Preventing violence against dementia sufferers in Mapotu, Lesotho

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by

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DECLARATION

I, Makoena Theresia Thafeng, declare that the content of this thesis represents my original work and I have not previously submitted it in any institution of higher learning for a degree.

Signature **Date** : 20/11/2020

ABSTRACT

The study sought to establish the interventions that can help in the prevention of violence against dementia sufferers. Therefore, the aim of the study was to prevent violence against dementia sufferers in Mapotu, Lesotho.

The research used an action research approach and a qualitative research design. The data collection methods that were used were interviews and focus group discussions. The findings indicated that dementia sufferers are subjected to violence, discrimination, and stigma, and their family members are being discriminated against and stigmatised by community members. It was revealed that most of the people in Mapotu do not know about dementia, and they attribute the symptoms of the disease to witchcraft, which leads them to subject the sufferers and their families to violence, discrimination, and stigma. This misinformation and behaviour are country-wide phenomena.

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TABLE OF CONTENTS

ACRONYMS

AVP	Alternatives to Violence Project
CBOs	Community-Based Organisations
GBV	Gender-Based Violence
LNFOD	Lesotho National Federation of Organisations of the Disabled
INCIDE	Instituto Centroamericano de Investigaciones para el Desarrollo y el Cambio Social
LMICs	Low- and Middle-Income Countries
LMIC	Lower Middle-Income Countries
PWD	People With Dementia
NGOs	Non-Governmental Organisations
SSA	Sub-Saharan Africa
HIC	Health Improvement Centre
LDCs	Less Developed Countries
MIPAA	Men In Partnership Against AIDS
LEDCs	Less Economically Developed Countries
PAR	Participatory Action Research
FGDs	Focus Group Discussions
TB	Tuberculosis
UK	United Kingdom
WHO	World Health Organisation
PLWD	People Living With Dementia

CHAPTER ONE
Introduction and Contextual Background

1.1 Introduction

This study seeks to prevent violence against dementia sufferers in Mapotu, Lesotho, based on the day-to-day lives of dementia sufferers and their families in their respective communities and how the communities treat them. The chapter introduces the contextual background for the study, the research question, and the objectives of the study. Secondly, it provides the motivation and justifications for this study. Lastly, it provides an outline of the remaining chapters of this thesis.

1.2 Background

Dementia is a disease that comes as a result of a part of the brain becoming damaged – this impairment in the brain leads to memory loss, and one’s personality changes and day-to-day activities or functions become impossible, thus the disease interferes with one’s social being hence the patient cannot do that which people without the disease do (George-Carey *et al.* 2012). Most people who have brain damage or cognitive problems can be a danger to themselves and to other people. This could be due to the lack of inhibition that comes with the disease. As some of the symptoms of this disease are anger, hallucinations, delusions, and aggression, people with dementia become violent and are easily agitated. These symptoms qualify dementia as a societal issue that needs immediate attention and collaboration of all stakeholders to help the patients, their families, and the society to understand the disease and to provide needed help to the affected parties.

The World Health Organisation (WHO 2017) states that carers of dementia sufferers experience a high strain. There is much pressure on the carers as in their day-to-day caring, they experience physical stress due to not having rest, especially for those whose patients are in the advanced stage of dementia, and they also become emotionally and economically drained. Therefore, the carers in Lesotho should be supported by the relevant ministries or departments such as the Ministry of Health, social development, and finance, and the legislative body should include dementia sufferers and their carers when making laws. On the other hand, Deist and Greef (2015: 103) identify social support to be the key contributing factor of resilience and the effective management of dementia sufferers. The social structures could be extended to family members, friends, and community members. In Lesotho, dementia sufferers are cared for by the family members since there are no health systems or infrastructures in place to take care of dementia sufferers. This means that the families taking care of demented people cannot effectively care for the patients without social support. However, based on the informal interview that the researcher had with the members of the community, families of dementia sufferers in Mapotu do not obtain any support from the community due to the stigma attached to the disease. Furthermore, friends and some members of the extended family distance themselves from the dementia sufferers and their families. In some cases, perceptions about dementia influence the decisions to seek help either from the community or the health centre. Social injustice and health disparities are some of the factors contributing to the abuse and violence against dementia sufferers in Lesotho.

There are different perceptions and beliefs surrounding dementia worldwide and those perceptions and beliefs lead to different reactions towards dementia sufferers. The researcher had an opportunity to speak to incarcerated men in Maseru central prison in Lesotho who had killed a demented woman in 2016, and those men were not ashamed of that which they had done to the extent that they were willing to kill again and, as they explained, if old men and women do not stop bewitching their families and acting crazy. These behaviours or actions could be curbed by improving the knowledge of people through education which should start from the grassroots level, such as in Mapotu, which would thus help to change the perception of people towards dementia sufferers and their carers. Promoting awareness and understanding of dementia across all levels of society would perhaps decrease the discrimination and improve the quality of life for people with dementia and their carers. It is the responsibility of the governments, through their relevant ministries, to raise awareness and advocate for dementia. Demented people experience different forms of violence which can be classified under three types of violence: structural, cultural and direct violence (Galtung 1990).

Galtung (1990: 291) mentions that “cultural violence, direct and structural violence look, even feel, right because they are legitimised by the societies”. From the foregoing discussion, it becomes evident that dementia is widely perceived and understood differently, and moreover, this implies that even the decision taken by the community members about dementia may differ to some extent resulting in misinformed and uninformed perceptions.

According to WHO (2017: 10), approximately 47 million people worldwide have dementia and there are projections of the number increasing to 75 million in 2030, and other predictions highlight that the number will be tripled in 2050. It is obvious that the number of cases of dementia will increase and this alone calls for the governments to take a significant step towards managing the disease. Projections show that the future increase in cases of dementia will challenge the health systems (WHO 2017: 10).

1.3 Dementia and Alzheimer’s Disease

The WHO (2017: 2) defines dementia in the following terms:

> Dementia is an umbrella term for several diseases that are mostly progressive, in nature in which there is deterioration in cognitive function (that is the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour or motivation.

Old age is the strongest risk factor for dementia, and it is most common in people over the age of 65 (Laban 2007: 432).

The terms *dementia* and *Alzheimer’s disease* have been used interchangeably to the extent that some people think that dementia is another word for Alzheimer’s disease. The main reason for this misinformation is that Alzheimer’s disease is the leading type of dementia. This means that Alzheimer’s disease is one of the types/causes of dementia which is more common than others. There are many types of dementia and these are named after the cause of dementia (George-Carey *et al.* 2012).

Dementia has become a burden due to its rising prevalence. De Jager *et al.* (2017) note that ignorance about dementia has resulted in cases of dementia sufferers in

Africa going undiagnosed which causes dementia to be largely underdiagnosed, and by the time a patient is diagnosed, the disease would have progressed to a late stage which makes it difficult to manage. They estimated a prevalence rate of 11% among those over 65 years of age living in low-income communities in South Africa. They argue that early diagnosis may help the people involved to be prepared of what to expect and to be aware of the changes as they take place. “The main risk factor for dementia is advancing age and after the age of 65 the prevalence doubles every five years” (De Jager *et al.* 2017: 1090). Currently, there is no treatment or cure for dementia, however, availability of information about the disease and support to the patients and the carers has helped in the reduction of psychological distress (George-Carey *et al.* 2012).

There is a saying which states that ‘knowledge is power’, which means that knowledge gives people the power to make informed decisions. The researcher believes that when people are educated on issues of dementia, levels of stigma and violence against dementia sufferers will diminish. The experience of HIV/AIDS gives support to this optimism. Support of dementia carers and the patients cannot be overemphasised. Moreover, there should also be systems in place to improve health and social care monitoring of dementia, and there is a need for increased research on dementia which could help in many ways. Although it has not been documented, during the researcher’s stay at Mapotu, the researcher witnessed elderly people with dementia being abused and being exposed to violence, discrimination, and dehumanisation. The evidence from other countries is that greater knowledge and understanding of dementia brings compassion and support for sufferers and their families (Gerrad 2019).

1.4 Research Context

Figure 1.1 depicts Lesotho and the Mafeteng district.

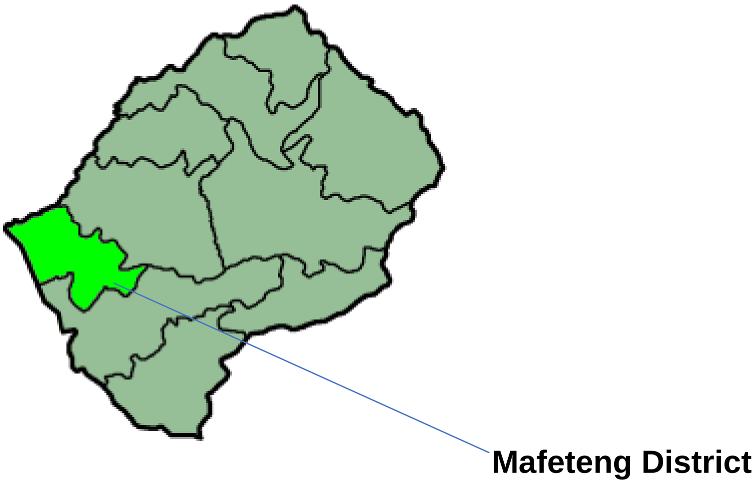

Figure 1.1: Lesotho and Mafeteng District.

Mafeteng district is located 76 kilometres south of Maseru (capital city). According to the 2016 census, the district has a population of approximately 178,222. In 2008, there were 40,990 unemployed people in Mafeteng and 127,664 employed people. There were 1,866 people involved in subsistence farming, and production was mainly of maize, wheat, sorghum, peas, and beans (Agricultural production in Lesotho 2008). Mafeteng has nine constituencies and Mapotu falls under Thaba-Pechela No. 47 constituency – the district has 12 community councils and Mapotu is under Metsimaholo E01 community council (Mafeteng district council information handbook 2008).

There are 110 villages in Thaba-Pechela with a total population of 21,480 (Bureau of statistics 2008). There are 380 people who are formally employed, 1,791 live on farming, and 458 survive on food aid (Mafeteng district council information handbook 2008). Thaba-Pechela is made up of 110 villages and there are only three government health centres in the constituency, and the community of Mapotu is one of those that has difficulties in accessing health facilities due to the long distances to reach them and bad terrains (Mafeteng district council information handbook 2008).

In Mapotu, there is no household with electricity or water toilets, and to obtain drinking water, people travel for long distances for periods lasting 30 minutes up to two hours.

There are three government primary schools and no high schools in Mapotu, and as of 2008, there were 46 initiation schools in the Thaba-Pechela constituency (Mafeteng district council information handbook 2008). There is one security service (Tsakholo police station) serving 104 villages, including Mapotu community. According to the Mafeteng district council information handbook (2008), there were 40 people with mental health problems and 14 people with schizophrenia in the constituency. The researcher knows very well how people with mental disorders are treated in Mapotu. The researcher grew up in Mapotu and has witnessed how dementia sufferers were and still are mistreated in Mapotu, Lesotho. The high level of violence against dementia sufferers in Mapotu caught the researcher’s attention, therefore the researcher was propelled to conduct a study of this nature to find out the reason for mistreating dementia sufferers as opposed to other patients, and also to find the remedy to this violence.

Furthermore, the study will assist the policy makers in social development and health in Lesotho in that it will provide empirical information on the causes of violence against dementia sufferers as well as the needs of the patients and their carers. It will also help in that which could be done to educate the community of Mapotu about the disease, and which could lead to the prevention of the prevailing violence and stigma against dementia sufferers and their carers. According to the National disability and rehabilitation policy (2011) in December 2019, the Disability Equity Bill passed in the parliament of Lesotho meant that people with certain disabilities would be recognised.

In Lesotho, dementia is not regarded as a disability, and the researcher believes that it is because dementia is mainly attributed to witchcraft rather than being a medical condition. The researcher therefore hopes that the study will inform the relevant stakeholders and policy makers to recognise dementia sufferers. There is an organisation called Dementia Lesotho which is a charitable organisation, but the organisation is not known in Lesotho, and is not even known in the city where it is based let alone to people in rural areas. In short, the organisation is not functional. The researcher hopes that this study will help in the establishment of a functional organisation that would fall under the Lesotho National Federation of Organisations of the Disabled (LNFOD), and that would serve as a representation of dementia sufferers before the government. The establishment of the organisation for dementia sufferers will also help with regards to disability grants. If dementia sufferers are not represented in any platform such that they do not benefit from the grants, this study will serve as a mouthpiece to advocate for the establishment of the organisation which could advocate for dementia sufferers' needs as with other disability groups. As stated by Alzheimer Europe (2013), dementia is recognised as a condition resulting in impairments which lead to disability. Additionally, Kelly (2018) argues that dementia is not a normal part of aging that can be ignored as it is the leading cause of incapacitation, and causes older people to become dependent on the family in South Africa.

WHO (2012) notes that there is limited information on dementia in South Africa. This research will not provide a more reliable estimate of the prevalence of dementia in Lesotho but will provide the information concerning the burden of the disease to families and the community of Mapotu.

1.5 Research Problem

According to Wu *et al.* (2017), there is a forecast of increasing statistics of dementia sufferers, therefore it is important to explain dementia as an organic condition since beliefs surrounding dementia as witchcraft and curses are common in South Africa as in many other countries including Lesotho. It is clear from the discussion thus far that there are misconstructions and misinformation from societies globally about dementia. This means that Lesotho is not exempt from these fallacies, hence the violence and killings of demented people in large numbers. It should be noted that Lesotho is landlocked in South Africa and, as a result, both countries share most of the beliefs and practices. It is a normal practice in Lesotho for a witch to be killed, either by burning or assaulting. It is also a belief that aged people are normally the ones who commit acts of witchcraft in the societies. According to Mkhonto and Hansen (2018: 169), fear and violence towards demented people among South Africans emanates on the belief that dementia sufferers are witches, and this is also the case in Lesotho where dementia sufferers are killed and abused because of the belief that they are witches.

There are several beliefs and definitions of dementia around the globe and this is the source of the violence and killing of dementia sufferers. On the other hand, it is very easy for people to abuse demented people because some of the abuse and violence seem good to normal people. This is because in most countries, including Lesotho, collaborative effort is needed to kill a witch and get rid of him/her before he/she bewitches the entire village. Thus, in Lesotho, killing a witch is considered a noble act of protecting the society from witchcraft and that act unifies the community hence, in most cases, it is done collectively.

Dementia patients face ill-treatment and are largely subjected to violence and abuse in Mapotu. In South Africa, as in Lesotho, dementia sufferers are killed without any ground reasons, and people consider them as witches who are bewitching their families hence they face brutal killings. These are confused and misinformed opinions because the perpetrators most often do not have evidence to support their accusations and killing of the victims (dementia sufferers). In Lesotho and elsewhere, there are no tribunals that deal with cases concerning witchcraft, thus witchcraft has never been declared as a criminal activity, and with that being the case, people attach certain feelings about the disease. Thus, the study seeks to find out that which causes people to regard dementia sufferers as witches, that which motivates and pushes people to consider dementia sufferers as witches rather than as having a medical problem, and why society does not regard dementia sufferers as medical patients rather than regarding them as witches. The study seeks to find out if these confused and misinformed opinions lead to violence against dementia patients and why they have to abuse and subject them to violence. Therefore, the study seeks to find out why the community attitude towards dementia sufferers is the negative one instead of the positive (helping one), and what can be done to protect dementia sufferers.

Additionally, dementia sufferers are subjected to abuse and violence because of their dependency and vulnerability. In many countries, dementia sufferers are kept in old-age institutions, where they are looked after by trained personnel who can take care of the behavioural and psychological symptoms of dementia sufferers (Kok, Berg and Scherder 2013: 361). The facilities are constructed in a way that they provide safety and security to dementia sufferers and other people. It is highly unfortunate that in Lesotho, the patients are cared for entirely by families in their homes, who are not skilled in working with dementia sufferers. The behaviours are mostly attributed to a person being cursed, punished by the ancestors, and possessed by evil spirits and witchcraft – this was revealed during the informal conversation with some family members and community members. Moreover, the families do not know how to calm or control the aggressive behaviours of the patients, and this could lead them to aggravate the behaviour instead of calming it.

On the other hand, the family may take all the valuables of the demented person with the good intention of saving them from being misplaced and lost, but this has an element of abuse. Locking the patient indoors while protecting him/her from being killed seems good and protective, but this is abuse. As stated by one of the carers, the abusers get away with abuse and violence because the victims fail to explain that which has happened to them, which could be due to memory loss or disorientation. As stated by one of the carers, it becomes a challenge to detect the abuse or violence with dementia sufferers especially because the signs and symptoms of the abused victim are similar to those of dementia, e.g. withdrawal and sadness (Cooper 2008; Downes 2013).

1.6 Aim and Objectives of the Study

The aim of the study is to establish how dementia sufferers in Mapotu can be protected against community violence and how best the community can be sensitised about the disease. The specific objectives are:

- To establish the nature, extent, causes, and consequences of violence and abuse against dementia sufferers in Mapotu community

- To plan and implement an intervention to raise awareness about dementia, with the purpose of reducing such violence and abuse

The main reason for undertaking this study is to raise awareness about dementia which, in turn, will prevent the violence, abuse, stigma, and discrimination against dementia sufferers and their families. The researcher also believes that the findings will influence the policy makers and health systems by including the needs of dementia sufferers and their carers in their budget, as is the case with the Human Immunodeficiency Virus (HIV/AIDS) in Lesotho. Much as the findings might not be able to be generalised due to the scope of the study, the researcher thinks that the study will be an eye opener and bring a sense of consideration for dementia sufferers. The study will also contribute to the available literature on dementia.

1.7 Limitations of the Study

There is not much literature about the topic in Lesotho, as well as in South Africa. As a result, the available literature is not adequate and this has impacted on the relevance and the authenticity of the reference. Also, the limited geographical coverage (only Mapotu community has been studied) might hinder the generalisation of the findings. Secondly, it is not uncommon that any study can go without the resource constraints. There are certain elements of the research (such as the number of churches that the research team intended to visit) that were reduced due to limited resources to undertake the research. Moreover, the outbreak of Covid-19 had a large impact on time for implementation of the interventions, which propelled the research team to revise the interventions due to restricted movement and the prohibited public gatherings.

1.8 Research Methodology

The research design outlines how the research intends to answer the research questions (Galletta 2013), and the study employed the qualitative research design, the main function of which is to permit flexibility for the researcher to plan and deploy the needed process which would ensure the validity of the eventual results. The employment of interviews and focus group discussions was structured to obtain the information on the experience of demented people and their families as well as the members of the community in Mapotu. The questions were also structured in a way such that the responses would yield the answers that captured whether a person was informed about dementia or not, and their perception about the disease and the patients.

1.9 Thesis Outline

This study is structured in terms of seven chapters which are as follows:

Chapter One provides an overview and introduction of the study. It sketches out the background, statement of the problem, aims, objectives, research questions, brief design and methodology, a brief literature review, the limitations of the study, and the framework of the chapters.

Chapter Two reviews the literature of the main variables informing the study, namely, dementia and violence.

Chapter Three explores the types of violence and how dementia sufferers become the subject of violence. The attention will be on the causes of violence and its trends, nature, manifestations, and effects.

Chapter Four looks at the research design and methodological issues. This chapter closely provides the rationale for the selection of participants, ethical considerations, and more importantly, how the data was collected and analysed to respond to the study objectives.

Chapter Five presents the findings from the exploration of components of the study where data will be categorised in terms of themes for ease of analysis.

Chapter Six provides the proposed interventions to curb violence against dementia sufferers and presents the implementation of the interventions.

Chapter Seven outlines the conclusion and recommendations based on the findings and discussions in Chapters five and six, respectively. It will finally propose areas for future research.

CHAPTER TWO

Violence, Dementia, and Africa

2.1 Introduction

The chapter explores literature concerning the nature of violence against People Living With Dementia (PLWD). The first part defines the phenomenon of violence in all its forms. The chapter provides a review of the experiences of dementia starting from across the globe and cascading to Africa and Lesotho. The major theme emerging from the literature is the structural violence undergone by PLWD. However, various authors offered solutions according to the studies undertaken. The chapter borrows heavily from case studies on dementia, people living with HIV, and violence prevention in general in Sub-Sharan Africa (SSA) and Lesotho.

2.2 Violence: Conceptual Definitions

The definition of violence is provided by WHO (2002 cited in Adams 2017: 15) as “the intentional use of physical force or power, threatened or actual, against oneself, another person, or a group or community, that either results in or has a high likelihood of resulting in injury, death, psychological harm, maldevelopment or deprivation”. The word “power” is used interchangeably with physical power as it broadens the nature of a violent act. This expands the conventional understanding of violence which are those acts that result from a power relationship, including threats and intimidation. The “using power also serves as a neglecting or acting omission, as obvious acts of violence” (WHO 2002 cited in Adams 2017: 15). Thus, the use of physical force or power should be understood in a context of neglecting and all types of physical, sexual, and psychological abuse, as well as suicide and other self-abusive acts. This conceptual definition of power covers a broad range of outcomes – such as psychological harm, deprivation, and maldevelopment. This reflects a growing recognition among researchers and practitioners of the need to include violence that does not necessarily result in injury or death. Nonetheless, this poses a substantial burden on individuals, families, communities, and health care systems at large. It has been established that many forms of violence against the elderly and those living with dementia, for instance, can result in physical, psychological, and social problems that do not necessarily lead to injury, disability, or death. On the other hand, the Oxford Dictionary (2010) considers violence as behaviour involving physical force intended to hurt, damage, or kill someone or something – ignoring that it becomes meaningful only through the ways it is understood both socially and culturally. It can be exercised through threats, and can also be legitimate and illegitimate, visible and invisible, necessary and useless, productive and destructive, purposeful and unintended – depending on who is judging (David 2007).

Violence tends to reproduce itself in specific forms which feed on, and are nurtured by, other forms such as political and structural violence. Political violence is usually discernible, behaviour learned in political realms, and it manifests in social relations. Structural violence is associated with oppression and social suffering caused by chronic poverty, hunger, social exclusion, and humiliation, and translates into intimate and political violence (Galtung 1969). Other scholars view violence as symbolic where victims take the blame themselves for the violence that they have suffered (Bourdieu 2004). Violence tends to dominate when more complex social pacts such as state-, community-, or religion-based are weakened (Bourdieu 2004).

The complexity of the term is also reflected in inadequate indicators. Although domestic violence is much more prevalent in society, it is more socially acceptable in many places and more difficult to track and to deal with (Adams 2011; WHO 2002). In the same way, the study conducted by WHO (2002) indicates that there are high levels of violence that exist in parts of Sub-Saharan Africa and in pockets of the Middle East and Asia. Most studies of violence focus on the high rates of homicides evident in recent decades, as some scholars argue that the violence often has much deeper historical roots. Additionally, Widner *et al.* (2011) note that national homicide rates in Mexico today are notably lower than they were for most of the 20th century. From a high of 77.4 homicides per 100,000 people in 1930, they dropped gradually until 1970, when they stayed between 17 and 18 until 1990. The literature shows that in Guatemala, homicide rates are much lower in the predominantly indigenous highlands, even though collective killings have exploded in indigenous areas among other groups living in the areas, since indigenous communities have also experienced a significant upsurge in homicides. According to Adams (2011), chronic violence is a relatively new phenomenon in most societies and communities. According to Pearce (2007), chronic violence occurs in contexts in all levels of violence are measured across three dimensions of intensity, space and time. “The acts of violence occur at several socialisation spaces, such as the household, the neighbourhood, and the school, contributing to the further reproduction of violence over time” (Pearce 2007: 7).

Adams (2011) further argues that chronic violence is provoked and reproduced by a range of deeply rooted drivers such as gender socialisation and family dynamics, and patterns of state formation and globalisation. These destroy social relations in specific and consistent ways, and provoke perverse social behaviour in ways that become increasingly naturalised among vulnerable groups. As such, this perverts the practice of citizenship and undermines social support for democracy, because it provokes further violence, which can be adopted by the next generations. Although it does not explicitly mention the term, the World Bank’s 2011 World Development Report approaches the question of violence in a similar fashion, recognising its recurrent nature, and that its embeddedness in diverse social spaces has a potential to cause trans-generational effects, which is a problem for both rich and poor.

2.2.1 Types of Violence

Research by Galtung (1969), Varobej (1981), and Goodman *et al.* (2016) have revealed the following types of interpersonal and community violence, as depicted in Figure 2.1.

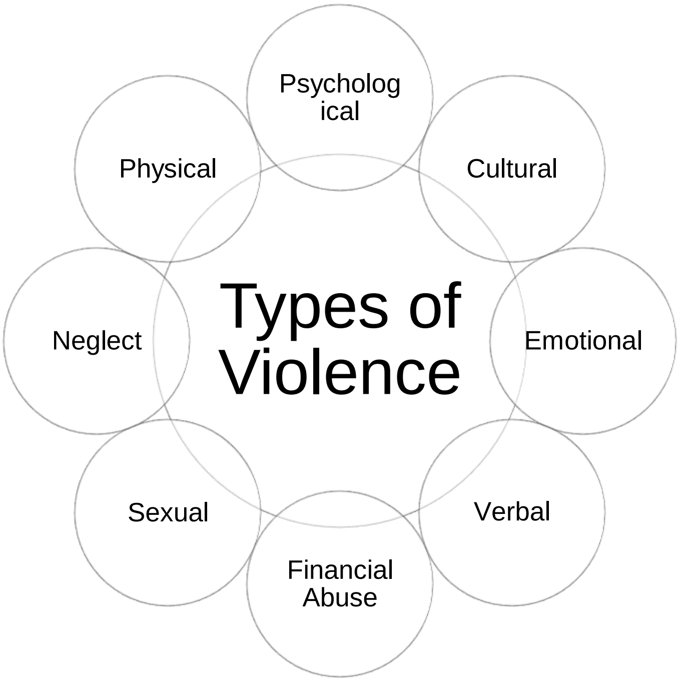

Figure 2.1: Types of violence.

The types of violence are described as follows:

- **Physical Violence** occurs when a person uses a part of their body or an object to control a person's actions such as using physical force which results in pain, discomfort, or injury.

- **Sexual Violence** takes place when a person is forced to unwillingly engage in sexual activity.

- **Emotional Violence** occurs when a person does something to make another person feel worthless.

- **Psychological Violence** occurs when a person uses threats and causes fear in another person to gain control over him or her.

- **Spiritual Violence** takes place when a person uses spiritual beliefs to manipulate, dominate, or control the other person.

- **Cultural Violence** results from cultural practices that a person poses to harm another. These are associated with cultural norms as religion and tradition. Cultural practices make violence direct and increase structural violence which later increases and promotes verbal violence (Galtung 1990: 292).

- **Verbal Abuse** occurs when a person uses spoken or written language that cause harm to a person.

- **Financial Abuse** occurs when someone controls a person's financial resources without the person's consent or misuses those resources.

- **Neglect** occurs when someone has the responsibility to provide care or assistance for one but does not.

