisoa ha ke botsa lipotso li tla ts'ireletsoa ka nomoro ea lekunutu ke nna le mookameli oaka. Ka morao ho lilemo tse hlano, tlasa lipehelo tsa univesithi, litokomane tse ngotseng likarabo tsa hao li tla taboloa le hona ho chesoa.
- Ha eba u lumela ho nka karolo, ke kopa u tekene tumellano e fanoeng ka tlase.

Ke fumaneha mona: Sekolo sa Litsebi tsa Sechaba, Univesithi ea KwaZulu-Natal, Howard College Campus, Durban. Imeile: [217043813@stu.ukzn.ac.za](mailto:217043813@stu.ukzn.ac.za). Nomoro ea mohala oa thekeng: +27 63 591 9477/ +266 62043199. Mookameli oa ka ke Dr. Nokwanda Yoliswa Nzuza, ea fumaneng Sekolo sa Sechaba sa Sciences, Howard College Campus, Durban ea Univesithi ea KwaZulu-Natal. Imeile: [nzuzan@ukzn.ac.za](mailto:nzuzan@ukzn.ac.za). Nomoro ea mohala: +27 73 903 0575. Litlhaloso tsa puisano tsa Komiti ea Boikarabello ba Botho le Boiketlo ba Sechaba ke tse latelang: Ms. Phumelele Ximba, Univesithi ea KwaZulu-Natal, Ofisi ea Lipatlisiso, Imeili: [ximbap@ukzn.ac.za](mailto:ximbap@ukzn.ac.za), Nomoro ea fono +27312603587.

Ke ea leboha ka tlatsetso ea hao boithutong bona.

## BOITLAMO

Nna.....ke netefatsa ke hona hore ke utloisisa se tokomane ena e se bolelang, ha mmoho le morero oa ho etsa lipatlisiso, 'me ke lumela ho kenya letsoho phuputsong ea lipatlisiso.

Ke ea utloisisa hore ken a le bolokolohi ba ho tlohela ho nka karalo nako e fe kapa e fe ha eba ke lakatsa joalo. Ke utloisisa morero oa lipatlisiso tsena. Ke lumela ho nka karalo.

Ke ea lumela/ ha ke lumele hore moqoqo oa rona o hatiso (ha eba ho hlokahala)

ITEKENE MONA

LETSATSI

.....

### Appendix three: Sesotho questions for Women in Ha- Sephapo community

1. Lilemo
2. Ka maikutlo a hao, ho etsahala eng ka boits'oaro ba motho ha a hola?
3. U tsebang ka Lefu la bolebali (Dementia)
4. U nahana ke eng a bakang lefu lee?
5. Pakeng tsa bo-ntate le bo-mme, u nahana lefu lee le lengata ho ba feng?
6. U nahana ke lilemong li feng moo lefu lee le iponahatsang haholo ho bo-mme?
7. Na hona le motho oa mme eo u mo tsebang a nang le lefu lee la nolebali?
8. Ke eng eo u e lebelletseng ho motho a nang le lefu la bolebali?
9. Ke boits'oaro bo feng boo u bo amahanyang le lefu lee?
10. Na motho oa mme a nang le lefu lee a ka lula a le mong? Hobneng?
11. U ka etsang ha e mong o abo mme be u amanang le bona ba qala ho bontsha mats'oao a lefu lee? hobaneng?
12. U ka ikutloa joang ha e mong oa lelapa leno a ka ba le lefu lee/Hobaneng?
13. Na u nahana ho na le ntho eo mmuso o e etsang ho sireletsa le ho thusa basali ba phelang le lefu lee? Haeba Karabo ke eya, ke eng seo ba se etsang?

Haeba Karabo ke che, ke eng eo ba ka e etsang?





## Appendix

### Four: Ministry of Social Development Interview Schedule

#### **Ministry of Social Development Interview Schedule**

1. At what age does the government of Lesotho regard a person as an older person?
2. What is the government doing to protect the older persons in Lesotho?
3. What are the gender issues around the effects of dementia in rural areas?
4. What are the government interventions that have been put in place in raising awareness and understating of dementia in rural communities?
5. What are the government interventions that have been carried out to protect elderly women with dementia in rural areas?
6. What arrangements have been done by the Ministry of Social Development to deliver those interventions in rural areas?
7. In your opinion, what are some of the challenges the Ministry of Social Development is facing in realising the implementation of those interventions?
8. How are women with dementia taken care of by the government in ensuring their safety and well-being?
9. How can different stakeholders collaborate to help older women with dementia to feel safe in their condition?