2.2.2 Causes of Violence in Communities

a. Underlying Causes

i. Masculinities

Most of the rural and even urban places in Lesotho are patriarchally oriented. Therefore, Mapotu is not an exception and this has cascaded to women being minor or inferior. The researcher's experience of growing up in Mapotu presented masculinity as being superior in almost everything and a woman who challenges that is regarded as a bad wife. In Mapotu, during the community meetings (*Pitso*), women do not talk or share their ideas, the men make decisions for women, and the women have to execute the decisions. Lesotho practices traditional circumcision (*lebollo*), and it is from *lebollo* where boys are taught about and oriented into manhood. They are taught how to treat women (sisters and their mothers). *Lebollo* was regarded as a good practice earlier but as of late, it has turned into an institution where boys are taught to be disrespectful. Our grandfathers and our fathers were initiated into *lebollo* and they were well-behaved and even encouraged the boys to go and join *lebollo*, but in present times, no father wants his boy child to go there because it has turned to be a bad institution.

Moreover, these days, those who have gone to *lebollong* mock and discriminate against those who have not gone. The ones who did not go to *lebollong* are called names (woman, dog, and uncircumcised ones) or in Sesotho, they are called *Mathisa*, and there is no other insult as worse as this for men. This issue of the traditionally circumcised versus the uncircumcised is one of the leading causes of violence in the rural communities. In short, in Mapotu community and in other rural communities, *lebollo* is an identity of a boy child and one that shows masculinity. Everyone who completes the harsh training of *lebollo* is regarded as a man.

ii. Inequality

Inequality is another factor that directly and indirectly contributes to violence in the communities. For Mapotu, inequality exists in many forms and occurs in different contexts. In a village of a community context, as mentioned earlier, in public gatherings, the men who have not undergone traditional circumcision do not have a sound voice as compared to those who have been to *lebollong*. More often, the man who has not been to *lebollong* cannot, under any circumstances, give orders or tell the one who is from *lebollong* to do something. Lesotho is a monarchy and the chieftaincy surnames and names are well known in Lesotho, thus everywhere one goes and mentions his/her name or surname immediately, one can tell if a person is a prince or princess and the treatment given to ordinary citizens and the royals is different. The difference of treatment is at all levels from the national, district, and even local levels. This inequality also causes violence to some extent as it cascades to discrimination.

b. Facilitating Factors

i. Availability of Guns

In Lesotho, as in other countries, there are illegal possessions of guns and this is among the leading causes of violence in the communities. It should be mentioned that Lesotho has unique music which serves as Basotho’s identity. There are many artists singing the traditional music (*famo*) in Lesotho. However, there are two leading artists and they are both from Mafeteng – their groups are called *Letlama* and *Terene*. Each district has one or more artists and they are all good. It is very unfortunate that the two main artists from Mafeteng do not see eye to eye, and they are the worst of enemies. They have different attires and one of the distinguishing attires is the blanket. This has led to the music being called a blanket music which, in Sesotho, translates as *mmino* *oa likobo*. Almost all the Sesotho artists have guns and they use the guns to fight their rivals as some artists have more followers than others. This issue of fights in *mmino oa likobo* exists everywhere in the country. In a community, people are very divided because of the traditional music. It is very sad because a blanket is a traditional attire of the Basotho people, thus people cannot wear their blankets because they will be associated with a certain group. The guns in the communities have mainly been bought by this issue of music and the deaths related to the music are rising rapidly. It is very sad as most of the people had to pack and not use their blankets. It is even more saddening when people attend funerals, as the wearing of a blanket shows the ultimate respect thus people have to do away with their culture because of blanket gangs. People in the community are not free to play the songs of their choice because if they are heard by the person who is not a follower of the artist playing, the person simply gets killed.

ii. Weak Social Controls

There is weak social control in Mapotu, and this has contributed to the cases of violence. In rural communities, the only person who has had a say in everything was the village chief until the emergence of councillors, though the councillors do not effectively deal with issues on the village level and they often come in when the chief has failed to solve the issue. Thus chiefs are not very effective when violence and criminal control are concerned, and they normally seek help from the police and, in the case of Mapotu, the police station is very far and the police take time to react to the issues. Besides the distance, the police stations do not have enough vehicles to do the job as expected.

c. Triggers

i. Grazing Land

Almost every household in the rural areas of Lesotho rears animals, and this is because in the rural areas, people live on farming and they use animals to plough their fields. Every village has a known portion of land for the grazing of its animals. Thus there is a clear demarcation which marks the territory of each village. The village may agree not to let the animals graze for a certain period to allow the grass to grow such that they can have attractive land for grazing. Thus, that which causes the fights, which have claimed the lives of many people, is that some villages do not preserve or allow time for the grass to grow and when they realise that village A has attractive grazing land (*leboella*), they take their animals at night to graze where village A has preserved the grass, or sometimes they do it during the day and they are heavily armed to fight back when the owners come to fight.

ii. Drug Abuse

Many villages in Lesotho grow weed/marijuana (*matekoane*). This is a dangerous drug which makes people go mad, especially when it is consumed in a high quantity. Because of its consequences, it was illegal to grow marijuana in Lesotho, or the person who was found with a certain quantity was sentenced to prison and the sentence was based on the grams that the person had possessed. Nevertheless, people still had to find a way of growing and hiding it during the police operations in the villages. The use of this is another factor of violence as the consumers lose their mind and carry out crazy actions. When the consumers are in an altered state of mind from the drugs, they would fight people for no reason, and destroy objects by breaking and hitting them. The explanation behind the crazy behaviour is that they are hallucinating hence they fight and break.

Moreover, Goodman *et al.* (2016: 165) argue that there are community contexts in which social relationships are embedded such as schools, workplaces, and neighbourhoods, which have some characteristics that are associated with victims or perpetrators of violence. These cause violence in the communities since people interact with one another daily. Similarly, because communities are characterised with problems such as drug trafficking, high levels of unemployment, coupled with widespread social isolation in which people do not know their neighbours or are not even involved in the local community, they are also more likely to experience violent behaviour (Goodman *et al.* 2016). Research conducted by WHO (2004: 7) on violence shows from the evidence that there are greater opportunities for violence in some communities than in others. There are instances such as high levels of poverty or physical deterioration, and instances where there are few institutional supports, since social inequality leads to inequality. Globally, there is a robust and well-established correlation between social inequality and incidences of crime which promotes violence and that enables people to bring the misleading notion that poverty itself provokes violence (Wilkinson and Marmot 2003: 22; Pearce 2007: 294).

It is noted that throughout Africa, social inequality remains high, with the top 10 percent of the population earning three times as much as the poorest 40 percent (Gureje *et al.* 2015). A great proportion of young people today are forced, from the economic conditions, towards long-term job informality and severely reduced social mobility, regardless of historically high educational levels (Ward *et al.* 2004). Within these chronically excluded populations, indigenous and Afro-descendant groups, such as women, children, and youth are the most vulnerable groups of people exposed to violence. Various analysts report that migration and income derived from criminal networks also produce additional internal stratification within communities and social groups, between those with higher income sources. This further widens the gap between aspirations and possibilities, and spurs increased conflicts and violence. In this context of an increased social fragmentation and state dysfunction, mass media also play an important role to produce, reproduce, and increase violence in the region (Adams 2011). As Putnam and others have pointed out with respect to the United States, television and other electronic entertainment media have direct and dramatic negative effects on social relations and social capita (Adams 2011). Trere (2015: 125), in studying Mexico, notes how narratives of fear circulated by the media generate the “reality” in which people live. It was established that fear is constructed socially and reinforced in the intimidating amplification of the media’s narration. These constructions contribute directly to the vilification and scapegoating of certain actors.

The concept of social capital should be in social support systems and relations that permit the existence of trust, mutual obligations, and respect in communities and the societies – social capital helps to understand the problem of chronic violence in society because people are bound by their social relations and activities that they do within their communities. This means that low levels of social capital could be both a cause and effect of chronic violence. In his study of United States (US) society over the past 50 years, Glaeser *et al.* (2002) note that civic engagement has been undergoing a process of systematic destruction. Hence, there has been a decrease in the levels of social capital, increases in the crime rates, more neighbourhood insecurity, and more interpersonal violence, as well as problems of child welfare and a lack of economic prosperity, health, happiness, and democratic participation. According to Glaeser *et* *al.* (2002: 287-367), higher levels of social capital are linked with more positive performance in all these arenas. Putnam (1995) postulates that in the United States of America, the decline in the levels of social capital is attributed to four major factors that include the increased use of television and other electronic media; long hours, pressure, and uncertainty in the work arena; suburbanisation and increased dependence on commuting; and an increasing tolerance for the lack of civic engagement in successive generations.

According to Adams (2011), there are other significant forces and factors that stimulate violence, and these are beyond the control of nation-states, all of which require a tactful approach to investigate in order to deal with and curb the problem of chronic violence. Amongst these are climate change, because it provokes natural disasters as they pose far-reaching effects and danger to vulnerable communities and food production through hurricanes, tsunamis, and flooding. Environmental degradation and the effects of the global economic downturn have proven to be a significant economic crisis (Adams 2011).

2.2.3 Consequences of Violence

In every society, violence affects both the human and economic conditions of nations, and costs economies many billions in health care, legal costs, and the loss in economic productivity (Goodwin-Hawkins and Dawson 2018: 270). Even though it is difficult to estimate the burden of all types of violence on health care systems, and how it has affected economic productivity, the available evidence of the cost of violence on the economic productivity shows that people who have experienced domestic and sexual violence have more health problems, which bring significant costs to health care facilities (WHO 2004: 8). This is also seen for the victims of abuse and neglect. The effects of the different types or forms of violence are summarised by Margolin and Gordis (2004) as short-term, post-traumatic, and long-term. Short-term effects are aggression and delinquency, depression, and anxiety. Post-traumatic stress disorder symptoms such as nightmares and flashbacks have also been reported. Exposure to family and community violence is also linked to long-term effects, because they lead to aggressive behaviour of the person later in life. This association is theorised to be the result of the social learning theory. Therefore, as people and children grow, they learn aggressive behaviours in their own environments in which they live (Margolin and Gordis 2004). These are recognised as the breakdown of traditional social systems that contribute to the rise in social violence (Margolin and Gordis 2004). Nash (1967) found the weakening of structural beliefs and the local systems of social checks and balances in one indigenous Guatemalan community where people resorted to individualised means of social control such as homicide (Nash 1967). However, 80 percent of Latin Americans living in urban areas were negatively impacted by rural to urban and international migrations, and family and community relations based on rural social structures that were transformed. A research study was conducted by Adams (2010) in which he explored the disintegration of family relations in marginal urban settlements. The findings conclude that social institutions, such as families, are more effective in rural areas than in urban areas to promote the social bonds that shape the behaviours of people, though they are based on the rigid hierarchical structures (Margolin and Gordis 2004). As noted by Adams (2010), the breakdown of traditional roles and relations are mostly experienced in rural areas. In addition, Adams (2010) notes that the INCIDE study of violence in four Mexican cities shows how the macro-level drivers described above as well as various national level dynamics have contributed to breaking down family structures and increased domestic and gender-based violence inside and outside the home. Hence, a decrease in actual earnings has forced people – especially more women – into the workforce and increased the number of jobs that all wage-earners needed to survive (Adams 2010).

Above all, significant urbanisation patterns and a lack of social services have reduced the informal and formal support for raising families, as more children now spend time at home unattended, and women are forced to spend less time at home to look out for their families and themselves. As a result, this increases the violence between men and women and intra-family conflicts which later contributes to femicides. This brings a decrease in nuclear families, an increase in divorce, women heads-of-households, and recomposed families (Adams 2010). These are linked to family breakdown and dysfunctional community structures as they are not ceasing in order to accommodate and work towards cementing the social roles and functions, thus increasing the capacity for violence (Baron-Cohen 2011). Integrating social, psychological, neurological and genetic analysis, Baron-Cohen (2011: 520) argues that human cruelty can be conceived as “zero degrees of empathy”. This means that broken bonds between infants and parents and certain neurological factors contribute to the development of people with little or no capacity for human empathy (Baron-Cohen 2011). These effects can later manifest extreme and irreversible levels of cruelty, with effects on their own children or other younger people, and that can become trans-generational (Baron-Cohen 2011).

High levels of violence go hand in hand with its growing social legitimacy. The evidence shows that self-justice, lynching, the use of private security forces, domestic violence, and high levels of alcohol and drug use wash away social legitimacy, that is, the high levels of violence in the societies means that people no longer trust the public institutions to enforce the laws (Baron-Cohen 2011). Younger generations in general exhibit higher levels of approval for violence than their elders. Although poorer and urban populations are the most vulnerable, support for social cleansing and summary executions cuts across all social classes (Baron-Cohen 2011). In Brazil, for example, Caldeira and Holston (2015) note that supporting social cleansing and summary executions exists within all the social classes. However, rich people are not abused by the police, and for many purposes, rich people are indirectly given more opportunities to operate outside the confines of the law, and are thus considered more privileged. The possible links between these tendencies and the patterns of extreme cruelty studied by Baron-Cohen (2011) at the individual level, as well as their trans-generational transmission, deserve concerted attention by policy makers.

2.3 Understanding Dementia

In understanding dementia, the definition of dementia has several scientific connotations that are attributed to it by different scholars. Dewing and Dijk (2016: 106) define dementia as a collection of signs and symptoms that include memory problems, communication difficulties, a lack of organising and planning one’s day-to-day life, changes in behavioural mood, and the gradual loss of control for effective physical functions. These symptoms, combined together, are taken as an indication of physical damage of the brain caused by chronic progressive degeneration in the nerve cells. This damage in the brain may be caused by a variety of different diseases such as depression and chronic illness. On the other hand, Alzheimer’s disease is the commonly and best-known cause of dementia such as vascular dementia which, in most cases, is associated with older people as the ageing (Ferri *et al.* 2012: 2112). Populations in developed and developing countries are ageing rapidly, and the number of people with dementia will increase, making it one of the most important public health issues of this generation (Gibson *et al.* 2003: 100). Prevalence rates for dementia vary relatively little from country to country, especially in countries with high-income rates. Different health and social care systems treat dementia in different ways. As such, these countries are able to identify and assess needs at different levels to respond to the illness. Additionally, higher amounts of resources are used to meet those needs of citizens, especially those who need government assistance to reallocate the resources equitably in ways that best deliver treatment and support, through channels such as formal services or by relying on families and carers (Hendrie 2006: 480). As Kirkman (2002: 75) argues, “underlying financing mechanisms also vary”. This depends on resource base, system response, and financing arrangements to respond to demographic pressures; socio-economic contexts; weakened macroeconomic capabilities; and societal attitudes which include cultural and religious attitudes, and to strengthen political commitment and policy priorities (Gibson *et al.* 2003: 100).

In the United Kingdom, because of the demographic changes, the government was forced to approach these changes accordingly to address them not as a social problem but as an economic phenomenon. The country saw an increase in the number of people with dementia from 940,000 in 2021 (28%) to a higher number of 1,735,000 in 2051 (154%) (Kirkman 2002: 75). Thus, dementia is seen as a major public health issue and challenge not only in developed countries but also in developing countries where the age structure determines the number of cases and relatively minor (Hendrie 2006; Ferri *et al.* 2005). It is shown in the literature that the nature of the clinical challenge of dementia, where behavioural and psychological symptoms are at high levels, has a negative impact on family carers and dependency. In a study conducted by Gibson *et al.* (2003: 100), the evidence shows that many people with dementia do not receive any diagnosis, early diagnosis, and are prone to a lack of access to treatment and care. Thus, the early detection was proposed as an appropriate health strategy to detect dementia before it escalates. These policy initiatives have been adopted in the United Kingdom, France, Spain, and Canada in which the importance of the early detection of dementia is given primary consideration to help patients and their families prepare for the burden of illness and caring. This enables individuals to express their choices, and to prevent future harm that could be posed by the illness to both the caregiver and person living with dementia. This, in these countries, has helped to develop positive attitudes towards dementia held by the general public, health and social care professionals, policy makers, relatives, and other people who have influenced the ways in which people view this set of conditions. Therefore, there is a willingness to pay for medical treatments and to see scarce tax or social insurance funds allocated to the support and care of people with dementia (Nolan *et al.* 2006: 20).

The stigmatising attitudes about mental health and the negative images of the ageing are related. According to Alzheimer’s Disease International (2014: 13), dietary factors have the possibility to increase or decrease the risk of dementia from the onset. The evidence from epidemiological cohort studies show that adherence to a Mediterranean diet, such as a high proportion of cereals, fruits, and fish, has the potential to reduce the risk of cognitive decline and dementia. It is essential to note that the undernutrition and weight loss in dementia are complex and different factors which are partly understood by the many people and health professionals (Alzheimer’s Disease International 2014). However, different scholars are of the view that in some forms of dementia, it may be that the central regulation of appetite and metabolism is disturbed as an inherent feature of the disease. Therefore, in communities where food is insecure and expensive, there is a likelihood of violence perpetrated against dementia care recipients because caregivers will be bearing the double-edged burden of making ends meet and again assisting the patients to eat. Weight loss is a common problem for people living with dementia and therefore undernutrition should be avoided, as stated by Alzheimer’s Disease International (2014: 10).

The nutritional benefits of educating and training caregivers was less apparent, although these interventions are popular and are likely to benefit other sections of the population. Thus, in caring for the dementia survivors, the focus should be given to staff training and mealtime environments because this can lead to and enhance calorie intake among residents. Eating is a social activity, and more thought should be given to how this can be optimised, normalised, and made a core aspect of care centres in every society (Bigby 2004). The caregivers and the societies need to focus on the problem of undernutrition in dementia since this has been largely neglected in research and practice which means that it is notably a research gap that needs to be filled, though there is no current evidence that nutritional supplementation can modify the course of dementia, because there is currently insufficient evidence to recommend the use of medical food potential therapeutic benefits. The report by Alzheimer's Disease International (2014) indicates that 20-45% of people with dementia in the community experience clinically significant weight loss over one year and that almost half of the people with dementia in care homes have inadequate food. It is imperative to note that much of the reports by Alzheimer's Disease International (2014) have focused on the experiences of those living in care homes in urban settings and neglecting those living in rural communities where care-giving is the primary responsibility of close relatives and very close friends, and that is a point of entry for this study.

Dementia Stereotypes

A pilot study on dementia and stigma beliefs by Phillipson *et al.* (2012: 8-10) revealed that despite most participants in this survey knowing someone with dementia, the findings suggest that the overall attitudes of the Australian community towards people with dementia were negative to lead to a stigma 'consciousness'. This is indicated by factors such as shame, humiliation, and some fear that people feel when they are diagnosed with dementia. This is significant because it is difficult to measure the experience of discrimination and evaluate the potential consequences of the stigmatisation of people living with dementia. This means that people living with dementia have an internalised shame and a fear of loss of power and respect to treatment in the work and health sector. However, there were people with a desire to avoid people with dementia, and there are still significant sections of people with positive views towards people living with dementia. These views include the importance of their value, their capacity to participate, and their desire to live a quality life.

However, the presence of beliefs is still important as such have been viewed and quantified in a community. Kirkman's (2006) coverage of Alzheimer's disease, which is one of the leading causes of dementia, revealed negative stereotyping. On the other hand, the literature also refers dementia to forgetfulness and memory loss being an unavoidable part of ageing as experienced by people. The corollary of memory loss being a part of ageing is that the onset of Alzheimer's disease at a younger age is portrayed as a greater tragedy than if it occurs at 70 years of age (Gerrad 2019).

Husband (2010) notes that there were frequent comments on the social unacceptability of dementia. These are images and stereotypes of people with dementia, who see people with dementia as violent. Instances of social isolation and avoidance by friends, colleagues and the public were spoken about (Husband 2010). The data collected confirmed that a diagnosis of dementia is a medical process, a social act that places the person with the diagnosis in a new social group (Husband 2010). Hence, social distance from those who are stigmatised has received much attention. Social isolation has a significant impact on those affected by dementia, and this reinforces dementia-related stigma (Husband 2010).

Some causes of violence are easy to see and result in the social, cultural, and economic fabric of human social lives (Goodman *et al.* 2016: 165). Recent research suggests that even though biological and individual factors explain some of the predispositions to aggression, more often, these factors interact with family, community, and cultural settings and create a situation where violence is likely to occur (Straus *et al.* 2017: 25; Hird 2017: 20).

The literature indicates that this takes place particularly through homicide, suicide, and war-related deaths which contribute to violence in a community and country (WHO 2004: 3). In comparing statistics to deaths, such data provides a useful indication of the burden created by violence-related injuries. Straus *et al.* (2017) further add that these can be used for monitoring changes in fatal violence by identifying groups and communities that are at a high risk of violence. In 2000, it was estimated that 1.6 million people worldwide died because of self-inflicted, interpersonal, or collective violence (WHO 2004: 4). In the African and American regions, homicide rates are three times greater than suicide rates, as Hird (2017: 21) mentions. According to an Overseas Security Advisory Council/OSAC (2017) report, in Lesotho, criminals resort to violence to subdue their victims to obtain items of value, or commit a sexual offense as a means of acquiring information regarding valuables in the households.

2.4 Dementia and Violence

Wharton and Ford (2014) examined the issue of agitation as behaviour manifestations in advanced dementia, and concluded that there is little in literature on the topic. They further argue that there is a need for interventions aimed to educate and protect the informal caregivers of dementia patients living at home and also to advance an understanding of the communicative properties of behaviour. According to Enmarker *et al.* (2011), there is the well-documented fact of physical aggression as the most common behaviour that manifests in dementia patients, and it is related to identifiable triggers. Even though there is not much in the literature regarding the impact and experience for caregivers, there are a range of triggers for aggression in care recipients. The evidence suggests that caregivers are given little information about the causes and triggers of the disruption of the behaviour itself. Ryden (1988: 343) points out that better empirical information regarding the phenomenon is important to develop strategies for the prevention and management of dementia and how best it can be cured. Enmarker (2011) concurs with the aforementioned argument as he states that only 21 published papers on dementia have met medium or high levels of scientific rigour. The above evidence and arguments suggest that there is much that needs to be done as researchers to address the subject matter of dementia and violence. The paper by Wharton and Ford (2014) examined the current state of literature regarding home-based dementia caregiving and care-recipient violence did not focus on the violence perpetrated by caregivers on patients but rather emphasised violence by care recipients.

On the basis of the above, it is imperative to note that studies on violence and chronic diseases are worth pursuing because they will unpack and close the aforementioned gap in literature. Ground evidence suggests interventions that focus on coping strategies for the caregiver as a way to increase the sense of personal reward, thus decreasing the overall subjective burden of caregiving in this type of situation. However, these strategies remain theoretical for caregiving with violence present. Cooper *et al.* (2010: 592) state that “emotion based coping strategies can mitigate the impact of burdens of dementia carer’s mental health”. In addition, Desai and Crossberg (2001) advance a range of behaviour interventions that may help in decreasing aggressive behaviours such as psychopharmacological intervention to reserve until these have been tried to obtain low rates of medication success.

Humanising the environment to reduce patient stress is one of the workable alternatives. However, the focus here is on institutional settings and this technique works well in home-care settings and concurs well with the objectives of this study despite the fact that much of the accent of the current study is on violence perpetrated by caregivers and not by dementia patients (Desai and Crossberg 2001). This is consistent with recommendations in literature particularly where cautions about the 'start low, go slow' approach to chemical interventions are noted and non-pharmacological interventions as the first line of approach. Therefore, it is important to gain insight on the lived experiences of caregivers and healthcare providers who take care of patients with dementia and those exhibiting violent behaviour.

This is because these strategies help to develop a theoretical model for violence and aggression in care recipients' impacts on the health outcome of both care recipient and caregiver. Also, such research will inform considerable points of interventions needed for feasible, effective and cost-effective interventions for families dealing with dementia patients. Vickrey *et al.* (2006: 719) argue that:

> [T]echnology guided management programs were both successful and cost-effective noting that improvements were noted in all domains, including caregiver education and support, where the evidence linking provision of such services to delays in institutionalization and safety which is chiefly essential because appropriate care could prevent rare but severe adverse outcomes.

2.4.1 Ageing, Gender, and Violence

In most studies, the elderly people are identified as mostly being the victims of violence. However, it has been noted that geriatric patients, especially people with dementia, display violent behaviour. The results of the study by Haller *et al.* (1989) show that violence is rooted in demented geriatric patients who need psychiatric hospitalisation. Their study was consistent with an earlier report of an increased assaultive problem associated with bimodal distribution with younger and elderly patients and amounts to violent behaviours. However, the study findings failed to address issues such as relative risk for violence from different age groups, as the conclusion was based on elderly patients being prone to violence.

The major weakness of the review by Haller *et al.* (1989) was that the study evaluated a homogeneity of elderly patients carrying the same diagnosis which is not the case with the current study which tends to borrow from more heterogeneous cases of people living with dementia. Both living with family before admission and being married were found to be associated with violent behaviour. One explanation for these associations is that when patients are married or living with family, there is an available victim, and therefore, there is a greater likelihood of aggressive behaviour by a patient who is at risk of committing violence, as argued by Haller *et al.* (1989).

When examining the impacts of sexual violence on older people and the challenges in accessing support through a critical feminist gerontology lens, it was found out that older survivors are more likely to experience a double disadvantage, as Mann *et al.* (2014: 20) point out, rooted in ageism and sexism. Also, a lack of awareness and acceptance of sexual violence which are later shown reflect ageist and sexist attitudes towards older people. As such, age and gender intersect to create specific impacts, challenges, and barriers (Mann *et al.* 2014: 20).

However, ageist constructions on older people weaken and pose vulnerability based on a perception of ageing as a process of decay, decline, and deterioration (Jones and Powell 2006). The types of interventions offered the success of support services provided, and this is because social attitudes and responses are experienced and associated with sexual violence and are translated to shame and silence (Patterson 2016). These are compounded by ageing which portrays older people as asexual, and therefore, they are not outside accepted boundaries of concern as survivors of sexual violence (Bows and Westmarland 2017). The police, media campaigns, and coverage cases reinforce stereotypes, which negatively impact on the likelihood of victims being believed and/or being reluctant to report cases and thus, keeping the stereotype (McMillan and Thomas 2009). This has important consequences for older people because they may be reluctant to report and disclose sexual violence because they do not fit the “real rape” model. In the context of sexual violence, an increase in age and health complications such as genital trauma and long-term urinary or colorectal problems after being sexual assaulted, exacerbate existing physical or mental health problems such as heart conditions, arthritis, or dementia (Bows 2018). This creates difficulties for survivors to access support and also creates challenges for practitioners to provide necessary support. Examples provided by practitioners include difficulties in conducting forensic medical examinations in situations where the older person had physical conditions which make it difficult to get onto medical beds and, where an older person has dementia, problems to gain consent to perform medical examinations (Bows 2018).

For counsellors, dementia is a concern for ethical consideration in providing counselling support (Flannery 2003). However, there is a lack of scientific research and guidance in this area. Further issues were expressed by practitioners with a lack of guidance to support older survivors living with dementia in relation to possible misinterpretation to disclose acts of sexual abuse and fear as attempts for supporting survivors with dementia may create unnecessary anxiety (Bows 2018). Even though there is a lack of literature that examines the coping strategies to support people who have experienced various forms of abuse such as physical and sexual abuse, especially the elderly, Bows (2018) states that there is a growing concern on the use of alcohol among older dementia survivors which exacerbates existing physical and/or mental health problems, and creates additional support needs and challenges. Therefore, there is an urgent need to develop more nuanced understandings of the effects of sexual violence and promote resilience among older people who experience sexual violence (Bows 2018).