## Appendix

### Five: Sesotho Questions for Officials at the Ministry of Social Development **Lenaneo la Puisano Lekala la Ntšetso-pele ea Sechaba**

1. 'Muso oa Lesotho o nka motho e le motho ea holileng ha a se fihletse lilemo tse kae?
2. 'Muso o etsang ho ts'ireletsa batho ba baholo Lesotho?
3. Ke litaba li feng tsa botona le bots'ehali tse amahangoang le ts'oaetso ea “dementia” lebakeng tse maheng?
4. Ke lits'ebeletso li feng tse 'muso o li behileng ho hlokomalisa le ho eketsa kutloisiso ea “dementia” mahaeng?
5. Ke lits'ebeletso li feng tse seng li entsoe ke 'muso ho ts'ireletsa basali ba holileng ebile ban a “dementia” li bakeng tse mahaeng?
6. Ke litokiso li feng tse entsoeng ke Lekal la Nts'etso-pele ea Sechaba ho fan aka lits'ebeletso tseo mahaeng?
7. Ka maikutlo a hau, ke mathata a feng ao Lekala la Nts'etso-pele ea Sechaba le shebaneng le ona ho bonahatsa mehato ee?
8. 'Muso o hlokometse basali ba nang le “dementia” joang ho bonahantsa ts'ireletso le boiketlo ba bona?
9. Makala a fapaneng a ka sebelisana joang ho thusa basali ba baholo ba nang le “dementia” hore ba isskutloe ba sireletsehile?

### Six: Gate Keeper's Letter

Appendix

Meeling Ha Sephapo  
Taung  
Mehale's Hoek 800  
Lesotho

07-02-2019

Moekameli  
University of Kwazulu Natal

Monghali

Lengolo la Tumello ea Boithuto

Ke le 'Mamonate Sephapo, Morena oa Ha  
Sephapo, Taung, Mehale's Hoek, Lesotho,  
Ke fana ka tumello ea hore Mametsie  
Margaret Mokhele (217043813) a etse  
boithuto ba hae motseng oa ka.

Ke tla leboha tšebeliso 'moho e ntle.

Kea leboha  
'Mamonate Sephapo.

MORENA OA HA SEPHAPO  
TAUNG  
HA SEPHAPO MALAKA  
07-02-2019  
M Sephapo  
MOHALES HOEK - 800 - LESOTHO



LESOTHO

Ministry of Social Development

P/Bag A 222

Maseru

Lesotho

16 December, 2019

To whom it may concern,

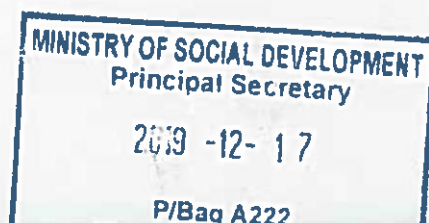
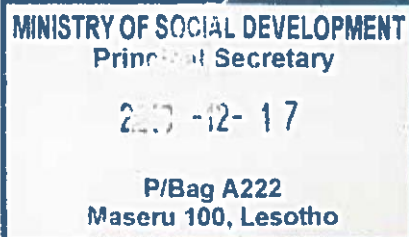
**Gatekeeper's letter**

I, the Director Elderly Care Services hereby grant **Ms Mamatsie Mokhosi (217043813)** from the University of KwaZulu Natal to collect data from any officials under the Department of Elderly Care Services in the Ministry of Social Development in alignment with the topic **“The effectiveness of the Lesotho Policy for Older Persons : Awareness and Understanding of Dementia among older women in rural areas. Mohale’s Hoek, Ha- Sephapo.** The researcher can collect data from the potential officials per appointment.

I look forward to working with you and hope the information provided by the officials will be of great contribution to the study and will contribute to the improvement of policy.

Yours Sincerely,

**Retselisitsoe Tsuinynane (Ms)**  
Director Eldery Care Services



20 December 2019

Ms Mamatsi Mokhosi 217043813  
School of Social Sciences  
Howard College Campus

Dear Ms Mokhosi

Protocol reference number: HSS/0575/019M

Project title: The effectiveness of Lesotho Older Persons Policy: Awareness and Understanding of Dementia among women in rural areas. Mohale's Hoek, Ha-Sephapo

### Approval Notification – Full Committee Reviewed Protocol

This letter serves to notify you that your response received on 6 June 2019 to our letter of 3 October 2019 in connection with the above, was reviewed by the Humanities and Social Sciences Research Ethics Committee (HSSREC) and the protocol has been granted **FULL APPROVAL**

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number. PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

**This approval is valid for one year from 20 December 2019.**

To ensure uninterrupted approval of this study beyond the approval expiry date, a progress report must be submitted to the Research Office on the appropriate form 2 - 3 months before the expiry date. A close-out report to be submitted when study is finished.

Yours faithfully



.....  
Dr Shamila Naidoo (Acting Chair)

/ss

cc Supervisor: Dr Nokwanda Yoliswa Nzuzo  
cc Academic Leader Research: Prof Uma Mahesvari Naidu  
cc School Administrator: Ms Nonhlanhla Radebe

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Humanities & Social Sciences Research Ethics Committee  
Dr Rosemary Sibanda (Chair)  
UKZN Research Ethics Office Westville Campus, Govan Mbeki Building  
Postal Address: Private Bag X54001, Durban 4000  
Website: <http://research.ukzn.ac.za/Research-Ethics/>

Founding Campuses:  Edgewood  Howard College  Medical School  Pietermaritzburg  Westville