It is important that practitioners in the fields of social work and social care, health, criminal justice, specialists on sexual violence, and Non-Governmental Organisations (NGOs) work collectively to develop knowledge of the social effects of sexual abuse on older people, and create knowledge to support survivors as a way to develop strategies for healthy recovery and long-term survival. In addition, other research has examined ways in which ageism and sexism are related, using feminist and gerontological frameworks as the lens to examine the interconnectedness between age and sex to the violence, and to develop and bring about understandings of the range of impacts and support needs of older people, and as such, provide the much-needed evidence that informs future policy and practice. The key findings of the study by Khonje *et al.* (2015) in the Western Cape revealed that there is no difference in the knowledge, attitudes, and practices towards people with dementia because of demographic characteristics.

In general terms, there is very limited knowledge and understanding of dementia in Xhosa-speaking communities in urban areas. The findings revealed that spiritual beliefs lack knowledge about the causes of dementia since people's tolerance towards People With Dementia (PWD) was not influenced by their knowledge about dementia. According to Khonje *et al.* (2015), people were able to identify indicators of abuse of elders with dementia. Most people denied knowing a person with dementia who had been abused. However, they know of the services available in the community for abused people. Hence, further research is needed to be conducted on this topic to enable the implementation of appropriate interventions, health promotion strategies, and workshops.

2.4.2 Violence against Dementia Sufferers

Wharton and Ford (2014) are of the view that a universally accepted definition of violence by dementia care recipients has not emerged since the language used by the scholars to discuss the issue can be very problematic and unclear in understanding the concise definitions of dementia. This is so because aggression and violence are value-laden terms. Again, it is established that in different situations of dementia, victims' responses to stimuli has not been agreed upon in literature. Therefore, there is a need for studies on the topic in order to develop a working definition although this was not the overriding objective in pursuing this research. According to Wharton and Ford (2014), violence is defined as physical aggression or hostile action with physical contact or attempts of physical contact and aggression. This involves hitting, pinching, shoving, grabbing, or biting. Thus, violence and aggressive behaviour can have substantial consequences on the quality of the care received, the use of medical and physical restraints, as well as the safety and health of the caregiver. Given this, there are more information and intervention means for the effective management of violent and aggressive behaviours, also preserving the communicative properties of these expressions needed. Orengo *et al.* (2008: 229), in a study of "newly dementia-diagnosed veterans found that 20% of all participating veterans exhibited aggressive behaviour at the baseline screening somewhat higher than estimates of early stage aggression in the general public". According to Petersen (2010), there are no indicators in a person's history that they will develop aggression, however, their study found a tenfold increase in injury rates related to violence by veterans with dementia cared for in their homes. Thus, it is in the opinion of Kunick *et al.* (2010) that further studies with such populations are necessary in the fight against dementia stigmatisation in the world.

There is some evidence in literature that shows the relationship between pre-morbid aggressiveness and violent behaviour in dementia patients. In the study conducted by Hamel (1990), the findings indicated that 34% of care recipients exhibited physical aggression and 10% were dementia patients with pre-morbid aggression. Chen *et al.* (2000) consider that the high correlation between aggressive behaviour and alienation from family members found in their study may be related to pre-morbid personality characteristics. Again, Orengo *et al.* (2002) link testosterone and oestrogen levels to aggression levels in elderly men and research seems to suggest that this correlation is both strong and worthy of continued study.

2.5 Dementia Experiences

2.5.1 Dementia Worldwide

Dementia trends in the world indicate that it is not a normal part of ageing. In 2013, it was estimated that 44 million people worldwide live with dementia with the number increasing every 20 years, hence it was projected that by 2050 it would reach 135 million (Wottman and Iddon 2014). It is however sad to note that most of the increase will occur in Low- and Middle-Income Countries (LMICs) which already house more than 62% of people living with dementia. World projections indicate that the figure will rise to 66% in 2030 and 71% in 2050 (Wottman and Iddon 2014). Without sounding alarmist, the aforementioned projections validate the need for further research on the disease not only in medical circles but also in academic discourses as well as policy fraternities (Wottman and Iddon 2014).

Dementia and cognitive impairment are considered as the most important contributors to chronic diseases leading to disability, dependency, and transition into residential and nursing homes. It is estimated that there are 7.7 million new cases of dementia being recorded each year worldwide (Wottman and Iddon 2014). Behavioural and psychological symptoms manifest later in the course of the disease, and this has a negative impact on the quality of the lives of most people especially the elderly, which in turn increase caregiver strain. This is supported by Wottman and Iddon (2014) that the total in the 2010 cost of dementia was approximately US$ 604 million on the Gross Domestic Product (GDP), and in low- and middle-income economies such as Lesotho, informal care costs two-thirds of the national GDP (Hendrie 2006: 480). Undernutrition is the most common nutritional problem affecting people with dementia, and the prevalence and incidence of undernutrition among older people in low- and middle-income economies is higher particularly in rural areas in less developed countries (Hendrie 2006: 480).

Prevalence rates for dementia vary relatively little from country to country, at least among high-income countries. However different health and social care systems identify and diagnose dementia in different ways, identify and assess needs in sometimes distinct ways and at different levels, devote variable amounts of resources to meet those needs, and choose a variety of ways to deliver treatment and support, whether through formal services or by relying on families and other carers (Hendrie 2006: 480).

In low- and middle-income economies such as Lesotho, where the patients are being cared for by their families, the cost of caring outweighs their income (Wottman and Iddon 2014). In high-income countries, there is a slight difference in the prevalence of dementia from country to country. Countries have different health and social care facilities, which also impacts on identifying and diagnosing dementia (Hendrie 2006: 480).

Kirkman (2002) notes that dementia not only affects old people, and there are young people with dementia although their numbers are low, and this is estimated to be 0.1% of the population aged from 44-45. Based on the prevalence rates of dementia in the United Kingdom (UK), it is estimated that there are approximately 684,000 dementia sufferers in the UK which is 1.1% of the population (Gibson *et al.* 2003: 100). It should be noted that from the 684,000, 562,000 are living in England, 55,000 in Scotland, 36,000 in Wales, and 15,000 in Northern Ireland. The numbers of dementia cases in the UK are expected to increase to 940,000 by 2021 (a 28% increase) and 1,735,000 by 2051 (a 154% increase) (Kirkman 2002: 75).

Dementia poses a major public health concern both in developed and developing countries (Hendrie 2006; Ferri *et al.* 2005). There is a small variation on how dementia impacts on the families due to behavioural and psychological symptoms. In a study conducted by Gibson *et al.* (2003: 100) across nine countries, the results revealed that in many countries, people with dementia go undiagnosed let alone getting access to treatment.

Nolan *et al.* (2006) highlight that people's attitudes towards dementia and its patients influences the way in which people perceive dementia. The reluctancy to pay and fund dementia as in medical systems and otherwise as well as support systems which are meant for dementia patients cause people to have a negative attitude towards them (Nolan *et al.* 2006: 20). It is sad to note that dementia as a disease has a negative connotation hence dementia sufferers experience stigmatising attitudes, and they also face rejections and are socially isolated because of old age, however, mental health has never received a negative attitude (Nolan *et al.* 2006).

2.5.2 Dementia Experiences across Africa

According to George-Carey *et al.* (2012: 2), approximately 2.10 million of them live in Sub-Saharan Africa and the prevalence of dementia in adults older than 50 years in Africa was estimated to be approximately 2.4% of people living with a disease in 2010, and this is mostly found amongst females aged 80 years and over. It was established that amongst others, Alzheimer's disease is the most prevalent cause of dementia (57.1%) followed by vascular dementia (26.9%). The main risk factors were increasing age, the female sex, and cardiovascular disease (George-Carey *et al.* 2012). In Ghanaian, South African, and Nigerian communities, symptoms of dementia meant that people living with dementia (PLWD) are the subjects of teasing, as mentioned by Adebiyi *et al.* (2016), van Wyk *et al.* (2017), and Mkhonto and Hanssen (2018). The meaning of teasing is interpreted differently by people in different communities. In Ghana, in particular, this has not been perceived to transgress the boundaries of respect for older people, though in South Africa, PLWD is viewed as a joke by some members of the community but interpreted as an indirect threat to the older person, and this means that their safety and well-being are not taken into consideration. On the other hand, in Nigeria, PLWD are seen as witches, and the fear inevitably results in discrimination, isolation, and instances that bring violent behaviour to dementia patients (Adebiyi *et al.* 2016: 270).

In Ghana, Congo, and Tanzania, it is stated that dementia patients are not stigmatised but dementia-like symptoms were accepted as a normal part of people aging and changes in the roles associated with the old people (Gureje *et al.* 2015: 170). In Ghana and Congo, PLWD are referred to as childlike, while in Nigeria, symptoms such as forgetfulness were associated with a loss of authority. “When persons act in strange ways the talk starts in villages and townships: they say ‘that one has been bewitched’ … they go to these old people, vandalise their houses, burn their houses ... they accuse them of being witches”, as stated by a residential facility nurse from South Africa (Alzheimer’s Disease International 2017: 46). It is noted that in South Africa and Tanzania, people living with dementia and caregivers dependent upon families and communities support for the care cost (Hindley *et al.* 2016: 135).

In a study by Mkhonto and Hanssen (2018: 170), the findings revealed that transportation costs to health care clinics were serious problems to other caregivers of dementia patients. In South Africa, the literature suggests that the government, through local, township-based elderly facilities, provides the service needed for PLWD, and this is intended to improve community understandings of the conditions and cause of dementia. In Tanzania, churches and NGOs are actively involved in solving the conditions of dementia as with other social problems and thus, the government has established day centres. Despite this fact, rapid demographic ageing across the region means that a government’s failure to address health conditions of older people will inhibit the attainment of development goals in Sub-Saharan Africa (SSA). This is because these countries mainly focus on the provision of services for curing infectious diseases, child health and adults of reproductive age. Thus, health sectors are not equipped to deal with chronic health problems associated with older age. As Hindley *et al.* (2016: 130) argues, healers outside the biomedical system are further ahead of biomedical health services to provide holistic, community-based care that meets and reflects the needs of older people and other segments of the population.

It is therefore the proportion of PLWD in SSA who seek help from non-biomedical healers which could increase significantly. According to Hindley *et al.* (2016), traditional and faith healers were positive and considered collaborating with biomedical services in the treatment and management of problems associated with older age. Indeed, this is a potential advantage of collaboration between different models of healing to recognise and fully implement functional modality to give an increasing access to mental healthcare in low- and middle-income countries.

Guerchet *et al.*'s (2017) systematic appraisal reveals a small and useful evidence base which offers important insights into the everyday life experiences of people with dementia in SSA. Living with dementia and the responses of families, health services, and communities is surrounded by the cultural understanding of dementia and beliefs about the causality of the conditions. The biomedical label of dementia is absent from people's narratives in all studies carried out in residential care facilities in South Africa (Mkhonto and Hanssen 2018). It has been found but is not viewed to be an inevitable component of the ageing process. As such, dementia is generally seen as a part of the broad conditions resulting from growing old. This means that normality helps to differentiate dementia from 'madness' that is considered to affect younger people. The findings of Guerchet *et al.* (2017) suggest that people's belief in witchcraft or other sorcery as a cause of dementia was a minority view, as opposed to one that was associated with negative consequences such as stigma and discrimination, violence, and the threat of violence. It is important to note that this finding is the result of a strong desire for information and knowledge about dementia among caregivers, care workers, healers, and the community, considering a lack of understanding of the condition (dementia) that has fuelled fear and discrimination, and perpetuated negative beliefs of those affected by the disease (Guerchet *et al.* 2017). Although it is reported that PLWD are not subjected to stigma or discrimination, the evidence suggests that their symptoms that were perceived such as regression to a childlike state are perceived to inevitably lead to infantilisation, loss of authority, and discontinuity of role.

In the Health Improvement Centre (HIC), maintaining a sense of continuity and participating in life have been identified as one of the important factors to determine the quality of life of PLWD. As such, the HIC findings indicate that older people and dementia are recognised as a public health priority. Thus, this makes the knowledge derived from the first-hand experience of dementia as an important key contributor for the comprehensive understanding of the disease and its impact on communities and people living with dementia. Seeking help for mental disorders also influences patterns of help-seeking and attitudes to the treatment of dementia. PLWD, caregivers, as well as healers believe that the cause of symptoms is supernatural, and that traditional or faith healing is more efficient than biomedical treatments to heal the dementia patients (Guerchet *et al.* 2017). Even though there is disagreement about the cause of ageing, the condition is incurable. In addition, families and healers focus on addressing remediable co-morbidities and providing holistic treatments to improve the comfort and well-being of the older person (Guerchet *et al.* 2017).

In many cases, these symptoms are common features of mid-stage dementia, and will only become common as SSA populations age rapidly. It is worth noting that the only evidence related to caregiving outside of the household comes from South Africa among all the countries in SSA. As argued by Alzheimer's Disease International (2017), training people about dementia and narratives to the challenges of managing difficult behaviour associated with dementia are illustrative of the challenges accompanying the necessary provision of long-term care around the world. Findings by Alzheimer's Disease International (2017) illustrate that financial pressure for caring for PLWD often bring problems to stretched households but it is the extent of traditional notions of filial duty and reciprocity that will hold fast in the face of societal change and 'modernisation'.

In a study carried out by Gurayah (2015), it was discovered that caregiving has an impact on or increases social isolation as the carers are always watching after the patients. It also contributes to restricting the activities of daily living, and the carers do not have time to do the activities that they used to do and they abandon some activities due to their busy days of caring for the patients. Thirdly, it was noted that caring for dementia patients increases unemployment and increases financial burdens. This is because caring for dementia patients is a full-time job. The family members must always be there for them, which means that other aspects must be left aside such as one's employment and other activities. As much as the jobs are at stake or are forsaken, the patients need to be taken to hospitals and there is also a need for supplements and medication which help in supressing the signs and symptoms, and all these aspects require money (Gurayah 2015).

2.5.3 Dementia Experiences in Lesotho

Information on the prevalence of dementia in Lesotho is very limited as little is written on the subject. Further research will not only provide a more reliable estimate of the prevalence, and consequently the burden of the disease, but will also raise awareness of the problem. This is critical to promote help-seeking behaviour change and generate the political commitment to take dementia as a public health priority in Lesotho. According to Dhemba and Dhemba (2015), in Lesotho, older people face significant physical and mental health challenges such as stress, dementia, and Alzheimer's disease. The plight of older persons in Lesotho is made worse by poverty and a lack of knowledge on proper diet and care practices. Dementia Lesotho is another local NGO, the intention of which is to promote the health of older persons by assisting them with lessons to cope with dementia, but thus far the organisation is only known to very few people in the capital city (Maseru) as there are many challenges of making it known (Dhemba and Dhemba 2015: 16). It also informs the public about dementia and advocates for policy and legislative reforms in the support and protection of people suffering from dementia and their family members and carers. It also liaises with partners and like-minded organisations both locally and internationally.

2.6 Responses to Dementia in Low- and Middle-Income Economies

According to WHO (2015), in LMICs, dementia care and services are provided by NGOs. To curb violence and support dementia patients, governments in these countries need to support NGOs and other community organisations to educate the public on dementia by using effective tools such as multimedia as preventative strategies to promote early recognition and help-seeking behaviour (WHO 2015). Education helps to engender positive attitudes towards the management and care of dementia and hence combat the stigma against dementia patients (WHO 2015). In addition, establishing structures such as clinic committees and hospital boards will help to facilitate the community's active participation in decision-making on health issues that concern the local community. Increases in the prevalence of dementia in

Less Economically Developed Countries (LEDCs) and notably all regions play a leading role in the substantial urbanisation in LMICs, as stated by WHO (2015). In the research studies done in Less Developed Countries (LDCs) on dementia, the findings show that a lack of primary knowledge about the disease detracts from an awareness of the disease and policy responses for dementia as well as the management of clinical and increased care burdens (Maestre 2008). Maestre (2008: 255) states that although dementia is an insidious and disabling disease, the diagnosis and management of dementia in older populations is not a priority of LDCs' governments healthcare systems because health systems face multiple and competing demands for healthcare, mainly for diseases of a developmental nature such as communicable ailments like Malaria, HIV, and TB, and these communicable diseases, unlike dementia, are given much priority.

There is a lack of awareness about dementia amongst most LDCs around the world, and this has been demonstrated in studies in India, as Patel *et al.* (2003 cited in Kalula and Petros 2011) revealed that features of dementia may be recognised, and these features are frequently attributed to explain factors such as literary childishness and a tired brain. It is essential to note that these findings concur with the finding of the study conducted by Mkhonto and Hassan (2008) in South Africa. According to Prince *et al.* (2008), none of the studies conducted in India found any awareness, in the setting in which they were conducted, of dementia being an organic brain syndrome and indeed a medical condition. In fact, symptoms of dementia were perceived as normal and part of people's ageing. Prince and Patel (2001: 31) acknowledge that since Alzheimer's disease and dementia are associated with stigma, using "these terms should be avoided", especially when a person is diagnosed with dementia and is refused admission to an old age home. In the words of Kalula and Petros (2011: 35), in Africa, medical doctors "at primary care level lack awareness and training in treating dementia and are found disinclined to investigate symptoms of dementia".

It was established that a lack of awareness of dementia and potential responses in LDCs lead to few families with afflicted elders seeking help from traditional healthcare services without adequate structures and training available for health practitioners on the recognition and management of dementia (Prince and Patel 2001). This make matters even worse as there is inconsistency in the resources available to place pressure on the government or policy formulators to provide responsive dementia care services. Given the above evidence, dementia is often stigmatised and misinterpreted which means that more needs to be done in academics as well as in communities to constantly concertise people about the disease. It is noted by Ferreira (2004) that dementia stigmatisation is gendered in nature, requiring a more profuse approach in dealing with its consequences. It is alleged that in Africa, persons with symptoms and signs of dementia, in particular women living alone, are labelled as witches and such women are at risk of having their assets seized and being exposed to violent assaults and even death (Mkhonto and Hassan 2008). This gendered stigmatisation and stereotyping only reflects how a lack of awareness on dementia as a disease has ruined the social fabric. Media in LDCs are receptive to the placement as part of the development role of informing the public and stimulating debate as core efforts to alert the media in LDCs to the importance of raising awareness on ageing and dementia (Ferreira 2004). There is a dearth of literature on dementia and policy in LDCs thus governments' responses to the condition and the burden of care on families may therefore be assumed to be sparse. The lack of policy responses to address the dementia crisis points to the fact that most jurisdictions contend that dementia care is indeed a family responsibility (Ferreira 2004).

2.6.1 Reducing Violence against People Living with Dementia

Several authors suggest different solutions to deal with violence against PLWD. Dementia has a unique and far-reaching impact on an individual's capacity for free and human living because the afflicted person resides in a multi-generational household, especially in less developed countries. This condition is overlooked in considering and proposing policies for the prevention and treatment of chronic diseases, including dementia (Epping *et al.* 2004).

In most low- and middle-income countries (LMICs), caring for persons with dementia only improves when incorporated in the management plan for chronic conditions. This strengthens responses to dementia and enhances the quality of care, thus translating into the quality of life of persons with dementia, and caregiver. Drawing on the 2006 Kyoto Declaration, "Minimal action is required for dementia care" of Alzheimer's Disease International (Access Economics 2006), such as educating people on dementia as the condition, the consequences associated with it, and strategic ways to effectively deal with dementia, as George-Carey *et al.* (2012: 2) show. Education is an important component in dealing with health problems in any community and society, because it promotes and improves knowledge and understanding of dementia among caregivers and local communities. In addition, it serves to counteract beliefs related to witchcraft perceived to put older people living with dementia at high risk. This is similar to South Africa and Tanzania where education was implemented as a necessary step to improve the level of support for caregivers in their role. In South Africa, NGOs (Dementia South Africa and Alzheimer's South Africa) were identified as useful sources to disseminate information (Barker and Ricardo 2005).

Notably, NGOs and civil society organisations have the potential to take the lead to strengthen knowledge using education to educate communities and caregivers about dementia. Education involves life skills to prevent violence to escalate further in the communities (Barker and Ricardo 2005). A recent review of the literature on life skills by Adams (2011) suggests that often weak and inconsistent definitions and the uneven implementation of curricula are used to educate younger people at the early age. However, educational programmes offer educational and training activities that are based on the same format of empowerment, group formation, and communication skills (Barker and Ricardo 2005). These activities focus on HIV/AIDS as peace education efforts, especially for violence prevention against people with dementia. It is suggested that school-based HIV/AIDS prevention and sexuality education initiatives have a long history in Africa, to prevent more occurrences and mitigating the violence in communities.

These have also included group discussions and educational activities on gender roles as including issues of masculinity, a tremendous opportunity to further enhance and reflect on gender and masculinity, but there are also major shortcomings and challenges (Adebiyi *et al.* 2016). Barker and Ricardo (2005), however, note that teachers – especially male teachers – still hold traditional beliefs and even misogynistic views about women, and are prone to take responsibility for sexual harassment and sexual violence. This means that strengthening the public education system is an effective way to educate younger people about dementia rather than expecting the school system itself to carry out effective gender sensitisation activities.

Barker and Ricardo (2005) argue that campaigns; training activities; and sensitisation of school principals, directors, and teachers is useful, because this encourages them to critically reflect on their own attitudes and behaviours related to gender norms.

George-Carey *et al.* (2012: 2) urge for the establishment of youth educational centres. In South Africa, youth centres, such as Love Life for example, are used as the approaches where activities based on a single site are established throughout Africa (Mkhonto and Hanssen 2018). Even though they are hailed as the “single solution” for youth development, there are challenges which include recruitment, retainment, and self-selection (Mkhonto and Hanssen 2018). Research suggests that youth largely self-select both young men and women, and most are vulnerable to participate in youth centres (Mkhonto and Hanssen 2018). In other cases, youth groups take over the centres, making them attractive to specific groups, and this has the potential to exclude others. Despite these challenges, these offer creative ways to discuss issues such as gender and masculinities in youth centres.

2.6.2 Laws and Policies

It is important for governments to promote the development by adopting national policies and programmes that address the current knowledge and human rights for the inclusion of dementia in healthcare services, social programmes, and benefits, by providing and allowing access to essential drugs for the treatment of dementia and associated symptoms to improve the management of dementia. The design of policies and services that meet the needs of PLWD and their carers will be impossible without the inputs from the lived experiences of the disease. The evidence from the research carried out in Ethiopia by Gureje *et al.* (2015: 170) suggests that societal stigma has limited the ability of people living with severe mental illness to participate in research-related activities for the design of mental health services, programmes, and policies. In this regard, the role of governments, non-governmental organisations, and researchers is important to increase efforts to address this disparity, and thus, find innovative ways to ensure that the voices of PLWD are heard (Gureje *et al.* 2015). This could be learnt from other successful global advocacy movements for disadvantaged and stigmatised groups such as people living with HIV as well as from the empowerment of PLWD in HIC settings, where the burden of dementia increases every day in the developing world. Gureje *et al.* (2015) argues that these countries have no dementia care policies, programmes that are strategies to support the community and family, with no specific education programmes in place. This means that without these policies and programmes in place, they cannot support health services for dementia. This is because dementia care services are supported and provided by NGOs.

This lack in the government taking initiatives to support dementia patients could be due to inaction due to a lack of awareness of government health care institutions to prepare for the present and future burdens of dementia and the lack of political will to be informed of the imperative and to respond concretely and timely. Hence, NGOs' efforts to lobby with their government for responses to the burden of dementia have typically drawn little success; their efforts need to be supported and intensified from a lack of political will by the government (Gureje *et al.* 2015).

Hendrie (2006) notes that the evidence suggests that changing societal norms and ageing populations and family systems have brought about social security struggles in coping with an increasing number of older people living with chronic health problems. This leads to indebtedness, family strain and conflict, and household rationing of healthcare and food. As the numbers of older people living with dementia are projected to rise in SSA, the total lack of governmental support for older people is increasing. Therefore, there is a need for governments to develop and implement policies that address the economic security of older people and the long-term care for chronic conditions associated with older age. Hendrie (2006: 481) argues for the promotion and provision of support services for PLWD. In Botswana, there has been a national alliance of governmental organisations and NGOs including the state defence forces, the police, the House of Chiefs and Parliament, and local NGOs where these institutions work collectively to address the issues of violence against dementia patients (Barker and Ricardo 2005). The alliance seeks to reduce HIV/AIDS by ensuring that men are well informed and involved in the prevention and caregiving. Involvement in these activities and initiatives means that men in HIV caregiving will also extend a helping hand to other men and other patients. Men would be involved in caring for dementia females as women do. As mentioned in Chapter one, the types of dementia are mentioned after their causes – there is dementia due to HIV/AIDS and this is called HIV Associated Dementia (HAD) (South African Medical Journal 2015). Thus, this means that the reduction of HIV/AIDS would mean the reduction of the numbers of dementia patients. However, a lack of funding has been one of the major problems that has hindered an alliance to achieve the mandate because it mainly focuses on workshops and meetings among members. This is because relatively, the work has been directed to men without comprehensive planning and joint action. Thus, an alliance presents an interesting model for governmental and NGO collaboration in working with men in HIV/AIDS, but it has been limited in its implementation (South African Medical Journal 2015). In Africa, South Africa has focused mainly on and directed its attention to the policy level to engage men in promoting gender equity (Hendrie 2006: 481). The Department of Health has established a broad-based countrywide forum, Men in Partnership against AIDS (MIPAA), to engage and support men's positive involvement. Similarly, in the 2000 National AIDS Campaign in Uganda which was led by UNAIDS had focused on men and HIV/AIDS (Gureje *et al.* 2015).

However, this campaign was not visible, and it was a reflection by NGOs and national HIV program officials to engage men as needed in all the health care activities. Barker and Ricardo (2005) posit that this is a priority of governments and development agencies to broaden violence and prevention policies to recognize the gender-specific needs and realities of men and to support strategies for their meaningful involvement in the promotion of gender equality. There are many starting points for communities who want to become dementia friendly. For example, according to Gonzalez *et al.* (2010: 112), in Debenham, members of the local church pulled together a broader community meeting because of their concerns about caring for people with dementia. In the village of Idle, the local Alzheimer's Society, working with the council's Neighbourhood Service and District Care Trust, joined with committed individuals to bring together a small action group to look at that which was working and that which could further be done to become dementia friendly. According to Gonzalez *et al.* (2010), in York, the dementia collaboration local partners which include the health and care sector, voluntary organisations, and local businesses work together, and they are supported by the local political leaders in many valuable projects. Gonzalez *et al.* (2010) state that the Dementia Action Alliances (DAA) have developed action plans to transform the quality of life of people living with dementia. These local alliances and other similar action groups bring together different stakeholders such as bus companies, taxi firms, police, fire and rescue services, high streets, local authorities, charities, care providers and health trusts, faith groups, and schools to solve the recurring problem of dementia. In these projects, communities are invited to sign up to the recognition process for dementia-friendly communities.

Conclusively, as argued by Mkhonto and Hanssen (2018: 170), this process enables communities to be part of a recognised group working towards becoming dementia friendly. Also, this ensures that all community members are working towards common evidence-based criteria to change aspects that matter to people affected by dementia. Under these criteria, people with dementia, regardless of whether they live or travel, then receive recognition in areas that are dementia friendly. Hence, the majority of communities are committed to working with the criteria, involving having a local dementia action alliance or similar group in place. This means that through criteria and alliances, communities are able to address living environments free of violence where the dementia patients and community can share the experiences and evidence from people with dementia and those of the communities.

Therefore, family support to family members of persons with dementia and their community should be involved in policy formulation on dementia care. In addition, governments and international organisations also support and equip caregivers through providing and making accessible education and training programmes for carers to establish self-help support groups under the guidance of relevant NGOs and Community-Based Organisations (CBOs) since this will strengthen the good working relationships to prevent dementia and the violence associated with it. These organisations have an important role in human development since they have the capacity to mobilise community action and advocacy around health issues. Multi-disciplinary teams should be established for home assessment and home-based care and support (Mkhonto and Hanssen 2018). To develop human capacity, health professionals training is essential to equip practitioners to diagnose and manage dementia at primary levels (Mkhonto and Hanssen 2018). Hence, the teaching of dementia should be included and be made compulsory in training curricula for health professionals at all levels of care and incorporated in the management plan of chronic conditions. Research, governments, and funding bodies should support research on dementia to improve awareness, recognition, management, support, and preventive strategies (Mkhonto and Hanssen 2018). Research plays an important role because it allows the generation of evidence-based information which provides a holistic picture of the impact of the burden of dementia on society and individuals, and to support NGOs' advocacy efforts.

The most cost-effective way to enhance dementia care in LMICs is to support persons with dementia and their informal and formal carers. This goal will be achieved through multi-pronged strategies that include the coordinated involvement of communities, healthcare providers, educators, funders, policy makers, and politicians in the process of enhancing cost-effective ways of dealing with dementia (Gureje *et al.* 2015).

2.7 Concluding Remarks

The systematic review of literature reveals information on how dementia sufferers live on a daily basis in SSA. Literature has further provided insight on how the patients, families, communities, and the government deal with the condition in their different settings. This has also shed light on the factors that contribute to how people perceive the patients and that which brings the different attributions about the disease. It has been noted that culture plays a major role in how people form world views, and it also has a tremendous impact on people's day-to-day life. Finally, the literature has revealed that there is much advancement in terms of policies, infrastructures, and health facilities responding to dementia in developed countries. However, it has also been noted that in LMICs and LDCs, there is very few or no development at all in most SSA countries and one may wonder if this lack of development is due to the economic status quo or because of the ignorance on issues related to dementia or the lack of knowledge about the disease and the burden that comes with it. Since literature has brought all matters to light now, the researcher believes that now is the time that all the governments in SSA together and individuals should make an effort in addressing the factors that make the countries nonresponsive to dementia issues.

CHAPTER THREE

Conceptual and Theoretical Framework

3.1 Introduction

This chapter will examine three relevant theories which will guide the study: the Peacebuilding Theory, the Social Learning Theory, and the Conflict Transformation Theory. This research emphasises the need for an elastic approach to the concept of peace since the universe is diverse, and consequently, so too are peace notions. According to Galtung (1981: 185), “if ‘peace of mind’ (inner harmony) is included in the peace concept, and this is interpreted as identity, then everything reducing or impeding identity becomes violence”. Similarly, if the societal agreement is defined as peace, disruption of the same is categorised as violence. Galtung (1990: 292) elaborated on the ideas of peace and violence and presented the idea of “cultural violence”.

Galtung (1996: 2) classifies violence into three categories, that is, direct violence, structural violence, and cultural violence. Apart from its direct form (for example assault, riot, terrorism, or war) violence also exists indirectly in the structure of society (for example poverty, hunger, discrimination, and social violence). Galtung (1990: 292) makes a conjecture that cultural violence is a feature of the culture deployed to legitimise direct as well as structural brutality thereby making them tolerable in the society and, as used in this research, this may be directed at people with dementia. Hereafter, Galtung distinguishes the clear performance of violence physically destroying the person or body; violence erected into a societal or economic structure, which results in some people feeling subjugated or powerless to experience their needs; and violence entrenched in cultural rules, principles, and traditions that make other categories of violence appear natural or ordinary.

It is in the words of Galtung (1996: 2) that direct violence may take any spoken or physical form and harms the body, mind, or spirit. Indirect violence comes from the social structure itself and the two major forms of it being repression and exploitation. Galtung (2002: 95) states that “cultural violence is identified by content: religion, law and ideology, language, art, empirical/formal science, and by carriers: schools, universities, media”. Therefore, violence is preventable insults to undeveloped human needs as well as mostly to human life. The basic needs of human beings consist of subsistence, health, personality, and freedom, and people living with dementia are not an exception.

Galtung’s peace theorising recompenses the current research. In the course of incorporating the notions of structural and cultural violence, Galtung offers a comprehensive concept of peace at all levels of human groups, especially at the community level, by being rapt with people affected by all forms of violence as well as discrimination. If researchers recognise peace as evolution, it develops into a pattern that can vary across several levels of peacefulness. Accordingly, peace becomes less ideal, since it will no longer mean the end. As all members of society commonly come together to establish the structure and culture, it compels every member of the community to fully engage in creating as well as upholding peace.

3.2 Peacebuilding

Berghof (2012) states that most scholars are of the opinion that it is possible to identify steps towards peace and measure the decrease of violence and increase of justice. However, it requires all parties from all levels of society to engage from time to time in working towards peace and upholding it. Working for peace requires that a distinct vision be developed. Peace is relatively based on one’s world view and the context. For instance, the perception of peace from the individual point of view will differ from international peace. One more aspect is that peace is culturally defined (politicians and artists), thus there are different cultures, which means that there are different definitions of peace. As mentioned earlier that peace is contextualised, there should be effort to strive to develop an inclusive and single definition of peace, and this is a vital aspect of peace work.

Gerstbauer (2010: 845) defines peacebuilding as “activities that non-violently prevent, limit, resolve or transform conflict and create peaceful justice”. Galtung, Jacobsen and Brand-Jacobsen (2002: 90) refer to peacebuilding as an explicit infrastructure within as well as among states that removes reasons for physical confrontation and offers options to violence in circumstances where it may occur. Ghali (1992: 202) concurs with the above as he states that peacebuilding “is the re-enactment of institutions and infrastructure of nations torn by strife and the building of bonds of serene mutual benefit among people formerly at conflict”. Francis (2008: 25) views peacebuilding as more than planning intermediations at the central causes and circumstances of the prevailing conflict. The author views it as entailing a continued process of scheming programmes that tackle the security as well as political experiences of the state in addition to looking at actions that will alter the individual, societal, and financial relationships of the residents of the certain nation. The eventual aim of peacebuilding in the Sub-Saharan African setting is the transformation of relations, asserting shared responsibility as well as solidarity (Gerstbauer 2010: 846). Gerstbauer states that there are three types of peacebuilding, namely, political, social, and structural. This is illustrated in Figure 3.1.

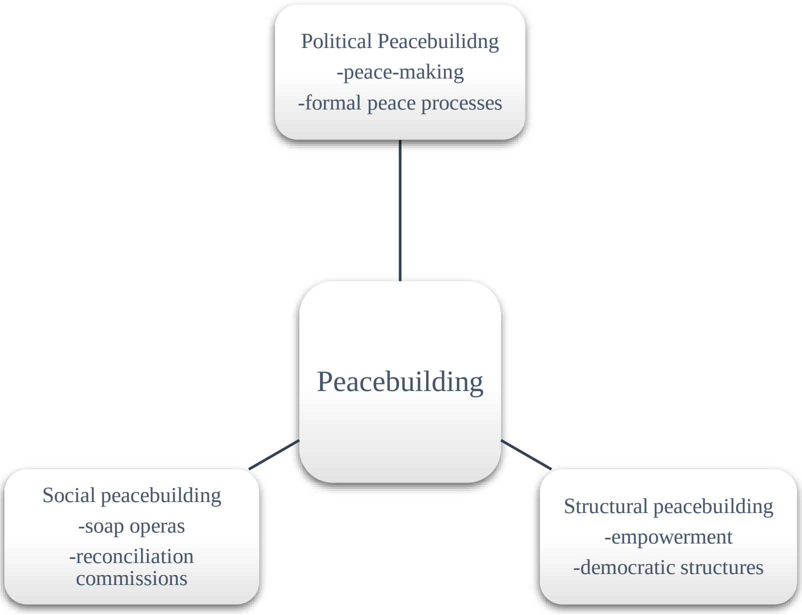

Figure 3.1: Types of peacebuilding.

Political peacebuilding cogitates on reducing differences between institutions and is concerned principally with the communications that engross resolving a disagreement and accomplishing an agreement. Peace processes may progress but usually suffer phases of relapse. Thus, the achievement of peacebuilding hinges on the political choices of those involved from the national to local governments as well as communities or donor agencies. In some cases, political peacebuilding is based on efficient leadership from the national to local and civil society, and on capitals such as human resources or donor funding.

Social peacebuilding deliberates on societal perception and attitudes which have a negative impact on peace and stability (for instance, dramas that break down dementia stereotypes, and truth and reconciliation commissions). Social peacebuilding activities are mainly aimed at changing the relationships between the groups that seem to have a potential for posing a conflict. Transformative peacebuilding is concerned with criminal offences (the perpetrator and the victim). Its focus is to attend to social justice issues, and it involves justice systems to bring about peace.

Structural peacebuilding deliberates on mending or reconstructing the underlying structures that support as well as help in the upkeep of a peacefully operational society (for instance, good governance for handling intergroup conflict and hostilities, and development aid to redistribute financial assets and ease economic deficiencies that have started the conflict) (Gerstbauer 2010: 850). De Rivera (2008: 20), in the *Handbook on building cultures of peace*, argues that:

> [S]tructural peacebuilding (building democratic institutions) is essential in countering the myth and stereotypes and propaganda that fuels ethnic conflict (social peacebuilding) … those engaged in structural peacebuilding should seek to minimise among groups (social peacebuilding) and maximise opportunities for resolving disputes peacefully (political peacebuilding).

Van der Leest *et al.* (2010: 100) assume that peacebuilding, comparable to expansion, should be a people-oriented course. It must be positioned on those greatest disturbed by conflict besides being ingrained in local settings. Peacebuilding emphasises the necessity for approaches, tactics, and programmes that are grounded on local requirements, possessions, and capabilities that permit local inhabitants to instrument these plans. Peacebuilding concentrates on people who are vulnerable and therefore side-lined, knowing that violence is most frequently rooted in prejudice and the segregation mainly of those with dementia. Inclusion denotes not merely identifying vulnerable groups, but also allows for their contribution to peacebuilding as well as other societal, financial, and development progressions via capacity-building as well as empowerment initiatives (Zelizer 2018: 2).

Spreading peacebuilding programmes across the nation requires the backing of local as well as government bureaucrats and established connections and partnerships amongst communities and the government. Thus, the steady process of intensification affords time and room for government bureaucrats to develop more familiarity which embroiled in an empathetic view of peacebuilding actions. Local along with national authorities might originally feel intimidated by these peacebuilding actions, "which is why efforts to achieve their 'buy in' are essential" (Berghof 2012). Intensifying also permits space for government organisations to accumulate the ability to run nation-wide peacebuilding programmes.

Changing individual attitudes and behaviour is critical to peacebuilding (Berghof 2012: 63). It means that people should be capacitated in peacebuilding issues which will help in transforming the thinking of people, hence stereotypical behaviours and activities will cease.

Having stated the above, it is important to note that peacebuilding is indeed a process that takes time to yield its merits. There are several peacebuilding types such as political, social, and structural peacebuilding from which the current study draws its arguments. Again, there are a multiplicity of tactics that can be used to achieve peace and end violence especially on people living with dementia such as the aforesaid.

3.3 Social Learning Theory

The use of the social learning theory is complementary to the key theory of conflict transformation being used in this study. This means that it compliments social change approaches in ensuring the learning of new behaviours to transform societies for peaceful outcomes.

This study adopts Albert Bandura's (1971) social learning theory to buttress on the behavioural patterns within communities pertaining to various existing problems and issues. This is so because the behaviour is learned and shaped by various beliefs, practices, and myths that exist within societies. The social learning theory will help in establishing how the violence and abuse of dementia sufferers in Lesotho has developed. It will help guide views of how the violent behaviour has been inhibited and also how such behaviour can be unlearned. Bandura (1971: 20) acknowledges that behaviour can be learned through observation or direct experiences. This means that a change in behaviour is possible if people are exposed to alternative experiences. Therefore, despite having certain unwanted behaviours being rooted in some community practices, they can be unlearned. In understanding the brutal killings and violence against dementia patients in Lesotho, adopting the social learning theory can facilitate in reflecting on such experiences to facilitate positive transformation of individual perception and behaviour pertaining to the problem. According to Bandura (1978: 2), aggression is a violent behaviour often resulting in personal injury and physical destruction.

Generally, people do not display aggression in manifestly open and direct ways where causal responsibility reveals someone and in turn risks retaliation. In essence, those who display aggression do it in covert ways to avoid self-reproof and social reprisal. Most injuries are perceived as aggressive by the victims but not the perpetrators.

The labelling of aggressive behaviour only comes in a broad picture where it is carried out collectively. Even government officials who possess coercive power can misuse it, leading to detrimental social effects. Disadvantaged segments of society can suffer from the effect of coercive and punitive means.

People in society tend to view the perception of aggression differently considering that those who are more advantaged view the highest level of violence as the genuine discharge of duty, and on the contrary, the disadvantaged members of society view the practices as the expression of organised aggression. The nature of aggression on whether it is intentional or unintentional depends on the one at the receiving end.

A proper theory of aggression should clearly highlight how the patterns of aggression are developed, the provocation behind such aggressive behaviour, and that which sustains such actions after they have been initiated. According to Bandura (1977: 14, 1978: 22), “People are not born with preformed repertoires of aggressive behaviour; they must learn them”. The above quotation means that the plain forms of aggression can be achieved with little effort and minimal guidance or vengefulness which require extensive learning. One can also learn from the behaviour of others in consequent of a reward, but the extensive aggressive deeds such as duelling and the military battles have in them complicated or exceptional skills that demand specific training. Practically, all learning coming from direct knowledge or encounters can also happen and different experiences can also occur on a vicarious basis by witnessing the behaviour of others and its consequences. The instigators of aggression facilitate, arouse, and stimulate aggression. Thus, this implies that certain behaviours regulate aggression since they are rewarded.

Aggressors can sometimes attribute blame to their victims in order to exonerate themselves. This means that victims will get blamed for bringing suffering on themselves as it is the case in Mapotu where demented sufferers are abused and subjected to violence. Also, some extraordinary circumstances are put in place to indicate irresponsible conduct (Bandura 1978).

The ability to acquire knowledge through direct surveillance permits individuals to obtain large, incorporated patterns of behaviour without having to establish them progressively by deadly trial and error. In a contemporary society, aggressive styles of behaviour may be acquired from three principal sources. One leading foundation is the aggression modelled and reinforced by family members. Studies of familial determinants of aggression reveal that in the case of parents who resort to aggression when solving issues, their children adopt and use it when dealing with other children or whenever they encounter problems (Bandura 1978).

The abuse and violence against demented people has come as a result of generations having witnessed the past generations doing it. However, all the learned behaviours are implemented and carried out if the behaviour is rewarded rather than being punished. People also learn through direct experience, thus this study seeks to provide various learning practices in facilitating the understanding of dementia as a medical condition rather than a superstitious sign of practising witchcraft. According to Schultz and Schultz (2009), behaviour is learned through imitating the people around one, and from childhood one learns from one’s immediate environment/models (family members) and one learns both good and bad, and normal and abnormal behaviour. Therefore, people become orientated by the cultural customs and acceptable behaviours presented in the society. In Lesotho, the prejudices of dementia as a sign of witchcraft have been passed from generation to generation.

Behaviourists are of a view that people can learn through observing models. In the community where the most appreciated people do harm and ill-treat demented people, the followers or those who look up to those models will definitely imitate and act in the same manner (Weisner and Silver 1981: 148). Bandura (1977: 17) argues that “the highest incidence of aggression is found in communities in which aggressive models abound and fighting prowess is regarded as a valued attribute”. In the case of Mapotu, violence and abuse against dementia sufferers do not get punished because those patients are regarded as evil and witches, therefore anything bad happening to them is good because they have brought it upon themselves by being witches.

If the abusive and violent acts were punished from the start, then no one would have carried out acts with stigma, stereotypes, and of a dehumanising nature against dementia sufferers. Understanding the development of such abuse as a learned behaviour provides a platform to engage and unlearn such bad behaviour through facilitating correct principles and ensuring that violent behaviour and acts against dementia sufferers are dealt with. It will help frame the approaches of facilitating new learning. Social learning takes place through symbolic information, for example, language (Weisner and Silver 1981: 147). In Mapotu, where dementia sufferers are called witches, people who use this word/name have learned it from other people in the community.

Social learning thinkers take an interactive viewpoint in the supposition that individuals are basically moulded by the situation through learning methods. These conservative accustoming processes include imitation, as individuals acquire knowledge by watching their models, exhibiting and strengthening work hand in hand in the social learning of aggression in everyday life. Types of aggression are mostly acquired though watching and are perfected largely through learned and reinforced activity/training. Thus, the researcher argues that society creates role models whom the majority of the society, especially children, observe and the comments of the influential in society are copied. If those with influence comment negatively or discriminate against people with dementia, then the pattern is replicated over generations. Consequently, the social setting is perceived as having a particularly vital effect on the person’s conduct. Bandura (1969) theorised social learning which emphasises the importance of developing “from observing others, one forms an idea of how new behaviours are performed, and on later occasions, this coded information serves as a guide for action” (Bandura 1969 cited in Hashemi and Shahraray 2009: 253). Studies grounded in this theory, for example, have fixated on the constructive and negative facets of media as a public source of replicas for people.

One set of disengagement practices operates at the level of the behaviour. Bandura (1971: 24) argues that people do not take part in bad conduct or actions unless they have vindicated to themselves the decency of their doings. Something liable can be made honourable through cognitive restructuring. In this procedure, a bad conduct is made personally and socially appropriate by portraying it in the service of moral ends.

“Attributing blame to one’s victims is still another expedient that can serve self-exonerative purposes. Victims get blamed for bringing suffering on themselves, or extraordinary circumstances are invoked to vindicate irresponsible conduct. By blaming others, one’s own actions are excusable” (Bandura 1977: 25). People in societies are helped in degrading and blaming groups organised in disfavour by negative stereotyping and training.

In order to deal with the challenge of aggression against people with dementia, there is a need to refocus energy on rewards to those who treat them humanely. When people are credited for acting harshly and horribly, they graduate to the next level of aggression, whereas when they portray a fairly low level of aggression, this does not yield praises (Bandura 1977: 18). Confirmation of a certain aggressive behaviour increases the chances of the repetition of such behaviour as well as other forms of aggression in the society. In addition, the encouragement to aggression and preventing measures against aggression do have an influence on how the aggressors respond under the threat of punishment. In a case where people can get what they want, the means of aggression that bear the possibility of punishment are hastily rejected. The social learning theory refers to cognitive structures that offer the referential ideals alongside the behaviour which is adjudicated.

3.4 Conflict Transformation

Lederach's (2003: 3) conflict transformation theory argues that it is common to experience divergence in human relationships, and such conflict/divergence is a driver towards a change in the community. It triggers action towards transforming the community towards a more harmonious change. It helps one to reflect on the various changes in behaviour that need to be changed which ranges between the individual, cultural, and structural levels to ensure that the future is different from the current experiences. Conflict transformation appreciates societal conflict as emerging from, besides creating modifications in, the individual, interpersonal, structural, and traditional extents of social understanding. It strives for the promotion of productive processes within all these aspects. In this study, violence against dementia patients in Mapotu is regarded as a condition of conflict that is structurally and culturally embedded. It represents prejudices that promote injustice and violent practices that need to be changed. Therefore, to achieve a peaceful society in Mapotu, there is a need to establish strategies for facilitating social changes.

According to Lederach and Maiese (2009), conflict transformation is centred and rooted in the heart of relationship which makes the relationship an integral part of conflict transformation, hence human relationships are regarded as the heart of conflict transformation. When conflict arises, there are several dimensions that become affected. Lederach and Maiese (2009) note that personal, relational, structural, and cultural dimensions are mostly affected during conflicts. This is why conflict transformation takes note of the changes caused by social conflict in those dimensions. Lederach and other scholars developed the theory of conflict resolution which was, and still is, applicable in solving conflicts. However, the conflict transformation complements conflict resolution as it takes care of some critical aspects in the society which conflict resolution leaves unattended. For instance, conflict resolution is content-centred while conflict transformation is relationship-centred. Moreover, conflict resolution focuses on that which is not desired and leaves aside building on that which is desired, whereas conflict transformation works on that which is not desired and that which can be desired (Lederach and Maiese 2009)

However, according to Lederach (2003: 4), the transformational approach tackles this state somewhat inversely. Conflict transformation “is more than a set of specific techniques. It is about a way of looking and seeing, and it provides a set of lenses through which we make sense of social conflict” (Lederach 2003: 33). These “lenses” bring consideration to some characteristics of conflict besides aiding to convey the general sense of the same into stronger attention. Lederach (2003: 33) summarises conflict transformation as follows:

> A transformational approach begins with two pro-active foundations: a positive orientation toward conflict, presence of conflict in our lives, relationships, and communities. This notion emphasizes the capacity of the transformational approach to building new things. Conflict transformation begins with a central goal: to build constructive change out of the energy created by the conflict. By focusing this energy on the underlying relationships and social structures, constructive changes can be brought about. … move conflict away from destructive processes and toward constructive ones and a willingness to engage in the conflict in an effort to produce constructive change or growth … Both ‘envision’ and ‘respond’ represent the ways … orient ourselves toward the presence of conflict in our lives, relationships, and communities. This notion emphasizes the capacity of the transformational approach to building new things.

Conflict transformation interprets peace as placed and rooted in the characteristics of relations. This comprises both direct interactions in addition to the methods in which people structure their societal, partisan, financial, and national relationships (Lederach 2003: 17). In view of this, peace then is the “process-structure”, the experience that is concurrently dynamic, adjustive, and transforming. Essentially, instead of understanding peace as an inert end-state, conflict transformation evaluates peace as “a continuously evolving and developing the quality of relationship”. Conflict transformation is defined by deliberate labours to tackle the natural increase of social conflict via nonviolent methods that address problems and increase insight, impartiality, and deference in relations.

The conflict transformation theory allows for the engagement of multiple peacebuilding tools in addressing various conflict challenges within communities. Therefore, Lederach (1997: 19) presents how conflict transformation engages various peacebuilding tools to ensure effective social changes that are contextual and practical in addressing relevant challenges within a specific environment. Lederach (1997: 20) defines peacebuilding as a “comprehensive concept that encompasses, generates, and sustains the full array of processes, approaches, and stages needed to transform conflict toward more sustainable, peaceful relationships", meaning that conflict transformation employs relevant and necessary tools in addressing the problems affecting a particular community. For example, the abuse of a dementia patient is facilitated by the prejudice of dementia as a sign of witchcraft whereas it is a medical condition. Therefore, through the guidelines of conflict transformation, the author engages education as a measure to bring awareness of dementia as a disease and engage with communities to reflect on the structural and cultural beliefs that facilitate the cycle of violence against dementia sufferers.

To achieve justice for people with dementia, there is a need for a proper campaign. Thus, conflict transformation helps to understand the poor relationships that exist within societies in understanding the challenges that affect them. The memories associated with particular conflict outcomes remain a bedrock of mistrust and the main driving factor of continuous conflict behaviour. Lederach (2003: 35) "reminds us that the immediate issues [driving factors of violence] are rooted in a context, in patterns of relationships and structures, all with a history". It cannot be overemphasised how important it is to establish and construct human relations and social structures that respect and value human rights and life and thus map the way to nonviolent ways of resolving the conflicts in the community. Therefore, Lederach's conflict transformation theory emphasises that people should look beyond the conflict in order to arrive at a permanent solution for it. Societies should see the context of the relationship that is involved in a conflict.

Lederach is of the view that relationships form the heart of the transformation process. Conflict transformation promotes the recognition, acknowledgement, and analysis of responses to conflict within the context of relationships. Lederach (2003: 30) states that understanding how people react to the conflict should include recognising their immediate problems. Thus, this study seeks to bring conflicting parties together to ensure tolerance, acceptance, and reconciliation amongst victims (demented people and families) and perpetrators of violence (community members) to ensure cooperation and support towards people with dementia. Therefore, this makes peace a social construct that requires collaboration and collective effort. To facilitate effective social change, there is a need to explore how social learning can be engaged and facilitated, thus the study also utilises the social learning theory.

Lederach (2005: 35) recognises the significance of relations in structuring peace. Appropriating time to shape relationships with each other, occasionally without immediate resolve or anticipation, can feel comparable to a disadvantage. However, he argues that it is vital to judiciously build relationships since this practice "brings people into the pregnant moments of the moral imagination (where people recognise) that the wellbeing of our grandchildren is directly tied to the well-being of our enemy's grandchildren" (Lederach 2005: 35). Seen in this light, conflict transformation becomes a method of occupying with and changing the relations, concerns, debates, and the composition of the community that aids the continuance of violence against people with dementia. This advocates for a complete and comprehensive approach, stressing support for clusters within the community in conflict as opposed to the intervention of foreigners. It similarly recognises that disagreements are transformed progressively, through a succession of minute or larger transformations and specific strides by ways of involving a variety of actors.

Berghof (2012: 24) argues that conflict transformation requires a holistic approach which is inclusive of all community members. It encompasses the ending of violence as well as introspecting on that which would deter the younger generation to engage in violent behaviours. The aim of conflict transformation is to eventually attain institutional and structural transformation hence it has to deal with social injustice.

3.5 Conclusion

The social learning theory suggests that behaviours are learned and modelled by one's environment and the same learned behaviours can be unlearned. One could ask, if people in Lesotho have learned to treat people with disabilities badly, then can they be re-educated, or their attitudes be transformed? In this respect, education can help people reject the myths, and allow them to understand that dementia is not witchcraft but a disease like HIV/AIDS and other diseases. On the other hand, conflict transformation emphasises the relationship as the vital part of transformation, and there cannot be a positive relationship if love does not prevail – this means that love is a prerequisite for a positive relationship which can be reflected by appreciating and respecting all mankind as well as loving the unlovely (dementia sufferers). Moreover, the respect for human rights can lead to the humane treatment of all disabled people and thus will erase the notion that old people are the lost cause. The researcher strongly believes that education regarding the nature of dementia can play an integral part in bringing change in people’s perception and misconception about dementia, hence the learned structural violence against people with dementia through observing others discriminating could be eliminated. It is through education that the misinformed attitudes can be corrected. The focus should be on how the young generation can transform from the learned attitudes for future change.

CHAPTER FOUR
Research Methodology and Design

4.1 Introduction

The choice of study location was influenced by the fact that the researcher grew up in the area. The researcher knows and remembers very well the perception that the researcher and community members had about dementia sufferers during her stay in Mapotu. There are positive and negative aspects of living in the rural area as experienced by the majority of the inhabitants who are illiterate. The researcher has witnessed how dementia sufferers are treated in their own communities who, at some point, were known to be good and important community members and the sudden change in their ability caused them to become unloved and invaluable, hence they became the subject of violence, rejection, stigma, and discrimination. All the good actions that a person used to do for the community were almost suddenly forgotten. Growing up in this community, one knows that at some stage ‘old’ people become witches and they are killed or beaten up brutally by community members. This led to some old people going missing for some days and they were later found either beaten or dead.

The researcher advanced her education and eventually left Mapotu community only to discover that which was referred to as witchcraft was in fact a medical condition. The researcher felt very bad about her community and felt sorry for the dementia sufferers, and especially more because dementia is more prevalent in Mapotu community. It is in the light of this background that the researcher was urged to conduct a study of this nature in Mapotu community.

This study followed a qualitative methodology which Silverman (2005: 1) sees as appropriate for use in applied research where emphasis is on unravelling people’s life history and daily experiences. Hence, it was appropriate to understand dementia from the spoken words of those suffering directly and indirectly from the disease and the consequences of this life-threatening experience in order to understand violence. Since the study sought to understand dementia and its consequences with regards to violence, qualitative research was important to understand the participatory nature between the researcher and the participants (Yorkshre and Humber 2009). Thus, this study employed Participatory Action Research (PAR) where both the researcher and participants work together in exploring the problem and finding solutions to the problem. This chapter will discuss the research design, sampling methods and techniques, data collection procedure, data processing, and analysis.

The researcher has asked herself why dementia sufferers are mistreated by fellow community members unlike other sufferers of HIV/AIDS and other chronic diseases. How is the daily life of dementia sufferers and their carers in the hostile environment of Mapotu community where they once lived in peace and harmony and were productive in different activities in the community? What can be done to protect dementia sufferers against community violence? The study, therefore, sought answers to these questions. Qualitative techniques were used to address the questions (why, how, and what), namely, interviews and focus group discussions. Yorkshre and Humber (2009) confirm that qualitative data is presented in words and narrative format and the two techniques have produced rich data. Table 4.1 presents the composition of the research team.

Table 4.1: Composition of the research team.

Name	Profession	Part played in the study
Moji Moji	Doctor and a director of dementia Lesotho	Conducted radio interview/presentation
Nkepile Thokoa Thabane	Nursing sister	Educating communities, pupils, congregations, and juveniles/inmates
Bokang Phiri	Social worker	Counselling and data collection
Thabiso Phethoka	Resident of Mapotu	Data collection

4.2 Study Area

Mapotu community is made up of eight small villages, each with its own chief. However, three villages report to a single chief. It is in the southern part of Mafeteng District, and it is very rural with a few basic infrastructures. The level of poverty and unemployment is very high due to the low level of education and illiteracy and these conditions are to an extreme level in rural areas where people cannot have or rarely have access to basic amenities (World Bank 1995a: IV). In addition, Gustafsson and Makonnen (1993: 55) add that a high level of unemployment, which has resulted in poverty, is more prevalent in the rural areas of Lesotho, thus, as mentioned earlier, Mapotu community is one of the most rural locations in Lesotho, thus poverty and unemployment are at a peak. These poverty conditions have indirectly led to many unpleasant situations in Mapotu community such as the stigmatisation of HIV/AIDS sufferers in the communities, but this stigmatisation has been reduced by the constant health talks and awareness creation done by health personnel.

Additionally, the availability of written material on HIV/AIDS has helped to reduce the stigma. One day, the researcher used public transport and was very impressed to see the HIV/AIDS stickers on public taxis and buses which people use on a daily basis. Nonetheless, there is still an element of stigma although it is no longer as prevalent as it used to be. The researcher found out from the research team’s casual talk with some community members that the food aid which was supplied to HIV/AIDS patients made those who were rejecting them to draw near and help them since they would receive food after helping them.

The level of ignorance and illiteracy influences the way people think and this is reflected in their behaviour. It happened that HIV/AIDS sufferers who had tuberculosis were given more food hampers by different NGOs and this made the community members who were not infected either by HIV or tuberculosis intentionally infect themselves such that the test could come out positive and they could benefit from the food aid – this has been stated by community members who seemed not to care or know much about the diseases, hence they intentionally exposed themselves to viruses for the benefit of food aid. This type of thinking shows that poverty has taken a serious toll on people and this has left them helpless and hopeless. This means that if there was subsistence help for dementia sufferers, they too were not going to be treated in the way that they are being treated. Furthermore, raising awareness and educating people through written material played a large role and if the same could be done about dementia, the level of violence, stigma, discrimination, and dehumanisation could be reduced.

4.3 Research Approach

The initial phase of undertaking an action research is exploration of the problem and how the results inform the intervention. O'Leary (2004) defines action research as seeking knowledge through participation and actions that follow cyclical steps. Therefore, the nature of this study was Participatory Action Research (PAR) and employed the qualitative research design which led to the use of interviews and focus group discussions for the collection of qualitative data. Young (2006: 449) defines PAR as a "form of inquiry that holds to a participatory view of knowledge generation". This means that PAR is an action research in which the researcher works together with participants through an iterative cycle (Young 2006). In other words, in using PAR, participants are not treated as objects but they are the drivers of the study and they work hand in hand with the researcher (Baum *et al.* 2006). This type of approach of making participants co-researchers in the study helps in the sustainability of the intervention as the participants themselves develop the solution/intervention and this gives them a sense of ownership which will lead to the longevity of the implemented interventions. The study will be the first and the pioneer explorative element of dementia which will be conducted in an explorative manner.

As Young (2006: 501) notes, PAR is suitable for social science research studies because it seeks to bring about change by challenging the inequalities. In this study, PAR helped to address the needs of dementia sufferers who are subjected to violence, marginalisation, and ill-treatment in the society (Young 2006). According to Feldman *et al.* (2019), PAR involves three components that are applied in a cyclical manner, namely exploration, intervention, and evaluation:

- **Exploration:** the nature of action research begins with exploration of the problem. In this phase, the community will thoroughly discuss the disturbing situation of violence against dementia sufferers in the community. Working together with the researcher, the participants will seek to understand and find solutions to the problem, then the next phase of the intervention will follow after finding the solution to the problem (Feldman *et al.* 2019).

- **Intervention:** this component means that PAR will be helpful since the people of Mapotu community have different feelings, perceptions, and meanings about dementia, since the approach will be inclusive and participants are oriented in the course of the research, and the correct views will be brought forth which will provide interventions to the confused perceptions that the people of Mapotu community have towards dementia. Therefore, this component of PAR will provide a solution on the little or no knowledge that the community of Mapotu community has about dementia, and the approach will intervene in their ignorance on the subject matter (Feldman *et al.* 2019).

- **Evaluation:** PAR will evaluate or test the degree of better understanding and comprehension about dementia. Thus, this will help the people of Mapotu community to evaluate themselves or introspect with regards to where they were before and how they move after gaining the information about the phenomena (Feldman *et al.* 2019).

Therefore, the above components qualify and justify why PAR is an appropriate research approach in this study since the study will explore matters, as this is a new area which has not been covered in Lesotho, particularly in Mapotu community, and people have different perceptions and opinions about dementia which are not documented in a scientific manner in Lesotho.

4.4 Research Design

Research design is defined as a framework for a study used to collect and analyse data (Pandey and Pandey 2015). In short, a research design is a map that directs the study. Zikmund (2010: 18) argues with Pandey and Pandey (2015) to extend the claim that research design is the structure that is employed in an exploratory manner so as to answer the research questions.

Hence, this study was guided by a qualitative approach as the study's methodological approach to collect and analyse data.

In order to understand the essence of research about violence against dementia sufferers, the study followed a qualitative research design. This was in the collection and will also be used in the analysis of data. A “Qualitative approach is a multi-perspective approach to social interaction, aimed at describing, making sense of, interpreting interaction in terms of meaning that subjects attached to it” (De Vos 1998: 240). Qualitative research is concerned primarily with how people make sense of their lives, experiences, and the structures around them (Babbie 2005). The collection of qualitative data is applicable in human behaviour investigations, for example, why people think or do certain actions (De Vos 1998: 240). Since the study seeks to address the violence against dementia sufferers which comes as a result of human behaviour, the qualitative research design was appropriate to discover the underlying motives and desires for violence against dementia sufferers and this was attained through the use of interviews and focus group discussions. The researcher collected qualitative data from which themes and patterns were drawn.

By using exploration under the qualitative approach, the intention was to understand the emotions, behaviours, and the needs of participants in Mapotu community. Therefore, this was helpful because the researcher was able to take into consideration the structural and cultural influences that contribute to violence against dementia sufferers in Mapotu community as well as the influence that they have on their status quo. This approach was appropriate because it allowed the researcher to interact with the participants since the intention was to understand the participants’ views within their own natural setting (Khothari 2004: 5). Five families that were directly affected by dementia and the community members had elicited insightful data to help the researcher develop interventions that will hopefully bring social change in Mapotu community.

According to De Vos (1998: 246), the importance of qualitative research cannot be overemphasised in behavioural science where the aim is to investigate the underlying motives of human behaviour. Therefore, from the data collected, one can analyse the factors that contribute to human behaviour. The analysis can therefore inform the intervention. Therefore, the qualitative research design was appropriate in this study because the study deals with people’s opinions and perceptions which are not quantifiable and can be analysed in a qualitative manner without the use of numbers (Babbie 2005).

4.5 Population and Sampling

The study was conducted in Mafeteng district at Mapotu community. Mapotu community consists of eight small villages estimated to have a population of approximately 250-300 in each community, according to traditional leaders in the community (village chiefs). Thus, the targeted population was five villages.

With regards to the sampling method and processes, the selection of the population was carried out following the phenomenology nature, in which participants were selected qualitatively based on their experience about the problem being researched, for example, families of dementia sufferers. As Eddles-Hirsch (2015) argues, phenomenological samples usually have a small number of participants to allow the in-depth study of human experiences for the collection of data. However, enough participants are needed to produce different experiences regarding the problem being studied. Hence the study had directly and indirectly affected participants.

In addition, Altmann (2014: 228) advises that “the researcher should be certain with what he wants to accomplish and what he wants to know, these two important questions had informed the choice of appropriate sampling strategy”. In short, sampling involves the set of events that must be sampled in order to answer the research questions. This means that the research sample should be knowledgeable about the phenomenon being investigated. On the other hand, Dolores and Tongoco (2007: 147) argue that the selection of the sampling method is largely informed by the question that the researcher is interested in answering. For this study, participants who directly suffered and experienced dementia were selected based on their knowledge and experiences to provide appropriate information. Therefore, the choice of the researcher’s sample was influenced by the sample’s relevance in the study. Purposive and snowball sampling were used to select participants.

4.5.1 Purposive Sampling

Purposive sampling is a method where a researcher selects a sample based on the purpose using his or her expertise with and objective of yielding insight into and understanding the phenomenon (Chadwick *et al.* 1984: 145).

Therefore, purposive sampling was based on the experiences of the directly affected people in the community who were the families of dementia sufferers and the patients (Strydom and De Vos 1998). Purposive sampling is the thoughtful or intentional choice of an informant which is influenced by the qualities possessed by informants. The selection is more concerned with the knowledge and experience that one has regarding the investigated problem. This technique was applicable in this study as it produced rich data from those infected community members in Mapotu community. Participants had to tell their experiences concerning the violence against dementia sufferers as they are the ones taking care of the patients. Thus, the researcher purposively chose family members who were affected by dementia for interviews. The aim was to understand how affected participants explain their lives and interact with members of the wider community.

4.5.2 Snowball Sampling

According to Babbie (1995) and Crabtree and Miller (1992), snowball sampling is the method that is mostly used in qualitative sociological research, and the sample is chosen through the referral made among people who possess some characteristics that are of research interest. In this study only, those people (participants) who live in Mapotu community and those who have directly or indirectly experienced violence against dementia sufferers were selected. Thus, snowball sampling was used to select the community members for interviews and focus group discussions. As such, in locating other participants, the researcher used snowballing techniques to accumulate more potential participants suggested by other family members of dementia sufferers and community members. This was helpful and appropriate because it was easy to locate other people who could take part in the study.

These two sampling methods helped the researcher to find the affected and infected community members hence the analysis of data will be informed by both categories (affected and infected). Moreover, the two techniques complemented each other in terms of the samples. Thus, this brought understanding and knowledge since dementia is complex and uncommon in social science discourse hence the combination of the two was justifiable.

4.6 Data Collection Methods

The data was collected through semi-structured interviews and focus group discussions and the interview and focus group questions are included in Appendices 1 to 3 at the end of the thesis. A semi-structed interview is defined as a conversational and an informal interaction between the researcher and participants through means of spoken words (Longhurst 2010: 105). Semi-structured interviews offer flexibility because the researcher is able to probe and direct the interviews to elicit more information from participants (Lume *et al.* 2010). All the interviews and discussions were conducted in Sesotho since the participants are Basotho and speak Sesotho and the consent forms were issued and signed by participants before the interviews and discussions took place.

Participants were also made aware from the start of the interviews that they were free to withdraw from the study/interview and discussion without any fear of reprisal (Rakotsoane 2012: 73). The interviews were recorded and transcribed verbatim. The interviews were conducted based on a pre-determined set of questions, thus the questions were prepared beforehand in order to help the researcher guide the entire process of the interviews to answer the research questions. The researcher had research assistants (refer to Table 4.1 in Section 4.1) who helped the researcher with data collection as well as a social worker whose work was to provide professional support when the need arose.

Before the initial interviews, the researcher held a meeting with her assistant and the social worker to inform them how they should proceed with the whole process of collecting data, especially the research assistant because the social worker was not part of the team collecting data. Working with the research assistant was not a challenge because he was someone whom the researcher knew on a personal level since the researcher and assistant grew up together and interacted very well, and he had conducted academic research previously. Therefore, it was relatively easy to access the participants because the research assistant was a resident of Mapotu community and he scheduled the dates for interviews and Focus Group Discussions (FGDs) as per the researcher and assistant’s agreement, and the researcher also called the chiefs to remind them of her coming when the days were approaching. The different village chiefs then called the meetings (*Pitso*) to inform the community members of the researcher's presence in Maputo community. Another aspect that made the research team's work easy was that the team stayed in the same location for the duration of the data collection, and as mentioned earlier, Mapotu community is the researcher's home thus the researcher stayed in the village until the data-collecting process was completed, and the team would only take breaks on Sundays and on Saturdays if there was a funeral in the village where the team had to collect data, and this saved the researcher time and money. The interviews were allocated 40-50 minutes but this varied between interviewees as some participants had more information. Hence, the researcher had to exercise patience to obtain richer information from the participants.

The interview questions were open-ended to allow the interviewees the opportunity to voice their own thoughts, opinions, as well as stating their daily experiences in the community. The interview questions were the same for directly affected participants and the questions for community members were also the same but different from those of the affected community members (see Appendices 1 and 3). Some participants were free to talk while others were somehow reserved and withdrawing information. In such cases, the researcher used prompts such that they could yield more information. Some questions were based on responses of the participants because of the open-ended nature of the questions that were prepared to guide the focus group interviews.

Some people (a great granddaughter of the dementia sufferers, a granddaughter whom the research team interviewed by telephone, a friend to a dementia sufferer, a daughter-in-law, and a pastor) suggested by participants (families of dementia sufferers) during interviews who were not part of the sample initially also gave rich information. At the beginning, the researcher did not intend to interview the dementia sufferers because of the assumption that they are completely confused and disorientated, thus they may not make sense. To the researcher's surprise, not all of them were disturbed and the researcher interviewed two of them and they were making sense. However, they would sometimes bring in some irrelevant issues, but nonetheless they gave very rich and useful information on how they were being treated by both the community and even their own families and how they would love to be treated.

Another tool for collecting data was the Focus Group Discussion (FGD). A focus group discussion is a gathering of people sharing the same background and having similar experiences. In a FGD, the participants discuss and express their opinions, beliefs, attitudes, and perceptions about the topic presented by the researcher (Morgan 2016). During the discussions, the participants were allowed to interact, ask each other questions, and answer other participants' questions. The FGDs produced rich and in-depth data because they were not limited to verbal information, and the gestures and stimulated activities were useful insights (Morgan 2016). The researcher conducted FGDs and each group had a maximum of eight members and the time allocated for discussion was 40 minutes, which was not rigid as people had much to offer in terms of information. Almost all the groups consisted of the chief, community members, and dementia sufferers' family members or relatives.

The focus group discussions were conducted in Sesotho and all participants were made aware that their involvement in the discussions was voluntary, and therefore they were free to quit or leave the discussions if they no longer wanted to participate. The research team conducted five discussion groups (one from each village) and the groups were composed of eight community members. The assistant and researcher facilitated the discussions using the guide though sometimes they had to let participants give more than that which they were asked. The researcher and assistant also used the recording device as well as a journal to take down some points.

The researcher used semi-structured interviews to gather information from 30 community members, and open-ended questions were used (see Appendix 2) to permit an unlimited number of possible answers (Neuman 1998: 241). During the interviews, all the family members were asked the same questions and all community members were asked the same questions which were different from those of the family members (see Appendices 1 and 3). Tables 4.2 and 4.3 provide a summary of the interviews and focus group discussions, respectively.

Table 4.2: Interviews.

Villages	Family members	Community members	Date of interview
Village 1	02	02	24/04/2019
Village 2	Dementia sufferer and a carer (02)	02	26/04/2019
Village 3	01 + 02 suggested: great grandchild and neighbour (03)	02	26-27/04/2019
Village 4	02	02	29-30/04/2019
Village 5	Dementia sufferer, a carer + Pastor (03)	02	01-02/05/2019

Table 4.3: Focus Group Discussions.

Community	Composition	Date of discussion
Community 1	• Chief • Four community members • Pastor • Two family members	6/05/2019
Community 2	• Chief • Five community members • One family member	7/05/2019
Community 3	• Chief • Deputy chief • Six community members	8/05/2019
Community 4	• Deputy chief • Six community members • Family member	9/05/2019
Community 5	• Chief • Deputy chief • Five community members	10/05/2019

4.7 Data Analysis

It was very important to take note and understand not only the spoken words but also the unspoken (such as that which was stated and how it was stated). The characteristics for language should also be taken into consideration i.e. tone of voice, pause, changes in intonation, and silence; these are narratives that are not heard yet they speak volumes (Muylaert *et al.* 2014).

Data analysis is the classification or arrangement of data into manageable themes (Mouton 2001: 244). In this study, data analysis was presumed to have commenced with the objectives of the study and literature reviewed, and this means that the analysis will be qualitative in nature. Qualitative data analysis involves non-numeric assessments of observations made through direct observation, focus group discussions, and in-depth interviews (Kumar 2005: 400-401; Sarandakos 1998: 228). Therefore, the researcher used thematic analysis, which is the qualitative analytic method used to classify patterns of themes in qualitative data (Maguire and Delahunt 2017; Bryman 2008: 700). As a matter of reiteration, themes were built from the objectives and those themes helped the researcher to address and understand the phenomenon. Thematic analysis makes transparent the assumptions about the nature of data, whatever they represent in terms of reality, and so forth.

After collecting data, the researcher transcribed and went through the data in order to become familiar with it. All the notes were kept safe for future use or for reference. The researcher used both the written notes and the recorder for grouping. Therefore, grouping was done to organise data into different themes (Flick 2000: 22). In order to develop the themes, the researcher bore in mind the objectives and from the responses of the participants, the researcher developed the themes to respond to the research objectives. For instance, four community members stated that dementia was not a disease but witchcraft. Thus, as the researcher listened to the recordings and referred to the notes, the grouping and categorising of the themes took place. Moreover, the researcher used coding to process the raw data in a manageable manner. Coding is the process of constructing labels to allow the grouping of multiple elements under one concept to have limited numbers of categories (Flick 2000: 11). There was much information given by participants, thus both coding and thematic analysis helped to narrow down the volume of data into manageable data because the researcher had to code and analyse the data, bearing in mind the research objectives. This is supported by Sarandakos (1998: 28) who states that in analysing data, the grouping method reduces data into manageable data to allow manipulation and integration of literature to arrive at meaningful conclusions.

4.8 Study Delimitations

This study was confined to five rural villages of Mapotu community in the district of Mafeteng in Lesotho. The names of the consulted villages are as follows: Leburu, which is under the leadership of Chief Matota Phoka and he has 250 community members; secondly, there are three villages, namely, Moeletsi, Marakong, and Ramotoho, and the population is estimated to be 612 in those three villages according to chief Thato Letlatsa; and lastly, there is Rachabeli under the chief Lebuajoang Chabeli, and the population in this village is 220, as per the chief's information. Geographically, Mafeteng is situated in the South region of four regions in Lesotho (Motsamai *et al.* 2017). The regions form eleven districts of which Mafeteng is one of the districts. The study focused exclusively on one district in eleven districts and one constituency in Mafeteng district. Secondly, the focal point of the study will be on abuse and violence against dementia sufferers and this leaves out other social challenges prevailing in the area. Therefore, based on the restricted scope of the study, the results cannot be generalised.

4.9 Validity and Reliability

Validity refers to the capability of instruments to measure that which is intended to be measured (Kumar 2013: 48). To ensure validity, research instruments, namely, interview schedules and the focus group guide, were analysed to ensure that the questions and the responses truly reflected the objectives of the research. Moreover, after recording the responses in the journal, the researcher had to verify with the participants whether she had interpreted that which they had stated correctly. It was important to ensure validity in the study such that the study could achieve the intended purpose and the instruments would be responsive and relevant to the core direction of the research. Therefore, reliability was ensured as the data was drawn from multiple sources and techniques (Kumar 2013: 48). Furthermore, the researcher believes that other researchers would obtain the same results as that which the researcher obtained from the study because the participants were genuine and not forced to participate in the study, and this had eliminated to a larger degree the chances of dishonesty. In addition to this, they were asked to tell the truth about their experiences regarding the problem being studied. The following were adhered to, as advised by Kumar (2013), to ensure reliability:

- Use of different tools for collecting data e.g. focus group discussions and face-to-face interviews
- The researcher used the language in which the participants were proficient (Sesotho).
- The researcher ensured that she ask clear and straightforward questions
- The use of the tape recorder was permitted to the participants as well as journals for keeping notes

4.10 Ethical Considerations

Throughout the entire process of the data collection, the researcher observed issues of ethics which are required particularly when dealing with human objects – ethics are requirements for any research exercise, and the researcher should adhere to a number of ethical issues. According to Rakotsoane (2012: 73), the researcher should try to obtain the informed consent of the participants before the study or the interview can begin, and to avoid posing sensitive questions before a good relationship has been established with the participants. In this study, the principle of informed consent was observed, and the participants were informed of the nature and objectives of the study. The researcher had also sought the gatekeeper's permission from the respective chiefs before conducting the study. The following was carried out:

- The researcher provided the consent forms to the participants before starting the study.
- The researcher ensured anonymity and confidentiality.
- Participation was voluntary.
- The researcher ensured that the participants did not share any deceitful information.
- The researcher observed the culture and beliefs of the community.
- The researcher had arranged for a community social worker to provide professional support in case such a need arose.

4.11 Summary

The next phase will be on the exploration of the findings from the collected data. The chapter will be outlined according to the emerged themes.

CHAPTER FIVE

Exploring Dementia in Lesotho: Presentation and Analysis of Empirical Findings

5.1 Introduction

This chapter presents the data collected from interviews with the family members of dementia sufferers and community members and the data acquired from focus group discussions, as well as the analysis of the data acquired from face-to-face interviews with respondents and focus group discussions, observation, and related literature. The data collected was analysed in line with the main objective of the study, which was to prevent violence against dementia sufferers in Mapotu. During the analysis, themes that emerged from the data were classified based on aspects that address the research questions, as recurring themes in the data should logically be derived from the research questions (Petty *et al.* 2012). Therefore, the findings are classified into themes as extracted from qualitative data, and according to Taylor and Gibbs (2010), qualitative data analysis involves multiple processes and procedures that allow the researcher to move from the qualitative data collected to form explanations, understanding, or interpretation of the people and situations being investigated.

It is worth mentioning that the reception that the researcher received from the interviewees was astonishing, especially from the family members of dementia sufferers. Their willingness to share their experiences forced the interviews to go beyond the initial allocated time of an hour. However, others were not very open, especially the community members.

There were different opinions, especially with the community members, regarding some of the issues but surprisingly, the family members shared almost the same opinion in most of the issues. There were 22 interviewees: 12 family members and 10 community members. To the researcher’s surprise, all the interviewees concurred that there was violence against dementia sufferers, and both the community and family members stated that there is violence against dementia sufferers. The discussion in this chapter will be based on the following themes:

1. Understandings of dementia
2. Causes of violence against dementia sufferers
3. Nature and extent of violence experienced by dementia sufferers
4. Assumed interventions to prevent violence against dementia sufferers

The data is summarised through qualitative analysis. Qualitative data analysis involves processes and procedures from qualitative data collected to explain, understand, or interpret people’s situations being investigated (Dey 1993: 10-11). For the sake of anonymity, the participants are coded numerically – for example, FG1 refers to a focus group from village 1, IC1 refers to a community member interviewee from village 1, and IF1 refers to an interviewee from village 1 who is a member of a family with a dementia sufferer.

The interview questions were the same for all family members from the five villages, the questions for the community members were the same for all five villages, and the questions for the focus groups were the same.

5.2 Theme 1: Understandings of Dementia

5.2.1 Introduction

The question asked under this theme was the same for all three categories (family members, community members, and focus groups), that is, what is dementia?

In responding to this question, most of the interviewees did not know what dementia was. Their explanations were based on their experiences of living with or experiencing dementia sufferers. Thus, they were somehow different as a result of the different behaviours portrayed by their patients. However, from 14 family members, nine stated that dementia was a disease for old people, three participants stated that dementia was a high level of stress, and the other two stated that dementia was ancestral punishment, it was caused by poverty and stress, and it mainly affected old people.

5.2.2 Interview with Family Members

As mentioned earlier, there were 14 family members interviewed including two dementia sufferers. Almost all the participants did not know what dementia was. Both dementia sufferers stated that they had not heard of that word and one added by stating that he did not even know whether it was a black or white person. The interviewees from IF1 and IF2 commented that they had never heard of the disease. However, a daughter from IF2 mentioned that the problem came as a result of witchcraft, and her mother was bewitched by her friend because of jealousy. On the other hand, IF3 stated that dementia was a disease for old people and that it caused forgetfulness and mental disturbance but she had never heard of it from anywhere. A daughter from IF3 stated that dementia was a disease that affected a person who was very much stressed and the disease did not have a cure. A participant from IF4 mentioned that she had heard of the disease on the radio and this was from a South African radio station. The neighbour from IF4 stated that dementia is punishment from the ancestors because the patient has a gift of being a sangoma and he/she does not want to be a sangoma. Also, a participant from IF5 commented that dementia is punishment from the ancestors since the wife refuses the ancestral calling (sangoma). Another participant from IF5 mentioned that dementia was a disease that affected the memory and the emotions of a person, and that it affected old people. A further participant from IF5, a pastor who was a friend of a dementia sufferer, stated that it was a disease which affected old people and that it caused forgetfulness.

5.2.3 Interviews with Community Members

To access more information that could bring validity and reliability to this study, the researcher had the opportunity to interview ten (10) community members individually, two (02) from each village. There were different opinions but often dementia was explained to be witchcraft and punishment from God. From these interviews, the researcher drew the conclusion that the community of Mapotu had never heard of dementia, let alone knew about it. This conclusion was drawn from their responses to the questions: what is dementia, or what is your understanding about dementia, or what do you know about dementia?

A participant from IC1 stated that “dementia is witchcraft, even the symptoms are plainly of witchcraft”. Another interviewee stated that “dementia is a punishment from God because these people have done evil things, so God is punishing them that’s why an old man like Mr. J walk naked during the day it is because the sins are burning him”.

A participant from IC2 stated that “dementia is witchcraft, that is why Mr. S has red eyes of witches like that, even the things which he does are all for witches”. With regards to the follow-up question: ‘what does he do?’, the response was “he walks around like a mad person and talking rubbish, even mentioning the names of dead people. He goes to people’s homes and claims to be his”.

An interviewee from IC3 responded that “dementia is caused by too much stress and abuse of drugs and alcohol because most of the people in this village with this problem were heavy drinkers and smokers. Some of them still smoke even now”.

Another one commented that “this a disease for old people, though it’s confusing because these patients do the same things as crazy people do, so in short, its madness”. With regards to the follow-up question: ‘what do they do?’, the response was that “these people talk incoherent things, they are disoriented, and they move around naked”.

According to a participant from IC4, “this is not a disease, it’s punishment from God because these people are witches, they kill innocent souls, so God avenge the deceased. These people pretend to have mental problem, they are witches”.

A participant from IC5 stated that “drug users, witches and mentally disturbed behave all the same, as well as these ones whom you are saying are having dementia. In short dementia is witchcraft and insanity. It’s a disease for old people who have a lot of stress in their families”.

5.2.4 Focus Group Discussions

In all the groups, the researcher found out that the participants had no idea about dementia as an illness. All the participants had an understanding that as one grows old, they practice witchcraft which normally leads to them walking naked and talking of incoherent matters.

For example, one participant in FG1 narrated that an elderly woman who was found naked in the yard of the neighbour was disoriented. Apparently, the same old woman was suspected to have bewitched one family member in the village who happened to have died under mysterious circumstances. That which struck the researcher more was that even the chiefs of these five communities had no idea of what dementia was. However, there was one lady in FG2 who had a little knowledge about the disease and this was because she had worked in South Africa as a domestic worker where there was an elderly man who had dementia in the neighbourhood. Most of the participants in FG3 stated that dementia was witchcraft, though there was a participant who stated that dementia was madness. Thus, there were two opinions from the group: witchcraft and madness. From FG4, there were different opinions, and dementia was explained to be witchcraft, ancestral punishment, God's punishment, as well as madness. FG5 explained dementia as witchcraft.

Moreover, every suspicious death that happens in those communities is blamed on dementia sufferers because they are regarded as witches. None of the participants from both the focus group and from the face-to-face interviews knew what dementia was. It was only one family that had an idea but only because the granddaughter had taken the grandfather to the doctor. The rest of the participants attributed the behaviour of dementia sufferers to witchcraft.

5.2.5 Discussion

Dewing and Dijk (2016: 16) define dementia as:

> [A] collection of signs and symptoms such as memory problems, communication difficulties, difficulties with organising and planning one's day-to-day life, changes in mood and behaviour, and the gradual loss of control of physical functions. These symptoms, when combined together, are an indication of physical damage to the brain as a result of chronic progressive degeneration of nerve cells. The damage to the brain may be caused by a variety of different diseases.

Therefore, the community of Mapotu attributes the same symptoms of medical illness to witchcraft, God's punishment, ancestral calling, a normal part of aging, and madness. The notion of dementia as a normal part of aging is popular as in countries such as Ghana, Congo, and Tanzania, dementia patients were not subjected to stigma as dementia-like symptoms were accepted as a “normal part of old age”, and symptoms were linked with a change of roles (Gureje *et al.* 2015: 170). Additionally, studies of Prince *et al.* (2012) conducted in India found that the symptoms of dementia were considered as a normal part of aging which is expected to happen to elders.

Nevertheless, Irwin *et al.* (2018) and Wottman and Iddon (2014) have a different opinion as they state that dementia is not a normal part of aging hence it is not a disease for old people as some family members think. It is because most of the changes in behaviour occur psychologically or become more severe as the disease progresses and thus negatively affect the lives of old people and their caregivers.

The family members of dementia sufferers explained dementia from a different point of view as opposed to community members. Almost all the community members stated that dementia was witchcraft and that the patients were witches, whereas some of the family members believed that their patients had been bewitched while others attributed the disease to ancestral calling. Only one family explained dementia from a medical point of view because she mentioned that it was a disease that causes forgetfulness and it came as a result of a high level of stress. None of the community members stated that dementia was a disease. The community even attributed red eyes to witchcraft. The Tanzanians also attribute red eyes and poverty to witchcraft (Longdon *et al.* 2013).

It is noted by Ferreira (2004) that dementia stigmatisation is gendered in nature, requiring a more profuse approach in dealing with its consequences. It is alleged that in most African places, women who live alone and exhibit the signs and symptoms of dementia are branded as witches. Therefore, such women are subjected to violent assaults and murders as well as vandalisation of their houses and other properties. In some countries, they are even chased out of the villages. Such gendered stigmatisation and stereotyping only reflects how a lack of awareness on dementia as a disease has ruined the social fabric. These misconceptions and misinformed attributions do not only occur in Mapotu community, and this is confirmed by Patel *et al.* (2003 cited in Kalula and Petros 2011) who also noted that though dementia sufferers may display the symptoms, people around them frequently attribute and explain the symptoms as being childish (*chinnan*) and having a tired brain (*nerva frakese*).

Moreover, in Ghana and Congo, dementia sufferers have been referred to as childlike, while in Nigeria, symptoms (forgetfulness) were linked to the loss of authority (Gureje *et al.* 2015: 175).

The above literature shows that most people do not know about dementia, thus a lack of knowledge from different nations gives different attributions and explanations of the symptoms. However, the common attribution is that dementia is witchcraft and a disease for old people, and there is much fear, stigma, and discrimination against dementia sufferers and their families. Fear of demented people and the violence towards them stems from the belief that dementia people are witches (Mkhonto and Hanssen 2018). Not only did the community members have no knowledge about the disease but the family members were also ignorant of the disease, as most of them stated that their patients were bewitched, and they were denying ancestral calling and being a punishment from God. Thus, family members state that their patients have been bewitched while the community members state that the patients are witches. As it has been reported, in Nigeria, dementia sufferers are perceived as witches, and it is certain that they face discrimination and isolation and experience all forms of violence (Adebiyi *et al.* 2016: 270).

One more factor that causes people to carry out violence against dementia sufferers is a lack of knowledge about the disease. The attributions of dementia to childlike behaviour, a loss of authority, a normal part of aging, and witchcraft, as mentioned by Guerchet *et al.* (2012, 2017), are not only present in Mapotu community but also in other countries, as mentioned above. Participants in this study also attributed the symptoms to witchcraft, God’s punishment, and a normal part of aging. This misinformation is both from the community and family members. The family members are equally clueless about this medical condition. Most of the family members interviewed showed that they have not heard of the disease hence some attributed the symptoms to insanity, a disease for old people, and that the patients are bewitched. To summarise, none of the participants explained the condition of the patients from a medical point of view.

5.3 Theme 2: Challenges in caring for Dementia Sufferers

5.3.1 Introduction

Under this theme, participants were asked similar questions in trying to find out if the carers and the community members were experiencing some challenges in taking care of dementia patients. Community members were also interviewed on this as the researcher believes that they should somehow take part in caring for dementia patients, as they had mentioned in the discussions that they would help to care for TB and HIV/AIDS patients.

5.3.2 Interviews with Family Members

Family members from all five villages experienced almost the same challenges in caring for dementia sufferers. All the families mentioned that the patients were aggressive, easily agitated, and the patients disappeared from their homes and as they disappeared, people would beat them badly because they would state that they were witches and experienced forgetfulness, a loss of weight, and poor appetite. They also mentioned that both the family members and patients are subjected to violence, discrimination, social isolation, and stigma. They all mentioned the same challenges though the degree of challenges would differ from family to family. However, some responses that the researcher found outstanding will be shared here.

An interviewee from IF1 commented that:

> I have a lot of challenges to the extent that I don't even know where to start when I tell you about my challenges. All I can tell is it's not easy to take care of a person with dementia. *Ntate* (husband) is 82 years and I am 76 years; we are staying with my great grandchild who is nine years. So, it's basically me who is caring for both as this child is still young and need my assistance with most of the things. I am old as you can see, and I don't have much energy to go up and down caring for dementia patient, but I must do it. My grandchildren hired a helper several times but *ntate* beat them up and chase them away, he claimed they came to steal his things.

After seeing the distressing situation in which the respondent was living, the researcher further inquired whether this couple had children. In response, the participant stated that:

I have one child, a son who gave birth to five girls and his wife passed on, and this child that I am staying with is a daughter to one of those five girls. My son is living in South Africa, he comes home occasionally and when he is home he has his house in town but he comes to visit when he is home, his wife passed on and that girl loved my husband as her own father, you would not believe that she was a daughter in law (a sad face) Even two of his daughters are in South Africa and three are in Maseru, they are married. But they come to visit. But there is one of them, Theresia, who loves his grandfather so much because she grew up here, she is the one who comes often and even take *ntate* to doctors. But due to the nature of her work, she cannot stay with *ntate* and she has very young children. So, I am all alone with this young child.

My main challenge is as you can see, I am also old, so caring for my husband is advancing my days to death. This thing affects me so much, I am finished (she said with tears rolling down her cheeks) (a pause) my child I am exhausted, and I am sick too. My whole body is very painful, this child (grandchild) is massaging me every night. I do not rest during the day and at night. *Ntate* sleeps for three hours maximum and he wakes up and once he is up, we also have to be up because he accuses me of giving out his things, he does not see his trousers, I gave them to my concubine (she laughs), imagine at my age what concubine can I have? He will turn everything upside down looking for his tools. And as he is doing this, we are up with a child raping with some blankets. Imagine in the morning this child must go to school and at night she does not sleep because of my husband.

Secondly my husband was a very hardworking man when he was still in a good health. He was doing all the hand works, like building houses, plastering houses, and woodwork such as plumbing. So, he had all the tools to perform those works and the tools are heavy as they are medals or steels. He used to wake up very early when going for work and come back very late. This is what he still wants to do even now. The tools bag its very heavy for him to carry now but he still finds a way of putting on the shoulder and going out as early as 3-4 am. You cannot stop him from going, if you dare try to stop him, he will beat you with whatever he is holding. So, after he goes out, I must dress up and follow him, remember I said he has poor eyesight and hearing and worse he is disoriented. So, I must follow him in the dark trying to sweet talk him and convincing him to go back home. Sometimes he listens but more often he does not. When we get to people’s house that early, I just tell people not to open for him. Or they tell him there is nothing that needs fixing.

Then we will go back, and I ask him to give me the bag so that I help him to carry it and I tell you that bag is very heavy. I had to take out some of the tools to make it lighter and he was aware that some tools were not there, and he said I sold them, and he fought me.

Another challenge is that it is very difficult to get him to eat. We have to give

> little food which he does not finish, and I have to break it as if I am serving a child. The only thing that he takes well is tea because he likes tea. He can take tea all day long not food. Even to take medication is a problem. He is taking hypertension medication but sometimes he says they have expired, and the nurses want to kill him, and he would refuse to take medication. He has lost weight so much and it pains me to see him like this.

In the researcher's discussion with the carer from IF2, the husband mentioned that the wife does not want to eat, and she goes around and even gets lost. She is always angry and cries over everything.

A daughter-in-law from IF3 mentioned that when the father-in-law is back to his senses, he always tells them that he wants to die. She mentioned that the father was aware of the disease when it was creeping in and he would tell them that his life was changing and that he wished to die because he did not want to be treated as dementia sufferers whom he knows in the village. She mentioned that his father was always feeling sorry for dementia sufferers, especially his friend in the other village, and he never wanted to have this disease:

> My father is always miserable, what makes the matter worse is he does not want to eat. He does not sleep for more than three hours so I give him some sleeping tablets and when he had taken them, he sleeps better other than that he can stay awake the whole night talking.

5.3.3 Interviews with Dementia Sufferers

The interviews with two dementia sufferers are shared below.

Participant from IC1

How do your family members treat you?

When responding to this question, the old man mentioned that the family treats him well though sometimes he is treated like a child. He mentioned that the family refuses to let him visit his friends and he is not allowed to do the activities that he loves to do. He mentioned that the wife refuses when he goes out to work as he used to do and she hides his toolbox, and this does not sit well with him since, as a man, he has to provide for the family. He added that since he does not have money, his wife is seeing a small boy in the village. He further mentioned that the wife is giving him expired tablets because she wants to kill him. Moreover, he stated that most of his possessions are missing in the house and he suspects that the wife is giving them to the small boy whom she is dating or selling them. He stated that he would put his possessions in a certain spot and the next moment when he goes for them, they are no longer there. Another point that he hates is that they give him a lot of food and expect him to finish the food.

How does the community treat you?

In response to this question, he stated that he misses his late friend. As for the community members, he noticed that they have developed much hatred towards him, and he does not even know what he has done to deserve such inhumane treatment from his community. Furthermore, even small children through stones at him or run away whenever they see him. He added that the taxi drivers refuse to take him in their vehicles, even when he explains to them that he is going to see his grandchildren in the city. He mentioned that people fight him for no reason, and they call him a lunatic or a witch. He wonders whether being old is causing him to deserve such ill treatment.

Participant from IC2

How do your family members treat you?

He mentioned that his family disrespects him and takes him for a fool. He is being excluded in most of the decision-making discussions. He mentioned that recently there was a meeting and he was not part of that meeting, and no one told him anything. He further mentioned that the family is tired of him and they are doing all that they can to get rid of him. He has noticed that because of his poor memory, the family members become annoyed with him when he asks them for his things.

5.3.4 Interviews with Community Members

From the ten community members interviewed, eight interviewees mentioned that they did not have anything to do with dementia sufferers. The patients are only cared for by their families. They mentioned that they cannot help or care for the witches who will in return kill them or their children, and they also commented that dementia patients are very aggressive. The community members mentioned that instead of helping, they beat and kill the witches and their families are subjected to severe discrimination, and even the children of dementia sufferers are subjected to abuse and discrimination in schools, thus causing them to drop out from schools. A participant commented:

> But it’s not only us the villagers who maybe beat or abuse them somehow, even their family members assault these people. I have seen Mrs. X pushing Mr. X and even talked to him badly as if he is no longer her husband. Another problem with Mr. X is that he has a problem with his hearing, so the wife and children lose patience when talking to him. They do not treat him well at all. That is why he sometimes beat them up.

The statements of the remaining two are covered as follows.

The woman from IC3 stated that she sometimes felt sorry for the old woman who was taking care of her old husband. She sometimes helped her to fetch water as the taps are very far from the village and sometimes they have to get water from the wells when the taps do not have water, thus she helps but she makes sure that other community members do not know that she is helping the old woman because she will be isolated and rejected for associating with witches. She mentioned that she knew the patient since she was young, and she does not think that the patient is a witch.

In response to the question: ‘What do you think is happening with the patients?’, the participant mentioned:

> I think he is just old and since he was very active and hardworking in his days, so now the body is tired. People are different so the way they age will differ hence the patient is like this, it’s just a matter of aging. But another thing is that Mr. X has become very aggressive towards people, maybe that is his defence mechanism because people beat and hurt them badly.

The man from IC5 stated:

> I grew up with the grandchildren of Mrs. X and I was very close with them to the extent that I was visiting this family every day and would eat the food. This family loved me and treated me as one of their grandchildren. Even when I got married to my wife, they bought a sheep as a contribution which I cannot forget because even my relatives did not contribute that much. I honestly do not think that Mrs. X is a witch, she is just confused or rather I can say she has a mental problem not to be a witch. Another thing that perhaps makes people to think that she is a witch is that she totally disoriented, she does not even remember me or her own grandchildren,

> and she has completely lost memory. People in this village they know my stand when it comes to the issue of Mrs. X and I always tell them that she is not a witch, and some hate me for that. If she was a witch, she could have bewitched me long time ago when I was visiting and eating her food.

5.3.5 Discussion

The report by Alzheimer’s Disease International (2014) indicates that almost half of the people suffering from dementia experience significant weight loss in a period of one year, and the numbers are estimated to be 20-45% who suffer weight loss and have dementia, and most of them are in homecare, thus due to insufficient food supply, they may experience this weight loss. It is imperative to note that the report by Alzheimer’s Disease International (2014) focused on the experiences of those living in care homes in urban settings and neglected those living in rural communities where caregiving is the primary responsibility of close relatives and very close friends, and this is a point of entry for this study.

All the family members commented that they had the challenge of getting their patients to eat. Even the two patients themselves mentioned that they had a poor appetite and they became offended when they were forced to eat. There is a correlation between dementia and poor appetite and this has been noticed by Alzheimer’s Disease International (2014: 13) as they state that there are many dietary factors that contribute enormously to the onset of dementia.

There is rather unswerving evidence that shows that adherence to a diet that has a high proportion of cereals, fruits, and fish has the potential of lowering the chances of cognitive deterioration. Thus far, there is only one trial with encouraging findings and that advocates for more research along that angle to discover new knowledge, especially on the correlation between certain foods and the onset of dementia. Alzheimer’s Disease International (2014) argues that the disturbed regulation of appetite and metabolism could explain the weight loss in some forms of dementia. Therefore, in communities where food is insecure and expensive, there is a likelihood of violence perpetrated against dementia care recipients because caregivers will be bearing the double-edged burden of making ends meet and again assisting the patients to eat.

It is worth mentioning that it is very common for dementia sufferers to lose weight, therefore undernutrition should be avoided, as stated by Alzheimer's Disease International (2014: 10). Moreover, much attention should be given to the training of staff in care-homes, and the staff should be trained on the mealtime environment as this has the possibility of enhancing calorie intake. Care centres should consider eating as a social activity as it is and it should be improved and made the core aspect in the process of caring for patients at all costs. Thus, this requires some innovations to enhance the dining rooms and kitchens as they can all make important contributions. Perhaps the changing of the environment such as the kitchens and dining room could happen in the cities, but the concern is how this can be implemented in the villages such as Mapotu where most of the families have one room for every activity.

As indicated by the family members and community members, aggression and agitation have been noticed in dementia suffers and this agrees with findings from Wharton and Ford (2014) as they examined the issue of agitation as behaviour manifestations in advanced dementia and concluded that there is little in literature about the topic. They further argue that it is vital to educate and protect the informal caregivers of dementia patients living at home while working on interventions to advance the understanding of the communicative properties of behaviour.

From the respondents' views, dementia sufferers are violent and aggressive, and this causes people to respond in a violent manner towards them. These opinions agree with Nolan *et al.* (2006) as they maintain that dementia sufferers are violent. On the other hand, Goodman *et al.* (2016: 165) comment that there are causes of violence which are economically, socially, and culturally rooted or oriented, though for some causes, it is easy to see or identify while others are not easy to see. Recent research suggests that individual factors that contribute to aggression are mostly interrelated with family, community, cultural, and other external factors and these are the factors permitting the occurrence of violence (Straus *et al.* 2017: 25; Hird 2017: 20). Furthermore, research on violence by WHO (2004: 7) argues that violence is more likely to happen in some communities than others and this could be due to contextual factors such as poverty, physical deterioration, or few institutional supports in the community.

Family members and dementia patients commented that they face social isolation, stigma, discrimination, and violence. The worst part of this is that even the children of dementia sufferers are subjected to all these factors. There is a skewed treatment between men and women suffering from dementia. It is true that violence against dementia sufferers affects both genders, but females are more at risk as compared to their male counterparts. Most women who show symptoms of dementia are regarded as witches as compared to men – this implies that the stigma is gendered, and this is why in most parts of the world, female dementia sufferers are at a high risk of being killed and their assets being taken or vandalised. This gendered stigmatisation and stereotyping show the serious impact of a lack of knowledge about dementia on humanity.

The strain caused by caring for dementia sufferers was stated by all the family members interviewed, and it was more evident with the 76-year-old lady caring for her 82-year-old husband. Fatigue and stress were written over her entire face. That which makes the caring for the patients worse for the families is the fact that they are ignorant about dementia and thus, this causes them to mismanage the condition. Enmarker *et al.* (2011) maintain that caregivers are not given enough information on dementia, hence they do not even know the causes and triggers of the disruptive behaviour presented by their patients, which makes the caregiving even more stressful, hence it becomes a burden to keep their loved ones at home. It is evident that a lack of understanding of the condition by both the patients and carers may brew fear, has the potential of resulting in discrimination, and could also give room for negative beliefs to those affected by the disease (Blum 1991).

Nankinga *et al.* (2020: 7-8) conducted a study in the south of Uganda which revealed that both the family members and community members worked hand in hand to care for dementia sufferers. Two themes came out of the study and under each theme, there were categories which made the caring for dementia sufferers very effective and less stressful for both the patient and the family. Under theme 1, which was “informal support provided in homes”, the categories were: supporting and reminding PWDs of the activities of daily living, reminding PWDs to attend social and family activities, creating a socially connected environment, enabling accessibility to medical care, assisting with occupational activities, recovering misplaced items, informal counselling and guidance, spiritual nourishing, providing of herbal remedies, looking for financial support, and sourcing carers from other families.

Theme 2, which was “perceived usefulness of the support”, had the following categories: happiness and feeling loved, fulfilment, peace of mind, relief, and occupation. The above findings are worth mentioning because their implementation has made the tedious and stressful work of caring for dementia sufferers easy and meaningful. They not only helped the caregivers, but the patients also developed a sense of belonging, and the humane treatment and care made them worthy of living. Their inclusion in family and community activities gave the patients a sense of worth in the community and in their families.

5.4 Theme 3: Nature and Extent of Violence against Dementia Sufferers

5.4.1 Introduction

The families, community members, and the focus groups had to discuss the nature and extent of violence against dementia sufferers in their community. Evidently, the responses were different as some parties were at the receiving end while others were perpetrators.

5.4.2 Interviews with Family Members

All the family interviewees commented that the level of violence against dementia sufferers is too high. That which makes the situation worse is that people who subject the sufferers to violence do not get punished. All in all, the violent and abusive behaviour against dementia sufferers is not punishable in Mapotu community because it has been a long practice and has been normalised. Thus, according to Mapotu community, it is good to kill or brutally beat a witch. The families stated that they become very worried once their patients disappear because they know that if it happens that they come back home alive, they would have been seriously injured. All the killings and beatings are done because the communities believe that dementia sufferers are witches.

An old lady had the following to state to show the extent of violence against dementia sufferers in Mapotu:

> As much as I make sure that my husband does not disappear from my sight, he has his ways of slipping away and it happens that he disappears for days. And I know for sure that when he appears, they would have rearranged his poor face, the feet and everybody full of injuries. These people are so cruel my child, the other time he went missing for four days and in my heart, I told myself he is dead where he is. I and my chief were summoned by Tsakholo police and that confirmed my thinking of him being dead. We went with chief and when we got to the police, we could not recognise him as we entered the office. The whole head was bandaged, and the face was swollen. The police asked him "Mr. X, who is this?", referring to me. He said I am a cashier in Mapotu supermarket. So, all in all, the level of violence against dementia sufferers is very high.

Furthermore, for a deep understanding, the researcher asked the respondent as to what makes the community state that *ntate* (husband) is a witch. She commented that:

> This disease has messed up with his mental health, he behaves like a mad person, he is disoriented, and he behaves inappropriate. Sometimes you find him in people's houses making tea or sleeping and that makes people to say he is a witch, he does that because they are using a strong MUTI or their sangoma is powerful, that's why "*ntate*" is doing all those. If he happens to mention the name of someone who died or anyone who is late, they say he mentioned that name because he killed that person. For example, my husband does not even remember his own children, when they are here, he asks them "who are you, who are your parents?". And if you mention your name, he sometimes says "ohh you are Peter's daughter?". So, if it happens that Peter whom he mentioned has passed on, they say he killed him. "*Ntate*" mentions any name of a person even the district's name that comes into his head. Two days ago, his son came to see us, and I asked him "*ntate*, who is this?" referring to my son, and he said "it's George, the son of Mantebaleng, the ones who are staying in Maputsoe". Mind you, we don't know mantebaleng and George, our son's name is not George…..

5.4.3 Interviews with Community Members

The interviews indicated that there is violence against dementia sufferers. All the five villages commented that they kill and beat dementia sufferers because they are witches, and this is how they deal with witches. Below are some of the responses from one interviewee in each village, but overall, they shared that the nature and extent of violence in the five villages of Mapotu is alarming.

An interviewee from IC1 stated that “These people pretend to be mentally ill and they move around disoriented and we beat them. Some are beaten to death”.

An interviewee from IC2 commented that “a witch (dementia patient) is put a necklace (a tyre around the neck) and we lit it then a person will burn to death”.

An interviewee from IC3 stated that:

> In this village, we kill without any remorse as they too kill mercilessly. We burn them in their houses because the chief and the police arrest us. We used to put a tyre around their necks and burn them. So now we burn the houses, and no one will know who did it.

An interviewee from IC4 commented that “why should you let the witch to leave because if you do, he/she will kill you. We kill them in two ways, for example, beating and burning. Even their children are victimised in our villages”.

An interviewee from IC5 stated that:

> Violence against witches is not anything new and I don’t see it ending because all the villages around here, even those far from us, it is known that witches are killed. Even in South Africa, these people who pretend to be insane are killed. We hear from radios and newspapers. So, what we are doing is not infrequent.

5.4.4 Focus Group Discussions

All the five groups mentioned, without remorse or shame, that they would kill the dementia sufferers because they are witches. Below are some comments from each group.

A participant from FG1 commented that:

> It is known in this area of Mapotu that a witch should not be led to see the following day. This means we kill witches here because if we don’t kill them, they will kill us. So, these people, whether young or old, if it is believed that a person is a witch, we kill him/her just like that. Even the police know that we don’t joke with witches and it’s not easy to arrest the whole or half of the

> village that had killed a witch so as much as it is not openly allowed but, in a way, we do it and most of the time get away with it.

A participant from FG2 stated:

> Not long time ago, if my memory serves me well, two weeks back, Mr. X was found in the neighbouring village and people in that village knew him, so they caught him and tied his hands at the back drove him to his village. It was not only the tying of hands but had also beaten him. As old as he is, he was pushed and dragged like a dog by the villagers.

One participant from FG3 commented:

> The last witch that we killed here was through a necklace (putting a burning tyre on the neck). That was done in the presence of other community members who discourage witchcraft. So even these ones if they do not stop, we are going to kill them like that. I think the other thing which has saved them up to date is that our experts of necklace are in prison – eight of them are in Mohaleshoek prison.

A participant from FG4 stated:

> For now, what we do is if one of these people is found in your yard pretending to be disoriented or maybe if she/he is found naked, we call the villagers and tie him/her then drag him/her to the chief and the chief will call his family members. But before taking him to the chief, we beat him.

A participant from FG5 stated:

> There is one lady here who sometimes loses her mind and behaves inappropriately, she came to my house and told my husband that I owe her, then my husband asked her, how much do I owe her and she said 20 cents and my husband laughed, she got so angry and slapped my husband so my husband had to defend himself. Even when people were gathered, she still maintained that I owe her 20 cents, but at the end, she was mentioning the different name of the person who owes her. This is a serious problem, she said, as she shook her head.

5.4.5 Discussion

The nature and extent of violence experienced by dementia sufferers is alarming and calls for collective effort from all stakeholders and the government to attend to the issue of violence as experienced by dementia sufferers in Mapotu. It is very unfortunate that this alarming violence does not only occur in Lesotho but also in other countries, especially in the neighbouring country of South Africa, as Mkhonto and Hanssen (2018) state that in South Africa, patients are subjected to violence and ostracising. Thus, this shows that violence against dementia sufferers is a global issue and should be treated as such.

The community of Mapotu mentioned in the focus group discussions that it is a normal practice to kill a witch because if not, the witch will kill the entire village. Thus, the killing is done collectively, and this practice has been passed on through generations. A spouse to a dementia patient stated that “Even the small children in this community, whenever they see my husband, they stone him for no reason”. This violence has caused animosity in the village, especially to the families and relatives of dementia sufferers. Stigma and discrimination, as a result, deprive the patients and their families of that which they are supposed to receive as the community members, such as receiving food as with anyone else in the village. This not only happens in Lesotho, and Adebiyi *et al.* (2016: 270) note that in Nigeria, the fear of dementia sufferers has resulted in discrimination, isolation, and violence. The children of the patients are being victimised at school by other children to the extent that they no longer feel safe, hence they have stopped schooling. Moreover, families and their patients are isolated and have no social support. The violence against dementia sufferers in Mapotu has caused hatred and divisions in the community. The discussions with community members revealed that there is much hatred and animosity in the villages between the community members and the patients’ families.

5.5 Theme 4: Caring for and protecting Dementia Sufferers and their Families

5.5.1 Introduction

Family members and community members were asked how the patients and their families could be protected against violence, and the families shared the same view that the community had nothing to do with the dementia sufferers. The researcher observed that the labelling of dementia was passed from one generation to the next in a very negative manner.

5.5.2 Interviews with Family Members

All the families mentioned that there was absolutely nothing that the community could do for them because they stated that they were witches and knowing how their communities deal with witches, there was no way that could be of any help to them. Below are some of the responses from participants.

A respondent from IFI reviewed that:

> There is nothing that these people can do, they have showed much hatred and disrespect to my husband and my family, so I don't want anything from them. I was expecting them to have compassion and be helpful as my husband was to them when he was healthy.
>
> "Ahahaha she laughs!!" … I don't think they have any role to play until their own will have this problem. You cannot believe that I no longer have friends in this village. The only person who is still the same to me is my neighbour on the left house, as for the rest of the community, they have distanced themselves from my family, even the extended family they don't want anything to do with me and my husband. You know what my child, this is the time I need people more than when my husband was well. I don't need their money, I just need someone who can come and ask me how am doing? Someone to tell me not to lose heart it shall be well. Sometimes I need to sleep for just an hour during the day, but I can't because I am afraid that when I wake up *ntate* would have gone. So, I sometimes sleep when my grandchild is back from school so that she can keep an eye on him. I need someone to say let me help you with your laundry. But there is no such a person only my son and grandchildren. From there people from church come as I am an elder at church, they come and encourage me even to pray for us and I think it's because we don't attend church in the village here.
>
> For the patients I think they still need to be respected. The way these people call him and drag him when they find him in their houses you would think they are talking to a dog. Name calling is another thing.

A respondent from IF2 stated:

> I don't think they can do anything even if they would be asked to. The way they hate and despise my family you would swear that my mother has killed one of their family members. So, there is absolutely nothing they can do to help us.

A respondent from IF3 stated that:

> I have come a long way on my own, not only the community members have abandoned me, even my own family members and friends deserted me so by the grace of God I have been managing though it's not easy.

A respondent from IF4 commented that:

> I don't want to see them anywhere near my family, not after the way they have beaten and disrespected my father in law. I don't like them and if it were easy, I would take my family and leave this village.

5.5.3 Interviews with Community Members

In response to the question on how the patients and their families could be protected, respondents shared the same view that there was no way in which the community could protect dementia sufferers and their families. They stated that there was nothing to do for a witch and his/her family other than deleting him/her completely.

5.5.4 Focus Group Discussions

In the same way, in the focus group discussions, the participants stated that they cannot help witches, and they plainly stated that they hated dementia sufferers and their families. One mentioned that in their village, they help sick people such as those with HIV/AIDS, thus the reason why they could not help or protect dementia sufferers was not because they were sick but rather because they were witches who killed people for no reason. All the groups shared the same opinion.

5.5.5 Discussion

There is one opinion from three groups of participants though the two groups being the communities and focus groups stated plainly that there was no care or protection that they could give to dementia sufferers and their families. On the other hand, the families of dementia sufferers feel that they need no help from the community due to the social rejection, discrimination, stigma, and brutal killings to which they are subjected. All these responses from the community stem from a lack of knowledge about the disease as they attribute the symptoms to witchcraft. Hence in one group, the members mentioned that they do help or even care for other patients such as HIV/AIDS and TB patients, and this means that if they perceived dementia as a medical condition they could help and protect the patients and their families. A lack of knowledge has killed the spirit of *ubuntu* and people, in their own communities where they used to live in harmony and peace, have become enemies.

Gerstbauer (2010: 846) states that there are three types of peacebuilding, that is, political, social, and structural. He maintains that social peacebuilding ponders on affecting generally held perceptions as well as attitudes (for instance, dramas that break down dementia stereotypes, and truth and reconciliation commissions). Social peacebuilding is aimed at changing the essential relationships between the groups which are in conflict.

From the interviews above, the community members showed that there was nothing that they could do for dementia sufferers because they explained dementia as witchcraft, thus there is a need for social peace in this community to break stereotypes and inform the misconceptions that people have about dementia.

On the other hand, Hindley *et al.* (2016: 135) mention that in South Africa and Tanzania, the community members and the external family members support dementia sufferers and their carers on the cost of care – this means that the community has been supportive to families with dementia patients unlike the community of Mapotu.

5.6 Theme 5: Attributing Dementia to Witchcraft

Many people have negative perceptions about dementia and the dementia sufferers and their family members experience rejection, isolation, and discrimination in their community as a result of a negative social perception about the disease. In Mapotu, the symptoms of dementia are attributed to witchcraft and, as a result, the patients and families suffer the consequences of misconceptions. According to Yang *et al.* (2016), dementia has not been regarded as a medical condition but rather as a punishment from God for the sins that a person has committed. Therefore, dementia was not rationally explained in that period hence the signs and symptoms were attributed to demon possession and thus caused the patients to be subjected to hatred. Moreover, dementia sufferers were representative victims of a witch hunt. It is very unfortunate that this is the case in Mapotu as some people attribute the symptoms to demon possession and others to witchcraft. However, these misinformed attributions exist not only in Mapotu. In Ghana, mentally ill patients are chained out on trees for years, and people with mental illnesses are dehumanised by their own relatives as some are chained to trees permanently – one relative had this to state: “Since we ran out of medication, the only thing on offer is the chain” (McVeigh 2020).

Yang *et al.* (2016) note a book entitled *Hammer of the witches* which was published by Roman catholic priests, at a time when church leaders were some of the people to whom people ran when they were being abused or mistreated, thus in those times, the same person to whom the dementia families and patients would run published the book which outlined the criteria to identify the witches, as well as the punishment for those who met the criteria, and even how the punishment should be carried out by the witches. The book was approved by Pope Innocent VIII. Thousands of people were burned in a dreadful manner. Dementia patients were burned to ashes on the rack solely for exhibiting the signs and symptoms of mental instability – they became victims of witch hunt.

Yang *et al.* (2016) note that witch hunt is still active and very much prevalent in some parts of the world. Yang *et al.* (2016) argue that in November 2010, a Ghanaian woman aged 72 years who portrayed one of the symptoms of dementia, such as amnesia, was burned to death at the stake because that memory loss was attributed to witchcraft. This attribution stands even now in Ghana. It is very common or a normal practice to chain people with mental health conditions in Ghana, as there is no cure or people cannot afford psychiatrist drugs, thus most families resort to chaining their loved ones at home or even take the patients to prayer camps where they are chained (McVeigh 2020). In 2014, there was an old lady of 76 years of age who was humiliated by people and media in Lesotho after she was found naked and disoriented. The picture of the nude old lady was displayed in all the newspapers, on the account that she was a witch hence disoriented and nude.

To date, dementia is still misunderstood in Ghana and other parts of the world as people regard it as spiritual and consider it as a mystical phenomenon (Yang *et al.* 2016). In fear of the social stigma from neighbours and relatives, such stigmatisation forces dementia patients and their families to hide themselves and keep themselves distant from their family and society. The only way to save dementia sufferers from violence and false accusation is through education. All means of communication should be engaged as that which is effective in the city might not be effective in rural areas. All means of disseminating information about the disease should be employed. Yang *et al.* (2016) argue that in order to understand the status quo of dementia, there should be knowledge or understanding of the past, such that the present would be effectively redressed, and this would also enable the projections on the future of dementia. Nehanda newspaper (2020) mentions that dementia sufferers are perceived as witches in Zimbabwe and they are brutally killed. Nehanda (2020) has stated that a 98-year-old lady stays alone on account of being branded a witch and she usually fails to retrace her footsteps home once she has left the house. One of the comments on the story read "This is sad, lack of knowledge for sure. People need to be educated about dementia".

5.7 Summary

During the exploration phase, five themes emerged which the researcher can state are the underlying causes of the ill-treatment of dementia sufferers in Mapotu. The community of Mapotu, including the caregivers, understand, perceive, and attribute dementia differently. The different perceptions, attributions, and understandings bring many challenges to caregivers as they mismanage the patients. It was noted that in Mapotu, dementia sufferers and their families are on their own, and the community does not help them due to the misconceptions around the disease. In many countries, including in Lesotho, symptoms of dementia are often attributed to witchcraft, and this has made dementia sufferers the subject of violence and killings in Mapotu.

5.8 Conclusion

Abuse of elderly people living with dementia has emerged as an area of concern in Maputo community as from the evidence gathered from the research that dementia sufferers are exposed to all forms of violence. The violence has resulted in some of them losing their lives or being physically injured. A wide range of preventive approaches are suggested as interventions that promote good mental health reducing depression and stressful life events of the affected person and family, independence, and resolving conflict without violence.

This brings the idea of establishing community support groups and training that emphasise capacitating the community with knowledge on that which dementia is and its causes and impacts to the affected people and their families. These programs can be in the form of the training of caregivers, community training, family counselling, and advocacy services. From the research, it was clear that people from Maputo community had no knowledge on that which dementia is. The way in which they defined dementia was violent in nature hence exposing dementia sufferers to any form of violence. Such outreach efforts to inform the community will result in the reduction of the potential for abuse or neglect of people living with dementia. Such programs need to be conducted at a large scale with specification of outcome measures and resources necessary for good evaluation.

More so, the interventions to curb violence and abuse against dementia sufferers in Mapotu should first deal with the source of violence against dementia sufferers. In this case of Mapotu, the root cause of violence is a lack of knowledge about the disease. This is a clear indication that the knowledge concerning dementia is well known mostly at the top leadership leaving out the grassroots people. Some of the study participants commented that the top leadership in the government does not share most of the matters at the community level, and if they ever bother to give any information, it is either shared through national television or on national radio to which most people, especially in rural areas such as Mapotu, do not have access hence the knowledge does not cascade to the grassroots level. Lederach (2005) argues that to build sustainable peace, all levels of society should be involved in an integrated manner. Lederach (1997) further asserts that the process of peacebuilding in society is largely influenced by three levels in the society and these three should by all means be involved in peacebuilding. These levels include the top leadership, middle-range leadership, and grassroots level, hence each level has an influence in the peacebuilding process resulting in the behaviour transformation of the community at all levels in protecting dementia sufferers against all forms of violence.

Finally, the learned behaviour of violence against dementia sufferers can and should be unlearned. Bandura (1971) argues that behaviour is learned and shaped by various beliefs, practices, and myths that exist within societies and the same learned behaviour can be unlearned through social learning which is by observation or direct experiences. This means that a change in behaviour is possible if people are exposed to alternative experiences. Therefore, despite having certain unwanted behaviours being rooted in some community practices, they can be unlearned. In understanding the brutal killings and violence against dementia patients in Lesotho, adopting the social learning theory can facilitate in reflecting on such experiences to facilitate the positive transformation of individual perception and behaviour pertaining to the problem. Thirdly, since the families are caring for patients on their own, they need support, whether it is social support or otherwise.

From the study findings, a conclusion can be reached that firstly, there is violence, discrimination, and abuse against dementia sufferers and their families. Dementia sufferers experience many forms of violence from both their family members and the community. However, the carers (family members) cause violence to their patients mainly because of mismanagement because of a lack of knowledge about the disease. Secondly, the community is ignorant about the disease as the family members are, thus they cause violence to dementia sufferers, attributing the symptoms to witchcraft. In addition, Berghof (2012: 63) mentions that changing individual attitudes and behaviour is critical to peacebuilding, and it means strengthening individual peace capacities, breaking stereotypes, empowering formerly disadvantaged groups, and healing trauma.

One frequently used measure for strengthening individual peace capacities is training people in non-violent action and conflict resolution. The community of Mapotu should also be trained on non-violent ways of resolving conflicts. This is similar to the finding of Czempiel (1996 cited in Smock 1998: 20) that peacebuilding is a continuing process “even if interventions themselves can be in the form of crisis-response measures”.

CHAPTER SIX

Interventions: Plans and Implementation

6.1 Introduction

It was discovered from the exploration phase that dementia sufferers and their family members are notably subjected to violence and abuse. Findings revealed that violence and abuse towards the patients stem from a lack of information about the disease (dementia). The community attributes the symptoms to witchcraft. This chapter will therefore present the proposed interventions to prevent violence and abuse against dementia sufferers as well as engaging some resources or vehicles that could possibly inform the community about the disease. The chapter reviews the literature about interventions while elucidating preventive experiences from other countries.

Violence and abuse of elderly people living with dementia has emerged as an area of concern to Maputo community, as demonstrated in the evidence gathered from the research. The violence has resulted in some of the dementia sufferers losing their lives or being physically injured. A wide range of preventive approaches are suggested as interventions that promote awareness and knowledge about the disease which will eventually bring back the spirit of *ubuntu* where people live for each other.

6.2 The Key Interventions

6.2.1 Community Education

The community of Mapotu is completely misinformed and ignorant of dementia as a medical condition. That which surprised the researcher more was that even the village chiefs, who are the community leaders, knew nothing about dementia. Violence, abuse, discrimination, stigma, beatings, and brutal killings in Mapotu community are as a result of limited knowledge. Mapotu is not an exception in Lesotho and even from other countries, literature has revealed that many nations have a limited knowledge about dementia hence the same treatment that dementia sufferers are receiving in Lesotho is also evident elsewhere. The misconceptions, to a large extent, are influenced by sociocultural practices within the societies. From collected data, it has been revealed that even the families of the patients do not know about the condition at all. As much as the community members subject the families and patients to violence, abuse, and discrimination, the families also mistreat and somehow abuse the patients due to a lack of knowledge on how to handle dementia patients.

In light of the collected data, some participants mentioned that education on HIV/AIDS helped to reduce the stigma attached to the disease and, as a result, the perception of the community towards the HIV/AIDS patients changed and misinformed deeds were regretted. Participants mentioned that they began to help and feel for HIV/AIDS patients. The bad treatment against HIV/AIDS patients was due to a lack of knowledge about the disease and education opened their eyes and made them accept them as fellow human beings.

Similarly, education programs could help to change perceptions (social and cultural) of Mapotu community against dementia sufferers. The wrong attributions that make them kill and subject the patients and their families to stigma, discrimination, and abuse could be transformed and changed by education. Educational interventions were found to improve the relevant knowledge of health workers, caregivers, and community members in Spain (Baker *et al.* 2016).

It was mentioned by community members that families of dementia sufferers also abuse and subject the patients to violence. Wolfe (2003) is of the opinion that elder abuse-screening instruments could be effective in the assessment of the patients who are at the risk of family violence and abuse. However, Wolfe states that caregivers' social shortages and past abuse could result in the mistreatment of patients. It was clear that the families of dementia sufferers are on their own in taking care of the patients, and this means that they lack social support as the community and relatives do not want to be associated with them. Wolfe (2003) notes that caregivers' personal problems/issues could result in violence and abuse of the patient. He therefore suggests counselling for carers as one of the interventions that could help minimise the violence and abuse of dementia sufferers.

In light of the above, it is evident that education is one of the key and probably most effective tools that could be used to address violence against dementia sufferers in

Mapotu. There are matters that might appear to be small, but they make a great impact, such as having stickers about dementia, as is the case with HIV/AIDS. They can also be placed in the public transport system.

Zaffalon (2014) notes that the early diagnosis of dementia could effectively help those dealing with the disease since it bears personal, medical, and social consequences. There is much ignorance in Lesotho concerning dementia. From the collected data, one family mentioned that they took the patient to hospital and the family was told that there is nothing that the health institution could do about the condition of the patient because the disease is not curable, thus they were literally told to go back home and care for their patient. This alone shows how ignorant people are including the health personnel who cannot even give information on how to take care of the patient. On the personal level, it has been highlighted by families that dementia has reduced the quality of life in patients. The issue of memory loss is the most disturbing. On a social level, Zaffalon (2014) argues that dementia is one of the costly diseases in health care for the elderly population. It is very unfortunate that in Lesotho, the health system does not cater for dementia patients hence the families will be told to go home with their patients since the disease is not curable and the health system of Lesotho does not cater for it. Contrary to how the Government of Lesotho treats dementia patients and their carers, South Africa, which has landlocked Lesotho, has non-contributory pensions, disability benefits, and “Grant-in-Aid” for South Africans aged from 50-60 years who have chronic conditions and “require regular care”, and this includes Alzheimer’s disease. The grant-in-aid was established after the government of South Africa, with its department of social development, recognised the cost of paid care at home, thus this was made to ease the burden of caring for the sick, old people (Sherlock and Coleman 2017: 65).

Availability of information about the disease could help all the parties affected and infected by the disease (patients, carers, communities, and health personnel). If information about the disease is ever made available, the patients would know what to expect and make appropriate decisions and interventions. Giving information on its own is enough to empower all the parties and this will lead to better and more humane treatment of patients.

Education about the disease would provide the understanding and this would help in the eradication of the spread of social stigma and thus would promote a caring society and improve public health. Moreover, Lai and Chung (2007) argue that informational pamphlets and media are the best way of disseminating information. However, media can be effective in the city or urban areas where almost every family has a radio or television. In the case of Mapotu, very few families own a radio let alone televisions, and in addition, most of the people cannot afford to buy one, and another factor might be that there is no electricity in that region. This makes holding meetings (*pitsos*) and educating the communities and their chiefs the best method to employ in Mapotu, and perhaps the pamphlets for the few who can read.

Lia and Chung (2007) maintain that it is important for families to be informed such that they can effectively deal with disturbing behaviours and when the patients are portraying the psychological symptoms. Most of the time, the carers become frustrated and caring becomes overwhelming when they have to deal with such disturbing behaviours and they do not know how to go about them. The old lady taking care of her husband stated that she was also sick because sometimes she would become overwhelmed by the symptoms and that stressed and frustrated her. This is in agreement with Lai and Chung (2007) who argue that families do not know about dementia hence they are incapable of dealing with the challenging behaviours exhibited by the patients and this leaves them frustrated, which means that carers need to be deeply educated about the disease. It was discovered that in America, informational pamphlets distributed by the hospital to the community were very effective and accessible to almost all the community members (Lai and Chung 2007). This could also be done in Lesotho, though very few people in Mapotu can read Sesotho. One activity that could work for the community of Mapotu is oral health talks. In the same way that the researcher had the focus group discussion, this would be the best way for the health personnel to teach the people about the disease. As mentioned earlier, family caregivers need to be equipped by means of educating them about dementia to capacitate them to care for dementia sufferers. Additionally, training workshops related to dementia have been stated to be working in China (Lai and Chung 2007).

Conducting Community Education

On 22 May 2020, the research team held a health talk which was for the people of Leburu and Moeletsi. The community was taught about dementia and they were given a chance to ask questions. One of their main concerns was that since the disease was not curable, what would this ultimately mean for the patient. They also asked if there were any tablets to minimise the symptoms because some of the patients were very aggressive. These two questions showed that the people now understood dementia as a disease and not as witchcraft as they perceived it previously. Another concern that deeply affected the researcher was when a community member asked the team to help the families with sleeping tablets which could sedate the patients such that the carers could rest, and she was referring to an old lady taking care of her old husband. Another member even mentioned that the patient had lost so much weight that the researcher and the research team should give him something to bring him back to shape. All these concerns truly touched the team's hearts. They also asked what caused the disease and how it could be avoided, showing that they truly needed to know more about the disease. The researcher remembers a young lady who went behind the house and who was calling a friend from another village telling her that she should come and listen. Unfortunately, the lady was in a village a little far from where the team was. This meant that the lady found the teaching to be very informative and wanted the friend to be informed as well. The composition of the people who attended the health talks were both the young generations and the old people, however the number of young people was a little more than the elders, and perhaps the ratio was 60/40, respectively.

6.2.2 School-Based Education

It was revealed that the children of dementia sufferers drop out of schools due to stigma, discrimination, and abuse by other pupils. There is a need to educate people about dementia because the children learn mainly by observing their models and the first models are their parents. If they see that the parents mistreat or even talk ill of dementia sufferers and their families, the children will surely imitate and do as their parents are doing. As much as the entire society of Mapotu needs to be educated on dementia, the younger generation and children at schools should be the major focus of that education because it is with them that the chain could be broken. If there is no passing of bad treatment to dementia sufferers and their families, then there will be no perpetrators of violence against dementia sufferers in future.

The school children should be taught about dementia, and once they are informed that it is a medical condition, the stigma, discrimination, and abuse that cause other students to drop out will end. This will also influence the way in which they perceive dementia sufferers. It was stated by a dementia sufferer that the children run away and even throw stones at him whenever they see him. With appropriate education, this may change.

Conducting School-Based Education for Young People

On 7 March 2020, the team visited two schools (Mapotu primary school and Leburu primary school) to educate the pupils and their teachers about dementia. The purpose was to break the stereotypic perceptions that young children have about dementia sufferers and their family members. It should be mentioned that some of the teachers were begging the research team to visit their villages and give some education. They stated that there was a need for their people to know about dementia and that there were many cases of dementia in their villages.

The pupils and most of the teachers did not know what dementia was, and they all attributed it to witchcraft. The pupils told the team that there were witches and wizards in their villages, and they were told by their parents not to play or even eat the food from the children of dementia sufferers. The teachers confirmed that such children, the parents of whom were stated to be witches, face serious discrimination and that they, as the teachers, try hard to fight against that. Then the children were asked: how do you know that a person is a witch? One child stated that “they go around the village naked”, and another stated that “*Nkhono* (grandmother) X was found in one house and she did not know why she was there, then people in the village beat her”.

Pupils were taught about dementia and at the end of the lesson, they were given a chance to ask questions. The child who had stated that the villagers beat *nkhono* asked the question “so why did the villagers beat *nkhono* if she was sick?”. This question showed that the child was now attributing the behaviour to a disease and he could not understand why the old lady was being beaten while she was sick.

The teachers also mentioned that they were not aware that the people showing those behaviours were sick. One of the teachers stated that “it is very sad because people died due to lack of knowledge, they were burned, and their houses were burned because we thought they were witches”. Another teacher commented that “some were chased out of the villages because we thought they were witches”. The teachers begged the research team to educate all the schools.

6.2.3 Support for Families of Dementia Sufferers

Winter and Gitlin (2007: 391) argue that caregivers are the “second victims” or hidden patients in dementia care. The carers are at risk for social isolation, stress, depression, and mortality. This was mentioned by one family member during an interview, where the lady mentioned that she was also exhausted as a result of taking care of the demented husband. The families of dementia sufferers need social support to cope with the challenges of caring for their loved ones. Since the communities and extended families reject them, it is best for them to come together and share their experiences. This could help them with the emotional support that they are not receiving from their community members and families. The sharing of ideas and experiences can help to lift the burden somehow and renew one’s stamina. As the disease progresses, caregivers are at risk of stress, depression, and sleep deprivation, thus they need to come together every once in a while for renewal of strength and for someone to encourage them (Winter and Gitlin 2007).

Support groups would help in reducing the social isolation experienced by the caregivers. Winter and Gitlin (2007) realised that some carers are house bound as they are the only ones to take care of the patients, thus attending face-to-face interviews is almost impossible. For such caregivers, telephone-based interviews would be provided. As stated by Gurayah (2015), caregivers experience stress, depression, and social isolation because of the work of caring for dementia patients. Support groups are therefore helpful as the caregivers reveal their distress and share their experiences and how one deals with day-to-day life. Gurayah (2015) also notes that caring for dementia sufferers is more stressful and psychologically draining as compared to other physical conditions. Dementia sufferers who are at the late stage of the disease are completely dependent on their relatives for everything and this demands a lot from the carers. Furthermore, as mentioned by Gurayah (2015), there are many life aspects that are directly and indirectly affected by caring for dementia patients, for example, one’s life changes and the carer no longer attends the community activities such as weddings, funerals, and other functions in the community, such that one’s social being changes. Additionally, caring impacts negatively on finances, as the patients are taken to hospitals for which there should be private cars, and if the family does not have a car, they will have to hire one. Caring for dementia sufferers needs collective effort as it has been stated in Nanking *et al.* (2020) that the children and grandchildren of the PWDs play a major role in financing the caring of the patient. Furthermore, it was also noted that the community in Uganda sources carers from other families. This means that the caring business does not only rely on the family but the community (neighbours, friends, and the leaders) takes part in caring and this alleviates the burden of caring from the family members.

Education for Dementia Sufferers’ Families

The initial plan was to gather all the family members and give them the education all at once, but the research team had to adopt a different approach of talking from family to family, and the discussions were held from 20 to 23 May 2020, outside their homes. The families were given education on how to manage the patients. From all the families, only one member from one family attended the meeting, and the rest of the family members from five families did not know what was discussed and how the discussion had proceeded. However, the families were told that the community was now concerned about them and their patients – they were very surprised and one of the family members (a man) who attended the meeting narrated how the community showed sympathy. Family members were told how to respond to the symptoms e.g. aggressive behaviour, and how to talk to the patients. They were taught in an in-depth manner about dementia. Family members also asked for something that could help their patients to sleep since most of the patients did not sleep at night.

Support Group formed

It was on 25 May 2020 when the first support group for dementia patients and their families was established. Several baselines were obtained, and the demographics included caregiver age, gender, education, and relationship to the patient. All the support group members were females from the ages of 36 to 74 years. The members agreed to meet at the church in the village of the elderly lady. The research team noticed that most of the families were emotionally, physically, and psychologically burdened by the duty of caring, therefore the team, with the help of the nurse, offered psychosocial support and counseling. The members let their emotions out. Most of them mentioned that they were overwhelmed by the disruptive behaviour of the patients and they did not know how to handle it.

The team left some pamphlets with them to further enrich their knowledge and understanding of dementia. It should be noted that the patients who were cared for were not in the same scale of sickness – some were in the advanced stage and two had mild dementia. It was very unfortunate that the old lady’s patient was in the advanced stage of dementia. There were six members of the group from different villages of Mapotu and one of the members was a dementia patient who was at the early stages of dementia. However, COVID-19 disturbed the schedule for the meetings, and the agreement was that the group would meet every last Friday of the month, and since the outbreak of COVID-19, members met only once after the research team had left. Thus far, the research team has been communicating with them by phone. According to Gurayah (2015), the behaviour of dementia sufferers is the one factor that makes caring even more difficult and thus caring becomes a burden, thus the formed support group will help the carers to share how each deals with the disturbing behaviour of the patient.

6.3 Other Complementary Resources / Means of Key Interventions

6.3.1 Churches

Some participants revealed that they were only visited by their church members who gave them comfort and hope and strengthened them. This concurs with Higgins (2013) who notes that faith practices can be a source of comfort to people living with cognitive impairment and their families. Due to the mental state of dementia patients, they and their families do not attend church, and it is advisable for a church service to be brought to their homes. It is argued that spirituality acts as a powerful determinant of health and influences the general care experience (Sivertsen *et al.* 2019). Therefore, the support from local churches can play a significant role in the proper care of patients and even for the patients themselves.

After giving education in Mapotu primary school, the research team went to the house of the pastor since it is within the school compound, but unfortunately, the team could not meet the pastor, however, the team met the elder of the church and told him of the team's mission, and immediately, he mentioned some of the church members who had the disease and the team asked whether he was aware that they were sick, and he stated that he did not know what to conclude because some people were stating that they were witches. Thus, he was very happy that his conscience was correct because he never believed that they were witches. He was told of the importance of religious support to those people and he stated that it was a good activity to do and that they would continue to do it as they sometimes go to Haleburu to visit one family that has a dementia patient. He also requested that the team visit the church one Sunday and teach the congregation about dementia because Christians attribute the disease to witchcraft. The team left the pamphlets about dementia to give the congregation. The team also talked with three different church leaders and agreed to support the patients and their families spiritually. They even mentioned that they would bring them Holy Communion whenever it was the time for that. After the team left Mapotu for interventions, the team agreed that on one Sunday they would visit at least one church. The researcher called the elder from Mapotu Church who asked the team to give the congregation health talk.

On 17 May 2020, the team visited Mapotu evangelical church to give a health talk on dementia, and the church had two services (the morning service, which began at 1000 hrs, and the afternoon service, which was at 1400 hrs) for the maintenance of social distancing. The congregation had the liberty of asking questions and the team gave answers. As a health minister once stated, "Basotho need to know about dementia", and there is notably a need for health talks on dementia to be held. The questions that the congregation asked showed clearly that people do not know about the disease. One of the questions was "if ever dementia is a disease, why does it only affect old people?".

6.3.2 Laws and Policies

Over the course of several years, there has been remarkable evidence proving that the legal system, with its sections or units, is tackling and reacting to many forms of violence. The response towards domestic violence and child abuse has been taken seriously and treated with the seriousness it deserves in Lesotho. These two categories are reflected in both criminal law and international human rights law. There are many conferences on child abuse and domestic violence held around the globe and this states that someone is concerned about the protection and the wellbeing of the subjects. To the researcher's surprise, there is one group that continually experiences violence in all its forms but there is a total silence surrounding it. Everyone is aware of the violence against dementia sufferers in Lesotho but there is nothing done legislatively to protect the patients and their families. In countries such as Canada and the United States, there is a new legislative initiative against women abuse, child abuse, and elderly abuse, and the elderly abuse includes the dementia sufferers (Wolfe 2003).

In Lesotho, there is no legislation that advocates for people with dementia, and even the bill that was passed in December 2019 does not include people with dementia. Chronic illnesses such as HIV are incorporated into the policies and laws of Lesotho. This is why every year, in the financial budget of the country, the Ministry of Health has a portion of money to cater and care for the HIV/AIDS patients in the form of their medication. Secondly, there is a health centre for HIV positive people in the capital city, though the centre is meant for the children but even their parents obtain some services there. Thus, the laws and policies of the country should protect dementia sufferers and their carers. This would serve as a deterrence to those who carry out violence against and abuse the patients. The policy or law would safeguard the dementia sufferers and their families. Lai and Chung (2007) argue that adult protection legislation resembles the protective services model and they protect them from harm while improving their functioning in societies. In 2016, the Minister of Health addressed the issue of the killings of and violence against dementia sufferers. He mentioned that "Basotho need information about dementia" but from that time to date, there is no development towards ensuring that the Basotho people are educated on dementia (Koloti 2016: 9).

6.3.3 Social Media

Social media is another effective way that could be used to disseminate information about dementia. Almost every youth in the city and the few in rural areas have access to phones. The only difference is that in the rural areas, there is no internet, but phone applications such as WhatsApp can be useful for those in rural areas. As for the cities, social media is used to reach many people from different parts of the country at the same time. Social media could also help with the suggestions on how to end violence against dementia sufferers in other parts of the country.

6.3.4 Radio Interviews

On 3 July 2020, the research team held an interview with Mafeteng community radio station in Lesotho. The interview was allocated one hour. Within that one hour, the research team managed to cover some important aspects of their presentation (what is dementia, and the signs and symptoms of dementia) and the team left some 20 minutes for listeners to ask questions for the team to clarify some of the issues that were not clear to them. The radio interview was very productive as it covered many audiences within a short space of time. The team's target was not only Mapotu community and the nearby villages but all the villages within the Mafeteng constituencies. It should be noted that people (listeners) showed much interest on the topic. It was revealed from the listeners' questions that people in many parts of the country do not know about the disease and the patients face the same treatment around the country. Many callers mentioned that they also attributed the symptoms to witchcraft. They asked the same questions that were asked by the community members, teachers, and the students, and others highlighted new issues that were important to this study. One of the questions that stood out for the team was "how do you differentiate a dementia patient from a mentally ill patient?", and the question made the doctor give a detailed answer that required more time as he had to explain the possible causes of each disease, because both patients portrayed almost similar symptoms, thus the team interacted with participants telephonically and they understood how some people feel about dementia and that which causes people to mistreat the patients and their families. Most of the callers asked the team to visit their communities and educate them about the disease, and the same was observed with the radio manager who asked the team to come back and touch on the areas that the team did not manage to touch on because of the limited time allocated for the interview.

6.3.5 Juveniles and Male Inmates-Based Education

On 10 March 2020, the research team held an educational talk with the juveniles from the juvenile training centre and selected the juveniles from the district of Mafeteng since the focus of the study was on the district of Mafeteng.

The team also held the same educational talk with male prisoners in central prison on 15 March 2020 and carried out the same selection procedure of only those who were from Mafeteng. The rationale behind the team's selection was that these inmates, after their release, would become the change agents in their villages and teach their fellow villagers about dementia. It was very interesting because in central prison, there were several inmates charged with the offence of murder merely because they had suspected the victims of being witches and wizards.

6.4 Summary and Conclusion

Table 6.1 provides a summary of the interventions undertaken.

Table 6.1: Overview and summary of interventions.

Intervention	Date of execution	Who attended
Education for families of dementia sufferers	20-23/05/2020	Family members
Community education	22/05/2020	Community of Leburu and Moeletsi
School-based education	07/03/2020	Pupils of Mapotu and Leburu Primary
Formation of support group	25/05/2020	Leburu, Moeletsi, and Mokhasi
Church-based education	17/05/2020	Congregation of Mapotu Evangelical Church
Radio interview/presentation	03/07/2020	Public
Education for juveniles and male inmates	10/03/2020	Juveniles and male inmates in Maseru

Dementia sufferers experience many forms of violence from both their family members and the community. However, the carers (family members) cause violence to their patients mainly because of mismanagement because of a lack of knowledge about the disease. Secondly, the community members are also as ignorant about the disease as the family members are, thus they cause violence to dementia sufferers attributing the symptoms to witchcraft. Bandura (1971) is of the opinion that behaviour is learned and shaped by various beliefs, practices, and myths that exist within societies, and the same learned behaviour can be unlearned through social learning. In addition, Berghof (2012: 63) maintains that changing individual attitudes and behaviour is critical to peacebuilding, and this means that once the attitudes and behaviours have changed, an end would be brought to the stereotypical and stigmatising acts and, as a result, this paves the way for peacebuilding and empowerment of those who were marginalised. Training people on non-violent actions in conflict resolution cannot be overemphasised, and non-violent actions bear positive and long-term results and they are sustainable. More often, this approach respects human rights and uses a win-win point of view, hence the approach has the ability to strengthen people’s capacity for peace.

The community of Mapotu should also be trained on non-violent ways of resolving conflicts. Nevertheless, Czempiel (1996 cited in Smock 1998: 20) suggests that peacebuilding is a continuing process “even if interventions themselves can be in the form of crisis-response measures”. There is never a “quick solution” or plan cast in stone for peacebuilding methods. Lasting commitment, nevertheless, offers the room for the peacebuilding to permit individuals to develop locally applicable and maintainable institutions and exercises that address the sources of the conflict. As has been indicated by some community members, they have felt that educating them about the disease would help with the positive treatment of and approach to dementia sufferers in Mapotu – this means that it is vital to involve the community in deciding what they think could solve the prevailing problem in their community.

The issue of violence against dementia sufferers is a global matter, as revealed by literature, therefore countries should work collectively to curb the brutal doings against dementia sufferers. More educational awareness about the disease should be conducted as the primary intervention and this would help the carers in Lesotho as well as other countries where dementia patients are cared for by their families to manage the disease instead of aggravating it.

Moreover, governments should see to it that policies at both the national and community levels include or cater for the needs of dementia sufferers and their carers.

CHAPTER SEVEN

Summary, Conclusion, and Recommendations

7.1 Summary of the Key Findings

The main aim of the study was to help prevent violence against dementia sufferers in Mapotu, Lesotho. The objectives of the study were:

- To establish the nature, extent, causes, and consequences of violence and abuse against dementia sufferers in Mapotu community

- To plan and implement an intervention to raise awareness about dementia, with the purpose of reducing such violence and abuse

The above objectives were met, though the main objective is yet to be measured after the implementation of the interventions. However, there is a change in the attitudes of the community members towards the patients and their family members, and this was mentioned by one family member of a dementia patient.

In summary, the results suggest that dementia sufferers are subjected to violence and ill-treatment because people do not attribute dementia to a medical condition. People perceive dementia sufferers as being witches because according to the community members, dementia sufferers portray the same symptoms as those of witches, therefore they regard them as witches. Additionally, community members have never heard of the disease previously, thus they have no idea at all about the disease. Violence against dementia sufferers not only occurs in Mapotu community, and it is a countrywide practice and is accepted in other communities as the patients are perceived to be witches in Lesotho. The findings revealed that the effective management of dementia and curtailing the stigma against dementia sufferers and their carers could be attained through a better understanding of dementia as a medical condition.

7.2 Implications

The study aimed to help prevent violence against dementia sufferers in Mapotu, Lesotho. The findings of the study will, to some extent, help in curbing the violence and violation of human rights as well as the criminal activities that come as a result of misattributing the medical condition. It became clear that the relationships between the families of dementia sufferers and the rest of the community members are not good due to the stigma and discrimination attached to the disease. Therefore, families are caring for their patients on their own. The researcher believes that the results will facilitate the establishment of health education on dementia, and also advocate for the inclusion of dementia sufferers on disability social grants in Lesotho. The results will also inform the policy makers as well as serve as a guide on planning future health issues. Dementia is a global health issue and it needs the involvement of the government, thus the results will serve as a road map to attending to the health issues concerning dementia.

7.3 Sustaining the Interventions

7.3.1 Sustainability of the Support Group

The researcher's intention is for the support group to be sustainable and the researcher agreed with the research assistant that since he was staying in Mapotu, he would ensure that the members met as per the schedule. On the other hand, the researcher would continue calling the members to hear how they were doing. During the last two meetings, the researcher was tele-meeting and this proceeded very well. The researcher also wishes to point out that she would go and meet the members in person and also to hear from the chief if there was any change in people's perception or attitude towards dementia sufferers.

7.3.2 Establishing Organisation – Involve Churches and Quakers

The researcher's intention is to work towards the establishment of an organisation which would be in Mafeteng district to cater for the issues related to dementia. In Lesotho, the Dementia Lesotho organisation exists but it is located in Maseru (capital city) and it is not functional at all to the extent that even the people living in Maseru do not know of its existence. During this study, the researcher met with some individuals and small organisations that have the same concern as the researcher regarding dementia sufferers, such as Quakers Lesotho and Lesotho churches. The researcher attended several meetings with them and they were willing to help and engage in any activity to help curb the violence against dementia sufferers as well as educate the nation about the disease.

The researcher also intends to engage the churches fully in all the activities as on a weekly basis, people go to church and the constant teaching about dementia will ultimately make a difference.

7.3.3 Monthly Radio Slots on Dementia

The researcher has noted that the Basotho nation does not know about dementia. This was discovered during the interview that the research team had with one radio station, and the way people exited and participated in that programme showed the researcher that radio could be used in sustaining the interventions. Therefore, the researcher has decided to have a slot in a radio station once a month to speak about dementia, and perhaps to invite a family member or even for a dementia patient to speak about their experiences.

7.3.4 Training on Nonviolent Ways of Conflict Resolution

Training on nonviolent ways of solving conflict could help in discouraging people from being bystanders when seeing dementia sufferers being abused/mistreated. The training could cover training on Gender-Based Violence (GBV) since the numbers of GBV incidences are rising rapidly in Lesotho. Almost every day in the news and on the radio, and even in the newspapers, there is/are case(s) of GBV.

The researcher knows of the Alternatives to Violence Project (AVP) training which the researcher strongly believes could change the way in which people in the communities approach conflicts or misunderstandings. AVP training could not only help with the reduction of violence against dementia sufferers but also help in issues of GBV. As mentioned earlier, the researcher grew up in Mapotu and is acquainted with the lifestyle of the people in Mapotu. There is much gender violence in that community and to them, it is a normal matter for a man to abuse in the way of beating or assaulting a woman or wife. This has made it difficult or taboo for a woman to report her husband for beating her. The GBV in Mapotu is socially constructed and in that community, the women who are being beaten by their husbands believe that the husbands are beating them because they love them. In short, the beatings or assaults show love. It is taboo for a woman to report the husband for beating and that woman would even be rejected by the rest of the village for reporting the husband.

7.3.5 Continuing educating Inmates about Dementia and encouraging them to spread Knowledge about Dementia

The researcher and the departmental nurse will continue to have educational talks with inmates about dementia, and encourage them to spread the knowledge when they arrive home after their release.

7.4 Reflections

That which the researcher observed during this study was the fact that people's behaviours and worldviews are influenced by many factors that form part of their being. The fact that people are interrelated and dependent on each other states that people are highly influenced by their experiences and interactions with each other as social beings. UNESCO's (1998: 213) declaration states that "violence begins in the minds of men, and peace also begin in the minds of men". Therefore, it is possible for the perpetrators of violent actions against dementia sufferers to change. This study revealed that the community of Mapotu has learned abusive and violent behaviour through observing other people doing it and that has instilled the behaviour which has been considered normal and as the way of treating dementia sufferers. The people of Mapotu have learned the abusive and violent behaviours against dementia sufferers from other community members. They have experienced brutal actions being carried out against dementia patients and those acts have been condoned within their community hence they have thought that it was the way of living, since that was the only way that they have experienced. On the same note, Bandura (1971) maintains that the social learning theory, which is learning through observing the models by performing some actions, is an effective way of learning. This states that the learned behaviour can be unlearned through exposure to different actions. If the models in Mapotu community could exhibit the different or positive actions towards dementia sufferers, the observers could also do the same.

7.5 Recommendations

The researcher recommends a provision of culturally sensitive education about dementia through the Ministry of Health and relevant stakeholders to hold health talks and teach people about the disease such that the community can have knowledge and stop attributing a medical condition to witchcraft. Alzheimer’s Disease International (2017) argues that the effective approach when dealing with sensitising people about dementia should be informed from the current concept, perceptions, or attributions that people have about dementia. This approach should also take note of the cultural factors that contribute to the status quo of dementia. This could help in providing informed education that would address the subjection of dementia sufferers to any form of violence.

Throughout the entire study, the researcher observed that people are social beings and their interaction and sharing of experiences establishes their lives (Marsh 2009). Most of the community members in Mapotu, especially those who are taking a lead in violent actions against dementia sufferers, are from the families that have a person known to be an expert in necklacing (putting a tyre around a person’s neck and burning them). There are those people in the village who are known to be the ones executing that punishment and most of them have been jailed. The study revealed that most of the people subjecting dementia sufferers to violence are mainly from a family with such people. The researcher recommends that the government develops activities that have a caring attitude towards dementia sufferers. The researcher also recommends that the government should establish the programs aimed at sensitising the community on the consequences of crime on individuals, the community, and the country at large, since most of the acts against dementia sufferers are criminal offences which need to be punished.

The researcher further recommends that the Ministry of Health disseminate the information about dementia to the grassroots level through proper channels of communication, such as written materials in Sesotho. Health workers should distribute the pamphlets to schools. The same pamphlets could be made available in clinics and hospitals as well as in public transport. The researcher further recommends that the village chiefs be educated about dementia such that they can pass the information to their communities and for them to be able to protect the dementia sufferers. Thus, this will also help the chiefs to be able to quickly identify those with such medical conditions and to offer the needed support and protection to the patient and the family.

The empowerment of traditional leaders (village chiefs) by the government is important because it improves and extends human relations in the community.

Traditional leaders and councilors should work together, and the researcher has observed that the issues related to the day-to-day activities in the village only concern a traditional leader. Even in the serious matters such as the violation of one’s human rights, such as that which is happening to dementia sufferers, the councilor does not become involved. The researcher believes that the two leaders (chief and a councilor) should work together to bring peace and stability in the societies. The councilors have only recently emerged in Lesotho, and the researcher thinks that they have been there for four years and notably, the chiefs feel that the counselors have taken their work, while on the other hand, the councilors do not want to invade the chiefs’ territories. Nevertheless, the researcher believes that synergy between traditional leaders and counselors should be reached. The researcher also believes that if the two work together, there would be positive results that could be attained within a short space of time as the counselor operates more on the regional level while the chief operates on the village level. Therefore, councilors would advocate for health talks and other essential aspects for the better treatment of dementia sufferers and their families. This could work because councilors are recognised by the government, thus they stand a better chance of being heard by the government. However, to some extent, the counselors have not been fully integrated into the system since, as mentioned earlier, they have just emerged within the hierarchy of the government. Nevertheless, it is important to redress the imbalance of powers entrusted to councilors, and the challenges that impede the village chiefs’ capacity to bring development of any kind to the village, for example, the village chiefs do not sit in the high meetings where decisions are made, but the councilors sit and make decisions for their respective constituencies.

The researcher also recommends for the Government of Lesotho (GoL), with its policy makers, to design policies and services that address and protect the needs of dementia sufferers and their carers, and this could be achieved through the inclusion of dementia sufferers and their families to tell their lived experiences of the disease. WHO has recognised the urgent need of capacity building to those who are taking care of the patients at home such as in Mapotu. Providing the primary caregivers with information will help them to effectively deal with duties of caring and thus will ease the burden of nursing, and it will also help them to manage other diseases that come with old age (Alzheimer’s Disease International 2017). This will benefit not only old-age patients in Lesotho but also their families and the entire country would benefit as this could help to lower the mortality rate of old people due to mismanagement of diseases. It will also help the health system to have skilled and competent human resources.

The researcher further recommends the development of synergy between the traditional healers, faith healers, and biomedical personnel to work together, as it has been revealed that some patients are taken to one of the three for treatment of dementia. This could also help the three entities (faith healers, traditional healers, and biomedical personnel) to learn from each other and finally develop an integrated way of treating the disease effectively. The study was only confined to a small region of Mapotu in Lesotho, and this alone limits the results to be generalised, therefore, the researcher recommends that further research be conducted which may involve conducting the same study at a larger scope to cover the district of Mafeteng or the country. Other research that the researcher feels needs to be conducted would be to compare the treatment of dementia sufferers in Lesotho with the treatment of other dementia sufferers from any other African country or from Sub-Saharan Africa.

7.6 Conclusion

The study has identified the key problem that causes people to carry out violence against dementia sufferers in Mapotu. The study pointed out that educating community members as well as the entire nation would curb the graph of violence and killings against dementia sufferers. The entire nation of Basotho needs education on dementia, and this was revealed by the listeners during the radio interview that the researcher had on dementia. It is difficult or it will be difficult for the country (Lesotho) or even other African countries to manage or deal with the challenges brought by dementia if the country does not have sufficient knowledge of the challenges brought by the disease. This will also affect the perception that the government has on dementia hence it would be difficult for it to be considered as a public health priority since the challenges and burdens brought by the disease are unknown by decision-makers in the country. Not only will the disease be underrated but also securing the resources needed for the management of the patients and their carers will not be done.

Religious institutions such as churches and Christian council Lesotho, NGOs, and civil society working together with the relevant ministries of the government can educate communities and also give health talks in the health centres. As has been mentioned by the participants, HIV patients have been subjected to stigma and mistreatment from the community members as well, until there was enough advocacy and sensitisation about HIV. The global advocacy movement would make people perceive the disease as a global concern and the disease would be treated as such.

The researcher strongly believes that the availability of policies and the services/centres for dementia sufferers would advocate and strengthen the voices of dementia sufferers and their families to be heard. The literature and the findings of the study have revealed that there is a common belief that dementia is caused by supernatural matters such as God’s punishment and ancestral wrath on the person, hence the stigma and rejection by the communities, thus this misinformation needs to be addressed from the source, and this could be done by using a culturally sensitive approach as the beliefs are culturally rooted. Gerrard (2019) notes that as a result of the high prevalence of dementia, the talk is no longer about ‘them’ but it is ‘us’ because the way in which the disease has taken over the world can be likened to the existence of a sniper somewhere. Therefore, how the world faces this challenge becomes a question of collective humanity. There is a need to design a sense of preciousness of every life into a system, a society such that people do not need to feel identification in order to rescue one another. According to Gerrard (2019: 17):

> We all have an obligation to one another – even to people we are hostile to. There is no ‘I’ without ‘You’, no me without us, we are at one another’s mercy in the end and we should have a passionate, unequivocal

commitment to everyone, to anyone – honoring them not out of love but out of common humanity.

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APPENDIX 1: INTERVIEW GUIDE FOR DEMENTIA FAMILY MEMBERS

INTRODUCTION

My name is Makoena Theresia Thafeng, I am a student at Durban University of Technology (DUT) in South Africa. I am Masters Student in Public Management – Peacebuilding in the faculty of Management Science. I like to thank you for agreeing to see me and be interviewed. The purpose of this interview is to get insightful information from those who are directly affected by dementia. This information gathered from this information will help in my research titled: **Preventing violence against dementia sufferers in Mapotu community, Lesotho.**

Ethical considerations

1. May I ask for your permission to record all that will be discussed, be ensured that all the information written and recorded will be deleted/ destroyed once the study is completed
2. The information presented in this interview will only be used for research purpose
3. I guarantee anonymity and confidentiality
4. Your participation in this interview is voluntary; this means you are free to withdraw from the discussion anytime and there will be no adverse consequences.
5. May I please ask you to switch off the phone or put it on silent mode to avoid distractions during our interview?

Additional information

1. How do you relate to the patient?
2. How old are you? (optional)
3. For how long did you have a dementia patient?

Interview questions for dementia family member

1. What is dementia?
2. What do you find challenging about taking care of dementia patient
3. What is the nature of violence against dementia sufferers in Mapotu

4. Based on your experience at which level is violence against dementia sufferers?
5. According to you, what are the causes of violence against dementia sufferers and what do you think should be done to prevent violence against dementia sufferers?
6. What role do you think the community can play in helping dementia sufferers and their families?

Closing

Thank you so much for your time, that was very insightful and detailed, and I believe the information will help to change the lives of this community

APPENDIX 2: FOCUS GROUP DISCUSSION GUIDE

INTRODUCTION

My name is Makoena Theresia Thafeng, I am a student at Durban University of Technology (DUT) in South Africa. I am master's Student in Public Management – Peacebuilding in the faculty of Management Science. I like to thank you all for agreeing to spare your time and engage in this discussion which will not take more than one hour. The study is titled: **Preventing violence against dementia sufferers in Mapotu community, Lesotho.** This study is participatory action research which will be conducted in five villages of Mapotu namely; Leburu, Moeletsi, Marakong, Ramotoho and Rachabeli. The purpose of the study is to establish the nature, extent, causes and consequences about old age diseases especially dementia. It is through this discussion that we will discover why so much abuse and violence against dementia sufferers in your community.

Ethical considerations

1. May I ask for your permission to record all that will be discussed, be ensured that all the information written and recorded will be deleted/ destroyed once the study is completed
2. The information presented in this discussion will only be used for research purpose and nothing else
3. I guarantee anonymity and confidentiality
4. Participation in this discussion is voluntary; this means you are free to withdraw from the discussion anytime and there will be no adverse consequences.
5. There are no right or wrong answers, therefore all opinions and answers are welcomed

Road map

1. Respect each other and allow enough time for others to share their views
2. Participants introduce themselves
3. May we all switch off the phones or put them on silent mode, this is to avoid distraction that may come with the ringing phone during discussion

Questions for discussion

1. When you hear of the word dementia, what comes to mind?
2. What can you say about the level of violence against dementia sufferers in the

community?
3. According to you, what are the causes of violence and abuse against dementia sufferers?
4. What are the consequences of violence against dementia sufferers in the community?
5. What role do you think the community can play in helping dementia sufferers and their families?
6. In your view, what do you think can be done to prevent violence against dementia sufferers and what do you think would be the sign/s of reduction of violence against dementia sufferers in this community?

Ending the discussion

Thank you so much for sharing this insightful information with us. The information will surely help us (community members and the researcher) to come up with interventions that will help in preventing violence against dementia sufferers in Mapotu.

Note. As mentioned earlier that the study will be conducted in five villages, the above discussion guide will be used in all those five villages.

APPENDIX 3: INTERVIEW GUIDE FOR A COMMUNITY MEMBER

INTRODUCTION

My name is Makoena Theresia Thafeng, I am a student at Durban University of Technology (DUT) in South Africa. I am Masters Student in Public Management – Peacebuilding in the faculty of Management Science. I like to thank you for agreeing to see me and be interviewed. The purpose of this interview is to get insightful information from those who are directly affected by dementia. This information gathered from this information will help in my research titled: **Preventing violence against dementia sufferers in Mapotu community, Lesotho.**

Ethical considerations

1. May I ask for your permission to record all that will be discussed, be ensured that all the information written and recorded will be deleted/ destroyed once the study is completed
2. The information presented in this interview will only be used for research purpose
3. I guarantee anonymity and confidentiality
4. Your participation in this interview is voluntary; this means you are free to withdraw from the discussion anytime and there will be no adverse consequences.
5. May I please ask you to switch off the phone or put it on silent mode to avoid distractions during our interview?

Interview questions for a community member

1. What is dementia
2. How does community treat dementia sufferers and their families?
3. What is the nature of violence against dementia sufferers in Mapotu?
4. Based on your experience at which level is the abuse and violence against dementia sufferers?
5. What are the consequences of abuse and violence against dementia sufferers?
6. Do you think community has any role to play in helping the dementia sufferers and their families?
7. In your view, what do you think can be done to prevent abuse and violence against dementia sufferers and what do you think would be the sign/s of

reduction of abuse and violence against dementia sufferers in this community?

Closing

Thank you so much for your time, that was very insightful and detailed, and the information will definitely help to change the lives of this community

Note: the same interview guide will be used to other fifteen interviewees.